Building an Inclusive Development Community

A Manual on Including People with Disabilities
in International Development Programs

2003 Edition

Edited by:
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All information in *Building an Inclusive Development Community: A Manual on Including People with Disabilities in International Development Programs* is subject to change without notice. To the best of their ability, Mobility International USA (MIUSA) verified the accuracy of the information prior to publication. Although efforts have been made to ensure accuracy, MIUSA cannot be held liable for inaccuracy, misinterpretation or complaints arising from this book. Any listing of an organization, company, service or resource should not be construed as an endorsement.

INTRODUCTION

The time has come. With over 500 million women and men with disabilities around the world, international development organizations must take proactive measures to bring people with disabilities into the development process, as policy makers, implementers and beneficiaries.

If we are to reach the Millennium Development Goals, international development agencies must include people with disabilities in education, health, economic, civil society and all other initiatives, because people with disabilities, particularly women with disabilities, are marginalized and among the poorest of the poor in every country. We must tap into the vast resources that people with disabilities offer to the development process, because, as we have learned from our work toward gender equality, inclusive development is effective development. Most importantly, we must invite women and men with disabilities to participate at every level of the development process because human rights are for every human being, and every human being is entitled to be a fully participating member of his or her community.

The *Building an Inclusive Development Community* manual is the result of a unique collaboration between disability and international development communities. The diverse content, styles and terminology found in the Manual reflect the diversity of the voices heard here: individuals with and without disabilities, professionals, leaders of disability-led organizations and international development agencies. Although this manual was designed specifically for InterAction member agencies, we hope that it will be used as a 'practical how-to' resource by international development organizations throughout the world.

The *Building an Inclusive Development Community* manual is a work in progress, and we invite your feedback. A second edition, planned for publication in six months time, will address an expanded list of topics, including HIV/AIDS, Youth, Employment, and Local Democracy. We will incorporate your comments, ideas and recommendations, to ensure that the second edition is even more comprehensive and effective.

Mobility International USA (MIUSA) wishes to thank all of you who contributed for your support and dedication to this project. We especially express our appreciation to the Office of Women in Development Bureau for Economic Growth, Agriculture and Trade, U.S. Agency for International Development for its sponsorship of the *Building an Inclusive Development Community* project. We also acknowledge, with pride, InterAction and its member organizations, for adopting disability amendments to the InterAction PVO Standards.

Working together, the international disability community, represented by people with disabilities in every country of the world, and the international development community can create a more equitable world, in which the human rights of **all** individuals are respected and achieved. MIUSA is proud to be a bridge between the two communities, and to do our part toward making this vision a reality.

Karen Heinicke-Motsch
Program Manager
Mobility International USA

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Executive Director
Mobility International USA

HOW TO USE THIS BOOK

The inclusion of people with disabilities in development is a topic that has been long-awaited by the international disability community, whose members have historically experienced marginalization from community and international development efforts. Disability and development, however, is still a relatively new topic for international development organizations.

As editors of *Building an Inclusive Development Community* Manual, our goal is to provide information, strategies, tools and resources that will assist international development organizations to promote good development practice through the inclusion of people with disabilities, especially women and girls with disabilities, at every level of the development process. Although no single book can comprehensively cover all of the cross-cutting issues related to disability and development, we believe that this Manual is a very good start.

The editors suggest that the reader use this book as a resource, not as a recipe, and we have chosen a format that we hope encourages this use. The Manual is divided into major sections, beginning with a simple checklist that can be used to assess a specific organization's level of inclusiveness, continuing through sections focused on management and human resource development, program accessibility issues, international and regional experiences, and development topics viewed through disability and gender lenses. The final appendix section provides the reader with general, relevant information.

The Manual is composed of a symphony of voices, and the editors have arranged the information in a format that provides the unifying melody. Each section begins with a discussion of disability-related considerations relevant to a particular issue or area, then offers strategies for building inclusive practice into the topic discussed, highlights Best Practice examples from around the world, and ends with a list of resources that readers may find useful as they plan and develop inclusive models within their own programs. We urge you to use the Manual as a tool. Space has been provided in the margins for your own notes.

While the Manual is far from a finished product, we feel compelled to get this vital information into the hands of practitioners immediately. We encourage readers to offer suggestions as to how we can improve the content or format of the Manual, as well as to recommend other development topics within which perspectives of people with disabilities should be explored. We have provided a form at the end of the book, which we invite readers to use for comments and suggestions. We also invite you to share with us your own experiences of inclusion of people with disabilities in development programs.

We all have much to learn. New partnerships between disabled peoples' organizations and international development organizations are already enriching development work and the lives of people with disabilities around the world. Much remains be done, however, to build partnerships, increase capacity of disability organizations in south countries and gain experience in effective inclusion of women and men with disabilities.

We are encouraged by the experiences of many people all over the world who are working on new strategies for inclusion and testing their efficacy in development projects, both small and large scale, around the globe. We look forward to future resources on this topic, which we expect will provide an even wider range of information and ideas, as development and disability communities gain experience and expertise, and work together to assure that *everyone* is included in shaping a better world.

The Editors

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Mobility International USA (MIUSA) thanks the many individuals and organizations that contributed to and collaborated on this project. We are especially grateful to the many people who freely gave their time and talents in order to see this book become a reality.

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BUILDING AN INCLUSIVE DEVELOPMENT COMMUNITY

A Manual on Including People with Disabilities in International Development Programs

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FOREWORD

Mobility International USA (MIUSA) joined InterAction in 1998 and has been an important catalyst within the coalition in the promotion of its mission and in educating member NGOs to extend their commitment to diversity and equity to include people with disabilities. In this short period, MIUSA urged and guided the drafting and passage of the disability amendments to InterAction's PVO Standards in December 2000[1]. In addition, MIUSA developed a survey of member readiness to meet these standards, and under its current grant from the U.S. Agency for International Development, is helping to provide technical assistance to NGOs on including people with disabilities in international development programs.

There are four hundred million people with disabilities living in developing countries today. All too often they live in poverty and isolation. If development is to truly address the needs of the poor and marginalized, the inclusion of people with disabilities is crucial. People with disabilities form a marginalized group that is disproportionately present in the poorest populations. They must be brought into the development mainstream if we are to meet our program goals and bring all excluded people into society.

The commitment of InterAction members to diversity is firm and unequivocal. However, they are at a watershed and need the resources, technical assistance and access to the networks that will help them to expand and diversify the pool of candidates available to them and to ensure that people with disabilities are included in service program delivery. The work of MIUSA will be invaluable to the coalition as each member moves ahead in meeting the commitment they have made.

This manual will provide much needed information and resources that will help InterAction members be proactive not only to comply with the Disability PVO Standards but also to become exemplary model organizations in their sector for the inclusion of people with disabilities in development programs. This inclusion coincides with our mission of fostering partnership, collaboration and leadership among InterAction members as they strive to help their beneficiaries overcome poverty and exclusion by advocating social justice and basic dignity for all.

Mary McClymont
President, InterAction

Kenneth Giunta
Vice President, InterAction

[1] InterAction's members developed the Private Voluntary Organization (PVO) Standards in 1992, nearly a decade ago, to help assure that its members are accountable in the vital areas of financial management, fundraising, governance and program performance. The standards were developed by the members themselves and are continually added to and strengthened. InterAction members took it upon themselves to hold themselves accountable through these PVO Standards in an attempt to help guide good practice within the sector and to protect the public trot. A standing committee governed by InterAction's Board of Directors was established to, help oversee compliance.

CHECKLIST FOR INCLUSION

CHECKLIST FOR INCLUSION

The international community can no longer afford to overlook the immense resources that people with disabilities have to offer, as administrators, agents and beneficiaries of the development process.

Development organizations can play a powerful role in counteracting the cycle of oppression through which disabled people, particularly women, are denied access to support and resources which would empower them to reach their potential and contribute to the community.

We invite you to use MIUSA's *Checklist for Inclusion* as a starting point for bringing the perspectives and contributions of women and men with disabilities into your organization and services.

INTERACTION PVO STANDARDS ON DISABILITY: GUIDELINES FOR INCLUSION

InterAction, a coalition of over 160 US-based international development, relief and refugee agencies, has long demonstrated an organizational commitment to increasing diversity within the international development assistance field. In 1996, InterAction adopted "Diversity Amendments" to InterAction's Private Voluntary Organization (PVO) Standards, requiring member organizations to ensure that no person is "excluded from participation in the organization, be denied the benefits of the organization or otherwise be subjected to discrimination by the organization on the basis of race, color, national origin, age, religion, disability or sex."

In 2000, InterAction amended the PVO Standards to include guidelines on inclusion of people with disabilities in governance, management practice, human resources, programs, material assistance, and child sponsorship. (See the Appendix for a complete list of PVO Standards on Disability.)

Checklist for Inclusion

MIUSA created the Checklist for Inclusion as a simple self-assessment guide for organizations on the inclusion of people with disabilities. The Checklist for Inclusion provides a template for InterAction member organizations to assess compliance with the PVO Standards on Disability, in areas of governance, administration and programs.

The Checklist for Inclusion is comprised of a list of simple questions divided into two general areas: administration and governance, and programs. Each question is followed by direction to relevant information in MIUSA's *Building an Inclusive Development Community Manual.* The specific PVO Standard to which the question refers is included for the user's reference.

Following are our suggestions for using the Checklist for Inclusion. However, we encourage users to tailor the self-assessment process to best fit with the structure of your organization.

SUGGESTIONS FOR USE OF THE CHECKLIST FOR INCLUSION

1) Assign the Checklist for Inclusion to appropriate staff, with a target date for completion.
   *Some organizations may find it most efficient to assign specific sections or questions to specific individuals, positions or departments (e.g. human relations, administration, program).

2) Compile and review results of the Checklist for Inclusion.
   *Discuss with Board, management, staff members, as appropriate to your organization.

3) For questions to which you have answered "YES":
   *consider submitting a "best practice" story or example for MIUSA's *Building an Inclusive Development Community* project!

4) For questions which you have answered "NO":

   a. Review information about the topic as suggested in the Checklist: "Where to find information about the topic in the *Building an Inclusive Development Community* Manual".
      *see MIUSA website for information on how to obtain the Manual.

   b. Identify priority Target Areas in which to focus Action Plans.

   c. Make *Action Plans* to address the Target Areas, including identification of action steps, assignment of staff responsibility, timeline, benchmarks, resources needed and evaluation plan.

   d. Contact MIUSA for information, resources and technical assistance for implementing your action plan.

5) Implement the *Action Plan*!
   *Review benchmarks according to your timeline, adjusting strategies as necessary.

6) Chose your next Target Area for inclusion of people with disabilities!

7) Send your "Success Stories" to MIUSA's *Building an Inclusive Development Community Manual Project* at: development@miusa.org, to provide ideas and models for other organizations.

Organizational Structure, Policy, Administration, Governance

Question	YES / NO	Reference in the Manual	InterAction Disability Standards Reference
Does your organization have a written policy on inclusion of people with disabilities? ***If yes, does the policy address:***	☐ Yes ☐ No	Section 3: Governance	"Written organizational policy on inclusion of women and men with disabilities in organizational structures and in staff and board composition, fully integrated into organization's plans and operations." (Reference: Amendment 2.6.3)
Organizational structures? Staff composition? Board Composition?	☐ Yes ☐ No ☐ Yes ☐ No ☐ Yes ☐ No	Section 3: Governance Section 1: Recruitment Strategies	
Is the policy on inclusion fully integrated into the organization's plans and operations?	☐ Yes ☐ No	Section 3: Governance	
Does the policy on inclusion incorporate a gender lens?	☐ Yes ☐ No	Section 7: Gender and Disability; Section 3: Governance. Also see Commission on the Advancement of Women, InterAction.	
Are people with disabilities employed in senior decision-making positions? ***If yes, how many?***	☐ Yes ☐ No ☐ No Data	Section 1: Recruitment strategies	"Increased number of people with disabilities in senior decision-making positions at headquarters, in the field and on Boards of Directors." (Reference: Amendment 6.4.3.1)
Headquarters _____ *Number*	☐ No Data	Section 1: Recruitment Strategies	
Field _____ *Number*	☐ No Data	Section 1: Field Offices-Developing Partnerships	

Organizational Structure, Policy, Administration, Governance

Question	YES / NO	Reference in the Manual	InterAction Disability Standards Reference
Board of Directors _____ *Number*	☐ No Data	Section 3: Board Recruitment. See also: Campaign for Gender Equity on Boards of Directors (CAW-InterAction).	
Are women with disabilities employed in senior decision-making positions?	☐ Yes ☐ No ☐ No Data		
If yes, how many?			
Headquarters _____ *Number*	☐ No Data		
Field _____ *Number*	☐ No Data		
Board of Directors _____ *Number*	☐ No Data		
Are people with disabilities involved, as staff or consultants in proposal writing, program implementation, and monitoring and evaluation?	☐ Yes ☐ No ☐ No Data	Section 5: Inclusion of Disability in Delivery of Programs/Services	
If yes, how many?			
Proposal writing _____ *Number*	☐ No Data	Section 1: Budgeting for Inclusion and Section 5	
Program implementation _____ *Number*	☐ No Data	Section 1 and Section 5	
Monitoring and evaluation _____ *Number*	☐ No Data	Section 5	

Organizational Structure, Policy, Administration, Governance

Question	YES / NO	Reference in the Manual	InterAction Disability Standards Reference
Is disability integrated into the organizational diversity sensitization program?	☐ Yes ☐ No	Introduction and Section 1: Training	"Disability integrated into the organizational diversity sensitization program for staff at all levels." (Reference: Amendment 6.4.3.2)
If yes, are people with disabilities involved in: Proposal writing Program implementation Monitoring/evaluation	 ☐ Yes ☐ No ☐ Yes ☐ No ☐ Yes ☐ No		
Are people with disabilities represented from a rights-based perspective, that is, are issues of people with disabilities viewed as human rights issues?	☐ Yes ☐ No	Introduction and throughout	
Is disability integrated into gender equality or integration policies and initiatives?	☐ Yes ☐ No	Introduction and Section 3	"Disability integrated into the organizational diversity sensitization program for staff at all levels."(Reference: Amendment 6.4.3.2)
If yes, is disability integrated into the organizational gender sensitization program?	☐ Yes ☐ No	Section 1: Training	
Are women with disabilities represented from a rights-based perspective, that is, are issues of women with disabilities viewed as gender equality and human rights issues?	☐ Yes ☐ No	Section 1: Training, and Section 6: Gender and Disability	

Organizational Structure, Policy, Administration, Governance

Question	YES / NO	Reference in the Manual	InterAction Disability Standards Reference
Does your organization have a financial plan to reasonably accommodate people with disabilities in member programs and activities? *For example: Are reasonable costs of inclusion of people with disabilities incorporated into project proposals and organizational budgets?*	☐ Yes ☐ No	Section 1: Budgeting for Inclusion	"Financial plan in place to reasonably accommodate people with disabilities in member programs and activities." (Reference: Amendment 7.4.3)

Programs

Question	YES / NO	Reference in the Manual	InterAction Disability Standards Reference
Is there a mandate from the CEO to promote and monitor the inclusion of people with disabilities in programs?	☐ Yes ☐ No	Section 3: Governance	InterAction Disability Standards: "Mechanism established to promote and monitor inclusion in programs with a mandate from the CEO to promote and monitor the inclusion of people with disabilities in programs." (Reference: Amendment 7.4.1)
Are mechanisms established to promote inclusion of people with disabilities in programs?	☐ Yes ☐ No	Section 5: Project Proposal, Evaluation Plan, and Program & Services	InterAction Disability Standards: "Mechanism established to promote and monitor inclusion in programs with a mandate from the CEO to promote and monitor the inclusion of people with disabilities in programs." (Reference: Amendment 7.4.1)
If yes then, have mechanisms to promote and inclusion of people with disabilities in programs been effective?	☐ Yes ☐ No	Section 5: Evaluation	
Are the mechanisms established to promote inclusion of people with disabilities gender-sensitive?	☐ Yes ☐ No	Section 5: Project Proposal, Evaluation Plan, and Program & Services	
Are images of people with disabilities incorporated into outreach and program materials?	☐ Yes ☐ No	Section 3	

Programs

Question	YES / NO	Reference in the Manual	InterAction Disability Standards Reference
Are mechanisms established to monitor inclusion of people with disabilities in programs?	☐ Yes ☐ No	Section 5: Inclusion of Disability in Delivery of Programs/Services	InterAction Disability Standards: "Mechanism established to promote and monitor inclusion in programs with a mandate from the CEO to promote and monitor the inclusion of people with disabilities in programs." (Reference: Amendment 7.4.1
If yes, do monitoring mechanisms incorporate gender-sensitive indicators?	☐ Yes ☐ No		
Have mechanisms to monitor inclusion of people with disabilities in programs been effective?	☐ Yes ☐ No	Section 5: Evaluation	
Are strategies for inclusion of people with disabilities integrated into each stage of program including:	☐ Yes ☐ No	Section 5: Project proposal	InterAction Disability Standards: "Strategies for inclusion of women, children and men with disabilities integrated into each stage of the program from review of project proposals to implementation and evaluation." (Reference: Amendment 7.4.2)
A) Review of project proposals	☐ Yes ☐ No	Section 5: Project Proposal, Evaluation Plan, and Program & Services	
B) Project implementation	☐ Yes ☐ No	Section 5: Program Services	
C) Project evaluation	☐ Yes ☐ No	Section 5: Evaluation	
Are the strategies for inclusion gender-sensitive?	☐ Yes ☐ No	Section 8: Gender & Disability	

Programs

Question	YES / NO	Reference in the Manual	InterAction Disability Standards Reference
Have strategies to promote inclusion of people with disabilities in programs been effective?	☐ Yes ☐ No	Section 5: Evaluation	
Does your organization collaborate with NGO Partner Organizations in the field on strategies to include people with disabilities?	☐ Yes ☐ No	Section 6, Section 7: Gender & Disability, and Section 1: Field Office-Developing Partnerships	InterAction Disability Standards: "Collaboration with NGO Partner Organizations in Field on Strategies to Include People with Disabilities." (Reference: Amendment 7.4.2)
If yes, do NGO partners address gender issues of people with disabilities?	☐ Yes ☐ No	Section 6 and Section 7: Gender and Disability	
Does leadership of NGO partner organizations include women with disabilities?	☐ Yes ☐ No	Section 5: Program Services and Section 7: Gender and Disability	
Are collaborations with NGO Partners effective in fostering inclusion of people with disabilities in programs?	☐ Yes ☐ No	Section 5: Evaluation	
Does your organization hold member programs and activities in accessible locations to the maximum extent feasible?	☐ Yes ☐ No	Section 1: Checklist for Existing Facilities and Section 4: Accessibility	InterAction Disability Standards "Member programs and activities held in accessible locations to the maximum extent feasible." (Reference: Amendment 7.4.3)

Programs

Question	YES / NO	Reference in the Manual	InterAction Disability Standards Reference
For example: Have project staff been educated on barrier free approaches to program planning?	☐ Yes ☐ No	Section 4: Accessibility Section 1: Training	
Are accessible locations (including venues on ground floor, with ramps or few or steps or working elevators, wide enough doorways, accessible bathrooms) prioritized for member programs and activities?	☐ Yes ☐ No	Section 4: Accessibility and Section 1: Checklist for Existing Facilities	
Are simple adaptations implemented to make activity locations accessible (ramps, doorways widened, etc.)?	☐ Yes ☐ No	Section 4: Accessibility and Section 1: Checklist of Existing Facilities	
Are accessible transportation options available to program locations to the maximum extent possible?	☐ Yes ☐ No	Section 4: Accessibility	
Does your organization provide materials and communications in alternative formats as applicable? For example:	☐ Yes ☐ No	Section 1: Alternative Formats and Section 4: Communications Accessibility and Website Access	InterAction Disability Standards "Training and conference materials and communications provided in alternative formats as applicable. (Braille, sign language interpreters, etc.)" (Reference: Amendment 7.4.3)
Does your organization provide non-print and large print versions of print materials (Diskette or Braille)?	☐ Yes ☐ No	Section 1: Alternative Formats and Section 4: Communications Accessibility and Website Access	

Programs

Question	YES / NO	Reference in the Manual	InterAction Disability Standards Reference
Does your organization provide qualified sign language interpreters for trainings, conferences and program activities?	☐ Yes ☐ No	Section 4: Communications Accessibility	
Does your organization own and use a TTY, or use a relay system?	☐ Yes ☐ No	Section 4: Communications Accessibility	
Is your website accessible to non-screen-reading (blind, low vision, etc.) users?	☐ Yes ☐ No	Section 4: Website Access	
Are all staff members trained to use, arrange for and produce materials and communications in alternative formats as applicable?	☐ Yes ☐ No	Section 1: Training and Alternative Formats	

MANAGEMENT PRACTICES AND HUMAN RESOURCE DEVELOPMENT

/

1.1

RESOURCES FOR RECRUITING AND ACCOMMODATING QUALIFIED PEOPLE WITH DISABILITIES

It is often assumed that people with disabilities are unemployable. People with disabilities possess a wide range of abilities. International development organizations are making changes and adjustments to work environments in order for qualified candidates with disabilities to participate in the job application process and to perform essential tasks in various projects and services. Accommodating qualified individuals with disabilities does not require a great amount of time and expense. There are many useful resources available for organizations to accommodate people with disabilities. The most effective way to identify an accommodation need is to have the individual with a disability identify their needs.

Reasonable accommodation includes making modifications to ensure that qualified people with disabilities have the same benefits and privileges of employment as staff members without disabilities.

STRATEGIES TO PROVIDE WORKPLACE ACCOMMODATIONS

- Identify limitations that impact the ability of the individual seeking the accommodation.

- Collaborate with staff, volunteers, and interns with disabilities to identify work place accommodations that are needed.

- Consider the types of equipment that are used or needed to complete the task.

- Provide the most appropriate accommodation that works both for the individual with a disability and the organization.

- Monitor and assess the effectiveness of the accommodations.

EXAMPLES OF TYPES OF REASONABLE ACCOMMODATIONS

- Modify work schedule
- Create part-time positions
- Acquire equipment
- Modify work station (i.e. Raising the height of a desk)
- Make existing facilities physically accessible (i.e. accessible parking, handrails, ramp)
- Modify policies and training materials
- Provide interpreters and readers
- Offer flexible leave options
- Provide accessible transportation options
- Restructure jobs
- Reassignment to a vacant position

HELPFUL (AND LOW-COST!) TIPS FOR ACCOMMODATING PEOPLE WITH DISABILITIES

Many professionals assume that accommodating people with disabilities in their offices will be prohibitively expensive. In fact, many accommodations are cost-free or quite inexpensive. The key to finding low-cost solutions is to foster open communication with the person with a disability and to think broadly about the possibilities and resources available to them and to your organization.

Do not be surprised if the disabled person does not require any special accommodations. Many people with disabilities own the equipment they need for everyday life and will only need minimal assistance from others. Remember that each individual will have a unique approach to his or her own disability. Recognize that finding reasonable adaptations is a process of creative problem solving.

SOME EXAMPLES OF ACCOMMODATIONS FOR SEVERAL DIFFERENT TYPES OF DISABILITIES

Accommodating People who Use Wheelchairs

- Buildings with few steps can be made accessible with portable ramps. People use everything from homemade wood ramps to motor cycle ramps, up to more expensive ramps designed specifically for wheelchair use. Use the resources available in the local community.

- Some people with disabilities may need to have tables, chairs or beds adjusted for their use. To make tables higher, place blocks of wood under the legs. To lower tables or chairs, cut the legs down with a hand saw.

- Another issue to consider is the availability of accessible toilet facilities. A portable commode can be an excellent solution to this problem. This can also double as a shower chair or a seat. Commodes can be rented or purchased through medical equipment suppliers. This simple adaptation can create improved access for people with physical disabilities.

- Shower chairs make it possible for many people with mobility impairments to shower independently. Shower chairs come in many shapes and sizes; consult individual participants to find out what works best for them. Plastic resin lawn chairs make inexpensive shower chairs if a regular shower chair is not available.

Accommodating Blind or Visually Impaired People

- Have tape recorders available for blind or visually impaired individuals who may wish to use them for note taking. Tape recorders can be used to respond to questions and conversations in which others are writing responses.

- In group discussions, activities and demonstrations, be aware of gestures and illustrations that must be seen to be understood and develop the habit of describing these things as they are taking place or being demonstrated. Sometimes during a visually oriented activity, a visually impaired person may request that a sighted partner carry on a running description of the action.

Accommodating People with Hearing Impairments

- When possible, plan ahead by including the cost of sign language interpreters as part of the program budget. For formal situations, such as orientation meetings, seminars or class sessions, hire skilled interpreters as needed. For informal situations, it may be possible to make do with gestures, writing back and forth and other creative solutions, if sign language interpreters are not available.

- Purchase a TDD (Telecommunications Device for the Deaf, costs about $300) for program offices. Devices can be purchased through telephone companies, vocational rehabilitation centers or speech and hearing centers.

- Within the U.S., utilizing the National Relay Service is a free and dependable way to communicate with someone who uses a TDD.

The relay systems work when a relay operator, who has access to a TDD, acts as an intermediary between two parties. The relay system makes it possible for someone who uses a TDD to have a conversation with someone who does not have a TDD. If a relay call is placed, an operator will explain procedures for communicating with the TDD caller. The National Relay Service number is 711.

Accommodating People with Learning Disabilities

- Some people with learning disabilities prefer to use taped materials in place of printed materials. Tape recorders may provide an option for people with learning disabilities when taking notes or writing documents and reports.

- When a person with a disability has difficulty with reading, use drawings, symbols, and actions rather than written words to illustrate ideas.

- As always, communicate openly with the person. Remember that each individual will have his or her own unique strategies for problem solving.

RESOURCES

AAPD American Association of Persons with Disabilities
1819 H St. NW suite 330
Washington, DC 20006
Tel: (800) 840-8844
TTY: (888) 712-4672
Fax: (202) 457-0473
E-mail: aapd@aol.com
Web: www.aapd-dc.org

The American Association of People with Disabilities (AAPD) is a non-profit, cross-disability organization that advocates for the rights of disabled Americans. AAPD strives to further the productivity, independence,

full citizenship, and total integration of people with disabilities into all aspects of society and the natural environment. Reducing poverty and unemployment are integral to their programs. See www.joboptions.com to post jobs.

ADA Information Line- Department of Justice
U.S. Department of Justice
950 Pennsylvania Avenue, NW
Civil Rights Division
Disability Rights Section - NYAVE
Washington, D.C. 20530
Tel: (800) 514-0301
Fax: (202) 307-1198
TTY: (800) 514-0383
Web: www.usdoj.gov/crt/ada/adahom1.htm

The U.S. Justice Department of Justice provides information on general and technical assistance regarding the ADA. A toll-free ADA Information Line allows organizations to ask about ADA requirements, order free ADA materials, and obtain information about filing a complaint.

ADA Technical Assistance Program
Tel/TTY: 800-949-4232

ADA Technical Assistance Program is a comprehensive resource for information on the Americans with Disabilities Act.

Careers and the disAbled
1160 East Jericho Turnpike
Suite 200, Huntington, NY 11743
Tel: (631) 421-9421
E-mail: info@eop.com
Web: www.eop.com

CAREERS & the disABLED Magazine is a career-guidance and recruitment magazine for people with disabilities who are at undergraduate, graduate, or professional levels.

disABLEDperson, Inc.
Web: Disabledperson.com
(http://www.disabledperson.com/recruitability.asp)
E-mail: administrator@disabledperson.com

The mission of disABLEDperson.com is to reduce high unemployment rates among people with disabilities. disABLEDperson.com offers a targeted recruiting site to connect proactive employers with qualified applicants with disabilities. The website provides recruitment tips, accommodation information, and general information on the Americans with Disabilities Act.

Disability and Business Technical Assistance Center (DBTAC)
Tel & TTY: (800) 949-4232
Web: www.adata.org/dbtac.html

Disability and Business Technical Assistance Centers provide information, referral, technical assistance, and training on the Americans with Disabilities Act in effort to create greater employment opportunities and better accessibility for people with disabilities. Call the toll-free number to receive the addresses and telephone number of your local DBTAC.

Disability Rights Education Defense Fund inc. (DREDF)
2212 Sixth Street
Berkeley, CA 94710
Tel: (510) 644-2555
TTY: (510) 644-2555
Fax: (510) 841-8645
E-mail: dredf@dredf.org
Web: www.dredf.org

The Disability Rights Education and Defense Fund, Inc. (DREDF) is a national law and policy center dedicated to protecting and advancing the civil rights of people with disabilities through legislation, litigation, advocacy, technical assistance, and education and training of attorneys, advocates, persons with disabilities, and parents of children with disabilities.

EARN Employer Assistance Referral Network

Tel: 1-866-EARN-NOW
Fax: (703) 820-4820
E-mail: projectearn@birchdavis.com
Web: www.earnworks.com

EARN is a national toll-free telephone and electronic information referral service designed to assist employers in locating and recruiting qualified workers with disabilities, as well as provide technical assistance on general disability employment-related issues.

HireDeaf.com site

E-mail: info@hiredeaf.com

HireDeaf.com site provides a highly resourceful and dynamic exchange between opportunity seekers and employers.

Hire ThisAbility

DVR, 730 Simms, Suite 105
Golden, CO 80401
Tel: (303) 462-6760
Web: www.hirethisability.com

Hire This Ability advocates hiring qualified individuals with disabilities and increasing awareness of employers on strategies to recruit, hire, and retain persons with disabilities.

Independent Living Research Utilization (ILRU)
2323 S. Shepherd, Suite 1000
Houston, TX 77019
Tel: (713) 520-0232
TTY: (713) 520-5136
Fax: (713) 520-5785
E-mail: ilru@ilru.org
Web: www.ilru.org

Independent Living Research Utilization (ILRU) is a national center for information, training, research and technical assistance for individuals with disabilities to live independently. ILRU publishes a listing of independent living centers in each state of the United States and the provinces of Canada.

Job Accommodation Network
West Virginia University
P.O. Box 6080
Morgantown, WV 26506-6080
Tel: 1-800-526-7234 - Accommodation Information
Fax: (304) 293-5407
1-800-ADA-WORK (1-800-232-9675) ADA Information
E-mail: jan@jan.icdi.wvu.edu
Web: www.jan.wvu.edu

Job Accommodation Network (JAN) assists in the hiring, retraining, retention or advancement of persons with disabilities by providing accommodation information. JAN also has a resume database of qualified job candidates with disabilities.

Just One Break, Inc.
120 Wall Street
New York, NY 10005
Tel: (212) 785-7300
TTY: (212) 785-4515
Fax: (212) 785-4513
E-mail: jobs@justonebreak.com
Web: www.justonebreak.com

Just One Break is a non-profit organization that offers job placement services for persons with disabilities. Employers are invited to post jobs online through their website.

Monster
Tel: (888) 666-7837
Web: www.monster.com

Monster.com is a website which provides employers with resources on hiring people with disabilities, tools to accommodate individuals with disabilities, and assists find qualified candidates. The website has a resume database and employers are invited to post jobs. The website also provide career-guidance tips for individuals with disabilities who are searching for work.

National Business & Disability Council
201 I.U. Willets Road. Albertson, NY 11507
Tel: (516) 465-1515
Fax: (516) 465-3730
Web: www.business-disability.com

The National Business & Disability Council is the leading resource for employers seeking to integrate people with disabilities into the workplace and companies seeking to reach them in the consumer marketplace.

National Council on Independent Living (NCIL)
1916 Wilson Boulevard, Suite 209
Arlington, VA 22201
Tel: (703) 525-3406
TTY: (703) 525-4153
Fax: (703) 525-3409
Email: ncil@ncil.org
Web: www.ncil.org

National Council for Independent Living (NCIL) is a national membership organization to support independent living centers by coordinating advocacy efforts on the national level. NCIL provides information and referral, a speaker's bureau and technical assistance. NCIL works with employers to place qualified candidates with disabilities.

New Mobility
Tel: (215) 675-9133
E-mail: prose@jvleonard.com
Web: www.newmobility.com

New Mobility Magazine and website are valuable resources covering a variety of disability issues. There is a $10 monthly fee for job postings.

Paralyzed Veterans Administration (PVA)
801 Eighteenth Street, NW
Washington, DC 20006-3517
PVA National Headquarters
Tel: 800-424-8200
E-mail: info@pva.org
Web:www.pva.org/publications/onlinepubs

The PVA website offers online disability advocacy and accessibility publications including "The Air Carrier Access Act: Common questions and answers for wheelchair users".

Silent News

E-mail: info@silentnews.com
Web: www.silentnews.com

Silent News Inc. is dedicated to improve education, employment, and social conditions of Deaf and hard of hearing people. Employers can post job advertisement on the Silent News website.

UC Berkeley Disability Career Services

Career Center
University of California
2111 Bancroft Way
Berkeley, CA 94720-4350
Tel: (510) 642-1716
Fax: (510) 643-6120
E-mail: tcd@uclink.Berkeley.edu
Web: http://career.berkeley.edu (click on students with disabilities)

UC- Berkeley has a large population of students with disabilities and a large international studies department.

US Equal Employment Opportunity Commission (EEOC)

1801 L Street, N.W.
Washington, D.C. 20507
Tel: (202) 663-4900
TTY: (202) 663-4494
Web: www.eeoc.gov

U.S. Equal Employment Opportunity Commission (EEOC)'s mission is to eradicate employment discrimination and to increase knowledge about individual rights under the anti-discrimination laws among the public and employee groups. EEOC provides valuable information for employers including information on the employment of individuals with disabilities with small businesses, and the ways in which employer can comply with the Americans with Disabilities Act.

US Department of Labor – Office of Disability Employment Policy (ODEP)

1331 F Street, NW
Washington, DC 20004
Tel: (202) 376-6200
TTY: (202) 376-6205
Fax: (202) 376-6219
Web: www.dol.gov/dol/odep

ODEP's mission is to increase employment of persons with disabilities through policy analysis, technical assistance, development of best practices, outreach, education, and constituent services. The website offers extensive resources on issues related to recruiting and hiring people with disabilities.
Also, contact the Disabled Student Services offices of Universities and Colleges

US Office of Personnel Management (OPM)

Office of Equal Opportunity Programs
Tel: (202) 721-0376
Web: www.opm.gov/disability

The US Office of Personnel Management (OPM) runs a disability website at: www.opm.gov/disability. This site provides a one-stop source of information for applicants, managers, and human resource professional. Information available at the site includes: training module for managers on reasonable accommodation; new guidance to make it easier for people with disabilities to apply for Federal jobs by obtaining an initial certification of disability; a recruitment brochure for people with disabilities; frequently asked question; an annotated list of Federal agencies with leadership responsibility on disability employment; and update version of People with Disabilities in the Federal Government: An Employment Guide.

Workforce Recruitment Program (WRP)
The Office of Disability Employment Policy
1331 F Street, N.W.
Washington, DC 20004
Tel: (202) 376-6200
TTY: (202) 376-6205
E-mail: infoodep@dol.gov
Web: www.wrpjobs.org

The Workforce Recruitment Program for College Students with Disabilities (WRP) is a resource for businesses nationwide to identify qualified temporary and permanent employees from a variety of fields. The service provides nationwide database of qualified candidates with disabilities who are available for permanent and temporary positions. Applicants are highly motivated post-secondary students and recent graduates eager to prove their abilities in the workforce. WRP is managed through the Office of Disability Employment Policy, which is part of the US Department of Labor.

LISTSERVS:

Black Disabled Listserv
E-mail: blackdisabled@onelist.com
Listserv for African-Americans with disabilities. Employers invited to post jobs.

d-wild E-mail List Service (California – Women's International Linkage on Disability)
E-mail: d-wild-subscribe@yahoogroups.com
Free international e-mail list service for women with disabilities and women allies.

1.2

FIELD OFFICE: DEVELOPING PARTNERSHIPS

HIRING LOCAL PEOPLE WITH DISABILITIES

According to the MIUSA's survey of InterAction member agencies on inclusion of people with disabilities in international development programs, many international development organizations are reluctant to hire people with disabilities in their field offices due to inaccessible work conditions caused by the poor infrastructure, dense urban areas, rural environments, geographical diversity and distance from program sites.

International development organizations are in need of assistance to develop strategies to recruit and accommodate people with disabilities for jobs in field programs. MIUSA's study reveals that various factors such as physical inaccessibility, lack of understanding on the importance of employment of people with disabilities in local communities (different cultural attitudes on employment of people with disabilities), and lack of legal requirements for access in developing countries, prevent hiring overseas local field staff with disabilities.

While US disability rights laws do not always apply to the programs that development organizations operate abroad, the underlying principles of inclusion and equal treatment are profoundly important to people with disabilities who are among the populations they serve. Adoption of these principles and incorporation of the spirit of US laws can guide the development of more inclusive programs. Furthermore, US architectural accessibility guidelines should not be dismissed as overly technical and costly for use in a development context. The accessibility principles they

contain can serve as a comprehensive guideline for usability. For example, simple ramps can open a program that could otherwise be closed to an eligible person with a mobility disability. In this example, the basic message that can be taken from the US accessibility guidelines is that ramps can make inclusion possible, not that ramps have to be constructed in accordance with US building guidelines. (Please see the Access section for useful accessibility resources from around the world.)

International development organizations can begin a process of elevating awareness about the role of people with disabilities in development by bringing staff and volunteers with disabilities into the development process. Combining their experience and expertise at problem solving in challenging environments, people with disabilities and development organizations can work together to find practical solutions to real problems.

Benefits of hiring local people with disabilities

- Improve the effectiveness of development strategies.
- Develop understanding of the status of people with disabilities in the host countries.
- By including local people with disabilities, development agencies can identify issues and problems affecting people with disabilities.
- Identify barriers that people with disabilities face in the target societies.
- Set a clear example for local communities that it is both possible and valuable to include all eligible and qualified individuals in development efforts.

International development organizations often presume that many people with disabilities have uniform mobility limitations. However, it is important to remember that disabilities include unseen conditions such as dyslexia, or epilepsy or other health conditions that can be controlled with drug treatment, or disabilities that result in no practical limitations such as amputation accommodated by a prosthesis. In these instances and many others, qualified individuals could be excluded from field assignments based on inaccurate stereotype alone.

PROMOTING INCLUSION OF PEOPLE WITH DISABILITIES IN INTERNATIONAL DEVELOPMENT PROJECTS

In order to locate and include local people with disabilities in your field office, it is important to develop partnerships with local disability organizations and relevant non-governmental organizations that are dedicated to disability concerns. Staff in field offices of international development organizations can initiate contact with local disability organizations, collaborate with local disability organizations and other relevant non-governmental organizations, and share project vision and goals with local disability organizations.

Include local people with disabilities in the decision-making process. Active participation of people with disabilities in development projects not only broadens the diversity of people who are involved in development projects, but also provides in-depth understanding of the local environment. Local people with disabilities are a valuable asset to your organization.

ASSURING REASONABLE ACCOMMODATION FOR PEOPLE WITH DISABILITIES IN FIELD PROGRAMS

When addressing accessibility issues, cost is often the first thing that comes to mind. The "program accessibility" concept, which requires bringing the program to the person if the person cannot get to the program, offers a strategy to provide access without making costly renovations. Delivering the service in an alternative location is one way to deal with many of the objections to costly infrastructure changes noted by the respondents. Alternative ways to achieve architectural access are also acceptable in such situations, including installing temporary ramps and removing bathroom doors to widen entryways for wheelchair access. Providing physical assistance to the individual who wishes to participate in the program can also be an option under certain circumstances.

The most important single step development organizations can take to

address accessibility issues in most situations is to establish linkages with indigenous disability organizations or individual leaders. If development organizations are committed to the inclusion of people with disabilities in their program, local organizations or individuals familiar with disability concerns can help identify acceptable solutions, join with the organization to negotiate with partner groups, landlords and others, and reach out to the disability community itself. Collaboration, however, can take place only after development organizations have made a serious commitment to serving people with disabilities who are among eligible groups.

Mobility International USA maintains a database of organizations run by people with disabilities in over 200 countries. The International Development and Disability Department can give you Disabled Peoples Organization (DPO) contacts upon request from throughout the world. Contact us at development@miusa.org or make use of our online database at www.miusa.org.

1.3

RECRUITING VOLUNTEERS AND INTERNS

Volunteers and interns are valuable assets to any organization. Volunteer and intern staff members not only obtain valuable work experience and develop skills, but also bring new perspectives to your organizations.

Because volunteers have a wide range of reasons for giving their time and can represent a diverse cross-section of the community, they add a unique dimension to the work place. Volunteer and intern staff may include community members, students and seniors.

Employers can look into the largely untapped pool of people with disabilities as potential volunteers and interns for their programs. Outreach to people with disabilities provides additional benefits to your organization.

Benefits:

- Diversify work place.
- Enhance staff resources.
- Develop relationships with local disability organizations.
- Increase understanding of accommodation issues.
- Improve awareness of the American with Disabilities Act (ADA).

RECRUITING STRATEGIES:

Many offices may already have developed procedures for recruiting volunteers and interns. These may include giving presentations at local schools or civic groups, posting information on volunteer and internship opportunities within the community or advertising in local publications or newsletters. Information may also be available on the organization's website.

To ensure that volunteer and internship applications are received from a diverse pool of people, outreach to new sources is essential. New sources may include community disability organizations and disability services offices on campus; student groups, such as minority student unions, disabled student unions, etc; independent living centers; and community centers and other places where people with disabilities meet. To find out about new places to advertise for volunteers and interns, consult the local telephone directory or contact local government and non government agencies serving people with disabilities and independent living centers to inquire about local resources. Furthermore, the student activities office on campus can usually provide a list of student unions and clubs where information about internships and volunteer openings can be distributed. Your organization can motivate students by promoting volunteer opportunities that provide students with the chance to learn useful skills. Tap into this resource.

Keep in mind that in many of the countries in which your organization works, you will find very few students with disabilities studying at universities because of exclusionary practices. You will need to seek out other sources for volunteers and interns; independent living centers and local organizations of and for people with disabilities can help you. If you are recruiting for your headquarters, please see the list of resources in the Recruitment Strategies chapter in this section of the manual.

To make sure that information is available to all potential volunteers and interns, materials describing openings and other information about the organization or office should be available in alternative formats upon request. This can be as simple as copying text files onto a disk or creating

documents in a large print size. These alternative formats will also be useful for staff with disabilities.

International development organizations should note that when posting an internship or volunteer position it is important to encourage people with disabilities to apply for volunteer or internship experiences. Project a disability-friendly image to encourage people with disabilities to apply for various positions by stating in the posting that your office is interested in receiving applications from people with disabilities.

Sample Ad

"Mobility International USA (MIUSA) is a US-based non-profit organization. The mission of MIUSA is to empower people with disabilities around the world through international exchange, information, technical assistance and training, and to assure the inclusion of people with disabilities in international exchange and development programs. MIUSA provides opportunities for community members and students to gain work experience as interns or volunteers. People with disabilities and others are encouraged to apply."

THE BENEFITS

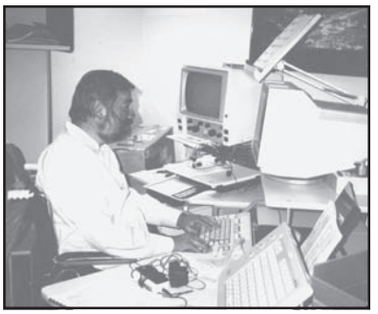
The active recruitment of people with disabilities for volunteer and internship positions can produce a number of rewards. In addition to the increase in staffing, organizations that have volunteers and interns with disabilities will usually develop a better understanding of accommodations issues and of the American with Disabilities Act (ADA). As organizations and offices gain experience including people with disabilities and learn more about accommodations issues, the entire office benefits from the increased knowledge and staff diversity. In turn, this can translate into feeling more comfortable and confident in interactions and leads to an increased awareness of what it takes to be inclusive of employees with disabilities in your organization.

Work experience provides opportunities for volunteers and interns with disabilities to make valuable contributions as future staff members,

directors, board members and participants in the international arena. Some people with disabilities may use their work experience as volunteers and interns as a springboard to a career working in government and non-government organizations in the US or abroad and as future ambassadors and policy makers who can influence international development and disability policy.

1.4

OFFICE ACCESSIBILITY: CHECKLIST FOR EXISTING FACILITIES



The following checklist provides a tool for analyzing whether or not a program activity or facility is accessible for people with disabilities. Administrators should consider using this information to analyze the accessibility of sites used for classes, meetings, interviews and homestay locations.

For more information on these guidelines, contact the Disability and Business Technical Assistance Center at Phone: (800) 949-4ADA.

The following information has been provided by Adaptive Environments Center, Inc.
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INTRODUCTION

Title III of the Americans with Disabilities Act (ADA) requires public accommodations to provide goods and services to people with disabilities on an equal basis with the rest of the general public.

The regulations require that architectural and communication barriers that are structural must be removed in public areas of existing facilities when their removal is readily achievable, in other words, if it is easily accomplished and able to be carried out without much difficulty or expense. Public accommodations that must meet the barrier removal requirement include a broad range of establishments, both for-profit and

nonprofit. These include hotels, restaurants, museums, retail stores, private schools, banks, medical offices, and other places that serve the public. Those who own, lease, manage or operate places of public accommodation in existing buildings are responsible for complying with the barrier removal requirement.

The removal of barriers can often be achieved by making simple changes to the physical environment. However, the regulations do not define exactly how much effort and expense are required for a facility to meet its obligation. This judgment must be made on a case-by-case basis, taking into consideration such factors as the size, type, and overall financial resources of the facility and the nature and cost of the access improvements needed. These factors are described in more detail in the ADA regulations issued by the Department of Justice.

The process of determining what changes are readily achievable is not a one-time effort; access should be re-evaluated annually. Barrier removal that might be difficult to carry out now may be readily achievable in the future. Tax incentives are available to help absorb these costs over several years.

PURPOSE OF THIS CHECKLIST

This checklist will help you identify accessibility problems and solutions in existing facilities in order to meet your obligations under the ADA. The goal of the survey process is to plan how to make an existing facility more usable for people with disabilities. The Department of Justice (DOJ) recommends development of an Implementation Plan, specifying what improvements you will make to remove barriers and when each solution will be carried out: "Such a plan . . . could serve as evidence of a good faith effort to comply."

TECHNICAL REQUIREMENTS

This checklist details some of the requirements found in the ADA standards for Accessible Design. The ADA Accessibility Guideline (ADAAG),

when adopted by DOJ, became standards. The Standards are part of the Department of Justice Title III Regulations, 28 CFR Part 36 (Nondiscrimination on the basis of disability, Final Rule.) Section 36.304 of this regulation, which covers barrier removal, should be reviewed before this survey is conducted.

However, keep in mind that full compliance with the Standards is required only for new construction and alterations. The requirements are presented here as a guide to help you determine what may be readily achievable barrier removal for existing facilities. The Standards should be followed for all barrier removal unless doing so is not readily achievable. If complying with the Standards is not readily achievable, you may undertake a modification that does not fully comply, as long as it poses no health or safety risk.

In addition to the technical specifications, each item has a scoping provision, which can be found under Section 4.1 in the Standards. The section clarifies when access is required and what the exceptions may be.

Each state has its own regulations regarding accessibility. To ensure compliance with all codes, know your state and local codes and use the more stringent technical requirement for every modification you make; that is, the requirement that provides greater access for individuals with disabilities. The barrier removal requirement for existing facilities is new under the ADA and supersedes less stringent local or state codes.

WHAT THIS CHECKLIST IS NOT

This checklist does not cover all of the requirements of the Standards; therefore, it is not for facilities undergoing new construction or alterations. In addition, it does not attempt to illustrate all possible barriers or propose all possible barrier removal solution. The Standards should be consulted for guidance in situations not covered here.

The Title III regulation covers more than barrier removal, but this checklist does not cover Title III's requirements for nondiscriminatory policies and practices and for the provision of auxiliary communication aids and

services. The communication features covered here are those that are structural in nature.

PRIORITIES

This checklist is based on the four priorities recommended by the Title III regulations for planning readily achievable barrier removal projects:

PRIORITY 1: Accessible approach and entrance
PRIORITY 2: Access to goods and services
PRIORITY 3: Access to rest rooms
PRIORITY 4: Any other measures necessary

Note that the references to ADAAG throughout the checklist refer to the ADA Standards for Accessible Design.

HOW TO USE THIS CHECKLIST

Get Organized
Establish a time frame for completing the survey. Determine how many copies of the checklist you will need to survey the whole facility. Decide who will conduct the survey. It is strongly recommended that you invite two or three additional people with various disabilities and accessibility expertise to assist in identifying barriers, developing solutions for removing these barriers and setting priorities for implementing improvements.

Obtain Floor Plans
It is very helpful to have the building floor plans with you while you survey. If plans are not available, use graph paper to sketch the layout of all interior and exterior spaces used by your organization. Make notes on the sketch or plan while you are surveying.

Conduct the Survey
Bring copies of this checklist, a clipboard, a pencil or pen and a flexible steel tape measure. With three people surveying, one person can number key items on the floor plan to match with the field notes, taken by a

second person, while the third takes measurements. Be sure to record all dimensions! Think about each space from the perspective of people with physical, hearing, visual and cognitive disabilities, noting areas that need improvement.

Summarize Barriers and Solutions

List barriers found and ideas for their removal. Consider the solutions listed beside each question and add your own ideas. Consult with building contractors and equipment suppliers to estimate the costs for making the proposed modifications.

Make Decisions and Set Priorities

Review the summary with decision makers and advisors. Decide which solutions will best eliminate barriers at a reasonable cost. Prioritize the items and make a timeline for carrying them out. Where the removal of barriers is not readily achievable, consider whether there are alternative methods for providing access that are readily achievable.

Maintain Documentation

Keep the survey, notes, summary, record of work completed and plans for alternative methods on file.

Make Changes

Implement changes as planned. Always refer directly to the Standards and your state and local codes for complete technical requirements before making any access improvement. References to the applicable sections of the Standards are listed at the beginning of each group of questions. For assistance in understanding the federal, state or local requirements, contact the Disability and Business and Technical Assistance Center.

Follow Up

Review the implementation plan each year to re-evaluate whether more improvements have become readily achievable.

PRIORITY ONE: ACCESSIBLE APPROACH/ENTRANCE

People with disabilities should be able to arrive on the site, approach the building and enter as freely as everyone else. At least one route of travel should be safe and accessible for everyone, including people with disabilities.

ROUTE OF TRAVEL (ADAAG 4.3, 4.4, 4.5, 4.7)

Questions

Is there a route of travel that does not require the use of stairs?

☐ Yes ☐ No

Is the route of travel stable, firm and slip-resistant?

☐ Yes ☐ No

Is the route at least 36 inches wide?

☐ Yes ☐ No

Width_____

In order to be detected using a cane, an object must be within 27 inches of the ground. Objects hanging or mounted overhead must be higher that 80 inches to provide clear head room. It is not necessary to remove objects that protrude less than four inches from the wall./

Can all objects protruding into the circulation paths be detected by a person with a visual disability using a cane?

☐ Yes ☐ No

Distance from wall/height_____

Do curbs on the route have curb cuts at drives, parking at drop-offs?

☐ Yes ☐ No

Solutions

- ☐ Add a ramp if the route of travel is interrupted by stairs (see the ramp section which follows).
- ☐ Add an alternative route on level ground.
- ☐ Repair uneven paving.
- ☐ Fill small bumps and breaks with beveled patches.
- ☐ Replace gravel with hard top.
- ☐ Change or move landscaping, furnishings, or other features that narrow the route of travel.
- ☐ Widen route.
- ☐ Move or remove protruding objects.
- ☐ Add a cane-detectable base that extends to the ground to protruding objects.
- ☐ Place a cane-detectable object on the ground underneath as a warning barrier.
- ☐ Install curb cut.
- ☐ Add small ramp up to curb.

RAMPS (ADAAG 4.8)

Questions

Are the slopes of ramps no greater than 1:12?

☐ Yes ☐ No

Slope is given as a ratio of the height to the length. 1:12 means for every 12 inches along the base of the ramp, the height increases one inch. For a 1:12 maximum slope, at least one foot of ramp length is needed for each inch of height.

Do all ramps longer than six feet have railings on both sides?

☐ Yes ☐ No

Are railings sturdy, between 34 and 38 inches high?

☐ Yes ☐ No

Height_____

Is the width between railings or curbs at least 36 inches?

☐ Yes ☐ No

Width_____

Are ramps non-slip?

☐ Yes ☐ No

Is there a 5-foot-long level landing at every 30-foot horizontal length of ramp, at the top and bottom of ramps and at switchbacks?

☐ Yes ☐ No

Length_____

Does the ramp rise no more than 30 inches between landings?

☐ Yes ☐ No

Rise_____

Solutions

☐ Lengthen ramp to decrease slope.

☐ Relocate ramp.

☐ If available space is limited, reconfigure ramp to include switchbacks.

☐ Add railings.

☐ Adjust height of railing if not between 30 and 38 inches.

☐ Secure handrails in fixtures.

☐ Relocate the railings.

☐ Widen the ramp.

☐ Add non-slip surface material.

☐ Remodel or relocate ramp.

PARKING AND DROP-OFF AREAS (ADAAG 4.6)

Questions

Are an adequate number of accessible parking spaces available (eight feet wide for a car, with a five foot access aisle?) For guidance in determining the appropriate number to designate, the table below gives the ADAAG requirements for new construction and alterations (for lots with more than 100 spaces, refer to ADAAG):

☐ Yes ☐ No

Number of accessible spaces_____

Note widths of existing accessible spaces:

TOTAL SPACES	ACCESSIBLE
1 to 25	1 space
26 to 50	2 spaces
51 to 75	3 spaces
76 to 100	4 spaces

Are eight foot wide spaces, with minimum 8-foot-wide access aisles, and 98 inches of vertical clearance, available for lift-equipped vans?

☐ Yes ☐ No

Width/vertical clearance_____

At least one of every eight accessible spaces must be van-accessible (with a minimum of one van-accessible space in all cases).

Are the access aisles part of the accessible route to the accessible entrance?

☐ Yes ☐ No

Are the accessible spaces closest to the accessible entrance?

☐ Yes ☐ No

Are accessible spaces marked with the International Symbol of Accessibility? Are there signs reading "Van Accessible" at van spaces?

☐ Yes ☐ No

Is there an enforcement procedure to ensure that accessible parking is used only by those who need it?

☐ Yes ☐ No

Solutions

☐ Reconfigure a reasonable number of spaces by repainting stripes.

☐ Reconfigure to provide van-accessible space(s).

☐ Add curb ramps.

☐ Reconstruct sidewalk.

☐ Reconfigure spaces.

☐ Add signs, placed so that they are not obstructed by cars.

☐ Implement a policy to check periodically for violators and report them to the proper authorities.

ENTRANCE (ADAAG 4.13, 4.14,4.5)

Questions

If there are stairs at the main entrance, is there also a ramp or lift or is there an alternative accessible entrance?

☐ Yes ☐ No

Do not use a service entrances as the accessible entrance unless there is no other option.

Do all inaccessible entrances have signs indicating the location of the nearest accessible entrance?

☐ Yes ☐ No

Can the alternate accessible entrance be used independently?

☐ Yes ☐ No

Does the entrance door have at least a 32 inch clear opening? For a double door, is there at least one 32 inch leaf?

☐ Yes ☐ No

Clear Opening_____

Is there at least 18 inches of clear wall space on the pull side of the door, next to the handle?

☐ Yes ☐ No

Clear Space_____

A person using a wheelchair or crutches needs this space to get close enough to open the door.

Solutions

☐ If it is not possible to make the main entrance accessible, create a dignified alternate accessible entrance. If parking is provided, make sure there is accessible parking near all accessible entrances.

☐ Install signs before inaccessible entrances so that people do not have to retrace the approach.

☐ Eliminate as much as possible the need for assistance—to answer a doorbell, to operate a lift or to put down a temporary ramp for example.

☐ Widen the door to 32 inches clear.

☐ If technically unfeasible, widen to 31-3/8 inches minimum.

☐ Install offset (swing-clear) hinges.

☐ Remove or relocate furnishings, partitions or other obstructions.

☐ Move door.

☐ Add power-assisted or automatic door opener.

Questions

Is the door threshold edge 1/4 inch high or less or if beveled edge, no more than 3/4 inch high?

☐ Yes ☐ No
Height_____

If provided, are carpeting or mats a maximum of 1/2 inch high?

☐ Yes ☐ No
Height_____

Are edges securely installed to minimize tripping hazards?

☐ Yes ☐ No

Is the door handle no higher than 48 inches and operable with a closed fist?

☐ Yes ☐ No
Height_____

The closed fist test for handles and controls: try opening the door or operating the control using only one hand, held in a fist. If you can do it, so can a person who has limited use of his or her hands.

Can doors be opened without too much force? (maximum five pounds for interior doors.)

☐ Yes ☐ No
Force_____

An inexpensive force meter or a fish scale can be used to measure the force required to open a door. Attach the hook end to the doorknob or handle. Pull on the ring end until the door opens and read off the amount of force required. If you do not have a force meter or a fish scale, it will be necessary to judge subjectively if the door is easy enough to open.

If the door has a closer, does it take at least three seconds to close?

☐ Yes ☐ No

Seconds_____

Solutions

☐ If there is a single step with a rise of six inches or less, add a short ramp.

☐ If there is a threshold grater than 3/4 –inch high, remove it or modify it to be a ramp.

☐ Replace or remove mats or carpeting.

☐ Secure carpeting or mats at edges.

☐ Lower handle.

☐ Replace inaccessible knob with a lever or loop handle.

☐ Retrofit with an add-on lever extension.

☐ Adjust the door closers and oil the hinges.

☐ Install power-assisted or automatic door openers.

☐ Install lighter doors.

☐ Adjust door closer.

PRIORITY TWO: ACCESS TO GOODS AND SERVICES

Ideally the layout of the building should allow people with disabilities to obtain materials or services without assistance.

HORIZONTAL CIRCULATION (ADAAG 4.3)

> ***A person in a wheelchair*** *needs 36 inches of clear width for forward movement and a five foot diameter or T-shaped clear space to make turns. A minimum distance of 48 inches clear of the door swing is needed between the two doors of an entry vestibule.*

Questions

Does the accessible entrance provide direct access to the main floor, lobby or elevator?

☐ Yes ☐ No

Are all public spaces on an accessible route of travel?

☐ Yes ☐ No

Is the accessible route to all public spaces at least 36 inches wide?

☐ Yes ☐ No

Width_____

Is there a 5-foot circle or a T-shaped space for a person using a wheelchair to reverse direction?

☐ Yes ☐ No

Width_____

Solutions

☐ Add ramps or lifts.

☐ Make another entrance accessible.

☐ Provide access to all public spaces along an accessible route or travel.

☐ Move furnishings such as tables, chairs, display racks, vending machines and counters to make more room.

☐ Rearrange furnishings, displays and equipment.

DOORS (ADAAG 4.13)

Questions

Do doors into public spaces have a least a 32 inch clear opening?

☐ Yes ☐ No

Clear Opening_____

On the pull side of doors, next to the handle, is there at least 18 inches of clear wall space so that a person using a wheelchair or crutches can get near to open the door.?

☐ Yes ☐ No

Can doors be opened without too much force?
(five pounds maximum for interior doors)

☐ Yes ☐ No

Force_____

Are door handles 48 inches high or less and operable with a closed fist?

☐ Yes ☐ No

Height_____

Are all threshold edges 1/4 inch high or less or if beveled edge, no more than 3/4 of an inch high?

☐ Yes ☐ No

Height_____

Solutions

☐ Install offset (swing-clear) hinges.

☐ Widen doors.

☐ Reverse the door swing if it is safe to do so.

☐ Move or remove obstructing partitions.

☐ Adjust or replace closers.

☐ Install lighter doors.

☐ Install power-assisted or automatic door openers.

☐ Lower handles.

☐ Replace inaccessible knobs or latches with lever or loop handles.

☐ Retrofit with add-on levers.

☐ Install power-assisted or automatic door openers.

☐ If there is a threshold greater than 3/4 inches high, remove it or modify it to be a ramp.

☐ If between 1/4 and 3/4 inches high, add bevels to both sides.

ROOMS AND SPACES (ADAAG 4.2, 4.4, 4.5)

Questions

Are all aisles and pathways to materials and services at least 36 inches wide?

☐ Yes ☐ No

Width_____

Is there a five foot circle or T shaped space for turning a wheelchair completely?

☐ Yes ☐ No

Width_____

Is carpeting low-pile, tightly woven and securely attached along edges?

☐ Yes ☐ No

In circulation paths through public areas, are all obstacles cane-detectable, or located within 27 inches of the floor or higher than 80 inches or protruding less than four inches from the wall?

☐ Yes ☐ No

Height/Protrusion_____

Solutions

☐ Rearrange furnishings and fixtures to clear aisles.

☐ Rearrange furnishings to clear more room.

☐ Secure edges on all sides.

☐ Replace carpeting.

☐ Remove obstacles.

☐ Install furnishings, planter or other cane-detectable barriers underneath obstacles.

EMERGENCY EGRESS (ADAAG 4.28)

Questions

If emergency systems are provided, do they have both flashing lights and audible signals?

☐ Yes ☐ No

Solutions

☐ Install visible and audible alarms.

☐ Provide portable devices.

SIGNAGE FOR GOODS AND SERVICES (ADAAG 4.30)

Different requirements apply to different types of signs.

Questions

If provided, do signs and room numbers designating permanent rooms and spaces where goods and services are provided comply with the appropriate requirements for such signage?

☐ Yes ☐ No

Character Height_____

Signs mounted with centerline 60 inches from the floor?

☐ Yes ☐ No

Height_____

Mounted on wall adjacent to latch side of the door, or as close as possible?

☐ Yes ☐ No

Raised characters, sized between 5/8 and two inches high with high contrast characters for room numbers, rest rooms, exits?

☐ Yes ☐ No

Character Height_____

Brailled text of the same information?

☐ Yes ☐ No

If pictogram is used, is it accompanied by raised characters and Braille?

☐ Yes ☐ No

Solutions

☐ Provide signs that have raised letters, Grade II Braille and that meet all other requirements for permanent room or space signage. See ADAAG 4.1.3(16) and 4.30 for more information.

DIRECTIONAL AND INFORMATIONAL SIGNAGE

The following questions apply to directional and informational signs that fall under Priority Two.

Questions

If mounted above 80 inches, do they have letters at least three inches high with a high-contrast, non-glare finish?

☐ Yes ☐ No

Letter Height_____

Do directional and informational signs comply with legibility requirements? Building directories or temporary signs need not comply.

☐ Yes ☐ No

Solutions

☐ Review requirements and replace signs as needed, meeting the requirements for character size, contrast and finish.

CONTROLS (ADAAG 4.27)

Reach ranges: *The maximum height for a side reach is 54 inches. For a forward reach, 48 inches. The minimum reachable height is fifteen inches for a front approach and nine inches for a side approach.*

Questions

Are all controls that are available for use by the public (including electrical, mechanical, cabinet, game and self-service controls) located at an accessible height?

☐ Yes ☐ No

Height_____

Are they operable with a closed fist?

☐ Yes ☐ No

Solutions

☐ Relocate controls.

☐ Replace controls.

SEATS, TABLE AND COUNTERS (ADAAG 4.2, 4.32, 7.2)

Questions

Are the aisles between fixed seating (other than assembly area seating) at least 36 inches wide?

☐ Yes ☐ No

Width_____

Are the spaces for wheelchair seating distributed throughout?

☐ Yes ☐ No

Are the tops of tables or counters between 28 and 34 inches high?

☐ Yes ☐ No

Height_____

Are knee spaces at accessible tables at least 27 inches high, 30 inches wide and 19 inches deep?

☐ Yes ☐ No

Height/Width/Depth_____

At each type of cashier counter, is there a portion of the main counter that is no more than 36 inches high?

☐ Yes ☐ No

Height_____

Is there a portion of food-ordering counters that is no more than 36 inches high or is there a space at the side for passing items to customers who have difficulty reaching over a high counter?

☐ Yes ☐ No

Height_____

Solutions

☐ Rearrange chairs or tables to provide 36 inch aisles.

☐ Rearrange table to allow room for wheelchairs in seating areas throughout the area.

☐ Remove some fixed seating.

☐ Lower part or all of high surface.

☐ Provide auxiliary table or counter.

☐ Replace or raise tables.

☐ Provide a lower auxiliary counter or folding shelf.

☐ Arrange the counter and surrounding furnishings to create a space to hand items back and forth.

☐ Lower section of counter.

☐ Arrange the counter and surrounding furnishings to create a space to pass items.

VERTICAL CIRCULATION (ADAAG 4.1.3(5) 4.3)

Questions

Are there ramps, lifts or elevators to all public levels?

☐ Yes ☐ No

On each level, if there are stairs between the entrance an/or elevator and essential public areas, is there an accessible alternate route?

☐ Yes ☐ No

Solutions

☐ Install ramps or lifts.

☐ Modify a service elevator

☐ Relocate goods or services to an accessible area.

☐ Post clear signs directing people along an accessible route to ramps, lifts or elevators.

STAIRS (ADAAG 4.9)

The following questions apply to stairs connecting levels not serviced by an elevator, ramp or lift.

Questions

Do treads have a non-slip surface?

☐ Yes ☐ No

Do stairs have continuous rails on both sides, with extensions beyond the top and bottom stairs?

☐ Yes ☐ No

Solutions

☐ Add non-slip surface to treads.

☐ Add or replace handrails if possible with existing floor plan.

ELEVATORS (ADAAG 4.10)

Questions

Are there both visible and verbal or audible door opening/closing mechanisms and floor indicators? (one tone = up, two tones = down)

☐ Yes ☐ No

Are the call buttons in the hallway no higher than 42 inches?

☐ Yes ☐ No

Height_____

Do the controls inside the cab have raised and Braille lettering?

☐ Yes ☐ No

Is there a sign on both door jambs at every floor identifying the floor in raised and Braille letters?

☐ Yes ☐ No

If an emergency intercom is provided, is it usable without voice communication?

☐ Yes ☐ No

Is the emergency intercom identified by Braille and raised letters?

☐ Yes ☐ No

Solutions

☐ Install visible and verbal or audible signals.

☐ Lower call buttons.

☐ Provide a permanently attached reach stick.

☐ Install raised lettering and Braille next to buttons.

☐ Install tactile signs to identify floor numbers at a height of 60 inches from floor.

☐ Modify communication system.

☐ Add tactile identification.

LIFTS (ADAAG 4.2, 4.11)

Questions

Can the lift be used without assistance? If not, is a call button provided?

☐ Yes ☐ No

Is there at least 30 by 48 inches of clear space for a person in a wheelchair to approach to reach the controls and use the lift?

☐ Yes ☐ No

Clear Space_____

Are controls between fifteen and 48 inches high? (up to 54 inches if a side approach is possible)

☐ Yes ☐ No

Height_____

Solutions

☐ At each stopping level, post clear instructions for use of the lift.

☐ Provide a call button.

☐ Rearrange furnishings and equipment to clear more space.

☐ Move controls.

PRIORITY THREE: USABILITY OF REST ROOMS

When rest rooms are open to the public, they should be accessible to people with disabilities.

GETTING TO THE REST ROOM (ADAAG 4.1)

Questions

If rest rooms are available to the public, is at least one rest room (either single sex or unisex) fully accessible?

☐ Yes ☐ No

Are there signs at inaccessible rest rooms that give directions to accessible ones?

☐ Yes ☐ No

Solutions

☐ Reconfigure rest rooms.

☐ Combine rest rooms to create one unisex rest room.

☐ Install accessible signs.

DOORWAYS AND PASSAGES (ADAAG 4.2, 4.13, 4.30)

Questions

Is there tactile signage identifying rest rooms?

☐ Yes ☐ No

Are pictograms or symbols used to identify rest rooms and, if used, are raised characters and Braille included below them?

☐ Yes ☐ No

Is the doorway at least 32 inches wide?

☐ Yes ☐ No

Clear Width_____

Are doors equipped with accessible handles, operable with a closed fist, 48 inches high or less?

☐ Yes ☐ No

Height_____

Can doors be opened easily with a maximum of five pounds force?

☐ Yes ☐ No

Force_____

Does the entry configuration provide adequate maneuvering space for a person using a wheelchair?

☐ Yes ☐ No

Clear Width_____

Is there a 36 inch wide path to all fixtures?

☐ Yes ☐ No

Width_____

Solutions

☐ Add accessible signage, placed to the side of the door, 60 inches to centerline, not on the door itself.

☐ If symbols are used, add supplementary verbal signage with raised characters and Braille below pictogram symbol.

☐ Install offset (swing-clear) hinges.

☐ Widen the doorway.

☐ Lower handles.

☐ Replace knobs or latches with lever or loop handles.

☐ Add lever extensions.

☐ Install power-assisted or automatic door openers.

☐ Adjust or replace closers.

☐ Install power-assisted or automatic door openers.

☐ Rearrange furnishings such as chairs and trash cans.

☐ Remove inner door if there is a vestibule with two doors.

☐ Move or remove obstructing partitions.

☐ Remove obstructions.

STALLS (ADAAG 4.17)

Questions

Is the stall door operable with a closed fist, inside and out?

☐ Yes ☐ No

Width_____

Is there a wheelchair accessible stall that has an area of at least five feet by five feet, clear of the door swing, OR is there a stall that is less accessible but that provides greater access than a typical stall, either 36 by 69 inches or 48 by 69 inches?

☐ Yes ☐ No

Length/Width_____

In the accessible stall, are there grab bars behind and on the side wall nearest to the toilet?

☐ Yes ☐ No

Is the toilet seat seventeen to nineteen inches high?

☐ Yes ☐ No

Height_____

Solutions

☐ Replace inaccessible knobs with lever or loop handles.

☐ Add lever extensions.

☐ Move or remove partitions.

☐ Reverse the door swing if it is safe to do so.

☐ Add grab bars.

☐ Add raised seat.

LAVATORIES (ADAAG 4.19, 4.24)

Questions

Does one lavatory have a 30 inch wide by 48 inch deep clear space in front?

☐ Yes ☐ No

Clear Space_____

A maximum of 19 inches of the required depth may be under the lavatory.

Is the lavatory rim no higher than 34 inches?

☐ Yes ☐ No

Height_____

Is there at least 29 inches from the floor to the bottom of the lavatory apron, excluding pipes?

☐ Yes ☐ No

Height_____

Can the faucet be operated with one closed fist?

☐ Yes ☐ No

Are soap and other dispensers and hand dryers within reach ranges and usable with one closed fist?

☐ Yes ☐ No

Is the mirror mounted with the bottom edge of the reflecting surface 40 inches high or lower?

☐ Yes ☐ No

Height_____

Solutions

☐ Rearrange furnishings.

☐ Replace lavatory.

☐ Remove or alter cabinetry to provide space underneath.

☐ Make sure hot pipes are covered.

☐ Move a partition or wall.

☐ Adjust or replace lavatory.

☐ Replace with paddle handles.

☐ Lower dispensers.

☐ Replace or provide additional accessible dispensers.

☐ Lower or tilt down the mirror.

☐ Add a larger mirror anywhere in the room.

PRIORITY FOUR: ADDITIONAL ACCESS

Note that this priority is for items not required for basic access in the first three priorities.

When amenities such as drinking fountains and public telephones are provided, they should also be accessible to people with disabilities.

DRINKING FOUNTAINS (ADAAG 4.15)

Questions

Is there at least one fountain with a clear floor space of at least 30 by 48 inches in front?

☐ Yes ☐ No

Clear Space_____

Is there one fountain with a spout no higher than 36 inches from the ground and another with a standard height spout or a "hi-lo" configuration?

☐ Yes ☐ No

Are controls mounted on the front or on the side near the front edge and operable with one closed fist?

☐ Yes ☐ No

Is each water fountain cane-detectable (located within 27 inches of the floor or protruding into the circulation space less than 4 inches from the wall?)

☐ Yes ☐ No

Height/Protrusion_____

Solutions

☐ Clear more room by rearranging or removing furnishings.

☐ Provide cup dispensers for fountains with spouts that are too high.

☐ Provide an accessible water cooler.

☐ Replace the controls.

☐ Place a planter or other cane-detectable barrier on each side at the floor level.

TELEPHONES (ADAAG 4.31)

Questions

If pay or public use phones are provided, is there clear floor space of at least 30 by 48 inches in front of at least one?

☐ Yes ☐ No

Clear Space_____

Is the highest operable part of the phone no higher than 48 inches or up to 54 inches if a side approach is possible?

☐ Yes ☐ No

Height_____

Does the phone protrude no more than four inches into the circulation space?

☐ Yes ☐ No

Protrusion_____

Does the phone have push-button controls?

☐ Yes ☐ No

Is the phone hearing-aid compatible?

☐ Yes ☐ No

Is the phone adapted with volume control?

☐ Yes ☐ No

Is the phone with volume control identified with appropriate signage?

☐ Yes ☐ No

Solutions

☐ Move furnishings.

☐ Replace booth with open station.

☐ Lower telephone.

☐ Place a cane-detectable barrier on each side at floor level.

☐ Contact phone company to install push buttons.

☐ Have phone replaced with a hearing-aid compatible one.

☐ Have volume control added.

☐ Add signage.

Questions

If there are four or more public phones in the building, is one of the phones equipped with a TDD?

☐ Yes ☐ No

Is the location of the TDD identified by accessible signage bearing the International TDD symbol?

☐ Yes ☐ No

Solutions

☐ Install a TDD.

☐ Have a portable TDD available.

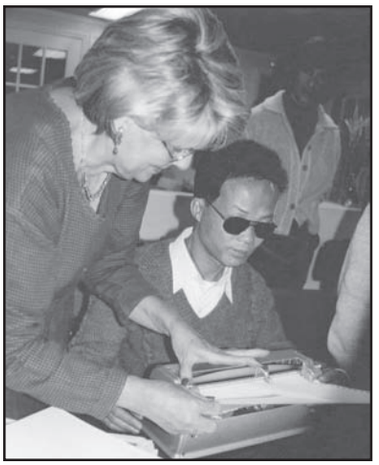
☐ Provide a shelf and outlet next to the phone.

☐ Add signage.

1.5

ALTERNATIVE FORMATS FOR PEOPLE WHO ARE BLIND OR VISUALLY IMPAIRED

To accommodate people who are blind or have a visual impairment, international development organizations can use alternative formats to facilitate communication.



ALTERNATIVE FORMATS AT-A-GLANCE

- *Large print*
- *Audiocassette*
- *Braille*
- *Floppy disk*
- *CD-ROM*
- *Making material available over the Internet*
- *Specially-encoded files on disk to be read with a Braille display.*

USE OF ALTERNATIVE FORMATS IN THE UNITED STATES AND ABROAD

The least expensive alternative format material to produce is large print; the most expensive is Braille. Less than 10% of the visually impaired population in the United States reads Braille proficiently enough to prefer information in this format. Documentation in Braille is generally produced only upon request.

By contrast, the European and Asian visually impaired communities use Braille much more heavily than do their United States counterparts. Braille should be considered when preparing general materials in alternative

formats for international use. For countries with less access to technology, personal readers or audiocassette tapes may be more common. When possible, ask the specific person what type of alternative format he or she prefers.

TYPES OF INFORMATION TO PROVIDE IN ALTERNATIVE FORMATS

All vital documentation should be made available to staff members with disabilities in a format they can access independently, and may include:

- All contact information for the organization in the form of business cards or flyers.
- Descriptions of the types of programs, projects and/or services provided by the organization in the form of brochures, pamphlets and application materials.
- Any legal documentation associated with the programs and/or services provided by the organization.
- Organizational policies relevant to staff.

GUIDELINES FOR ALTERNATIVE FORMATS

Large Print

The simplest alternative format to produce, large print is widely used to convey information to people with low vision. When using a photo-copier to enlarge a paper document, ensure that the paper upon which it will be printed is large enough to capture all of the information without cutting off the edges of the document or the ends of the lines on the document. When producing a document in large print, consider:

Point size: While the legal limit for large print is 14-point type, most

large-print readers consider this to be too small. Therefore, most large print documents should be produced with the body text in 18-point type and major headings in 24-point type.

Font type: People who have been readers of regular print in the past tend to prefer serif fonts such as Times New Roman or Helvetica. However, people who have always read large print tend to prefer sans-serif fonts such as Arial. (The official large print font of the Library of Congress is Times Roman.) Therefore, large print documents may best meet most people's needs if produced with major headings in Arial and with body text in Times New Roman. Italics should be avoided if possible; bolding and underlining can be substituted.

Paper contrast: While most regular print is produced on paper with a gray or yellow cast because it is easier on the eyes than true white, people with low vision find print on off-white paper difficult to read. Therefore, large print documents should be produced on true white paper with highly contrasting print.

Audiocassette

Next to large print, audiocassette is probably the most commonly used alternative format in the United States. Generally speaking, a document can be read onto a standard cassette and duplicated for distribution to individuals with visual impairments at a fairly low cost. When producing materials in audio, consider:

Graphical content: Depending on the nature of the graphics in a document, it may or may not be possible (or practical) to include descriptions of them in the audio version of the document, and they may already be described in the body of the text. A general rule is to include any information that is in tables or picture captions. However, maps and flow charts should be generally omitted because they are extremely difficult to convey with words. In this case, the reader should note any omission for the listener.

Four-tracking: While commercial cassette players can play a single track on each side of a cassette, the specially designed players developed for visually impaired people can play two tracks per side of a cassette. This means that each tape can actually contain four tracks of material, thus reducing the number of cassettes needed to produce a lengthy document on cassette. However, not all users possess or have access to a four-track player. So the choice of producing an audio recording on four-track or commercial two-track player should be made with the intended audience specifically in mind.

Speed: Even more important than the issue of four-tracking is the issue of speed. Many players can record at a slower-than-normal speed. The Library of Congress standard recording speed is 15/16ths inches per second (ips), while the standard commercial recording speed is 1-7/8ths ips. If a player cannot play at 15/16ths, it cannot play a recording that was produced at that rate. Therefore, such a recording may not be accessible to all individuals wishing to listen to it. As with four-tracking versus two-tracking, the choice of recording at 15/16ths or 1-7/8ths should be made with the intended audience in mind to ensure that all individuals wishing to listen to the recording can do so.

Type of producer: The clarity of the recording, proficiency of narrator and delivery of the content are critical to assure a usable product. Therefore, many organizations choose to outsource the recording of their documents. While numerous volunteer organizations around the country can record documents on demand, the quality of the finished product can vary widely. The choice of producer should be made based on the expected need of the user.

Braille

As a rule, producing a document in Braille is the most expensive alternative format. However, it is an option worth considering, especially when the intended audience may include DeafBlind people, since Braille may be their only means of accessing written materials. (Some DeafBlind individuals may have access to technology that would allow them to

utilize floppy disks as well.) Braille also is a good option if the visually impaired person will need to refer to the document during a meeting, such as with a meeting outline or agenda.

In the United States, Grade II Braille is the most widely accepted form of Braille. However, when documentation is converted into Braille for international individuals' use and is in English, the Grade I equivalent of that language should be used since that is more common outside of the United States. When the documentation is translated into a particular language, Grade I or Grade II Braille in that specific language may be used. The decision should be made based on the Braille skills of the user that can be estimated by consulting with blind schools or organizations in the country.

The Braille Authority of North America (BANA) has announced a change in terminology to what has been traditionally known as "grade 1" and "grade 2" braille. These categories will now be referred to as "uncontracted" and "contracted" braille respectively.

The change is being made at the request of many in the blindness field. People often confuse grades of braille with first and second grades in elementary school. BANA believes that the change to more accurately descriptive language will increase awareness and improve the overall understanding of how braille is learned, read, written and transcribed.

When producing a document in Braille, consider:

Size of the document: It generally takes three to four Braille pages to equal one print page. Braille may be inexpensive for a small document, but it can be a significant cost for a lengthy print document. Furthermore, a lengthy print document produced in Braille may make up several volumes of Braille, making the finished product very thick for practical use. Therefore, it may be more efficient to produce a lengthy document in Braille only upon request.

Frequency of updating: If a document (especially a longer document) tends to be updated frequently, it may not be practical to produce it

in Braille due to the cost of Braille production. It may make more sense to produce such a document in Braille only upon request.

Type of paper: There are several grades of Braille paper (including 24-pound, 100-pound, and Thermoform). While 24-pound paper is the cheapest option, it is also the least durable. Braille magazines tend to be produced with 24-pound paper, while hard-cover textbooks tend to be produced with 100-pound paper. Thermoform, a plastic paper, produces very durable Braille but is difficult to read, physically heavier and much more expensive. If the document is meant for long-term use and is unlikely to need updating, the best option is probably 100-pound paper; if the document is meant for short-term use and/or is likely to need frequent updating, 24-pound paper might serve best.

Size of paper: Braille paper can measure 8.5 by 11 inches or 11 by 11.5 inches. For easier storage in file folders and mailing in standard envelopes, organizations may choose to select the 8.5 by 11 inch paper, unless the other size has been requested by an individual.

Production costs: Braille is more expensive to produce than all the other alternative formats because it requires special equipment, software and a trained transcriber or producer to assure a quality product. Cost varies widely, depending on volume, size of document, type of paper and producer. In-house production may be cheaper in the long run, because equipment, software and training of a staff member to do the work are all one-time costs. The choice of in-house versus outsourcing should be made based on the expected need.

Type of producer: Many organizations choose to outsource Braille production. The major Braille publishing house in the United States offer volume discounts and individual pricing. While independent small producers offer less expensive pricing, they may not have the resources to do the work as quickly or as professionally as a major publishing house. The choice of producer should therefore be made based on all the criteria mentioned above and located by reviewing the information provided in the Resources section.

The National Library Service for the Blind and Physically Handicapped (NLS) has extensive resources on providing alternative formats. For further information, call NLS at 1-800-424-8567 or see http://duxburysystems.com/resource.asp.

Floppy Disk

Since most documents today are produced electronically before they are ever printed, it is generally a simple, inexpensive process to produce such a document on disk for people with a visual impairment. When producing a document on floppy disk, consider:

File format: While Microsoft Word is generally used in the United States as a word processor, not all users have access to this particular software. ASCII text file format produces a document without frills (no boldfacing, graphics, varying font types, etc.), but ASCII text files can be read by virtually all word processing software. Therefore, documents to be distributed on floppy disk should be converted into ASCII text files unless it is known that the user base can read documents in a particular file format. Rich text format (RTF) should be avoided since people using a screen reading program will not be able to access files in this format.

Organization of files: Depending on the size and nature of a document, it may be practical to organize the document into smaller, more manageable, pieces. This is especially true when the document contains several sections or chapters. Generally speaking, a floppy disk should contain a file called "contents," containing the document's table of contents. In addition, a floppy disk version of a document may contain a file called "cover" or "contact," containing the cover page or contact information for the organization.

Document layout: Screen reading programs still have a tough time figuring out tabular information, flow charts, and so on. When a document is converted into ASCII text files, much, if not all, of this formatting is lost. Therefore, when a document is distributed to an individual with disabilities who will be accessing information with a

screen reading program, the document should be reformatted to remove complex layouts; otherwise, the document may be somewhat difficult to access.

EQUIPMENT, SKILLS, AND TRAINING REQUIREMENTS

When an organization chooses to acquire equipment for producing its own documentation on audiocassette or in Braille, there are several factors to consider. These include not only what equipment to buy but also who will run it, maintain it and update it, as well as how duplication and distribution of the information will be handled.

For Larger Print

Most commercial printers are capable of producing large print, and most word processors can be made to format a document for large print. In this case, equipment and costs for this alternative format are minimal. Operation and maintenance of the printer is no different than normal printing, so any member of the staff familiar with printing from a word processor should be able to handle it.

For Audiocassette Recording

Decide whether to record on a commercial cassette recorder or a specially adapted one. The specially adapted recorders can record up to four tracks and record at 15/16ths ips. The cost of commercial machines varies greatly from inexpensive models to be found at the nearest discount store to professional-quality models found only in specialty stores.

The specially adapted tape recorders are available from many of the organizations that sell adaptive equipment. Preferred machines for heavy use include several models from the American Printing House for the Blind.

Although not all visually impaired individuals have access to specially

adapted cassette players, the Library of Congress can make such players available to any print-impaired person upon request. Contact local public libraries or regional Talking Book libraries for information on how to obtain these players.

Operations and maintenance of tape recorders—whether commercial or adapted ones—is basic. Nevertheless, a member of the staff should be designated to be responsible for knowing how to operate it, when to clean it and where to send it in for repair. Generally, maintenance involves cleaning the heads from time to time, and repairs can usually be handled by the manufacturer.

In addition to obtaining the right recorder for the organization's recording needs, a staff member should be trained in how to narrate documentation on tape. While this may seem an unnecessary step, there are several things to keep in mind that untrained readers may not be aware of:

- The reading speed should be well-paced to accommodate people who may be hearing-impaired as well as print-impaired.

- Proper names and locations, as well as acronyms and unusual abbreviations, should always be spelled the first time they are read in a document.

- When possible, sections of the document should be indicated by a pause or a tone to make it easier for the listener to find distinct areas of the document.

- Background noise should be minimal or removed from a recording to avoid distractions that may make the document difficult for the listener to absorb.

For Braille

Braille embossers are quite costly, noisy and can require high maintenance. Their prices range according to quality of Braille and speed – from the low-end Braille Blazer manufactured by Blazie Engineering (around $1,200)

to the highspeed Juliet-Pro manufactured by Enabling Technologies (over $12,000).

Some embossers can produce Braille on only one side of the page; others can produce interpoint Braille (that is, Braille on both sides of the page). While interpoint Braille is clearly more economical, embossers that can produce it tend to be more expensive.

There is no getting around it: embossers are noisy. Even a "quietizer," a cabinet intended to soften the sound of the printer at work, cannot significantly reduce the noise made by an embosser. Most staff will have a tough time adjusting to the noise level. So if an organization chooses to have a Braille embosser on site, it should be prepared to set aside a room (a storeroom or seldom-used conference room) to house the unit.

Paper for the embosser is an issue as well. Some embossers can work only with 8.5 by 11-inch paper while others can accommodate 11 by 11.5-inch paper. Also, the quality of the Braille differs on different weights of paper and different embossers. So decisions about paper should be made depending on the volume the organization expects to generate, the lengths of documents and the process of distributing them.

In addition to the embosser, Braille translation software is needed to convert word processed documents into properly formatted Braille. There are several such programs on the market, but most producers use the Duxbury Braille Translator from Duxbury Systems. (MegaDots from the Braille Planet was another option up until the summer of 1999 when Duxbury Systems and the Braille Planet merged into a single entity.)

The Duxbury Braille Translator can format most word-processed documents into readable Braille, usually with appropriate Braille formatting. However, when documents have complex layouts, fine-tuning should be done to assure a quality Braille document.

Finally, the Duxbury Braille Translator can accommodate Braille graphics and foreign language Braille, so this software is especially effective for organizations that need to produce documents for international use.

In addition to obtaining the right Braille embosser, Braille translation software and paper for an organization's Brailling needs, a staff member should be trained to run the Braille translator on documents and perform quality control on them before Brailling. It is important to proofread a document that has been run through the translator. The software allows someone who does not know Braille to visually do this on the screen; however, for the most accurate proofreading, a person who knows Braille should review the printed document. Even simply formatted documents can have improper Braille formatting due to a hitch in the Braille translator's programming. Unfortunately, most organizations that opt for producing their own Braille have limited knowledge of proper Braille formatting. This can easily be resolved by using the skills of a proficient Braille reader to assure quality results.

For Floppy Disk

The cost of equipment is minimal since floppy disks are widely available. Staff members should be made responsible for knowing how to convert documents into ASCII text files, how to remove complex layouts from the documents and how to reorganize the document into manageable files on the floppy disk.

RESOURCES

The following is a listing of some resources for equipment, training, website accessibility information, Braille and audio description or closed captioning producers. Most manufactures and producers have websites that can provide detailed information about their products and services. Also consider checking with your local Commission for the Blind office or Independent Living Center for local service providers.

American Foundation
for the Blind

11 Penn Plaza, Suite 300
New York, NY 10001
Tel: (212) 502-7600
Web: www.afb.org

American Printing Hours
for the Blind

1839 Frankfort Ave.
Louisville, KY 40206
Tel: (502) 895-2405

Associated Services for the Blind

919 Walnut St.
Philadelphia, PA 19107
Tel: (215) 627-0600
Web: www.libertynet.org/asbinfo

Blazie Engineering

105 East Jarrettsville Rd.
Forest Hill, MD 21050
Tel: (410) 893-9333
Web: www.blazie.com

Braille Institute of America

741 N. Vermont Ave.
Los Angeles, CA 90029
Tel: (323) 663-1111 or
(800) 272-5443

Braille International, Inc.

3290 S.E. Slater St.
Stuart, FL 34997
Tel: (561) 286-8366

Clovernook Printing House

7000 Hamilton Ave.
Cincinnati, OH 45231-5297
Tel: (888) 234-7156
Web: www.clovernook.org

Descriptive Video Service
WGBH

125 Western Ave.
Boston, MA 02134
Tel: (637) 300-3490
E-mail: dvs@wgbh.org
Web: www.wgbh.org

Duxbury Systems, Inc.

270 Littleton Rd., Unit 6
Westford, MA 01886-3523
Tel: (978) 692-3000
Web: www.duxburysystems.com

Enabling Technologies

1601 Northeast Braille Pl.
Jensen Beach, Florida 34957
Tel: (561) 225-DOTS (3687)

National Braille Press

88 St. Stephen St.
Boston, MA 02115
Tel: (617) 266-6160
Web: www.nbp.org

Potomac Talking Books Services, Inc.

4940 Hampden Lane, Suite 300
Bethesda, MD 20814
Tel: (301) 907-3822
E-mail: research@cutt.com

Usability.gov

http://usability.gov/accessibility/

Educational Tape
Recordings for the Blind

3915 W. 103rd St.
Chicago, IL 60639
Tel: (312) 445-3533

HotBraille.com, Inc.

Free Web-based
Transcribing Service
Web: www.hotbraille.com

National Library Service
for the Blind and Physically
Handicapped

Library of Congress
Washington, DC 20542
Tel: (202) 707-9275
Web: www.loc.gov/nls

Recordings for the Blind
and Dyslexic

20 Roszel Rd.
Princeton, NJ 08540
Tel: (800) 221-4792
Web: www.rfbd.org

1.6

BUDGETING FOR INCLUSION

Cutting-edge international development organizations are weaving diversity into the core of their programs by including individuals from diverse backgrounds and experiences as:

- staff
- volunteers
- interns
- members of the board of directors and
- project beneficiaries.

Investing in the full participation of individuals with disabilities helps your international development organization fulfill diversity goals and makes your organization more inclusive in all your program service delivery systems in the US and abroad.

BUDGETING FOR REASONABLE ACCOMMODATION

Investment of financial resources is a critical benchmark of an organization's commitment to diversity. Budgeting for the inclusion of people with disabilities should be an integral part of overall budgets. Effective budget planners anticipate all the expenses that are required to ensure a successful program: equipment, office space and supplies, salaries and benefits, accounting and insurance. Costs associated with ensuring that people with disabilities have the opportunity to participate should be just as proactively incorporated into the budget, ensuring that people with disabilities will be able to contribute fully to the goals of the program.

TOOL BOX TIP!

If you budget for inclusion you'll have all the resources in place to make your environment disability inclusive!

HOW DO THE ADA AND OTHER DISABILITY RIGHTS LAWS APPLY TO INTERNATIONAL DEVELOPMENT ORGANIZATIONS' OPERATIONS IN THE US AND ABROAD?

Employment:
Two primary federal disability-rights laws apply to US-based international development organizations. Section 504 of the 1973 Rehabilitation Act, modeled after the 1964 Civil Rights Act, prohibits discrimination against people with disabilities by programs that receive federal financial assistance. This law applies to all employment practices, regardless of the number of people who work for the organization. The Americans with Disabilities Act (ADA) contains almost the same requirements but applies to most public and private entities regardless of whether they receive federal financial assistance. The ADA prohibits employment discrimination by organizations that employ fifteen or more employees. Other state laws can also apply.

The employment provisions of the ADA and 504 cover employees hired in the US by US based development organizations, even if they are assigned to work abroad,

Programs:
In addition to employment practice, the ADA and 504 also apply to programs operated in the US by international development organizations. Section 504 sets forth specific circumstances under which architectural and program accessibility are required, and requires modification of discriminatory policies and practices. The ADA applies architectural accessibility and accommodation requirements to programs operated in the US, including accommodations to assure effective communication for individuals with speech, language, hearing or cognitive disabilities. Both laws apply to services or programs provided in the US by development organizations through contract with other organizations or vendors.

The ADA potentially covers individuals with disabilities in the United States whether or not they are U.S. citizens. Strategies to ensure that they have an equal opportunity to participate could include:

- holding meetings and events in wheelchair-accessible buildings, or using ground-floor spaces and providing ramps
- arranging accessible means of transportation or finding creative solutions
- providing sign language interpreters
- including personal assistants as needed for a person with a disability to participate fully.
- offering print materials in alternative formats (Braille or large print, diskette or audio cassette).

The organization has the responsibility to provide reasonable accommodations for people with disabilities under most circumstances. Exceptions are made only if the organization proves that the accommodation creates an undue administrative or financial burden to its overall operation. For this reason, it greatly benefits an organization to anticipate accommodation and accessibility costs, even if people with disabilities have never previously participated in its programs.

Many organizations are concerned about the cost of providing an equal opportunity for people with disabilities to participate, but accessibility and accommodation are not always expensive. For example, a recent study indicated that of the 436 reasonable accommodations provided by the Sears company, 69% involved no monetary cost, 28% cost less than $1,000 and only 3% cost more than $1,000 (US Department of Justice).

CREATIVE BUDGETING STRATEGIES

Budgeting for accessibility and accommodation can take several forms. Incorporating a "disability accommodation" line item into every project and administrative budget is a reliable way to ensure that resources are at hand to include people with disabilities. Since specific arrangements will vary depending on the number of people with disabilities and types of disability, Mobility International USA (MIUSA) recommends using a percentage formula to predict disability accommodation expenses in

budget requests. MIUSA has found that allocating 5% – 7% of the program budget will be adequate for meeting most disability-related accommodation needs. Because hiring people with disabilities, as staff and interns is one of the most effective strategies for expanding the diversity of participants and volunteers, MIUSA also recommends incorporating into the organization's administrative budget a disability accommodation line item of 1%-3% of the overall administrative costs. With funds set aside, organizations will be able to make reasonable accommodation to ensure that any employees with disabilities can do their jobs most effectively.

BEST PRACTICE

InterAction's budget has incorporated a "Reasonable Accommodation" line item!

If any of these budgeted funds are not used at the end of the year, they may be able to be used for other projects or may be able to be moved into the following year's budget for reasonable accommodation.

Architectural accessibility is central to participation by individuals with mobility disabilities. Organizations should undertake a survey of their physical buildings and facilities where they operate programs to determine if accessibility standards are being met. Sometimes organizations must plan to modify their facilities to achieve accessibility. The ADA standards for accessible design are based on the ADA accessibility guidelines (ADAAG), issued by The Architectural and Transportation Barriers Compliance Board. They serve as a guide for identifying the various kinds of measures that can be taken to remove barriers and provides priority guidelines for how best to remove them. If it would result in an undue burden to modify the buildings or facilities then organizations must take steps to offer the program or activity in alternative settings.

> "Undue burden is defined as significant difficulty or expense when considered in light of a variety of factors including the nature and cost

of the auxiliary aid or service and the overall financial and other resources of the business. The undue burden standard is intended to be applied on a case-by-case basis" (Access Equals Opportunity-Council of Better Business Bureau Foundation).

Budgeting for the inclusion of people with disabilities is a proactive goal that all organizations committed to diversity can embrace. With funding established, international development organizations will be able to respond positively and creatively when outreach efforts pay off and an outstanding disabled job applicant, intern, volunteer, or potential board comes knocking at the door.

Mobility International USA is committed to collaborating with international development organizations to assure the full and equal participation of people with disabilities in international development. For further information on making your programs inclusive of people with disabilities, please contact MIUSA.

1.7

INCLUSION OF PEOPLE WITH DISABILITIES THROUGH STAFF DEVELOPMENT AND TRAINING

> "In order to embrace diversity in its organizational culture, agencies will integrate disability into the diversity sensitization program within an organization's human resource development program for staff at all levels. This will improve organizational effectiveness, promote non-discriminatory working relationships and create a respect for diversity in work and management styles." (InterAction Disability Standards, Amendment 6.4.3.2)

DISABILITY INCLUSION IN GENDER AND DIVERSITY TRAINING

InterAction's PVO standards call for "diversity sensitization [to] be fully integrated into an organization's human resource development program for staff at all levels". Women and men with disabilities are a part of every population and make up one of the world's largest minority groups. Disability, therefore, is an important diversity issue. Disability can and should be incorporated, along with gender, ethnicity, socioeconomic level and other differences that are addressed in diversity trainings.

Examples of disability-related topics that might be included in diversity trainings include:

- Human rights perspectives (vs. medical / treatment perspectives) on disability issues

- Misconceptions vs. facts about people with disabilities (including international statistics)
- Issues and organizing strategies of women and girls with disabilities for empowerment and rights
- Practical suggestions for creating disability-positive organizational culture
- Practical suggestions for including people with disabilities in programs
- Political movements and organizing strategies by and for people with disabilities worldwide; legislation and policy affecting civil rights of people with disabilities in specific countries
- "Best practice" examples of inclusive programs and partnerships

"Organizational policies and procedures on inclusion of people with disabilities will be effective only if staff have up to date training to carry them out."

MIUSA and other disability-led organizations, and individual consultants both in the US and abroad, are available to be part of your diversity training team.

STAFF TRAINING FOR INCLUSIVE ORGANIZATIONS

Organizational policies and procedures on inclusion of people with disabilities will be effective only if staff have up to date training to carry them out. All staff members must be aware of the organization's policies on inclusion of people with disabilities. Program and administrative staff need to be proficient at using equipment and procedures to make facilities, avenues of communication and materials accessible to people with disabilities.

New employee orientation, staff development inservices and annual employee reviews provide opportunities for staff to develop competencies that will facilitate effective inclusion of people with disabilities in the workplace and in programs. Training topics related to disability inclusion might include:

- Overview of organizational commitment to inclusion of people with disabilities, and policies and departmental action plans to promote inclusion

- Instruction on use of adaptive office equipment, such as TTYs or telephone relay systems
- Procedures for producing alternative format versions of print materials
- Procedures for arranging for accessible transportation alternatives.
- Resources for information to assist with outreach and inclusion of people with disabilities

Trainings also provide invaluable vehicles to indirectly promote inclusion of people with disabilities, both within and outside of the agency. Recommendations include:

- Refer to women and men with disabilities in all training courses, in every sector, on every topic. Whenever possible, use people with disabilities in examples that do not focus on the disability.
- Incorporate images of people with disabilities in all training materials.
- Incorporate positive messages about inclusion of people with disabilities in training sessions with partner organizations and community members.

"Trainings also provide invaluable vehicles to indirectly promote inclusion of people with disabilities, both within and outside of the agency."

LEGAL POLICY ISSUES

2

2.1

INTERNATIONAL LEGAL FRAMEWORK FOR DISABILITY LAW

Excerpted with permission from Theresia Degener and Gerard Quinn, "A Survey of International, Comparative and Regional Disability Law Reform," in Disability Rights Law and Policy: International and National Perspectives *(Papers Conceived and Commissioned by the Disability Rights Education and Defense Fund (DREDF), eds. M.L. Breslin and S. Yee 3-125 (Ardsley, NY: Transnational Pub., 2002) [Endnotes have been revised and re-numbered for this excerpt.]*

PART 1

The Paradigm Shift in International and Comparative Law

A. THE BASIS OF THE SHIFT: PEOPLE WITH DISABILITIES AS SUBJECTS AND NOT OBJECTS

Disability law has not been a field of legal research and teaching at many universities in the United States, nor has it been widely acknowledged in other countries around the world. In North America and most European countries, disability as an issue of law has commonly been addressed as an aspect of social security and welfare legislation, health law or guardianship. Thus, disabled persons were depicted not as subjects with legal rights but as objects of welfare, health and charity programs. The underlying social policy behind such a legal response has been one that segregates and excludes people with disabilities from mainstream society, sometimes providing them with special schools, sheltered workshops, and separate housing and transportation. This policy was justified by the pervasive belief that disabled persons were incapable of coping with either society at large or all or most major life activities.

Fortunately, when some countries eventually made attempts to take a more integrative and inclusive approach to disability policy, major legal reforms resulted. Attempts to open up employment, education, housing, and goods and services for persons regardless of their disabilities have

accompanied the growing understanding that disability belongs in a social and not a medical category. A key element of this new concept is the recognition that exclusion and segregation of people with disabilities do not logically follow from the fact of impairment, but rather result from political choices based on false assumptions about disability. Inaccessibility problems are not inevitably raised by mobility, visual or hearing impairments, but instead are a corollary of political decisions to build steps but not ramps, to provide information in printed letter version only, or to forgo sign language or other forms of communication. Instead of viewing disability as an individual's problem, the focus finally has shifted to how the environment and society as a whole fails to consider human differences.

"A key element of this new concept is the recognition that exclusion and segregation of people with disabilities do not logically follow from the fact of impairment, but rather result from political choices based on false assumptions about disability."

1. THE SIGNIFICANCE OF VIEWING DISABILITY AS A HUMAN RIGHTS ISSUE

With the paradigm shift from the medical to the social model of disability,[1] disability was reclassified as a human rights issue under international law. Reforms in this area were intended to provide equal opportunities for disabled people and to expose their segregation, institutionalization and exclusion as typical forms of disability-based discrimination. With the evolution of such civil rights legislation for disabled persons as the Americans with Disabilities Act (ADA), national legal paradigms shifted even further, from welfare law towards civil rights law. This new dimension of disability law has been welcomed as a major milestone on the path toward eventual recognition of the human rights of disabled people, a path which more and more governments seem to be willing to take.[2]

3. A MULTI-LAYERED REFORMS PROCESS: INTERNATIONAL, REGIONAL AND NATIONAL DEVELOPMENTS

The reform process in disability law has been going on in all parts of the world. The United States and Canada were the first countries to adopt anti-discrimination laws and other human rights legislation for persons with disabilities, starting with scattered equality provisions in various

areas of the law in the 1970s and following with more comprehensive laws in the 1990s.[3] The 1990s in particular was a banner decade for disability law; more than 40 nations enacted disability discrimination laws during this period. New equality laws for disabled persons emerged at the national as well as at the supranational and international level. Today we have binding and non-binding international human rights instruments adopted by the General Assembly of the United Nations that explicitly protect the rights of disabled persons. At the regional level, the Organization of American States (OAS) and the European Union (EU) have passed strong equality legislation on disability. The OAS is the first intergovernmental organization to have a binding human rights treaty on disability. In 1999, the *Inter-American Convention on the Elimination of All Forms of Discrimination Against Persons with Disabilities* (IACPWD) [4] was adopted. While it does not contain individual rights, it is the first regional treaty to define disability-based discrimination.

National disability rights movements, which seem to have been able to learn quickly from each other as well as cooperate among themselves at the international level, have been a major driving force behind the above legal changes.

B. INTERNATIONAL HUMAN RIGHTS AND DISABILITY: DEVELOPMENTS WITHIN THE UNITED NATIONS HUMAN RIGHTS MACHINERY

1. Soft Law Policy Developments

Despite being one of the largest minority groups in the world, encompassing 600 million persons (of which two out of three live in developing countries), disabled people had been rather ignored during the first three decades of the United Nations' existence. The drafters of the International Bill of Human Rights did not include disabled persons as a distinct group vulnerable to human rights violations. None of the equality clauses of any of the three instruments comprising this Bill (the *Universal Declaration of Human Rights* (1948), the *International Covenant on Civil and Political Rights* (1966) (ICCPR), and the *International Covenant on Economic, Social and Cultural Rights* (1966) (ICESCR)) mention disability as a protected category.[5] If disability is raised as an issue in

these documents, it is only in connection with social security and preventive health policy.[6 6]

Only in the 1970s, with the promulgation of the *Declaration on the Rights of Mentally Retarded Persons* (1971)[7] and the *Declaration on the Rights of Disabled Persons* (1975),[8] did persons with disabilities become subjects of human rights declarations. Even so, these early instruments still reflect a notion of disability that falls within the medical model, according to which disabled persons are primarily seen as persons with medical problems, dependent on social security and welfare and in need of segregated services and institutions. It was also during this time that the General Assembly clearly affirmed that disabled persons were covered by the "other status" category listed in the equality provisions found in the International Bill of Human Rights.[9]

Throughout the 1970s and the 1980s the General Assembly of the United Nations passed a number of resolutions that eventually led to the 1982 *World Programme of Action Concerning Disabled Persons* (WPA), the guiding instrument for the United Nations Decade of Disabled Persons 1983–1992.[10] The first two goals of the WPA, prevention and rehabilitation, reflected a more traditional approach to disability law and policy, but the third goal, equalization of opportunities, set the scene for change at the international level. "Equalization of opportunities" was defined as:

> the process through which the general system of society, such as the physical and cultural environment, housing and transportation, social and health services, educational and work opportunities, cultural and social life, including sports and recreational facilities, are made accessible to all.[11]

Throughout the decade, the equal rights component of disability policy and law became the main target of the emerging international disability rights movement.

Other major influences that helped to shift the paradigm from the medical to the human rights model of disability were two thematic reports, one on human rights in the field of mental health and one on human rights violations with regard to disabled persons; both prepared by the United Nations Commission on Human Rights.[12] These reports

were the first to recognize disability as a thematic subject within the human rights division of the United Nations, which in turn helped disabled persons to be regarded not only as recipients of charity measures but as subjects of human rights (violations). While one report resulted in a non-binding international human rights instrument aimed at the protection of disabled persons in institutions,[13] the outcome of the other has been rather poor. No significant follow-up activities were taken under the auspices of the United Nations Commission of Human Rights. Other significant guidelines and standards were adopted during the decade,[14] but proposals for a binding treaty on the human rights protection of disabled persons did not find majority support within the 3rd Committee of the General Assembly in either 1987 or 1989, years in which Italy and Sweden respectively raised the possibility of such a convention.

As a compensatory alternative, the General Assembly eventually adopted the non-binding UN *Standard Rules on the Equalization of Opportunities for Persons with Disabilities* (Standard Rules) in 1993.[15] The Standard Rules firmly build on the WPA and clearly accentuates equality, now defined as follows:

> The principle of equal rights implies that the needs of each and every individual are of equal importance, that those needs must be made the basis for the planning of societies and that all resources must be employed in such a way as to ensure that every individual has equal opportunity for participation. Persons with disabilities are members of society and have the right to remain within their local communities. They should receive the support they need within the ordinary structures of education, health, employment and social services.[16]

In contrast with other non-binding international disability instruments, the Standard Rules have a Special Rapporteur and a panel of experts who have been given the mandate to promote and monitor the implementation of the rules. The panel of experts consists of ten representatives from six major international non-governmental organizations in the disability field.[17] Their reports reflect a clear human rights orientation towards monitoring, although the monitoring body was placed under the auspices of the United Nations Commission for Social Development instead of the Commission on Human Rights.[18]

2. Hard Law Developments: Protection under General Human Rights Instruments

Non-governmental organizations which focus on disability have had an increasing impact on how traditional human rights norms are interpreted and implemented, as well as on how modern human rights instruments are being designed.[19] While disability was a forgotten category when the ICCPR and the ICESCR were drafted, these treaties are currently interpreted in a way that supports the human rights approach to disability. General Comment No. 18 to the ICCPR, which deals with the right to equality (ICCPR, Art. 25), clearly rejects the concept of formal equality in the human rights context. The Comment affirms that equal treatment does not always mean identical treatment, and that states have a duty to take steps to eliminate conditions that perpetuate discrimination.[20]

The Committee on Economic, Social and Cultural Rights went even further and adopted a General Comment on how to interpret and implement the ICESCR with respect to persons with disabilities.[21] General Comment No. 5, which the committee adopted in 1994, is the only legal United Nations document to date that broadly defines disability-based discrimination:

> Both de jure and de facto discrimination against persons with disabilities have a long history and take various forms. They range from invidious discrimination, such as the denial of educational opportunities, to more "subtle" forms of discrimination such as segregation and isolation achieved through the imposition of physical and social barriers. For the purpose of the Covenant, "disability-based discrimination" may be defined as including any distinction, exclusion, restriction or preference, or denial of reasonable accommodations based on disability which has the effect of nullifying or impairing the recognition, enjoyment or exercise of economic, social or cultural rights.[22]

The Comment also emphasizes the human rights approach to disability by including a clear demand for anti-discrimination legislation:

> In order to remedy past and present discrimination, and to deter future discrimination, comprehensive anti-discrimination legislation in

> relation to disability would seem to be indispensable in virtually all States parties.[23]

In a similar vein, the Committee on the Elimination of Discrimination Against Women has adopted General Recommendations that ask state parties to include specific information in their reports on the status of disabled women,[24] and has addressed the issue of disability in other thematic recommendations.[25]

More recent human rights treaties, such as the International Convention on the Rights of the Child, also include specific provisions concerning persons with disabilities that reflect a strong human rights approach.[26]

C. THE REFORM PROCESS IN COMPARATIVE LAW

At the domestic level, disability law in many countries underwent significant changes during the last decades. More than 40 out of 189 United Nations member states have now adopted some kind of anti-discrimination law for persons with disabilities.[27]

Most of these anti-discrimination laws were enacted during the last decade, with some countries enacting laws in the 80s. The United States was exceptionally early in adopting the Rehabilitation Act of 1973 as one of its first pieces of anti-discrimination legislation for disabled persons. U.S. law has subsequently been instrumental for the evolution of disability discrimination law in many countries. The Americans with Disabilities Act (ADA) of 1990, in particular, has had such an enormous impact on foreign legal development that one is tempted to say that the international impact of this law is larger than its domestic effect.[28] [28] Another incentive to enact disability discrimination legislation came from the UN *Standard Rules for the Equalization of Opportunities of 1993* (Standard Rules) which states in Rule 15:

> States have a responsibility to create the legal bases for measures to achieve the objectives of full participation and equality for persons with disabilities. . . . States must ensure that organizations of persons

> with disabilities are involved in the development of national legislation concerning the rights of persons with disabilities, as well as in the ongoing evaluation of that legislation. . . . Any discriminatory provisions against persons with disabilities must be eliminated. National legislation should provide for appropriate sanctions in case of violations of the principles of non-discrimination. . . .[29] [29]

The history of disability discrimination law in a number of countries reveal that either the ADA and/or the Standard Rules served as the model law for the development of domestic legislation. With respect to the legal character of the Standard Rules, this finding is an interesting example of the kind of impact a soft law can have internationally if taken seriously by governments.

3. The New Agenda: Towards a New International Treaty on Disability?

The lack of binding human rights law for persons with disabilities at the global level has prompted disability rights activists and scholars to press for the adoption of a new convention on the elimination of discrimination against disabled persons.

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Advocates of this idea recognize that States are reluctant to adopt yet another special human rights treaty. They appreciate the concern that an abundance of current human rights treaty obligations has created "treaty fatigue" in member states that are already burdened by and unable to fulfill their existing reporting obligations.[30]

However, at least six principal arguments can be marshaled in favor of a new treaty on disability rights. First, a new treaty would be a significant advance in the creation of binding law and the ability to take action to prevent disability discrimination. In contrast, the current international standards represent a regime that is little more than a "toothless tiger" when it comes to actual human rights advocacy. Second, a new treaty would legitimize claims for additional attention and resources from the human rights division of the United Nations, governments and other organizations. Third, a treaty on disability rights would provide an opportunity to both add specific content to the human rights of persons with disabilities and address hitherto unexplored areas, such as the right

to be different. In light of recent developments in the area of bioethics and biomedicine concerning the detection and appropriate "treatment" of physiological differences, the right to be different might be as fundamental as the right to equality for persons with disabilities.[31] Fourth, a new treaty would give disability rights organizations a specific tool for promoting human rights for persons with disabilities in domestic contexts and to their own governments. Fifth, a treaty would be a catalyst for empowering and mobilizing the global disability rights movement. Finally, the adoption of a disability treaty would place the disability agenda squarely within the United Nations human rights program. Thus, this step would underscore the fact that disability was primarily a human rights rather than a social welfare issue.

For these reasons, the United Nations, its member States and disability rights organizations should initiate the process for the adoption of an international treaty dealing specifically with the human rights of disabled persons.

Editorial Note: Since the completion of this paper, a number of steps have been taken towards the creation of an international treaty on the rights of persons with disabilities. The following excerpt is taken from the "Introduction" of *Disability Rights Law and Policy: International and National Perspectives*, *supra* at xxiii.

> Responding to increasing pressure from the international disability community, the UN General Assembly, on December 19, 2001, adopted a resolution to create an Ad Hoc Committee "to consider proposals for a comprehensive and integral international convention to protect and promote the rights and dignity of persons with disabilities" – a resolution that was first passed by the General Assembly's Third Committee on November 28, 2001.[32] Momentum towards achieving a convention continues to build this year, with the passage of a *Resolution on a comprehensive and integral international convention to promote and protect the rights and dignity of persons with disabilities* by the Commission for Social Development.[33] The Resolution recommends the adoption of the convention by the UN's high-level Economic and Social Council, including the convention's requirement for ECOSOC to remain apprised of the matter.

[1] There is a large body of literature on this subject. *See*, e.g., Victor Finkelstein, *Attitudes and Disabled People: Issues for Discussion* (New York, World Rehabilitation Fund, 1980); Michael Oliver, *The Politics of Disablement: A Sociological Approach* (London, St. Martin's, 1990); Michael Oliver, *Understanding Disability: From Theory to Practice* (New York, St. Martin's, 1996); Jenny Morris, *Pride Against Prejudice: Transforming Attitudes to Disability* (Philadelphia, New Society, 1991).

[2] *See* United Nations, General Assembly, *Implementation of The World Programme of Action Concerning Disabled Persons; Report of The Secretary-General*, U.N.Doc. A/54/388/Add.1 (1999).

[3] The landmark law being the ADA of the United States. *See Americans with Disabilities Act*, Pub. L. No. 101-336, 104 Stat. 327 (July 26, 1990) [42 U.S.C. § 12101 *et seq.*]. In Canada the 1982 *Canadian Charter of Rights and Freedoms* and the 1985 *Human Rights Act* contain anti-discrimination provisions for disabled persons. *See* Can. Const. (Constitution Act, 1982) pt.1 (Canadian Charter of Rights and Freedoms); The Canadian Human Rights Act, R.S.C., ch. H-6, § 1 (1998) (Can.).

[4] *Inter-American Convention on the Elimination of All Forms of Discrimination Against Persons with Disabilities*, A.G. Res. 1608, 29th Sess., O.E.A. Doc. OEA/Ser. P AG/doc.3826/99 (1999). For the period prior to the new treaty *see* Rodrigo Jiménez, *Los Derechos Humanos de la Personas con Discapacidad* (San José, Costa Rica, INAUD, Programa Mujer, Justicia y Género, Instituto Interamericano de Derechos Humanos, Disabled People International, 1996).

[5] *See Universal Declaration of Human Rights*, G.A. Res. 217 A(II), U.N. Doc. A/810, at 71 (1948) [the *Universal Declaration of Human Rights* may also be viewed *at* http://www.unhcrh.ch/udhr/index.htm, where it is available in most major wold languages]; *International Covenant on Economic, Social and Cultural Rights*, 16 Dec. 1966, 993 U.N.T.S. 3; *International Covenant on Civil and Political Rights*, 17 Dec. 1966, 999 & 1057 U.N.T.S. 171 & 407 respectively.

[6] *See Universal Declaration of Human Rights*, *id*. art. 25; *International Covenant on Economic, Social and Cultural Rights*, *id*. art. 12.

[7] G.A. Res. 2856, U.N. GAOR, 26th Sess., Supp. No. 29, at 93, U.N. Doc. A/8429 (1972).

[8] G.A. Res. 3447, U.N. GAOR, 30th Sess., Supp. No. 34, at 88, U.N. Doc. A/10034 (1976).

[9] For a more comprehensive analysis see Aart Hendriks, "The Significance of Equality and Non-Discrimination for the Protection of the Rights and Dignity of Disabled Persons," *in Human Rights and Disabled Persons: Essays and Relevant Human Rights Instruments* 40-62 (Theresia Degener & Yolan Koster-Dreese eds., Dordrecht, Boston, London, Martinus Nijhoff Publishers, 1995).

[10] G.A. Res. 37/52, U.N. GAOR, 37th Sess., Supp. No. 51, at 185, U.N. Doc. A/37/51 (1983).

[11] United Nations, General Assembly, World Programme of Action Concerning Disabled Persons; Report of the secretary-general: Addendum, at 21, U.N. Doc. A/37/351/Add.1 (1982).

[12] See United Nations, Sub-Commission on Prevention of Discrimination and Protection of Minorities, Principles, Guidelines and Guarantees for the Protection of Persons Detained on Grounds of Mental Ill-Health or Suffering from Mental Disorder; Report by the Special Rapporteur: Mrs. Erica-Irene Daes, U.N. Doc. E/CN.4/Sub.2/1983/17/Rev.1, UnN. Sales No. E.85.XIV.9 (1997); U.N. Sub-Commission on Prevention of Discrimination and Protection of Minorities, Human Rights and Disability: Report by Special Rapporteur: Leandro Despouy, U.N. Doc. E/CN.4/Sub.2/1991/31, U.N. Sales No. E.92.XIV.4 (1993).

[13] *See The Protection of Persons with Mental Illness and the Improvement of Mental Health Care*, G.A. Res. 46/199, U.N. GAOR, 46th Sess., Supp. No. 49, at 188, U.N. Doc. A/46/49 (1992).

[14] See, e.g., The Talline Guidelines for Action on Human Resources Development in the Field of Disability, G.A. Res. 44/70. U.N. GAOR, 44th Sess., Supp. No. 49, Annex, at 196, U.N. Doc. A/44/49 (1990).

[15] *See Standard Rules on the Equalization of Opportunities for Persons with Disabilities*, G.A. Res. 48/96, U.N. GAOR, 48th Sess., Supp. No. 49, Annex at 202-11, U.N. Doc. A/Res/48/49 (1994) [hereinafter *Standard Rules*]. For comment, see Theresia Degener, "Disabled Persons and Human Rights: The Legal Framework," *in Human Rights and Disabled Persons*, *supra* note 9, 9-39, and Bengt Lindqvist, "Standard Rules in the Disability Field –A New United Nations Instrument," *in Human Rights and Disabled Persons*, *id*., 63-68.

[16] *Standard Rules*, *id.*, ¶¶ 24-27, at 204.

[17] The organizations were as follows: Disabled Peoples' International, Inclusion International, Rehabilitation International, World Blind Union, World Federation of the Deaf, and World Federation of Psychiatric Survivors and Users.

[18] See United Nations, General Assembly, Report of the Special Rapporteur of the Commission for Social Development on Monitoring the Implementation of the Standard Rules on the Equalization of Opportunities for Persons with Disabilities, U.N. Doc. A/50/374, Annex at 4 (1995) [first report]; United Nations, General Assembly, Final Report of the Special Rapporteur of the Commission for Social Development on Monitoring the Implementation of the Standard Rules on the Equalization of Opportunities for Persons with Disabilities, U.N. Doc. A/52/56, Annex at 3 (1996) [second report]; United Nations, Economic and Social Council, Final Report of the Special Rapporteur of the Commission for Social Development on Monitoring the Implementation of the Standard Rules on the Equalization of Opportunities for Persons with Disabilities on His Second Missions, 1997-2000, U.N. Doc. E/CN.5/2000/3 (1999) [third report]; see also Dimitris Michailakis, "The Standard Rules: A Weak Instrument and a Strong Commitment," in *Disability, Divers-ability and Legal Change* 117-30 (M. Jones & L.A. Basser Marks eds., Hague, Boston, London, Martinus Nijhoff Publishers, 1999).

[19] While we focus here on the human rights division of the UN, it should be mentioned that specialized international agencies such as WHO, ILO or UNESCO have also taken an equal opportunity approach to disability in recent years. As a strong binding instrument, ILO Convention No. 159, Convention Concerning Vocational Rehabilitation and Employment (Disabled Persons), 1983 is worth mentioning. *See* "Convention No. 159: Convention Concerning Vocational Rehabilitation and Employment (Disabled Persons)," *in International Labor Organization, 2 International Labour Conventions and Recommendations* 1919-1991 (1992). For an overview of the specialized agencies *see* Theresia Degener, "Disabled Persons and Human Rights: The Legal Framework," *supra* note 15, at 20-33.

[20] *See General Comment No. 18, Report of the Human Rights Committee*, U.N. GAOR, 45th Sess., Supp. No. 40, at 175, U.N. Doc. A/45/40 (1990).

[21] *See* Philip Alston, "Disability and the International Covenant on Economic, Social and Cultural Rights," *in Human Rights and Disabled Persons*, *supra* note 9, 94-105.

[22] *General Comment No. 5 (1994) on Persons with Disabilities, Report on the Tenth and Eleventh Sessions*, U.N. ESCOR 1995, Supp. No. 2 [according to U.N Doc. E/1995/22/Corr.1-E/C.12/1994/20/Corr.1], at 102, ¶ 15, U.N. Doc. E/1995/22-E/C.12/1994/20 (1995).

[23] *Id.* ¶ 16.

[24] See General Recommendation No. 18, Report of the Committee on the Elimination of Discrimination Against Women, U.N. GAOR, 46th Sess., Supp. No. 38, at 3, U.N. Doc. A/46/38 (1992).

[25] See, for example, General Recommendation No. 24, Report of the Committee on the Elimination of Discrimination Against Women, U.N. GAOR, 54th Sess., Supp. No. 38, at 6, ¶ 25, U.N. Doc. A/54/38/Rev.1 (1999).

[26] For a discussion of article 23 of the United Nations Convention on the Rights of the Child, see Thomas Hammerberg, "The Rights of Disabled Children–The UN Convention on the Rights of the Child," *in Human Rights and Disabled Persons*, *supra* note 9, 147-158.

[27] We have found anti-discrimination laws in the following countries: Australia, Austria, Bolivia, Brazil, Canada, Chile, China, Costa Rica, Ethiopia, Finland, Fiji, France, Gambia, Germany, Ghana, Greece, Guatemala, Hong Kong (SAR), Hungary, India, Ireland, Israel, Korea, Luxembourg, Madagascar, Malawi, Mauritius, Namibia, New Zealand, Nicaragua, Nigeria, Philippines, South Africa, Spain, Sri Lanka, Sweden, Switzerland, Uganda, United Kingdom, United States, Zambia and Zimbabwe.

[28] Within the US legal literature there is today no consensus on whether the ADA has been successful. See the ADA Symposium Issue: "Backlash Against the ADA," 21 *Berkeley J. Employment Lab. L.* (2000).

[29] *Supra* note 15.

[30] For more on this problematic aspect of human rights implementation, *see* Henry Steiner & Philip Alston, *International Human Rights in Context* at 559 (Oxford, Clarendon Press, 1996).

[31] For more on this issue see Theresia Degener, "Disabled Persons and Human Rights: The Legal Framework," *supra* note 15, at 36; Katarina Tomasevski, "The Right to Health for People with Disabilities," *in Human Rights and Disabled Persons*, *supra* note 9, 131–46.

[32] G.A. Res., 56th Sess. [on the report of the 3rd Committee on the draft resolution concerning a comprehensive and integral international convention to promote and protect the rights and dignity of persons with disabilities (A/56/583/Add.2)], U.N. Doc. A/RES/56/168(2001).

[33] Agenda item 3(b)(ii), adopted at the 40th Sess. of the Committee for Social Development (Feb. 11-27, 2002) available at http://www.un.org/esa/socdev/csd/2002disabilityres(B).htm.

2.2

A CONVENTION ON THE HUMAN RIGHTS OF PEOPLE WITH DISABILITIES

This information is excerpted with permission from the Canadian Council on Disability's CCD International Developments Special Edition for International Human Rights Day 10 December 2002.

People with disabilities and their allies have been aware of the shortcomings of the human rights system for many years. Organizations like Disability Awareness in Action have been profiling human rights abuse of people with disabilities for some time. Discussions at meetings of the International Disability Alliance (IDA), an informal alliance of Disabled Peoples' International, World Federation of the Deaf, World Blind Union, Rehabilitation International, Inclusion International, and World Network of the Users of Psychiatry, helped put the proposed Convention on the international political agenda. Consumers also began to advocate at the national level for changes to the international human rights system.

As a result of these discussions, in December 2001, the UN General Assembly passed the government of Mexico's resolution calling for consideration of a convention on the human rights of people with disabilities. With the passage of this resolution, the UN machinery geared up, setting in motion a variety of preliminary activities. Experts held meetings in regional settings, consumers met, all leading to an ad hoc committee meeting. From 29 July – 9 August 2002, the ad hoc committee met in New York at the United Nations to examine proposals regarding the Convention. Experts and NGOs made arguments in favor of a Convention. They included:

- ***Incresed Profile***—The need to make visible the fact that all human rights are applicable to people with disabilities
- ***Monitoring***—the contributions that a specific Treaty monitoring body focused on human rights can make

- ***Mainstreaming***—a specific Convention will not undermine, but contribute to the mainstreaming of disability in the other six human rights treaties.
- ***Clarification***—a disability convention would clarify states' responsibilities regarding people with disabilities.

At the ad hoc committee meeting there were a variety of viewpoints regarding the content of a Convention. The disability NGOs advocated a Convention that would need to have sufficient scope to ensure that people with disabilities enjoy all human rights: civil, political, economic, social and cultural. The NGOs supported referencing the Standard Rules in a Convention. Consumers advocated an effective monitoring mechanism, one in which consumers and their organizations could lodge complaints. During the meeting of the ad hoc committee, Committee Chairperson Ambassador Luis Gallegos stated that, "In seeking an integrated community and a sense of society for persons with disabilities, one must always look for the universalization of human rights as the aspiration of all mankind."

"In seeking an integrated community and a sense of society for persons with disabilities, one must always look for the universalization of human rights as the aspiration of all mankind."

The Ad Hoc Committee prepared a draft resolution recommended to the General Assembly.

ACTIVITIES SINCE THE AD HOC COMMITTEE MEETING

In October of 2002, people with disabilities from all over the world assembled in Sapporo, Japan, for Disabled Peoples' International's Sixth World Assembly. The conference devoted considerable time to the Convention, and for which delegates expressed strong support.

On 22 November 2002, the United Nation's Third Committee (Social, Humanitarian, Cultural) unanimously approved a resolution for the UN General Assembly directing the ad hoc committee considering the Convention to meet from 16-17 June 2003 at the United Nations. Prior to this the resolution calls for preparatory meetings to take place in each of the five UN regions. The meeting for the Americas Region is expected to take place in the first half of 2003, in Ecuador, while other meetings are being planned in Europe, Africa and the Asia Pacific.

2.3a

AMERICANS WITH DISABILITIES ACT (ADA)

The ADA prohibits discrimination on the basis of disability in employment, State and local government, public accommodations, commercial facilities, transportation, and telecommunications. It also applies to the United States Congress.

To be protected by the ADA, one must have a disability or have a relationship or association with an individual with a disability. An individual with a disability is defined by the ADA as a person who has a physical or mental impairment that substantially limits one or more major life activities, a person who has a history or record of such an impairment, or a person who is perceived by others as having such an impairment. The ADA does not specifically name all of the impairments that are covered.

While the definition of disability has not changed, recent court cases have modified the interpretation. For specific questions related to the ADA please refer to the ADA resources listed at the end of this document.

ADA TITLE I: EMPLOYMENT

Title I requires employers with 15 or more employees to provide qualified individuals with disabilities an equal opportunity to benefit from the full range of employment-related opportunities available to others. For example, it prohibits discrimination in recruitment, hiring, promotions, training, pay, social activities, and other privileges of employment. It restricts questions that can be asked about an applicant's disability

before a job offer is made, and it requires that employers make reasonable accommodation to the known physical or mental limitations of otherwise qualified individuals with disabilities, unless it results in undue hardship. Religious entities with 15 or more employees are covered under title I.

Title I complaints must be filed with the U. S. Equal Employment Opportunity Commission (EEOC) within 180 days of the date of discrimination, or 300 days if the charge is filed with a designated State or local fair employment practice agency. Individuals may file a lawsuit in Federal court only after they receive a "right-to-sue" letter from the EEOC.

Charges of employment discrimination on the basis of disability may be filed at any U.S. Equal Employment Opportunity Commission field office. Field offices are located in 50 cities throughout the U.S. and are listed in most telephone directories under "U.S. Government."

For the appropriate EEOC field office in your geographic area, call:

(800) 669-4000 (voice) (800) 669-6820 (TDD) www.eeoc.gov

US Equal Employment Opportunity Commission (EEOC)'s mission is to eradicate employment discrimination and to increase knowledge about individual rights under the anti-discrimination laws among the public and employee groups. EEOC provides valuable information for employers including information on the employment of individuals with disabilities with small businesses, and the ways in which employer can comply with the ADA.

For information on how to accommodate a specific individual with a disability, call the Job Accommodation Network at:

(800) 526-7234 (voice/TDD) Fax: (304) 293-5407
1-800-ADA-WORK (800) 232-9675 ADA information
E-mail: jan@jan.icdi.wvu.edu Web: www.jan.wvu.edu

Job Accommodation Network (JAN) assists in the hiring, retraining, retention or advancement of persons with disabilities by providing accommodation information. JAN also has a résumé database of qualified job candidates with disabilities.

ADA TITLE II: STATE AND LOCAL GOVERNMENT ACTIVITIES

Title II covers all activities of State and local governments regardless of the government entity's size or receipt of Federal funding. Title II requires that State and local governments give people with disabilities an equal opportunity to benefit from all of their programs, services, and activities (e.g. public education, employment, transportation, recreation, health care, social services, courts, voting, and town meetings).

State and local governments are required to follow specific architectural standards in the new construction and alteration of their buildings. They also must relocate programs or otherwise provide access in inaccessible older buildings, and communicate effectively with people who have hearing, vision, or speech disabilities. Public entities are not required to take actions that would result in undue financial and administrative burdens. They are required to make reasonable modifications to policies, practices, and procedures where necessary to avoid discrimination, unless they can demonstrate that doing so would fundamentally alter the nature of the service, program, or activity being provided.

Complaints of title II violations may be filed with the Department of Justice within 180 days of the date of discrimination. In certain situations, cases may be referred to a mediation program sponsored by the Department. The Department may bring a lawsuit where it has investigated a matter and has been unable to resolve violations.

For more information or to file a complaint, contact:

ADA Information Line – Department of Justice

U.S. Department of Justice
950 Pennsylvania Avenue, NW
Civil Rights Division
Disability Rights Section - NYAVE
Washington, D.C. 20035-6738
(800) 514-0301 (voice) (800) 514-0383 (TDD)
(202) 307-1198 (Fax)
Web: www.usdoj.gov/crt/ada/adahom1.htm

The US Department of Justice provides information on general and technical assistance regarding the ADA. A toll-free ADA Information Line allows organizations to ask about ADA requirement, order free ADA materials, and obtain information about filing a complaint.

Title II may also be enforced through private lawsuits in Federal court. It is not necessary to file a complaint with the Department of Justice (DOJ) or any other Federal agency, or to receive a "right-to-sue" letter, before going to court.

ADA TITLE II: PUBLIC TRANSPORTATION

The transportation provisions of title II cover public transportation services, such as city buses and public rail transit (e.g. subways, commuter rails, Amtrak). Public transportation authorities may not discriminate against people with disabilities in the provision of their services. They must comply with requirements for accessibility in newly purchased vehicles, make good faith efforts to purchase or lease accessible used buses, remanufacture buses in an accessible manner, and, unless it would result in an undue burden, provide paratransit where they operate fixed-route bus or rail systems. Paratransit is a service where individuals who are unable to use the regular transit system independently (because of a physical or mental impairment) are picked up and dropped off at their destinations.

Questions and complaints about public transportation should be directed to:

Federal Transit Administration
U.S. Department of Transportation
400 Seventh Street, S.W.
Washington, D.C. 20590
Information, questions and complaints:
(888) 446-4511 (voice/relay) (202) 366-2285 (voice)
(202) 366-0153 (TDD)

Documents and Questions:
(202) 366-1656 (voice/relay)
Legal Questions:
(202) 366-4011 (voice/relay)

ADA TITLE III: PUBLIC ACCOMMODATIONS

Title III covers businesses and nonprofit service providers that are public accommodations, privately operated entities offering certain types of courses and examinations, privately operated transportation, and commercial facilities. Public accommodations are private entities who own, lease, lease to, or operate facilities such as restaurants, retail stores, hotels, movie theaters, private schools, convention centers, doctors' offices, homeless shelters, transportation depots, zoos, funeral homes, day care centers, and recreation facilities including sports stadiums and fitness clubs. Transportation services provided by private entities are also covered by title III.

Public accommodations must comply with basic nondiscrimination requirements that prohibit exclusion, segregation, and unequal treatment. They also must comply with specific requirements related to architectural standards for new and altered buildings; reasonable modifications to policies, practices, and procedures; effective communication with people with hearing, vision, or speech disabilities; and other access requirements. Additionally, public accommodations must remove barriers in existing buildings where it is easy to do so without much difficulty or expense, given the public accommodation's resources.

Courses and examinations related to professional, educational, or trade-related applications, licensing, certifications, or credentialing must be provided in a place and manner accessible to people with disabilities, or alternative accessible arrangements must be offered.

Commercial facilities, such as factories and warehouses, must comply with the ADA's architectural standards for new construction and alterations.

A public accommodation that provides transportation services, but that is not primarily engaged in the business of transporting people, is subject to the general and specific provisions in Title III. Examples of transportation services subject to this section include, but are not limited to, shuttle services operated between transportation terminals and places of public accommodation, customer shuttle bus services operated by private companies and shopping centers, student transportation systems, and transportation provided within recreational facilities such as stadiums, zoos, amusement parks, and ski resorts.

Complaints of title III violations may be filed with the Department of Justice. In certain situations, cases may be referred to a mediation program sponsored by the Department. The Department is authorized to bring a lawsuit where there is a pattern or practice of discrimination in violation of title III, or where an act of discrimination raises an issue of general public importance. Title III may also be enforced through private lawsuits. It is not necessary to file a complaint with the Department of Justice (or any Federal agency), or to receive a "right-to-sue" letter, before going to court.

For more information or to file a complaint, contact:

U.S. Department of Justice
950 Pennsylvania Avenue, NW
Civil Rights Division
Disability Rights Section - NYAVE
Washington, D.C. 20035-6738

(800) 514-0301 (voice) (800) 514-0383 (TDD)
(202) 307-1198 (Fax)
Web: www.usdoj.gov/crt/ada/adahom1.htm

ADA TITLE IV: TELECOMMUNICATIONS

Title IV addresses telephone and television access for people with hearing and speech disabilities. It requires common carriers (telephone companies) to establish interstate and intrastate telecommunications relay services (TRS) 24 hours a day, 7 days a week. TRS enables callers with

hearing and speech disabilities who use text telephones (TTY's or TDD's), and callers who use voice telephones, to communicate with each other through a third party communications assistant. The Federal Communications Commission (FCC) has set minimum standards for TRS services. Title IV also requires closed captioning of Federally funded public service announcements.

For more information about TRS, contact the FCC at:

Federal Communications Commission
445 12th Street, SW
7th Floor
Washington, D.C. 20554

Documents: (202) 857-3800 (voice) (202) 293-8810 (TDD)
Questions: (202) 418-0976 (voice) (202) 418-0484 (TDD)

Myths and Facrs About the Americans with Disabilities Act

MYTH: ADA suits are flooding the courts.

FACT: The ADA has resulted in a surprisingly small number of lawsuits — only about 650 nationwide in five years. That's tiny compared to the 6 million businesses; 666,000 public and private employers; and 80,000 units of state and local government that must comply.

MYTH: The ADA is rigid and requires businesses to spend lots of money to make their existing facilities accessible.

FACT: The ADA is based on common sense. It recognizes that altering existing structures is more costly than making new construction accessible. The law only requires that public accommodations (e.g. stores, banks, hotels, and restaurants) remove architectural barriers in existing facilities when it is "readily achievable", i.e., it can be done "without much difficulty or expense." Inexpensive, easy steps to take include ramping one step; installing a bathroom grab bar; lowering a paper towel dispenser; rearranging furniture; installing offset hinges to widen a doorway; or painting new lines to create an accessible parking space.

MYTH: The government thinks everything is readily achievable.

FACT: Not true. Often it may not be readily achievable to remove a barrier — especially in older structures. Let's say a small business is located above ground. Installing an elevator would not, most likely, be readily achievable — and there may not be enough room to build a ramp — or the business may not be profitable enough to build a ramp. In these circumstances, the ADA would allow a business to simply provide curbside service to persons with disabilities.

MYTH: The ADA requires businesses to remove barriers overnight.

FACT: Businesses are only required to do what is readily achievable at that time. A small business may find that installing a ramp is not readily achievable this year, but if profits improve it will be readily achievable next year. Businesses are encouraged to evaluate their facilities and develop a long-term plan for barrier removal that is commensurate with their resources.

MYTH: Restaurants must provide menus in braille.

FACT: Not true. Waiters can read the menu to blind customers.

MYTH: The ADA requires extensive renovation of all state and local government buildings to make them accessible.

FACT: The ADA requires all government programs, not all government buildings, to be accessible. "Program accessibility" is a very flexible requirement and does not require a local government to do anything that would result in an undue financial or administrative burden. Local governments have been subject to this requirement for many years under the Rehabilitation Act of 1973. Not every building, nor each part of every building needs to be accessible. Structural modifications are required only when there is no alternative available for providing program access. Let's say a town library has an inaccessible second floor. No

elevator is needed if it provides "program accessibility" for persons using wheelchairs by having staff retrieve books.

MYTH: Sign language interpreters are required everywhere.

FACT: The ADA only requires that effective communication not exclude people with disabilities which in many situations means providing written materials or exchanging notes. The law does not require any measure that would cause an undue financial or administrative burden.

MYTH: The ADA forces business and government to spend lots of money hiring unqualified people.

FACT: No unqualified job applicant or employee with a disability can claim employment discrimination under the ADA. Employees must meet all the requirements of the job and perform the essential functions of the job with or without reasonable accommodation. No accommodation must be provided if it would result in an undue hardship on the employer.

MYTH: Accommodating workers with disabilities costs too much.

FACT: Reasonable accommodation is usually far less expensive than many people think. In most cases, an appropriate reasonable accommodation can be made without difficulty and at little or no cost. A recent study commissioned by Sears indicates that of the 436 reasonable accommodations provided by the company between 1978 and 1992, 69% cost nothing, 28% cost less than $1,000, and only 3% cost more than $1,000.

MYTH: The government is no help when it comes to paying for accessibility.

FACT: Not so. Federal tax incentives are available to help meet the cost of ADA compliance.

MYTH: Businesses must pay large fines when they violate the ADA.

FACT: Courts may levy civil penalties only in cases brought by the Justice Department, not private litigants. The Department only seeks such penalties when the violation is substantial and the business has shown bad faith in failing to comply. Bad faith can take many forms, including hostile acts against people with disabilities, a long-term failure even to inquire into what the ADA requires, or sustained resistance to voluntary compliance. The Department also considers a business' size and resources in determining whether civil penalties are appropriate. Civil penalties may not be assessed in cases against state or local governments or employers.

MYTH: The Justice Department sues first and asks questions later.

FACT: The primary goal of the Department's enforcement program is to increase voluntary compliance through technical assistance and negotiation. Under existing rules, the Department may not file a lawsuit unless it has first tried to settle the dispute through negotiations — which is why most every complaint settles.

MYTH: The Justice Department never files suits.

FACT: The Department has been party to 20 suits under the ADA. Although it tries extensively to promote voluntary compliance, the Department will take legal action when entities continue to resist complying with the law.

MYTH: Many ADA cases involve frivolous issues.

FACT: The Justice Department's enforcement of the ADA has been fair and rooted in common sense. The overwhelming majority of the complaints received by the Justice Department have merit. Our focus is on fundamental issues related to access to goods and services that are basic to people's lives. We have avoided pursuing fringe and frivolous issues and will continue to do so.

MYTH: Everyone claims to be covered under the ADA.

FACT: The definition of "individual with a disability" is fraught with conditions and must be applied on a case-by-case basis.

MYTH: The ADA protects people who are overweight.

FACT: Just being overweight is not enough. Modifications in policies only must be made if they are reasonable and do not fundamentally alter the nature of the program or service provided. The Department has received only a handful of complaints about obesity.

MYTH: The ADA is being misused by people with "bad backs" and "emotional problems."

FACT: Trivial complaints do not make it through the system. And many claims filed by individuals with such conditions are not trivial. There are people with severe depression or people with a history of alcoholism who are judged by their employers, not on the basis of their abilities, but rather upon stereotypes and fears that employers associate with their conditions.

For an analysis of the ADA and it application to US organizations operating outside of the United States please read: Kanter, Arlene S., "Taking it on the Road – The Presumption against Extraterritoriality as applied to Study Abroad Programs," Stanford Journal of Legislation and Policy (forthcoming 2003).

2.3b

HOW DO THE ADA AND THE OTHER DISABILITY RIGHTS LAWS APPLY TO INTERNATIONAL DEVELOPMENT ORGANIZATIONS' OPERATIONS IN THE US AND ABROAD?

The following information is excerpted from Gender and Disability: A Survey of InterAction Member Agencies. Findings and Recommendations on Inclusion of Women and Men with Disabilities in International Development Programs; Mobility International USA (MIUSA); T. Singleton, ML Breslin, C. Lewis

Two primary federal disability-rights laws apply to US-based international development organizations. Section 504 of the 1973 Rehabilitation Act, modeled after the 1964 Civil Rights Act, prohibits discrimination against people with disabilities by programs that receive federal financial assistance. This law applies to all employment practices, regardless of the number of people who work for the organization. The Americans with Disabilities Act (ADA) contains almost the same requirements but applies to most public and private entities regardless of whether they receive federal financial assistance. The ADA prohibits employment discrimination by organizations that employ fifteen or more employees. Other state laws can also apply.

In addition to employment practice, the ADA and 504 also apply to programs operated in the US by international development organizations. Section 504 sets forth specific circumstances under which architectural and program accessibility are required, and requires modification of discriminatory policies and practices. The ADA applies architectural accessibility and accommodation requirements to programs operated in the US, including accommodations to assure effective communication for individuals with speech, language, hearing or cognitive disabilities. Both laws apply to services or programs provided in the US by development organizations through contract with other organizations or vendors.

For an analysis of the ADA and it application to US organizations operating outside of the United States please read: Kanter, Arlene S., "Taking it on the Road—The Presumption against. Extraterritoriality as applied to Study Abroad programs," Stanford Journal of Legislation and Policy (forthcoming 2003).

ADA RESOURCES:

ADA Regulations and Technical Assistance Materials:
http://www.usdoj.gov/crt/ada/publicat.htm#Anchor-14210

ADA Technical Assistance Program:
http://www.adata.org/

Information for Individuals and Communities:
http://www.usdoj.gov/disabilities.htm

U.S. Department of Justice ADA:
http://www.usdoj.gov/crt/ada/adahom1.htm

Disability Rights Education and Defense Fund (DREDF)
www.dredf.org

For further information on disability rights law and policy from both national and international perspectives contact:

Disability Rights Education and Defense Fund (DREDF)
2212 Sixth Street, Berkeley CA 94710 USA
Phone: (510) 644-2555
Fax: (510) 841-8645
TDD/TTY: (510) 644-2555
Email: dredf@dredf.org
Website: http://www.dredf.org

A full description of DREDF is found on the resource pages of this legal policies section.

2.3c

AIR CARRIERS ACT

International development organizations rely heavily on air travel as a means of transport. When organizations invite people with disabilities to participate in events, or send staff and consultants with disabilities on assignments that require air travel, it is important to be aware of the rights of travelers with disabilities. This section will discuss the Air Carriers Access Act of 1986, which prohibits airlines from discriminating on the basis of disability and affects seating and accessible facilities in terminals and aboard aircraft. The US law applies to all US air carrier companies whether on a domestic or international flight. This law does not apply to airlines from other countries. It is important for people with disabilities on staff, or staff people responsible for making travel arrangements, to check on accessibility and other travel issues in advance of the trip.

The following summary of the **Air Carriers Act** is available at www.disabilitytravel.com.
The Air Carrier Access Act prohibits discrimination on the basis of disability in air travel and requires air carriers to accommodate the needs of passengers with disabilities. In 1990, The Department of Transportation issued a rule defining the rights of passengers and the obligations of air carriers under this law. The following is a summary of the main points of the DOT rule (Title 14 CFR, Part 382).

Prohibitions of Discriminatory Practices

* Carriers may not refuse transportation to people on the basis of disability. Airlines may exclude anyone from a flight if carrying the person

would be inimical to the safety of the flight. If a carrier excludes a handicapped person on safety grounds, the carrier must provide the person a written explanation of the decision.

* Airlines may not require advance notice that a person with a disability is traveling. Carriers may require up to 48 hours' advance notice for certain accommodations that require preparation time (e.g., respirator hook-up, transportation of an electric wheelchair on an aircraft with less than 60 seats).

* Carriers may not limit the number of handicapped persons on a flight.

* Carriers may not require a person with a disability to travel with an attendant, except in certain limited circumstances specified in the rule. If the person with the disability and the carrier disagree about the need for an attendant, the airline can require the attendant, but cannot charge for the transportation of the attendant.

Accessibility of Facilities

* New aircraft (planes ordered after April 5, 1990 or delivered after April 5, 1992) with 30 or more seats must have movable aisle armrests on half the aisle seats in the aircraft.

* New wide body (twin-aisle) aircraft must have accessible lavatories. DOT is continuing to seek more data on accessible lavatories for smaller aircraft.

* New aircraft with 100 or more seats must have priority space for storing a passenger's folding wheelchair in the cabin.

* Aircraft with more than 60 seats and an accessible lavatory must have an on-board wheelchair, regardless of when the aircraft was ordered or delivered. For flights on aircraft with more than 60 seats that do not have an accessible lavatory, carriers must place an on-board wheelchair on the flight if a handicapped passenger gives the airline 48 hours' notice that he or she can use an inaccessible lavatory but needs an on-board wheelchair to reach the lavatory.

* Airport facilities owned or operated by carriers must meet the same accessibility standards that apply to federally assisted airport operators.

RESOURCES:

For more information about traveling abroad with a disability see:

Survival Strategies for Going Abroad: A Guide for People With Disabilities,
Mobility International USA.
Mobility International USA (MIUSA)
PO Box 10767
Eugene, OR 97440
(541) 343-1284 (V/TTY)
(541) 343-6812 (fax)
Visit the website at www.miusa.org, or write to info@miusa.org.

For further information about the Air Carriers Act and the latest updates contact:

Paralyzed Veterans of America
801 Eighteenth Street, NW
Washington, DC 20006-3517
Visit the website at www.pva.org or write to info@pva.org.

If you feel you have been discriminated against while traveling, contact a complaints resolution official (CRO) official at the airport as well as the airline. In addition, for further information or if you believe that an airline has violated the law you may contact:

Department of Transportation
Office of Consumer Affairs
400 7th St. SW, Room 10454
Washington, DC 20590
Phone (202) 366-2220 (voice) or (202) 755-7687 (TDD

2.4

RESOURCES AVAILABLE

Disability and Business Technical Assistance Centers (DBTACs)
Tel: 1 (800) 949-4232 (V/TTY)
Web: www.adata.org/dbtac.html

The National Institute on Disability and Rehabilitation Research (NIDRR) has established ten regional centers to provide information, training, and technical assistance to employers, people with disabilities, and other entities with responsibilities under the ADA. The centers act as a "one-stop" central, comprehensive resource on ADA issues in employment, public services, public accommodations, and communications. Each center works closely with local business, disability, governmental, rehabilitation, and other professional networks to provide ADA information and assistance. Programs vary in each region, but all centers provide the following:
technical assistance, education and training, materials dissemination, information and referral, public awareness, and local capacity building.

Disability Rights Education and Defense Fund (DREDF)
Contact: Susan Henderson
2212 Sixth Street
Berkeley, CA 94710 USA
Tel: (510) 644-2555 or (800) 348-4232
TTY: (510)- 644-2555
E-mail: dredf@dredf.org
Web: http://dredf.org

The Disability Rights Education and Defense Fund (DREDF) was established on October 1, 1979 in Berkeley, California. A nonprofit national law and policy center run primarily by people with disabilities and parents of children with disabilities, DREDF is dedicated to protecting and advancing the civil and human rights of people with disabilities through law and policy development, litigation, advocacy, technical assistance, and the education and training of attorneys, advocates, persons with disabilities and parents of children with disabilities. DREDF serves as one of the disability community's primary national legal defense organizations.
With offices in Berkeley and Washington, DREDF has approximately 20 staff members, the majority of whom are people with disabilities or parents of children with disabilities.

DREDF has been a national leader in developing federal disability civil rights laws and policies, most notably the landmark 1990 Americans with Disabilities Act, and enforcing these policies through litigation in the United States. DREDF has also forged alliances with disability organizations around the world and has consulted on disability policy and programs in 17 countries, including Costa Rica, Bosnia, Vietnam, New Zealand, Ecuador, South Africa, and Japan. The DREDF website houses a listing of international disability laws worldwide and DREDF is developing an Internet-based International Clearinghouse on Disability Law and Policy. In 2002, DREDF published *Disability Law and Policy: International and National Perspectives*, the first comprehensive analysis of global disability rights.

UN Special Rapporteur on Disabilities
Bengt Lindqvist
Spektern, S-103 33
Stockholm, Sweden
Tel: (46) 8 405 2421, or (46) 8 405 1768
E-mail: un-spec.rapp@telia.com
Web: www.disability-rapporteur.org/index.htm

The United Nations Standard Rules on the Equalization of Opportunities for Persons with Disabilities were adopted by the UN General Assembly in 1993. In the last chapter of the Rules - Monitoring Mechanism – it is

indicated that a monitoring mechanism should be established. "A Special Rapporteur with relevant and extensive experience in disability issues and international organizations shall be appointed."

The purpose of the monitoring is to further the implementation by member states of the Standard Rules. The Special Rapporteur goes on missions to individual countries and participates in various forms of seminars, workshops and conferences, promoting the implementation of the rules. The Special Rapporteur shall seek to establish a direct dialogue not only with states but also with local non-governmental organizations.

GOVERNANCE

3

3

GOVERNANCE

"Written organizational policy on inclusion of women and men with disabilities in organizational structures and in staff and board composition, fully integrated into organization's plans and operations." (InterAction PVO Standards, Amendment 2.6.3)

"Increased number of people with disabilities in senior decision-making positions at headquarters, in the field and on boards of directors." (Reference: Amendment 6.4.3.1)

"Mechanisms established with a mandate from the CEO to promote and monitor the inclusion of people with disabilities in programs." (Reference: Amendment 7.4.1)

CEO AND SENIOR STAFF COMMITMENT

Commitment at the executive level is essential for an organization's successful implementation of standards on gender and disability-based inclusion. CEO mandates communicate that inclusion of women and people with disabilities are priorities to which organizational time and resources will be dedicated. Each CEO of MIUSA's five Model Partner Organizations marked the inauguration of the *Building an Inclusive Development Community* partnership with a clear and passionate statement of commitment to the inclusion of people with disabilities.

Leadership by departmental directors, program managers and other senior staff is essential for establishing departmental commitments to inclusion. Program heads of MIUSA's five Model Partner Organizations issued written and oral statements of commitment to each department, and provide ongoing guidance to department staff to create and execute action plans to meet organizational standards for inclusion of people with disabilities.

Suggestions for senior level actions to promote inclusion of people with disabilities include:

"Add 'reasonable accommodation' as a line item in the organizational budget and in all program and project budgets to provide funds for including people with disabilities."

- Produce and disseminate an organizational statement signed by the CEO endorsing gender-appropriate policy on inclusion of people with disabilities in administration, governance and programs.
- Review and revise organizational policies addressing all areas including hiring, employment, program, partnership, contractors, facilities, materials, communications and public relations, to make sure they are inclusive of persons with disabilities,
- Allot time and resources to full integration of organizational policies on disability inclusiveness.
- Include information about the organization's policies on disability inclusiveness and the impact of the policies during presentations on the organization's programs and projects.
- Add "reasonable accommodation" as a line item in the organizational budget and in all program and project budgets to provide funds for including people with disabilities.
- Ensure that new building and facilities are designed according to universal design principles.

BEST PRACTICE: GOVERNANCE

The following statement from John Williams then-CEO of Holt International Children's Service, provides a vibrant example of leadership for inclusion. MIUSA thanks Holt for allowing us to reprint (and modify to make generic) this letter.

EXAMPLE CEO ENDORSEMENT LETTER

May 16, 2003

Dear,

The purpose of this letter is to enthusiastically endorse the new technical assistance project of Mobility International USA (MIUSA) entitled Building an Inclusive Development Community: Gender Appropriate Technical Assistance to InterAction Member Agencies on Inclusion of People with Disabilities. This project is made possible thanks to a grant awarded to MIUSA by the United States Agency for International Development (USAID).

When I was first contacted about this project by MIUSA's executive director, Susan Sygall, I was immediately interested in becoming one of the model partner organizations. However, it wasn't until the first official training session that was recently conducted by Susan and members of the MIUSA staff that I truly began to appreciate the benefits that will come to our organization and those whom we serve through our participation in this project.

In so many ways our organization and MIUSA are about empowerment. Both are about enabling people to reach their own full potential. MIUSA has challenged us to envision a higher level of opportunity and involvement for persons with disabilities in our development programming and projects.

Through this project MIUSA is creating greater worldwide awareness of the capabilities of persons with disabilities. By promoting opportunities for persons with disabilities, not only as recipients of services but as participants at all levels from the formulation of policies on Boards to deliverers of direct service in the workforce, they are not only expanding the horizons of disabled people; they are creating a better world for us all.

I look forward to working with MIUSA on this project as a model partner over the next few years, both here in the United States and overseas. I wholeheartedly commend Mobility International USA for its vision to create a better world in which everyone benefits from the inclusion of people with disabilities at all levels of our world community.

Sincerely,

EXAMPLES OF ORGANIZATIONAL POLICIES

The American Friends Service Committee's Affirmative Action Plan provides a clear example of an organizational policy that values diversity and recognizes disability as a part of diversity.

BEST PRACTICE: GOVERNANCE

The following information is excerpted from the American Friends Service Committee (AFCS) Affirmative Action Plan. MIUSA thanks AFSC for allowing us to reprint this excerpt.

THE SIX AFSC AFFIRMATIVE ACTION POLICIES

The AFSC Affirmative Action Policies are listed below. Each policy is stated and is immediately followed by its rationale and/or implications.

Policy on equal opportunity:

It is the policy of the AFSC to provide equality of opportunity in employment, participation on committees, and other activities. Therefore, the AFSC will not exclude people on the basis of the following group associations when these are unrelated to their capacity to perform the job and to forward the work and programs of the AFSC: race, color, gender, class/caste/economic status, sexual orientation, religious affiliation, ethnicity, education level, family or marital status, immigration or refugee status, language or accent, nationality, age (younger/older), cognitive or physical disability, previous criminal record, or resistance to military involvement.

This policy means that the AFSC will consider people on their merits and for their capacities to do what is expected or required of them.

Policy on employment and committees:

It is the policy of the AFSC to ensure the presence and participation of persons in the groups covered by this Plan throughout all levels of employment and committees.

In the process of responding to Quaker concerns, the AFSC has drawn on many others who share Friends' values and express them through AFSC. Ever since its establishment, the AFSC has continually reached out to find persons to serve on its staff and committees. Our objective is to include persons in sympathy with the beliefs, testimonies, and practices of the AFSC who would not otherwise have the opportunity to be involved.

The AFSC employees and volunteers are expected to feel as members of the AFSC family who share in its mission. As a "spirit-led" organization the AFSC must provide for continuing employee and volunteer satisfaction. The AFSC must provide a healthy, respectful and mutually supportive atmosphere for all employees and volunteers, but especially those from oppressed groups. When these expectations are realized they help to create an atmosphere of commitment, understanding, mutual support and effectiveness.

Policy on programs:

It is the policy of the AFSC to include people from the groups covered by this Plan in program development, program constituencies, mid-program reviews and evaluations, consideration of program devolvement, and evaluations of the range and balance of AFSC programs as priorities are determined.

The AFSC seeks to respond to human needs. Its programs are the organized expression of the response. Affirmative action in program design and execution rests on the twin assumptions that AFSC'S programs will be strengthened if they reach out to broader constituencies and that making our work on issues of peace and justice more relevant to a broader range of people will expand our perspectives, draw in new constituencies, and broaden the base of people working for positive social change.

Policy on coalitions:

It is the policy of the AFSC to encourage coalitions in which we participate to have active affirmative action practices.

The AFSC'S formal participation in coalitions, where the AFSC name is used, must be approved by the Board, regional, or unit executive

committees. The AFSC should encourage our coalition partners to comply with our affirmative action standards. Our affirmative action plan can be important in raising issues about composition, inclusiveness, and leadership which might otherwise be overlooked. When coalitions decide not to meet or exceed our affirmative action goals for people from groups covered by this Plan, the AFSC must decide whether the coalition's work is sufficiently vital to continue our participation and, if so, under what terms.

Policy on contractors:

It is the policy of the AFSC to place AFSC business with corporations, contractors, banks, and other business establishments owned and/or controlled by persons in the groups covered by this Plan, or those having an active affirmative action plan.

"Recognizing the essential right of all persons to be treated as individuals, one of AFSC'S goals in affirmative action is the involvement of disabled persons in all parts and levels of the organization."

The AFSC affirms its commitment to affirmative action in contractual relationships. The AFSC must do some business with firms, institutions, contractors, sub-contractors, or other entities (all herein referred to as contractors), that have an effective diversity and inclusion plan in operation or that are owned or controlled by persons in the groups covered by this Plan.

Policy on facility accessibility:

It is the policy of the AFSC to ensure that all facilities utilized by the AFSC are barrier-free and accessible to disabled persons.

The AFSC recognizes the tendency to segregate and hide people with disabilities from the mainstream of society. We support the efforts of those with disabilities to be productive members of society. We value the contributions of disabled individuals to the work of the AFSC as committee members and volunteers. Recognizing the essential right of all persons to be treated as individuals, one of AFSC'S goals in affirmative action is the involvement of disabled persons in all parts and levels of the organization. To further that goal, any building or facility constructed, purchased, or newly leased by the AFSC must be accessible to disabled persons.

BOARD AND SENIOR STAFF DIVERSITY

Inclusive development practice requires that development agencies promote opportunities for people with disabilities to take leadership in governance, management and service delivery, as well as participating in programs and services. "*Nothing about us without us*," the rallying call of disability rights movements around the world, serves notice that people with disabilities insist not only on the right to participate, but also to be seated at the decision-making table.

Diversity among Board members is widely endorsed as an important tool for increasing inclusionary practice throughout an organization, and for ensuring that the voices of a diverse constituency are reflected in management and services. InterAction's Commission for the Advancement of Women (CAW) provides technical assistance and training for increasing the participation of women and people with disabilities, on boards of directors. CAW offers resources for use by InterAction member agencies to promote gender equity, including referrals provided by MIUSA to prominent women with disabilities with international experience who may be willing to serve as Board Members. Responsibility lies with InterAction members to use these and other such resources to assure Board diversity.

"Nothing about us without us," the rallying call of disability rights movements around the world, serves notice that people with disabilities insist not only on the right to participate, but also to be seated at the decision-making table."

Organizations seeking to increase participation of people with disabilities in governance and administration need to explore new avenues and mechanisms for recruitment and for promoting an organizational culture that is "disability-positive." Suggestions include:

- Use magazines and websites frequented by people with disabilities for hiring and Board recruitment. (See the Recruiting and Accommodating Qualified People with Disabilities chapter in the first section of this manual).
- Ensure that sufficient and appropriate opportunities for professional development and career advancement are available to people with disabilities in your organization.
- Portray positive images of people with disabilities throughout your

organization and in the materials that represent your organization.

- Include images of women and men with disabilities as staff members, volunteers or contributors as well as beneficiaries in annual reports, brochures and on websites.
- When posting job announcements, use non-discriminatory but disability-positive phrases such as "persons with disabilities and others encouraged to apply."
- Communicate a strong positive message about inclusion of people with disabilities in organizational materials by indicating that your facilities are wheelchair accessible.
- Send the message that your organization values people who are deaf, hearing impaired or have other disabilities that affect communication, by ensuring that your organization has a TTY (tele-typewriting device) and that staff are consistently able to use it. List the TTY number in your brochures. (See the Accessible Communication chapter in the Access section of this manual.)
- Convey respect for and value people with disabilities who have visual or information processing disabilities by providing organizational materials available in alternative formats, including on diskette, in large print or Braille or on audiocassette. (See the Alternative Formats chapter in the first section of this manual.)
- Once a person with a disability is hired, request information from the individual about accommodations that will best support that person to work most efficiently. (See the Reasonable Accommodation chapter and the Office Accessibility chapter of the first section of this manual.)

For more information on human resource issues, including recruitment and hiring, see the Management Practices and Human Resource Development section (first section) of this manual and MIUSA's Human Resources Toolbox, which is available on MIUSA's website (www.miusa.org).

BEST PRACTICE: GOVERNANCE

NGO policy

The Swedish Disabled International Aid Association (SHIA) promotes a rights-based approach to sustainable development for persons with disabilities through an emphasis on satisfying five basic principles:

1. ***Social Protection:*** People with disabilities should have access to basic social protection, defined as housing, health care, rehabilitation services and access devices.

2. ***Accessibility:*** People with disabilities should have access to education, credit, information, and income earning opportunities.

3. ***Consciousness:*** People with disabilities are conscious of their own needs and rights. They are aware of the consequences of neglecting and discriminating attitudes in the society.

4. ***Influence:*** People with disabilities are entitled to have equal opportunities to influence decision and policy making through processes of participation.

5. ***Control:*** People with disabilities are entitled to take initiatives to assert their influence, and promote awareness of their rights. This enables increased control over the distribution of resources and benefits.

SHIA seeks to advance these principles through support to the development and strengthening of organizations of disabled people in developing countries. It prioritizes programmes that enable people with disabilities to speak for themselves and which, in turn, strengthen their human rights.

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Department for International Development, 2000

ACCESSIBILITY

4

4.1

WHEELCHAIRS AS AN EXAMPLE OF APPROPRIATE ASSISTIVE TECHNOLOGY AND APPROPRIATE MATERIAL AID

Making sure assistive technology is appropriate means checking to make sure the technology is: **affordable** (if only the wealthy are able to afford the device, it will have limited impact in people's lives and on development); **accessible** (if acquiring the assistive device entails a complicated application process, a long trip, or the acquisition of a foreign currency money order, few people will be able to make use of the device); **low maintenance** (if maintaining the device requires specialized knowledge and training that is not available or not provided by the manufacturer, the device will have a limited life of usability); **reparable locally** (if the device must be shipped away for repair because spare parts are not available locally or because no one locally knows how to do the repair work, the device will sit in the corner to collect dust, sometimes for want of something as simple as a screw).

Appropriate assistive technologies around the world consist of a wide variety of devices from solar powered hearing aids to adapted well pumps, from information communication technology to artificial limbs. The following article by Marc Krizack discusses one such device – wheelchairs. It is estimated that twenty million people in developing countries need a wheelchair and do not have one. Looking more closely at one example of appropriate assistive technology and its implications for appropriate material aid allows us to examine at a deeper level the implications for development and practical solutions to people's problems.

"It is estimated that twenty million people in developing countries need a wheelchair and do not have one."

IT'S NOT ABOUT WHEELCHAIRS

By Marc Krizack
Disability Policy and Planning International

People wanting to provide wheelchairs to those in developing countries who need them are most often guided by their hearts. The problem, however, is vast and complex, and unfortunately, things are not always as simple as they appear.

"Providing free wheelchairs is likely to be a waste of money without there being a system or mechanism in place (both in the U.S. and in the target country) to ensure that only good quality wheelchairs will be sent and that they will be appropriate for each person who will use them."

Many well-intentioned people donate old hospital-style wheelchairs that granny used before she died to one or another charitable organization which more likely than not merely stuffs them into a container paid for under U.S. humanitarian assistance. Many, many chairs still need to be refurbished upon arrival, and will sit collecting dust and rust in some warehouse or storage yard waiting in vain for a local volunteer to clean them up and repair them. Those in good condition are not accompanied by instructions or spare parts to keep them in working order, so even if they start out being usable, they soon end up collecting dust or rusting away like the others. Providing free wheelchairs is likely to be a waste of money without there being a system or mechanism in place (both in the U.S. and in the target country) to ensure that only good quality wheelchairs will be sent and that they will be appropriate for each person who will use them.

Providing wheelchairs is not about wheelchairs. It is about integrating people with disabilities into their society. As long as wheelchair donors focus on the wheelchair and not on the end user, people with disabilities will remain dependent and unproductive, a drain on society's resources. When the needs of the end user are considered first, the most appropriate wheelchair (not merely the cheapest) can be provided, and with other targeted assistance, the wheelchair rider can go to school, get a job, and become a net contributor to society.

The underlying problem is that the usual market forces are not present in any significant way when it comes to the purchase of wheelchairs in developing countries. The end user most often cannot afford to pay for his or her wheelchair. The market for wheelchairs is made primarily by

government agencies, development organizations, and charitable and religious institutions. Historically, the end user has been a mere object of charity, with unfortunate human and economic consequences. People who could be active with the right wheelchair for their situation receive an inappropriate chair that does not provide any significant improvement in their mobility, independence, or integration into society. A chair that is too wide, for example, is difficult to push and may be impossible to get through doorways. Besides the human cost, it is a waste of money.

The key player that is most often overlooked is the wheelchair rider him/herself. Or, rather, it is the local and national self-help service and advocacy organizations of people with disabilities. These organizations are in a position to advocate on behalf of those who need wheelchairs before the government agencies and charitable and development organizations that purchase wheelchairs to ensure that the recipient of a chair receives one that is appropriate for his or her situation (physical condition, age and size, geographic setting, personal goals, etc.).

"With assistance in organizational development, such as training in grant writing and management, the disability organizations can increase the local market for wheelchairs, which not only benefits a greater number of end users, but can also provides market stability for local wheelchair manufacturers, who are also potential employers of people with disabilities."

With assistance in organizational development, such as training in grant writing and management, the disability organizations can increase the local market for wheelchairs, which not only benefits a greater number of end users, but can also provides market stability for local wheelchair manufacturers, who are also potential employers of people with disabilities.

It works in Siberia. The scenario just described has worked, and is currently working in Novosibirsk, Siberia. In 1993, with grants from USAID, a disabled sports club transformed itself into an Independent Living Center, a service and advocacy center run by and for people with physical disabilities. At the same time, an Aeroflot helicopter repair facility and a newly established local small private company went into the wheelchair-building business. At the time, the government was buying wheelchairs from Russia's only then-existing wheelchair factory located near Moscow. In fact, there was no mechanism for buying wheelchairs anywhere else.

The activists from the disabled sports club persuaded local rehabilitation administrators to make the case with Moscow to allow them to buy wheelchairs made locally, and they were successful. The rider-activists also convinced the local rehabilitation administrators to allow them to

choose whether they wanted a chair from the Aeroflot factory or from the private company, whose wheelchairs were better built.

Today, the Novosibirsk Regional Center for Independent Living "FINIST" (Phoenix) is a sales agent for the private wheelchair company (the Aeroflot facility stopped building wheelchairs) and receives commissions. When it writes grants for job training programs, for example, it makes sure to include some amount for the purchase of appropriate wheelchairs so that each of the program participants will have a suitable wheelchair. FINIST also is involved in the annual Novosibirsk Regional budget process. In these ways, FINIST helps maintain a market for locally built wheelchairs.

Efficiency and effectiveness. Assuming no increase in available funding, spending money on the development of an organizational infrastructure in the target country will mean less money now for wheelchairs. In the long run, however, it will prove to be a more efficient use of resources. Wheelchairs that are sent will be used, not left to collect dust or rust. The average life of a wheelchair will be prolonged through proper maintenance and repair. Wheelchair recipients will have increased mobility and independence with all the benefits that that implies. A well-supported infrastructure can mean jobs and income for those least likely to be employed. If all of this is integrated into a comprehensive program of physical, social, and vocational rehabilitation, it can become sustainable.

Pooling resources and efforts with other international aid organizations. In almost every place where there is an international aid organization, there are two or more such organizations. Often, there are a half dozen or more. These organizations can share resources, such as a warehouse and the costs of maintaining a repair shop. Each can also provide a separate, non-duplicative function, with one providing wheelchairs, others training physical therapists, others providing organizational development assistance, etc. The ideal situation would be a sharing of some resources on the one hand and the continuation of individual activities on the other, even if these would be duplicative, in order to promote a healthy "competition" and give wheelchair users a choice of service providers.

Finding a partner. The first step a donor organization must take is to secure a capable and reliable counterpart in the target country. That counterpart can either be a branch of the donating organization, another international development agency, or a purely local organization. The ideal local organization is one that represents the interests of people who use wheelchairs. Preferably, this is an organization run by wheelchair users themselves because no one knows the problems wheelchair riders face better than wheelchair riders themselves. Where this is not possible, or in the case where the international development agency chooses to partner with a non-disabled run organization, such as is the case with many church-affiliated programs, wheelchair users and/or local disability groups that represent wheelchair users should be actively involved to ensure that the needs of the end user will be met.

T. Haskell, WFP

The local partner needs to have the capacity to gather and relay accurate information to the US-based office. It needs to be able to handle all customs paperwork, and have a place to store the wheelchairs until they are distributed. It will need to be able to make final adjustments to the wheelchairs before they are distributed so they will best fit the recipient. Depending on the arrangement with the US-based office, the local group may also need to have the capacity to refurbish the donated chairs.

Assessing the need. The second step in any wheelchair donation program is an assessment of the actual need. It is not enough to simply send down wheelchairs with the idea that any wheelchair is better than no wheelchair. Important information to be gathered in an assessment includes:

a) Surveying consumer groups and identifying the individuals who need wheelchairs;

b) Evaluating each prospective recipient's personal needs, including age, size, physical condition, geographic setting (rural or urban), personal goals, etc.). This is best accomplished through the services of a qualified physical or occupational therapist who can accurately measure and assess each prospective recipient and make appropriate recommendations for the type of wheelchair the individual needs. Local non-professionals, however, especially other people with disabilities, can be trained for this purpose.

c) Determining how the wheelchair rider will get his/her wheelchair repaired. Issues include 1) the availability of a person (usually a family member or a wheelchair or bicycle mechanic, but it could be the wheelchair user him -or herself) who is able to maintain and repair the wheelchair; 2) the availability of spare parts, especially those parts that wear out most often, including tires, inner tubes, and bearings; and 3) the source of adequate funds to repair the wheelchair. The life expectancy of the wheelchair (usually between two and five years for active use) and the annual cost of wheelchair repairs must also be estimated.

There are currently three organizations worldwide that specialize in appropriate wheelchair design for developing countries. They are Whirlwind Wheelchair International, based at San Francisco State University; Motivation, based in Bristol, England; and Handicap International, based in Belgium. Depending on the target country, the assessment phase should include consultations with at least one of these organizations.

Setting up the program. The simplest situation is one where new wheelchairs are sent to a city or region that has a parts distributor who sells parts very cheaply. Of course, the simplest situation is rarely ever the real one. This is because most donated wheelchairs are likely to be used wheelchairs. These chairs need to be cleaned and often adjusted or repaired. Because of the difficulty in acquiring replacement parts in many places around the world, it is often best to have the chairs cleaned and repaired before shipment. (On the other hand, a big advantage to repairing the chairs once they reach the target site is the creation of local job opportunities, and of course, it will be more cost-effective to have the chair repaired in the target country where labor is considerably cheaper.)

Standardization is a good idea. The wide variety of wheelchairs, not only of different types but from different manufacturers, makes the spare parts problem all the more difficult. Rather than accept any wheelchair that is donated to it, the U.S. organization might want to concentrate on only a few types of wheelchairs from only one or two different manufacturers. This strategy has the advantage of making it easier to acquire spare parts. Chairs that cannot be repaired can be stripped of their parts, which can be sent along with the shipment of complete wheelchairs. For the wheelchair

users in the target country, standardization means that a broken down old wheelchair will still be useful as a source for spare parts. Funds raised to purchase new spare parts can also take advantage of bulk pricing. Standardization should not be confused with the one-size-fits-all model. Here we are referring only to standardization of types and models of chairs. Different sizes and customization remain indispensable options.

The problem of electric wheelchairs. Extra careful attention should be paid when considering the donation of an electric wheelchair. All of the problems discussed above are multiplied many times over with an electric wheelchair. Parts are expensive, almost always unavailable, and special training is usually required to diagnose and repair problems. Although an electric wheelchair can increase a person's range of mobility and allow for independent travel, the lack of accessible architectural features such as curb ramps, building ramps, and elevators, not to mention kneeling buses and the like, can make it more difficult for the rider with a heavy electric wheelchair. Assessing the local conditions for electric wheelchair riders is an important prerequisite.

Seat cushions are indispensable. One area that is usually overlooked by wheelchair donors is the critical need for adequate seat cushions. Far from providing new life to a previously immobile person, a wheelchair without a proper cushion can mean death from pressure sores. Pressure sores, also known as *decubiti*, are breakdowns of the skin caused by continuous pressure of the underlying bones against a hard surface. People with full feeling in their buttocks and legs frequently and automatically adjust their sitting, lying and standing postures in order to relieve the pain and discomfort that can be caused by these pressures even after only a few minutes in one position. A person with a spinal cord injury, however, does not feel pain from sitting in one position, and general discomfort may arise only after a long time when the body's internal mechanisms try to cope with an injury that has already occurred. The best possible cushion, correct posture, and awareness of techniques to frequently relieve pressure and adjust weight distribution are necessary if the spinal-cord-injured person is to avoid pressure sores.

In a paper titled "Coordinating Wheelchair Provision in Developing Countries", presented at the RESNA 2000 conference (Rehabilitation

"Some of the most important lessons in life are not only learned by the mind, but also the heart. The human destiny to fulfill one's life to the best of one's personal ability is just such a lesson. Inclusive policies and practices are a way for development agencies to transfer this philosophy to action."

Engineering Society of North America – now known only by its acronym), Matt McCambridge, MSE, discussed principles of "responsible wheelchair provision." "The rider must receive training in pressure ulcer management and the use and care of a wheelchair," writes McCambridge. "Provisions must be made to ensure that the chair can be repaired, and follow up assessment should be done to determine whether the equipment meets the person's needs."

Three basic choices are available when providing a cushion. One is to provide a standard foam or air-filled cushion with each donated chair. Another is to send a cushion that has been custom made for the recipient. The third is to have cushions made in the target country using available low-cost materials.

"If one of the goals of international aid organizations is to develop sustainable programs, free imports of used wheelchairs from the U.S. defeats that purpose in an important way: it undermines the development of local wheelchair manufacture."

THE UNSEEN DANGERS OF DONATED WHEELCHAIRS

Unfair Competition. If one of the goals of international aid organizations is to develop *sustainable* programs, that is, to help people to help themselves, then free imports of used wheelchairs from the U.S. defeats that purpose in an important way: *it undermines the development of local wheelchair manufacture*. If any foreign company, in any other industry, sold its products below cost in another country, it would be accused of unfair competition and dumping, in violation of international trade agreements. Yet we applaud the free distribution of wheelchairs that cost a lot to refurbish, ship, and distribute, even if these costs are hidden because they are paid for through donations, volunteer labor, and 100 percent subsidized shipping.

To avoid competition with an existing wheelchair manufacturer, it is not enough that a person who gets a free wheelchair lives far from the factory, or that his or her family could not afford to buy a wheelchair anyway. In a free market, wheelchairs, like all goods, will insinuate themselves into the marketplace. There are many, many examples of wheelchair users with perfectly good chairs who have learned that a quick buck is to be made by crawling in to the local church wheelchair giveaway site, or showing up in a decrepit old wheelchair, in order to receive a free chair, which he later sells to a trader at the flea market. And a family that lives hand to

mouth will sell its donated wheelchair, trading any advantages the wheelchair might give, so it can survive for the next few months.

Of course, for every wheelchair sold, there must be a buyer. But since the buyers of wheelchairs are principally government agencies and charitable and development organizations, there is pressure on these organizations to buy cheaper chairs on the open market, rather than from the local manufacturer. In at least one case, a wheelchair manufacturer himself bought the imported, donated wheelchairs at the flea market and included them in a batch of wheelchairs purchased by the international funding source. The manufacturer may not have lost money, but his employees, some of whom were wheelchair riders themselves, lost an opportunity to earn their wages.

The right tool for the right job. There are many wrong, even if wellintentioned, reasons to be involved in providing wheelchairs to people with disabilities in developing countries. There is only one right reason: To provide the wheelchair user with real mobility that will improve his or her opportunities to be an active, integrated member of the local community and of society in general, by being able to leave the confines of home or hospital in order to go to school, get a job, shop for food, and engage in all those other activities independently mobile people do every day. The wrong wheelchair won't help its rider do any of that.

"There is pressure on these organizations to buy cheaper chairs on the open market, rather than from the local manufacturer."

Note: Special thanks to Alicia Contreras, Director, Whirlwind Women, for the ideas she contributed to this paper.

About the Author: Marc Krizack has 20 years of experience working on disability issues in developing countries, Eastern Europe and Russia. He currently is managing a project for Whirlwind Wheelchair International that is developing the wheelchair industry in Nicaragua. Since 1993 he has focused much of his efforts on developing programs that mainstream people with disabilities in Novosibirsk, Russia.

GENERAL, CROSS-DISABILITY STRATEGIES THAT DEVELOPMENT ORGANIZATIONS SHOULD CONSIDER IN THEIR MATERIAL AID PROGRAMS:

1. View the problem not as one of providing material aid, but as one of promoting the independence of people with disabilities and their integration into society.

2. Find committed local partners in the target country and help them develop their organizational capacity. An organization of people with disabilities is likely to be the most committed to improving the condition of people with disabilities. It is easier to build organizational capacity than it is to build commitment.

3. In your operations within the US, include people with the same types of disabilities as those of the recipients of your material aid in the targeted country.

4. In your operations in the targeted countries, include end users of the material aid. At the very least, develop an assessment and feedback system to ensure that the recipients of your material aid receive equipment that is appropriate for their needs.

5. Include people with disabilities in your teams when you visit target countries. Shared disabilities transcend linguistic and cultural differences and can be a great help in developing good partner relations with your local counterpart. Also, some of the best assistance can be provided by one disabled person to another who has a similar disability.

6. Seek to develop joint operations with other similar organizations working in your target countries. Where your resources alone might be insufficient, your joint resources may make it cost-effective to develop a local infrastructure that can support everyone's operations and result in improved services for your target population.

RESOURCES

ABLEDATA

8630 Fenton Street, Suite 930
Silver Spring, MD 20910 USA
Tel: 800-227-0216
Fax: 301-608-8958
TTY: 301-608-8912
E-mail: abledata@macroint.com
Web: www.abledata.com/

ABLEDATA is an on-line database of disability-related consumer products. The ABLEDATA database contains information on more than 29,000 assistive technology products (over 19,000 of which are currently available), from white canes to voice output programs. The database contains detailed descriptions of each product including price and company information. The database also contains information on non-commercial prototypes, customized and one-of-a-kind products, and do-it-yourself designs.

ActionAid

ActionAid Asia
13th Floor, Regent House Building
183 Rajdamri Road
Pathumwan, Bangkok 10220 THAILAND
Tel: +66 2 651 9066/7
Fax: +66 2 651 9070
E-mail: mail@actionaidasia.org
Web: www.actionaid.org/

The Disability Division of ActionAid supports projects for persons with a disability in India through local non-government organizations (NGOs). Technology development is one aspect of rehabilitation services that ActionAid supports.

ADD Mobility
Action on Disability and Development
Vallis House, 57 Vallis Road
Frome, Somerset, BA11 3EG UK
Tel: +44 (0)1373 473064
Fax: +44 (0)1373 452075
E-mail: add@add.org.uk
Web: www.add.org.uk/

ADD Mobility, a division of ADD India (Action on Disability and Development), is an organization that supports activities aimed at improvements in all aspects of rehabilitation technology in developing countries. This center assists current and prospective grassroots organizations working in rehabilitation technology provision and development.

The Canadian Abilities Foundation
340 College Street, STE. 650
Toronto, Ont. M5T 3A9 Canada
Tel: (888) 700-4476

The Canadian Abilities Foundation distributes a large variety of publications for people with disabilities. A book of interest titled *88 Easy-to-Make Aids: For Older People and Special Needs,* is a handbook with tested helpful hints, easy to follow illustrated step-by-step instructions, and uses only basic household tools or sewing equipment.

The Center for International Rehabilitation Research Information and Exchange (CIRRIE)
State University of New York at Buffalo
515 Kimball Tower
Buffalo, NY 14214-3079 USA
Tel: (716) 829-3141 ext.149
Fax: (716) 829-3217
E-mail: ub-cirrie@buffalo.edu
Web: http://cirrie.buffalo.edu/

CIRRIE's mission is to facilitate the sharing of information and expertise in rehabilitation research between the US and other countries. Its main objectives involve developing an international rehabilitation research database assisting rehabilitation research conference organizers in the US, and establishing an international component within domestic conferences by involving colleagues from other countries. It also disseminates information to rehabilitation service providers on cultural issues to meet the needs of foreign-born persons in the US, with a focus on recent immigrants.

CICAT, Centre of International Cooperation and Appropriate Technology

Postbus 5048
2600 GA Delft NETHERLANDS
Tel: +31 15 2783612
Fax: +31 15 2781179
E-mail: cicat@ct.tudelft.nl
Web: www.cicat.tudelft.nl/

CICAT stands for Centre of International Cooperation and Appropriate Technology. CICAT is a research center at the Delft University of Technology (DUT) in Delft, The Netherlands that has produced many reports on appropriate designs and fabrication techniques for wheeled mobility devices in developing countries. CICAT works on request as a consultant to small and medium-sized wheelchair and tricycle producers to facilitate the design and fabrication of wheelchairs in these countries.

Communication Service for the Deaf (CSD)

Rick Norris, Corporate Communications Associate
102 N. Krohn
Sioux Falls, SD 57103 USA
Tel: (605) 367-5760
TTY: (605) 367-5761
E-mail: rnorris@c-s-d.org
Web: www.c-s-d.org/

CSD is a private, nonprofit organization dedicated to providing broad-based services, assuring public accessibility and increasing public awareness of issues affecting deaf and hard of hearing individuals. CSD provides direct assistance to deaf and hard of hearing individuals in six basic areas — human services, relay, interpreting, communications technology, media and community relations, and training and development. Through education, counseling, training, advocacy, communication assistance and equipment distribution, CSD provides the opportunity for self-actualization, professional growth, and independence for deaf and hard of hearing individuals.

Disability Information Service (DIS)
Uppsala University Hospital Entrance 11
SE-751 85 Uppsala Sweden
Tel: +46 18 611 59 99
Fax: +46 18 50 80 13
E-mail: IMCH.DIS-databas@kbh.uu.se
Web: www.kbh.uu.se/imch/databases/

DIS, Disability Information Service, provides access to information on disability and rehabilitation in developing countries. It offers a collection of written materials including books, journal articles, manuals and unpublished reports. The emphasis is on Community Based Rehabilitation, CBR.

EnableMart
400 Columbia Street
Suite 100
Vancouver, WA 98660-3413 USA
Tel: (888) 640-1999
Fax: (360) 695-4133
360-695-4155 (Outside the US)
E-mail: Sales@enablemart.com
Web: www.enablemart.com

The EnableMart mission, vision and goal is to assist individuals in the search for computer access solutions by locating, supporting, and selling

computer hardware, software and related technologies designed for their specific need. Their vision is to bring about awareness within the community, to increase the number of individuals using assistive technologies, and thus provide the link to the benefits computer hardware, software, and related technologies have to offer them.

Healthlink Worldwide (formerly AHRTAG)
Cityside, 40 Adler St.
London E1 1EE UK
Tel: +44 20 7539 1570
Fax: +44 20 7539 1580
E-mail: info@healthlink.org.uk
Web: www.healthlink.org.uk

Healthlink Worldwide works in partnership with organizations in developing countries to improve the health and well being of poor and vulnerable communities by strengthening the provision, use and impact of information. Healthlink Worldwide works with partners in Africa, Asia, Latin America and the Middle East. They also publish newsletters, resource lists, training materials and booklets.

HealthWrights
P.O. Box 1344
Palo Alto, CA 94302 USA
Tel: (650) 325-7500
Fax: (650) 325-1080
Web: www.healthwrights.org/aboutus.htm

HealthWrights is a non-profit organization committed to advancing the health, basic rights, social equality, and self-determination of disadvantaged persons and groups. They focus on community health, disability issues, critical analysis of the man-made causes of poor health, and the development and distribution of educational materials.

The Hesperian Foundation
1919 Addison Street, suite 304
Berkeley, CA 94704 USA
Tel: (510) 845-1447
Fax: (510) 845-0539
E-mail: hesperianfdn@igc.apc.org
Web: www.hesperian.org/

The Hesperian Foundation's goal is to promote health and self-determination in poor communities throughout the world by making health information accessible. They produce books and other educational resources for community-based health care. Hesperian's approach to health recognizes that people in poor communities can greatly improve their health through local programs that are practical, creative and respectful of the knowledge, experience and resources already existing in the community. Women and men with little or no formal education can understand, apply and share medical information if it is presented simply and appropriately.

Independent Living Research Utilization Program
2323 South Shepherd, Suite 1000
Houston, TX 77910 USA
Tel: (713) 520-0232
Fax: (713) 520-5785
E-mail: ilru@ilru.org
Web: www.ilru.org

The Independent Living Research Utilization (ILRU) program is a nationally based organization that focuses on information, training, research and technical assistance in independent living for persons with disabilities. Since ILRU was established in 1977, it has developed a staff that is made up primarily of people with disabilities that can serve independent living centers, statewide councils, federal rehabilitation agencies, consumer organizations, educational institutions, medical facilities, and others, both nationally and internationally. A comprehensive list of independent living programs for persons with disabilities in the United States can be

obtained from ILRU upon request, as well as ADA materials in English, Spanish and audiocassette tape, and information on how to set up and manage an independent living center.

International Commission on Technical Aids (ICTA)

9 Mosman Square, Mosman
Sydney, NSW 2088 AUSTRALIA
Tel: +61 02 9960 4222
Fax: +61 02 9968 2490
E-mail: icta@accesskey.com
Web: www.ictaglobal.org/

The ICTA mission is global promotion and implementation of more equitable and accessible environments, technology and information. Among other activities, ICTA has facilitated important international conferences on appropriate rehabilitation technolofy and has published the proceedings. The conferences have allowed those working at various sites and centres to share and puclish their knowledge and experience.

ISAAC

49 The Donway West Suite 308
Toronto, ON M3C 3M9 CANADA
Tel: (416) 385-0351
Fax: (416) 385-0352
E-mail: secretariat@isaac-online.org
Web: www.isaac-online.org/

ISAAC is a committee to create greater awareness and activities in alternative and augmentative communication among professionals and other organizations. This mandate is carried out internationally through the ISAAC Developing Countries Committee. Activities are aimed at professionals, administrators, and organizations, but the ultimate beneficiaries are persons with communication disabilities.

Motivation

Brockley Academy, Brockley Lane,
Backwell, Bristol
BS48 4AQ UK
Tel: +44 (0) 1275 464012
Fax: +44 (0) 1275 464019
E-mail: motivation@motivation.org.uk
Web: www.motivation.org.uk/lite/

The members of Motivation are involved in setting up workshops to produce their low-cost wheelchair design. Motivation's vision is, to improve the quality of life of as many wheelchair users worldwide as possible. Motivation deals with the comprehensive provision of suitable wheelchairs designed specifically for the local environment and the associated training and education that must accompany their distribution if an individual is to achieve their maximum potential.

National Council For the Welfare of Disabled Persons

2nd Floor, SRA Annex Building
North Avenue, Diliman
Quezon City PHILIPPINES
Tel:(632) 926 1165 or (632) 920 1503
Fax: (632) 929 8879
E-mail: council@ncwdp.gov.ph
Web: www.ncwdp.gov.ph/index2.htm

The National Council publishes a journal summarizing available technical information on disability prevention, rehabilitation and equalization of opportunities in the Asia-Pacific region.

Quota International (QI)
1420 21st Street NW
Washington, DC 20036 USA
Tel: (202) 331-9694
Fax: (202) 331-4395
E-mail: staff@quota.org
Web: www.quota.org

Quota International (QI) is an international volunteer service organization committed to assisting disadvantaged women and children, and increasing public awareness of issues facing deaf, hard of hearing and speech impaired people. Quota members perform service globally and locally initiating and funding six world service projects such as the Quota Home for Abandoned and Destitute Women in New Delhi, India, a high school for the deaf in The Philippines, and the Housing Assistance Relief Trust which helps improve living conditions in a local village in Ba, Fiji. QI also provides grants to students at institutions conducting hearing research.

Rehabilitation International (RI)
25 East 21st Street 4th floor
New York NY 10010 USA
Tel: (212) 420-1500
Fax: (212) 505-0871
E-mail: rehabintl@rehab-international.org
Web: www.rehab-international.org

Rehabilitation International (RI) is a federation of national and international organizations and agencies working for the prevention of disability, the rehabilitation of persons with disabilities and the equalization of opportunities within society on behalf of persons with disabilities and their families throughout the world. RI is currently composed of 200 organizations involved in disability prevention and rehabilitation service development in 90 nations in all of the world's regions.

Swedish Handicap Institute
Box 510
S-162 15 Vallingby SWEDEN
Fax: 41 22 798 86 85
Web: www.hi.se/english/default.

The Swedish Handicap Institute aims at improving the quality of life for people with disability. Its major task is to ensure access to high quality and well-functioning assistive technology and to work for an increased access to society. The Institute's work includes stimulation of research and development, analyses of needs and testing of assistive technology. It also gives out information and performs training to professionals regarding assistive technology for different categories of disabilities.

Whirlwind Wheelchair International (WWI)
San Francisco State University
1600 Holloway Avenue, SCI 124
San Francisco, CA 94132 USA
Tel: (415) 338-6277
Fax: (415) 338-1290
E-mail:whirlwind@sfsu.edu
Web: whirlwind.sfsu.edu/

Whirlwind Wheelchair International (WWI) is dedicated to creating wheeled technology that maximizes the quality of life for people with disabilities throughout the world. A primary goal of WWI is the development of a worldwide network of wheelchair inventors, designers, users and manufacturers to address the need for wheelchairs in developing nations. A major aspect of WWI's work is the Whirlwind Wheelchair Network The network links independent wheelchair manufacturing workshops in developing countries, led by skilled technicians who themselves use wheelchairs. The network continually updates the design of the Whirlwind wheelchair, a lightweight, low cost, practical and durable wheelchair designed to be effective in the rough urban and rural conditions of developing countries.

Whirlwind Women
San Francisco State University
1600 Holloway Avenue
San Francisco, CA 94132 USA
Tel: (415) 338-6277
Fax: (415) 338-1290
E-mail: whirlwind@sfsu.edu
Web: http://whirlwind.sfsu.edu/general_info/whirlwind_women/whirlwind_women1.html

Whirlwind Women is a project of Whirlwind Wheelchair, Inc. (WWI), a US non-profit organization that works internationally to develop grassroots wheelchair production, and to remove barriers to wheelchair travel through social and political change. Whirlwind Women's goal is to enable women with disabilities to take an active role in increasing their own and other' mobility. Whirlwind Women's goals are to: introduce women with disabilities to wheelchair production in developing countries; train women to maintain and repair their own wheelchairs while developing leadership and business skills; expand the global network supporting women with disabilities in learning essential technology. Whirlwind Women conducts outreach and training, and offers support to women involved in WWI programs. In addition it offers technical information and resources on an international scale to women with disabilities.

4.2

ACCESS TO CONFERENCES, MEETINGS, AND OTHER EVENTS

ALL ARE WELCOME:

The InterAction PVO Standards provide member organizations with a clear standard regarding the accessibility of agency programs. "Member programs and activities should be held in accessible locations to the maximum extent feasible. Organizations will provide training and conference materials in alternative formats as applicable (Braille, sign language interpreters, etc.). Member agencies should plan financially to reasonably accommodate people with disabilities in member programs and activities." Although there are differences in what accommodations are reasonable in other countries, US international development organizations can play an important advocacy role by planning for and encouraging the inclusion of people with disabilities in conferences, meetings, and events held both in the United States and in other countries.

"Most organizations do not set out to exclude people with disabilities from their programs, events, or services. Do people with disabilities, in fact, participate in your events and programs? Probably not if you have not given thought to outreach and you have not considered the accessibility of your event. "

Ask anyone from any community or international development organization if people with disabilities are welcome to participate in their programs. The overwhelming response is "yes." Most organizations do not set out to exclude people with disabilities from their programs, events, or services. Do people with disabilities, in fact, participate in your events and programs? Probably not if you have not given thought to outreach and you have not considered the accessibility of your event.

Inviting people with disabilities to participate in your planned event is a positive step. However, the invitation does not hold much value if you do not make efforts to ensure that participation is actually possible.

Making your event accessible means looking at both physical structures and methods of communication. Thinking through and planning for accessibility is a process that benefits everyone: elderly people, pregnant women, people who speak different languages, people with hidden impairments, young people, people with different learning styles, parents and caregivers, and people with disabilities, among others. For instance, large print and audiotapes benefit not just people with visual impairments, but also people for whom the language used for the event is not a first language, children and young people.

An accessible event requires the organizer to consider:

1. How people will find out about the event
2. How people will get to the event
3. How people will be able to participate in the event
4. How people will be able to access support services and facilities

For each of these four areas, there are things to consider for successful participation. Below we list some of these key points. For additional points of consideration and further information regarding accessible environments, see the Office Accessibility section of this manual. For other access issues, see both the other topics in this access section or the resource list at the end of this topic.

Creating an event that is prepared to include people with disabilities in all of its activities means changing attitudes as well as creating physical accessibility.

KEY POINTS TO CONSIDER ABOUT OUTREACH AND PUBLICITY:

1. Publicize your event at places and through channels that are frequented or used by people with disabilities. Make note of accessibility features in your publicity.
2. Inform the local disabled peoples organizations (DPOs) about the planned event.

3. For any public meetings, put "Sign-language interpreters available upon request" in advertisements. Provide interpreters as needed. Employ qualified sign-language interpreters and language interpreters in advance, rather than relying on participants to interpret for each other. Arrange for backup interpreters to be available in case of emergencies or during long events. Most sign language, interpreters work in teams, alternation every 10-20 minutes.
4. Provide interpreters with papers, data, etc. in advance so they are prepared.
5. Make sure staff and volunteers helping out with the event know what accessibility features are available, and where to find them, and how to use them.
6. Ask presenters and (if possible) participants with disabilities what sorts of accommodations or modifications they will require for the event.
7. Prepare alternative formats of the materials to be used during the event.

KEY POINTS TO CONSIDER ABOUT GETTING TO THE EVENT:

1. In many South (and even North) countries, people using public transportation to reach your event will find it difficult or impossible to get there. Consider arranging a transportation service through a generic transportation company or through a disabled peoples' organization (DPO) in order to facilitate participation. Reimburse the cost of a taxi if public transportation is not an option.
2. Set up temporary curb ramps if curb cuts are not already in place.
3. Set up some temporary accessible parking spots if accessible parking is not available.
4. Go over the route from major transit stops in the area and use low-tech means of dealing with accessibility barriers along the routes. A barrier-free pathway to your meeting space should not have stairs, any sudden changes in surface height over 1 inch,

slippery or unstable ground, doorways less than 32 inches wide, or objects obstructing walkways.

5. Have someone stand by the main entrance to direct people to the meeting room and help those who may need assistance.

- Contact the local transportation company (or a few private transportation providers where no public transportation is available) to find out what transportation options are available for people with disabilities in the community.

- Make use of portable ramps for cars and trucks without lifts.

- Arrange for a volunteer with a vehicle who can help with transportation if generic services are not available. In some South countries there may be no other option than to lift a person with a physical disability into or out of the vehicle. When this is the case, be sure to ask permission of the person first and ask if there are issues you should be aware of when lifting.

"For a visually impaired participant, furniture may be arranged to reduce obstacles. Be sure to provide orientation to the site. "

KEY POINTS TO CONSIDER ABOUT EVENT PARTICIPATION:

- Use a table rather than a lectern when your presentation roster includes people who are wheelchair riders.

- Make sure the interpreters are well positioned both to hear what the presenter is saying and to be seen by people with hearing impairments in the audience.

- Ask ahead of time what accommodations people with disabilities will need both as presenters and as participants.

1. Make sure the event space is accessible. Check width of doors, seating space in the event room, turn around space for wheelchairs, door handle height, surface stability and changes in floor levels, lighting, ambient noise, head-level obstructions, etc.

2. Make sure the audio equipment is working properly and is well positioned. Check both the volume and the clarity.
3. Have signs that are high contrast and low glare and are approachable for people who are using tactile characters or Braille.
4. Make sure your event materials are available in alternative formats. A few copies of materials should be available in at least 16-point font. All important material that is written should be announced during the meeting. Create Braille or audiotape versions of impor tant or lengthy printed material.
5. Think about timetabling, regular breaks and work days to suit all participants.

- Usually one or two steps can be ramped easily. Even a longer flight of stairs to an entrance can be ramped, temporarily or permanently.

- Remember to consider all entrances; a back entrance might be easier than the front. Sometimes the installation of a handrail can make a set of stairs manageable. Some doorways will be wide enough if the door is removed; a curtain can be hung if privacy is necessary. Carpeting and floor surfaces can be covered with plastic runners or low pile carpet strips to make an accessible path.

KEY POINTS TO CONSIDER ABOUT SUPPORT SERVICES AND FACILITIES:

1. Make sure the bathrooms are accessible. Use neighboring building facilities that ARE accessible or low tech, temporary means of improving accessibility if there is no other option. An accessible bathroom is one that has a stall with a doorway at least 32 inches wide; grab bars installed by the toilet and enough space for a wheelchair to maneuver (at least 36 inches by 69 inches). Also at least one sink should have adequate space open beneath it.

2. Make sure people have access to drinking water, shade, etc.
3. Check to see if the pay telephones on site or around the location are accessible. If not, consider providing a courtesy phone.
4. If TTY is available in your area, consider renting a portable TTY if one is not available at the location. Make sure staff and volunteers know how to use it.

- Removing the door often makes narrow doorways wide enough for a person using a wheelchair to enter.
- Placing a kitchen chair or a stool inside the doorway may also work for people who can transfer.
- A plastic resin chair in the tub or shower or hand-held shower attachments can make a shower or bath accessible if you are planning an event that requires participants to stay overnight.

"Telecommunications Devices for the Deaf (TDDs) can be attached to phones to make it possible for people with haring impairments to communicate. In the US these can often be borrowed or rented from school districts in the summer months. "

WHO IS RESPONSIBLE?

Accessibility for all is the responsibility of everyone. Each of us needs to think of accessibility issues as a routine part of the planning process. When each of us considers accessibility issues as an integral part of the way we work, we will truly be contributing to an inclusive society.

RESOURCES:

Make sure to take a look at the resource list at the end of the Universal Design chapter in this section, which provides some excellent tips for further information. Also contact:

Mobility International USA (MIUSA)
http://www.miusa.org
PO Box 10767
Eugene, OR 97440
USA
(541) 343-1284 (V/TTY)
(541) 343-6812 (fax)

MIUSA has available free of charge resources and information sheets about accessible meetings, including the *Human Resources Toolbox* which is available for free on the website.
Find it at http://www.miusa.org/development/toolbox.pdf.
MIUSA's *Building Bridges* is also includes useful guides and tips for accessibility.
Please also see the accessibility checklist in section one of this manual.

The Center for Universal Design
http://ncsudesign.org
College of Design
Campus Box 7701
North Carolina State University
Raleigh, NC 27695
USA
USACampus Box 7701 RaleighNC 27695
Among the center's publications is:
Accessible Temporary Events: A Planning Guide.

Save the Children UK
http://www.savethechildren.org.uk
17 Grove Lane
London SE5 8RD
UK

Tel: +44 (0) 20 7703 5400 ext. 2565
Fax: +44 (0) 20 7708 2508

Among Save the Children's publications is *Access for All: Helping to make participatory processes accessible for everyone*, which is available for free at its website: www.savethechildren.org.uk/development.

4.3

ACCESS TO TRANSPORTATION SYSTEMS

By Tom Rickert
Access Exchange International

(Adapted from Mobility for the Urban Poor, *a report prepared for the World Bank*

"The freedom to travel, to go and come as one would like is a fundamental right. The challenge [of an accessible transportation system] is not one of cost; a good urban project does not cost more if it includes universal design concepts. The challenge is changing notions of what our urban environment should look like and whom it should accommodate." Enrique Iglesias, President, Inter-American Development Bank, from the IDB newsletter, *Social Development*, November 2001.

"The freedom to travel, to go and come as one would like is a fundamental right. The challenge [of an accessible transportation system] is not one of cost; a good urban project does not cost more if it includes universal design concepts. The challenge is changing notions of what our urban environment should look like and whom it should accommodate."

Accessible transportation benefits the whole population. The reality for people with disabilities in most countries is that transportation systems do not allow them access. Children are unable to attend schools, adults are unable to work, and people are unable to participate in community life because there is no means of transport that takes into account their needs.

A pro-poor national transport policy must address the barriers to employment caused by the design and operation of public transport in a manner inaccessible to persons with mobility, sensory, or cognitive disabilities. Lack of access to transport also results in an inability to participate in existing education, training, health or social services that would otherwise be available. This is of special concern for the disabled poor in developing countries, given the correlation between poverty and rates of disability.

However, whether a person is transportation-disabled depends to a great extent on how public transportation is operated and designed. When

operated in a highly unsafe manner, public transportation may cause far more than 10-12 percent of the population to "become disabled" in terms of the ability of older persons, children, women, and all those with even the most modest mobility concerns to safely board, ride and alight from buses, jitneys, and other transport vehicles. Most of the design features and operational practices that assist disabled passengers also assist all other passengers. They are often very low cost. Examples include:

1. VEHICLE AND INFRASTRUCTURE DESIGN FEATURES

"Most of the design features and operational practices that assist disabled passengers also assist all other passengers. They are often very low cost."

- Vehicle design should include large print destination signs to assist those with visual impairments; prioritized seats for disabled and elderly passengers; adequate hand grips and plentiful vertical stanchions at doors and inside vehicles, painted in a bright contrasting color; non-skid materials for step and floor surfaces; and, where feasible, a retractable first step at a bus entrance (or a movable stool) to assist semi-ambulatory passengers.

- Transit terminals should have well-located signs with high-contrast large print to assist deaf and visually impaired passengers or with icons to assist passengers who cannot read; a low ticket counter for use by wheelchair users and short persons; tactile guide ways to and within transit terminals and stops, and tactile warning strips at curbs and platform edges to assist blind persons.

- Unpaved bus stops could be made more accessible with a short (e.g., 2 meter) yellow curb piece, thus helping blind persons to position themselves behind the curb piece, persons with reduced vision to see the stop marker, and persons with reduced mobility to step up on the curb as a way to reduce the distance to the first step of the bus (usually the most difficult step to reach).

- Pedestrian pathways and buildings serving the public should incorporate inclusive design (level pathways of adequate width, curb ramps serving wheelchair users and all other pedestrians, ramps to public buildings, accessible bathrooms, etc.), noting that new construction can be made accessible at relatively little cost compared with retrofitting old

construction. Village roads, tracks, and paths should be kept free of obstacles and maintained in as accessible a state as possible.

Nearly all of these low-cost features also benefit all other passengers. There are also a variety of measures to assist passengers using wheelchairs, some of which are low-cost (policies permitting friends to assist a wheelchair user into a vehicle and fold his/her chair, ramped wayside platforms at key sites), others with greater cost (such as lift-equipped buses), and others of varying costs which serve all passengers (such as low floor buses; or high-floor buses with bridges serving all passengers from high platforms, as in Curitiba, Brazil; Quito, Ecuador; and Bogotá, Colombia).

David Werner

2. OPERATIONAL PRACTICES FOR PASSENGERS WITH DISABILITIES ALSO TEND TO ASSIST ALL OTHER PASSENGERS. THESE INCLUDE:

- Establish regulatory mechanisms to enforce safe vehicle operation by private and especially informal sector transit operators, and establish positive and negative reinforcements to encourage safety and courtesy to all passengers.

- Provide sensitivity training to transit personnel (including bus drivers and fare collectors) so that they will have direct experience of what it is like to use a wheelchair or crutches for mobility, to board a bus when blind, etc.

- Require that buses and jitneys come to a complete stop at bus stops and remain stopped until passengers have entered and positioned themselves for their ride.

- Require drivers to call out key stops and require audible announcements at transit terminals, as an aid to passengers who are blind or partially sighted.

- Disaggregate data on bus accidents where possible, to gain public support for key safety practices related, e.g., to injuries while trying to

board a moving vehicle, injuries while crossing traffic lanes to get to a vehicle, or on-board injuries due to bad driving. Elders are far more likely to suffer severe injuries during a fall or accident than are other passengers suffering the same fall or accident, but specific data in each country will assist in quantifying this problem.

- Explore increased employment of women as potentially safer bus drivers.

- Consider alternatives to paying drivers "per passenger," to remove the major incentive for unsafe operation. (For a more detailed discussion of the correlations between per passenger pay systems and unsafe, inaccessible transportation systems see the editorial in the June 2001 edition of *Accessible Transportation Around the World*, available from Access Exchange International).

In addition to design and operational features, the following should be noted:

- Disabled persons and their NGOs should be consulted throughout the process of designing, operating and monitoring access to public transportation and related infrastructure. This avoids expensive mistakes. It is always best to do it right the first time.

- While many countries have national legislation requiring some level of access to transportation, all countries need detailed regulations and work plans to implement and monitor such legislation.

- Small pilot projects using different accessible transport modes (non-motorized, fixed route, door-to-door) provide an opportunity to learn about accessibility issues and expand their use in a local context.

- Constituencies benefiting from improvements in non-motorized transport (NMT), and NGOs serving poor people and women, should work together with disability agencies and other stakeholders, given their shared interests in the inclusive design and operation of all transport.

For further information, see *Mobility for All: Accessible Transportation Around the World* at www.independentliving.org.

BEST PRACTICE

BEST PRACTICES IN ACCESSIBLE TRANSPORTATION SYSTEMS IN THE SOUTH COUNTRIES:

South Africa: Comparing different modes of accessible transport in Durban and Cape Town

Recognizing the need to address the mobility needs of people with disabilities in an incremental manner, the South African government decided in 1998 to experiment with various forms of accessible transport. Accessibility solutions could not simply be imported from First World countries with vastly different cultures, opportunities, and levels of resources. Instead the home-grown versions of systems developed elsewhere were designed to find a "best fit" for local conditions.

The city of Cape Town was the site for testing a door-to-door "dial-a-ride" system. Use of the service was restricted to disabled residents of two low-income residential areas. Four ramp or lift equipped vans were operated by the local bus contractor. Eligibility screening was undertaken by a participating disability organization.

Another service concept – a fixed-route, scheduled bus service operating on the service route model – was tested in the city of Durban. Two used buses were fitted with wheelchair lifts and other features, and used to transport disabled passengers daily from two outlying low-income residential areas to the city center. The route ran via frequently visited destinations such as hospitals, special schools, and pension pay points.

Both services were very popular with users and demonstrated the need for public transport services to cater to people with reduced mobility. The projects helped to leverage local political will to continue and expand the services. Plans have been made to expand the door-to-door service to cover the entire Cape Metropolitan Area, while the fixed-route system may be included with local bus contracts.

Monitoring of the services has yielded a wealth of information on cost effectiveness, user impacts, and operational issues. Echoing international experience, the door-to door service was almost twice as expensive as the fixed-route system (on a per passenger basis), although it served a wider range of users. This information is now being incorporated in developing a national strategy for accessible transport in South Africa.

Prepared by Christo Venter at CSIR Transportek, Pretoria, South Africa.
To learn more, e-mail cventer@csir.co.za.

Mexico: City departments look to NGOs for help in planning a network of accessible transport and infrastructure in Mexico City

An office of disability affairs was formed in the executive branch of Mexico's government following the election of its new president. This office is headed by a disabled person and includes other disabled persons including an architect on its staff. A very strong advisory role was delegated to a non-governmental organization, Libre Acceso (Free Access), whose founder is coordinating a work group involving government agencies such as the Integral Family Development System of Mexico City, the Department of Public Roads and Transportation, the Metropolitan Transport System, the Department of Services and Construction, and, most recently, the Passenger Transport Network, with the collaboration of different non-governmental organizations.

The work group began with the evaluation of accessible public transportation and with an accessibility project for selected Metro (subway) stations. Later, Libre Acceso became involved in curb ramp evaluation and design review. Efforts focused on prioritizing the placement of curb ramps throughout Mexico City in order to optimize the use of a relatively low budget for this activity. Design guides have been published as well, to assist in performing accessibility audits of buildings and infrastructure needing improvements in order to become accessible to those with mobility, sensory, or cognitive disabilities. Libre Acceso points out that it is far less expensive to provide full accessibility to new construction than to modify old construction.

Later, the work group participated in the decision making process to

authorize more than 3,500 new curb ramps (beveled "curb cuts" to assist wheelchair users and others) on main avenues each year, taking care that they follow international standards and prioritize accessible pedestrian routes to the five newly accessible Metro stations.

Twenty lift-equipped buses and four lift-equipped trolley buses were deployed several years ago along high use routes and acted as a feeder to these five stations. More recently, fifty new buses equipped with lifts and other accessibility features were added, serving five complementary bus routes that also connect with the original accessible routes and subway stations. The resulting integrated inter-modal network (pedestrian routes, buses, trolley buses, and subway) illustrates the results of involving disabled people and all other stakeholders in a decision making process which maximizes impact in spite of severe budget constraints.

It is hoped to copy this model in each of Mexico's 32 states in order to build a National Accessibility and Transportation Program for Disabled People.

Based on a paper by Francisco Cisneros Rivero of Libre Acceso in Mexico City. To learn more, e-mail fcisneros@presidencia.gob.mx.

Brazil: City officials implement a master plan to provide accessible pedestrian routes in Rio de Janeiro

In Rio de Janeiro, the urban revitalization process was initiated using the principles of universal design. The "Rio City Project," implemented by the municipal government in 1994, incorporated the demand for inclusive barrier-free design put forward by the Independent Living Center of Rio de Janeiro (CVI-RJ), a non-governmental organization that has accumulated expertise in this field. The main structuring axes in the city were chosen, including the most important thoroughfares in 14 districts. A competition was held for architectural projects aimed at solving common neighborhood problems. A different architecture firm, with its own autonomous urban renewal proposals, studied each stretch.

This partnership launched a rich experience of transforming a previously inaccessible city. It lasted three years, from drawing board to construction.

During this period, CVI-RJ supervised the implementation of inclusive (universal) design through weekly meetings, daily visits to construction sites, and drafting reports to the city government.

When the accessibility process was launched in the Rio City Project, the goal of universal design including a focus on design with all users in mind, regardless of their physical abilities, based on estimates that over half of the population does not fit the standard stereotyped individual for which most infrastructure has been designed around the world. Based on this principle, universal solutions included ramps at crosswalks which serve all pedestrians as well as more specialized solutions such as texture-coded footways to guide the visually impaired. The goal was to guarantee accessible routes on repaved footways serving some 560 square kilometers.

During the Rio City Project, CVI-RJ had to deal with the fact that accessibility is still a recent trend in Brazil. Hundreds of architects and engineers were dealing for the first time with the issue of eliminating barriers, yet they took a serious and open-minded approach. CVI-RJ had to accept the limitations of adapting an existing city, which is very different from working accessibility into a city's original design. Even so, the project became a benchmark for accessibility in Brazil, visited by professionals from other areas of Brazil. Also, disabled people began moving to the city's remodeled areas to live.

Accessibility is subject to unceasing dynamics and modifications. No place that has been accessibly remodeled can be considered permanently accessible. External factors interfere constantly and must be monitored. The success of pro-accessibility efforts thus depends directly on a commitment to maintenance, publicity, and monitoring.

An accessible infrastructure also increases the viability of accessible public transportation. Rio de Janeiro's expanding Metro (subway) system provides an example. CVI-RJ won a legal action in 1994 and followed up with technical assistance to a commission formed to have oversight over access improvements in Rio's subway stations. New access features include stair lifts for wheelchair users, which, while not representing universal design principles, do improve the mobility of wheelchair users and others with mobility concerns.

Prepared by Verônica Camisão of CVI-RJ, the Independent Living Center of Rio de Janeiro. To learn more, e-mail at vcamisao@openlink.com.br.

Peru: Architects and an NGO plan a demonstration project for accessible pathways in a neighborhood of Lima

Since 1998 APRODDIS (The Association for the Development of People with Disabilities) has played a vital role in the quest to remove architectural barriers in Peru and to reduce poverty among people with disabilities by more fully integrating them into mainstream society. In the process, APRODDIS has produced a design manual for architects, based on accepted international architectural design regulations, that has since been used to review architectural plans and existing structures in two Lima districts.

Over a six month period in 2000, local work groups of architects, city officials, local citizens, and APRODDIS' team worked closely in the Bellavista Pilot Project. The initial goal of the project was to raise community awareness of the need to provide access to public places and to specifically identify architectural barriers within Bellavista.

The District of Bellavista of Callao (Metropolitan Lima) is a unique community in that people with disabilities have formed cooperative living sectors where human ingenuity and perseverance have worked to overcome many of the social and architectural barriers that limit people with disabilities' access to public resources. Home to five major health centers, Bellavista must accommodate an even greater number of people with disabilities who visit the district to use these services from throughout the nation.

Unfortunately, the very people in need of service are frequently denied access to these centers and to other community resources due to inaccessible conditions. Thanks to the community-based approach in this pilot project, a path was forged towards a district-level commitment to follow through on a long-term plan to make Bellavista accessible to all citizens, as well as to provide a model for both Peru and the developing world.

APRODDIS hopes that these successes will lead to a multi-phase project that will develop new district-level accessibility codes and regulations in Bellavista, re-construct and retrofit the district, and implement accessible transportation services. At the same time, this project seeks to launch an extensive local media campaign and hold neighborhood meetings with the goal of providing critical awareness about the issues facing people with disabilities and the universal benefits of facilitating their more active participation in society. The project draws on the support of various public and private sector agencies and may demonstrate relatively low cost approaches to addressing barriers in the developing world and in demonstrating the leadership of grass roots organizing in the socioeconomic development of Peru.

Prepared by Ben Ried of APRODDIS in Lima, Peru. To learn more, e-mail to aproddis@terra.com.pe

RESOURCES AVAILABLE:

Resources from Access Exchange International, 112 San Pablo Ave., San Francisco, CA 94127-1536, USA. Telephone: (415) 661-6355, Fax: (415) 661-1543 Email: globalride-sf@att.net, Web: www.globalride-sf.org.

"Mobility For All: Accessible Transportation around the World." This is a guide to making transportation accessible for persons with disabilities and elders in countries around the world. Also available in Spanish, Portuguese, Japanese, and Chinese versions. English and Spanish versions can be downloaded from www.independentliving.org, the web site of the Swedish Institute on Independent Living.

"Making Access Happen: Promoting and Planning Transport for All." This is a follow-up guide to *"Mobility for All."* This new guide contains useful information for those working for accessible public transport and includes an extensive resource list.

"Accessible Transportation Around the World" The newsletter of AEI, published twice each year.

Other resources for advocacy, planning, and implementation of accessible transport systems are available on or as links to the website of Access Exchange International at www.globalride-sf.org

ABOUT THE WRITER

Tom Rickert is the Executive Director of Access Exchange International, an NGO in San Francisco, California, with the mission of promoting accessible transportation in the developing world. See the resources in this section for guides Tom has authored which describe accessible design as well as the promotion and planning of inclusive transport. Tom has led workshops and presentations on accessible transport in 18 countries in the Americas, Asia, Africa, and Europe. Prior to founding AEI in 1991, he was Manager of Accessible Service for San Francisco's public transit agency.

4.4

WEBSITE ACCESS

Website access for people with disabilities is one way to contibute to the elimination of barriers in information technology and make available new opportunities for people with disabilities. Inaccessible technology interferes with an individual's ability to obtain and use information quickly and easily. Internet accessibility gives the disabled members of society access to information that is comparable to the access available to others.

TIP: Adobe Acrobat Reader is required for viewing PDF files. If someone does not have this software on their computer, they can download Acrobat Reader for free <http://www.adobe.com/products/acrobat/readstep2.html> on Adobe's web site. It is also possible to convert PDF files into HTML and/or ASCII text by using the accessibility tools available on Adobe's web site <http://access.adobe.com/onlinetools.html>. This will allow people who cannot access PDF files to convert the content of such documents into a more accessible format.

CAST (Center for Applied Special Technology): *http://www.cast.org/bobby/*
A non-profit organization whose mission is to expand opportunities for all people, especially those with disabilities, through the innovative uses of computer technology. They created the online tool Bobby to help make web site accessibility possible to all. The "Bobby Approved" seal — means all pages are fully-accessible to people using assistive technologies to view web pages, or people with physical limitations that can hinder web browsing. Bobby is a useful tool used to guide web development process.

Compumentor: *http://www.compumentor.org/default.html*
A Nonprofit organization specializing in technology solutions for community-based organizations and schools. They offer hands-on planning and implementation programs, technology products at deeply discounted prices, and online resources for information and advice.

EASI: Equal Access to Software and Information: *http://www.rit.edu/~easi*
A nonprofit organization, part of the Teaching Learning & Technology Group, affiliated with the American Association for Higher Education with a mission to help make information technologies more accessible to users with disabilities. EASI sponsors an online workshop on designing web pages accessible to everyone including people with a variety of disabilities.

Knowability: *http://www.knowbility.org/*
Knowability connects people with disabilities to greater opportunities by advancing barrier-free information technology. Knowability is working to bridge that gap through three sets of services: awareness initiatives; educational initiatives and employment initiatives

Section 508: *http://www.section508.gov/*
Section 508 requires that Federal agencies' electronic and information technology is accessible to people with disabilities. The Center for Information Technology Accommodation (CITA), in the U.S. General Services Administration's Office of Government wide Policy, has been charged with the task of educating Federal employees and building the infrastructure necessary to support Section 508 implementation. Using this web site, Federal employees and the public can access resources for understanding and implementing the requirements of Section 508.

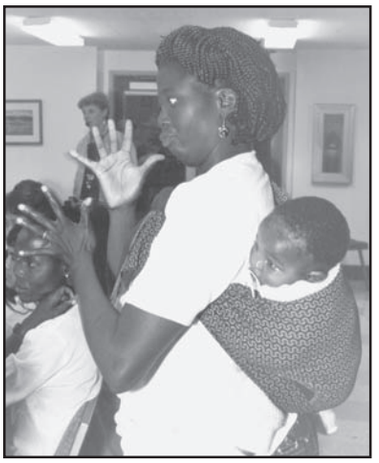
WebABLE!: *http://www.webable.com/*
An authoritative Web directory for disability-related internet resources. WebABLE!'s database lists hundreds of internet based resources on accessibility. Includes information on: making web sites accessible for the blind and visually impaired and writing accessible HTML documents, etc.

World Wide Web Consortium (W3C): *http://www.w3.org/WAI/*
W3C's Web Accessibility Initiative (WAI). WAI pursues accessibility of the Web through five primary areas of work: technology, guidelines, tools, education and outreach, and research and development.

4.5

ACCESSIBLE COMMUNICATION FOR PEOPLE WHO ARE DEAF OR HARD OF HEARING

Many people who are Deaf do not necessarily consider themselves people with disabilities. Rather, they base their identity on the fact that they share a visual language and a unique culture.



People with mild hearing loss are able to function with little adaptation in group and individual conversations. People with more significant hearing impairments usually have difficulty understanding speech from a distance of more than a few feet and may not be able to follow group conversations without the aid of an amplifier. People with profound hearing impairments cannot understand spoken language and speech by ear alone, even with amplification and must use other methods for communication. Hearing aids and other amplification systems are not effective for all people who are Deaf or hard of hearing.

COMMON COURTESIES FOR INTERACTING WITH A PERSON WHO IS HARD OF HEARING

- *Do not shout.*
- *Speak clearly and at a moderate pace.*
- *Avoid noisy backgrounds.*
- *Do not hide your mouth, chew food or smoke while talking.*
- *Use facial expressions and gestures.*
- *Rephrase your words if they are not understood at first.*
- *Be patient!*
- *Talk to a hard of hearing person, not about him or her.*
- *Ask the hard of hearing person how he or she prefers to communicate.*

Adaptive technology helps convey information and facilitate communication with people who are Deaf or have a hard of hearing.

ADAPTIVE TECHNOLOGY AT-A-GLANCE

- *Open or closed-captioning on video productions (open captioned display captions for all, closed-captioned allows the user to select captioning as an option).*
- *Visual option for audio information presented on a website.*
- *Teletypes TTYs (Telephone devices with keyboards enabling deaf, hard of hearing, and speech impaired people to communicate by telephone. Also known as Telecommunications Device for the Deaf-TDD).*
- *Visual alert telephones that ring with a flashing light.*
- *Amplified telephones.*
- *Hearing loops and other amplification systems for presentations, movies, etc.*
- *Strobe and amplified fire alarms.*
- *Real time captioning.*

The following technologies and services are readily available in the United States and other north countries. Availability in south countries will vary from country to country. Contact the national affiliate of the World Federation of the Deaf for information about technologies and services available in the countries in which your organization works.

TECHNOLOGICAL ADAPTATIONS

Teletypes (TTYs)

TTYs enable hard of hearing, speech-impaired, and Deaf individuals to communicate by telephone. TTYs users connect a typical telephone receiver or telephone line to a TTY device and communicate by using the TTY keyboard. The person on the other end of the line must also have a TTY where the message can be received. In the United States, organizations that do not have TTYs can use a telephone relay service to communicate with a TTY user. TTYs can be purchased through telephone companies, vocational rehabilitation centers or speech and hearing centers. Many states offer free or low cost TTYs to people with disabilities. TTYs from the US can be used in other countries, as long as functioning telephone lines are available

Telephone Relay Systems

Relay systems work when a relay operator, who has access to a TTY, acts as an intermediary between two parties. The relay system makes it possible for someone who uses a TTY to have a conversation with someone who does not have a TTY. If a relay call is placed, an operator will explain procedures for communicating with the TTY caller.

Speak directly to the caller instead of using a third person.
Correct: "Do you want to meet at two o'clock?
Incorrect: "Ask her if she'll meet me at two o'clock."

Relay centers or Deaf and hard of hearing organizations can provide you with common abbreviations and etiquette tips when using a TTY. Some relay services now allow for video calls using computer technology so callers can communicate using sign language in real-time.

In communities in which no relay service exists, informal "relay systems" may be set up, if a minimum of two TTYs and functioning phone lines are available, to facilitate telephone communication for Deaf community members.

- US National Relay Service: 711

- 24-hour Telecommunications Relay Service is provided at no cost to callers. Long distance calls will be billed accordingly.

- Federal Relay Service: 1-800-877-8339 (Voice, TTY, Spanish)
  U.S. General Services Administration provides Federal Relay Service for accessing federal agencies, programs, and Congressional offices.

Instant Messaging / Pagers

Instant messaging allows the user(s) to send online messages instantly to one or more users and groups for immediate delivery. A pager is a portable device that uses wireless technology to receive and send alphanumeric messages. These technologies are accessible to people who are Deaf and people with hearing impairments.

Captioning

The Americans with Disabilities Act requires that all television public service announcements, which are funded by the federal government include closed captioning. Captioned videos/dvds are increasingly available for people who are hearing impaired. New television sets generally contain closed caption decoders as well. Video companies that do subtitles have the technology capabilities to do captioning.

Interpreters

Although there is a wide range of communication preferences among people who are Deaf or hard of hearing— from speech reading with hearing aids to different types of sign language—these individuals require interpreters or other assistance devices or services in large group settings with hearing people. The interpreter's skills need to match the needs of the Deaf or hard of hearing person. For example, an oral interpreter (who is usually a hearing person and will generally be a few words behind a speaker in the smooth repetition of statements), would be unsuitable for someone who needs an American Sign Language (ASL) interpreter. Sign language interpreters are trained, skilled professionals who are paid to interpret for people who are Deaf. Interpreters may be certified by the Registry of Interpreters for the Deaf (RID). It is recommended that organizations requiring interpreter services hire through a referral service or agency. Resources include school districts, University Disability Services offices, the State Disability Commission or local agencies referred by RID. The person using the interpreter services can give you valuable feedback on the skill level of the interpreter.

It is important to note that not all Deaf people use sign language. Some prefer to be exclusively oral, read lips and use their voice to communicate.

Policy Adaptations

One of the key policy issues regarding inclusion of people who are Deaf or hard of hearing is availability of assistive services or devices. It is important to remember that people who are Deaf and people who are hard of hearing have different identities and different disabilities. Needs, therefore, will be different, and so will the adaptations required. Involving

people who are Deaf and hard of hearing in project planning is a useful strategy for insuring that your program responds to these needs. When possible, international development organizations are encouraged to be proactive by including the cost of these services or communication systems as part of their program budget. For formal situations, such as orientation sessions, meetings, seminars or academic situations, organizations must hire skilled interpreters. For informal situations, the Deaf or hard of hearing person may be comfortable writing back and forth if no interpreter is available.

Considerations

When including Deaf or hard of hearing people in international programs, be aware of communication, cultural and technical differences that may exist between countries. While Gestuno is the international sign language, it is not universally known. Many people use only the sign language of their home country, region, or local area. Availability of sign language interpreters varies from region to region.

RESOURCES

Captioned Films for the Deaf
Modern Talking Pictures Services
5000 Park Street North
St. Petersburg, FL 33709
Tel: (800) 237-6213 (V/TTY)

ClosedCaption Maker
Online. Available:
www.ccmaker.com
1500A Lafayette Road, #226
Portsmouth, NH 03801
Tel: 1-800-527-0551

National Captioning Institute
5203 Leesburg Pike
Suite 1500
Falls Church, VA 22041
Tel & Fax: (800) 999-0958

Typewell
Online. Available:
www.typewell.com
TTY: (805) 682-2687
Fax: (801) 457-2400

4.6

UNIVERSAL DESIGN

Kristin Hoobler, Mobility International USA

Equitable access to all arenas of life is the pre-requisite for universal human rights and fundamental freedoms of people.

Striving towards an inclusive society for all is the essence of sustainable social development

"Universal design is the design of products and environments to be usable by all people, to the greatest extent possible, without the need for adaptation or specialized design", as stated by Ron Mace, founder and program director of The Center for Universal Design [1]. The intent of universal design is to simplify life for everyone by making products, communications, and the built environment more usable by as many people as possible at little or no extra cost. Universal design benefits people of all ages and abilities.

The concept of universal design emphasizes the need for inclusion of all people, including people with disabilities. Inclusion by design brings into focus both access as a human right as well as access as a necessity for productivity. If facilities and systems are accessible to all, more people will be able to get an education and seek gainful employment, which lowers the burden on social welfare systems.

"Inclusion by design brings into focus both access as a human right as well as access as a necessity for productivity."

THE SEVEN PRINCIPLES OF UNIVERSAL DESIGN[2]:

1. **Equitable Use:** The design does not disadvantage or stigmatize any group of users.
2. **Flexibility in Use:** The design accommodates a wide range of individual preferences and abilities.
3. **Simple, Intuitive Use:** Use of the design is easy to understand, regardless of the user's experience, knowledge, language skills, or current concentration level.

4. **Perceptible Information:** The design communicates necessary information effectively to the user, regardless of ambient conditions or the user's sensory abilities.
5. **Tolerance for Error:** The design minimizes hazards and the adverse consequences of accidental or unintended actions.
6. **Low Physical Effort:** The design can be used efficiently and comfortably, and with a minimum of fatigue.
7. **Size and Space for Approach and Use:** Appropriate size and space are provided for approach, reach, manipulation, and use, regardless of the user's body size, posture, or mobility.

IN PHYSICAL TERMS —THE PROVISION OF A BARRIER-FREE ENVIRONMENT

Buildings should be required to comply with barrier-free environment accessibility standards for people with disabilities, including all public buildings, governmental facilities and institutions, office buildings, residential buildings, commercial buildings, health facilities, educational institutions, restaurants, recreational facilities, sports facilities, religious buildings and all other building types normally used by the general public[3].

UNIVERSAL DESIGN CAN INCREASE THE FUNCTIONALITY FOR NON-DISABLED USERS

Curb cuts are designed for people who use wheelchairs. It is estimated that for every individual in a wheelchair using a curb cut, somewhere between ten and one hundred bicycles, skateboards, shopping carts, baby carriages and delivery carts use the same curb cut. It is also not uncommon to see individuals walk slightly out of their paths in order to walk up a curb cut rather than stepping up onto the curb, indicating a preference for the curb cut even when walking[4].

In general, when products, environments or systems are made more accessible to persons with limitations, they are usually easier for more

non-disabled persons to use. Some of the potential benefits include lower fatigue, increased speed and fewer errors.

THE CONSEQUENCES OF NOT PROVIDING ACCESSIBLE DESIGN

- An estimated 386 million of the world's working age people are disabled. These people have the potential to make a valuable contribution in the workforce, as employees, entrepreneurs or employers of others.
- Many people with disabilities who are willing and able to work are unemployed – as many as 80 %.
- 75% of women with disabilities are unemployed[5].

UNIVERSAL AS OPPOSED TO ACCESSIBLE DESIGN

Universal design makes a great deal of sense as an alternative to accessible design because it can be more generally available at lower cost than assistive technology or specialized settings. With the advent of an independent living movement in the less developed countries, there is an opportunity to avoid the trap of special products and special places. Universal design also presents an opportunity for economic development. The creation and production of consumer products that are easier to use for everybody can improve competitiveness[6].

BEST PRACTICE EXAMPLE OF UNIVERSAL DESIGN:UNIVERSALLY DESIGNED COMMUNITY BASED REHABILITATION 'PROJECT PROJIMO' IN MEXICO[7]

The following examples are taken from HealthWrights' documentation of "Community Based Rehabilitation at PROJIMO, Keynote Speech at the 5th Anniversary Seminar of JANNET" and the book *Disabled Village Children: A guide for community health workers, rehabilitation workers, and families.*

One of the first activities started in the new community-based rehabilitation program of PROJIMO was organizing the schoolchildren to build a playground for all children. A good way to start a village or neighborhood rehabilitation program is to involve the local people in building a low-cost rehabilitation playground. It is important that the playground be built for use by all children, both disabled and non-disabled. With a little help from adults, the local children can build most of the playground themselves.

Building a playground for all children is a good way to get enthusiastic community participation. It can be built quickly as a group project at low cost using local resources and gives quick, easily seen, fun results.

Example strategies to maintain a successful all-inclusive children's playground:

1. Involve as much of the community as possible in building and maintaining the playground.

2. Keep the playground simple and build it from local low-cost materials. Only this way can it serve as a model for families of disabled children to build the most useful equipment for their children in their own homes. Resist offers from the local mayor or politicians to build an impressive metal frame playground. This will eliminate community participation and makes the equipment too costly for poor families to build at home.

3. For poles that are put into the ground, use a kind of wood that does not rot quickly. Or paint the posts with old motor oil, creosote, tar, copper sulfate or some other insect - and fungus - resistant substance. If poles are used that will rot quickly, to avoid accidents, check strength of poles frequently and replace them at regular intervals, especially during the hot rainy season.

4. Swings can be hung from ropes or chains. Rope or vines are cheaper but may rot or wear through fairly quickly. Plastic or nylon rope will not rot in the rains, but will gradually grow brittle and weak with the sun. As with posts, to avoid accidents, check the strength of ropes frequently by having several heavy persons hang on them at one time. Replace ropes at regular intervals, before they get weak.

5. Regular maintenance of the playground is essential, and this will require planning and organization. Perhaps once a month the village children can take an expedition to cut new poles to replace rotting ones, to repair old equipment, and to build new units. Adult coordination of such activity is usually necessary.

6. To boost enthusiasm, keep lists in a public place of all the children and adults who help with the playground — and put a star for each time they help.

ADAPTING THE HOME AND COMMUNITY:

The Home:

The kind of *adaptations* needed in the home will partly depend on the *kind of disability* a person has, the *severity of the disability,* and the *age* and *size* of the person. Adaptations for a person who is blind are very different than those for a person who is paralyzed and uses a wheelchair. The person with a disability who can do a lot may be helped by adaptations that make self-care and work in the house easier. For example:

- A wheelchair user would want each sink and table to be down low enough to use while sitting in the wheelchair.

- A person who is visually impaired would prefer cupboards that do not jut out.

- The restroom in a home may be adapted for both the wheelchair user and the person with the visual impairment by making it with broad walls big enough for a wheelchair and without any obstructions between the toilet and washing facilities. This serves two purposes: the accessibility needs of the wheelchair user and the ease of access without obstruction for the person with the visual impairment.

The kinds of adaptations needed will also depend on the local living situation, style of house, and customs. For example:

- A simple ramp may work well for a wheelchair entrance to a house near ground level.

- A system of ropes and pulleys may be the best way for a person with strong arms to lift herself without help to a 'house on stilts'. The 'lift' can be made with a platform so that the whole wheelchair can be lifted. But if the house is small and people cook and eat at floor level, it may be best to leave the wheelchair outside.

A universally designed home in the rehabilitation center at PROJIMO in Mexico is made of simple mud bricks although it has many adaptations for the inclusion of persons with disabilities, such as:

- The kitchen has been adapted for wheelchair accessibility to sinks, tables, and cabinets.

- A ramp serves as the entrance to the home, which is both useful for people with and without disabilities — whether the individual uses a walker, is carrying a large weight, or uses a wheelchair.

- A one-story home with floors made of material that is smooth for cane users, wheelchair users, able-bodied persons who are elderly, etc.

The Community:

In many villages, people with disabilities have a hard time going places because streets or paths are rough, rocky, or sandy. Also, there may be

high steps for getting into stores, the cinema, and even the town meeting hall, school, and health center. A reaction to inaccessible services is having members of the village ask storekeepers to build ramps so that people in wheelchairs can enter their stores. People with disabilities and their families can promise to give their business to those who cooperate in this way, and if necessary, can boycott those who do not.

Another example of making services accessible to all is when a village rehabilitation program encourages the villagers to make it easier for persons with disabilities to go places and to participate in community activities. For example, a village swimming pool can be used by children with and without disabilities for both enjoyment and good exercise.

10 STRATEGIES FOR IMPLEMENTING UNIVERSAL DESIGN

1. Use local resource materials.
2. Speak with local people with disabilities so they can come up with their own ideas on universal design for use in the village.
3. Consult people with disabilities, and make sure to get a diverse group of people that represent different needs in the community (e.g. women, children, hearing impaired, visually impaired, wheelchair user, crutch user, a person with a mental disability, delayed person, etc.).
4. Hire a person with a disability to lead the implementation, monitoring and evaluation processes of the universal design programs that are run by the development organization. Preferably hire a local person from the community.
5. Encourage the people with disabilities in the community to manufacture the resources used for universal design. Remember, universal design works in favor of all, whether people are pushing a barrel, carrying a large load, or are elderly with arthritis – a universally designed ramp entrance to a building helps everyone. When people with disabilities fabricate the resources used for universal design, community members see people with disabilities as assets in the community.

6. Organize to advocate within the community, encouraging local businesses to modify existing establishments using universal design principles.
7. Once adaptations are made in the community, encourage local businesses to hire people with disabilities.
8. Create a line item in the annual development budget to pay for any additional changes in the community that will make it more accessible and aesthetically pleasing for community members.
9. Ask local persons with disabilities to do routine maintenance of the adaptations that are universally designed, be it a playground or a ramp going into the local store, etc.
10. Disseminate information about these strategies (remember to produce information in alternative formats as well – see section 1 of this manual). Make local development agencies, businesses, government, and community members aware of the benefits of universal design. Evaluate progress towards your goal.

Universal design is a win-win situation for all. People with disabilities who were previously unable to participate in community life will have the opportunity to become proactive members of their communities. Although not all people in a community have a disability, universal design will benefit everyone: mothers with small children, pregnant women, elderly people, people who are recuperating from illness or an accident, people who work with heavy loads — in short, everyone. Universal design works in the favor of ALL people in a community.

For further detail on universal design and accessibility standards, please refer to the resource list on the next page and the other chapters of this section on access

[1] Ron Mace, founder and program director of The Center for Universal Design. http://www.design.ncsu.edu/cud/center/history/ronmace.htm
[2] Center for Universal Design ©, School of Design, North Carolina State University. http://www.accessiblestructures.com/homes.htm
[3]Accessibility for the Disabled. http://www.un.org/esa/socdev/enable/designm/AD3-01.htm
[4].Vanderheiden, G.C. (1990). Thirty-something million: should they be exceptions? Human Factors, 32(4), pp. 383-396. http://trace.wisc.edu/docs/30_some/30_some.htm
[5] International Labor Organization (ILO). http://www.ilo.org/public/english/employment/skills/targets/disability/diswork.htm
[6] *The Concept of Universal Design.* By Edward Steinfeld, Professor of Architecture. http://www.ap.buffalo.edu/idea/publications/free_pubs/pubs_cud.html.
[7]*Disabled Village Children: A guide for community health workers, rehabilitation workers, and families*, by David Werner. http://www.dinf.ne.jp/doc/english/global/david/dwe002/dwe00253.htm#part2chap51.

Accessibility Standards and Universal Design Resources

Accessibility:

There are many resources in the United States and abroad for information on accessibility standards for buildings, also known as universal design. The following organizations offer publications and/or technical assistance on accessibility. Some of these organizations base their standards on the Americans with Disabilities Act (ADA). While the Americans with Disabilities Act is a U.S. law, accessibility standards produced under this law can serve as guidelines for use by any organization seeking to assure the accessibility of their facilities.

RESOURCES

Access Board

1331 F Street NW, Suite 1000
Washington, DC 20004-1111 USA
Tel: (800) USA-ABLE (800-872-2253) or
(202) 272-5434 (for technical assistance)
TTY: (800) 993-2822 or 202-272-5449
Fax: (202) 272-5447
E-mail: info@access-board.gov (general information) or
ta@access-board.gov (technical assistance questions)
Web: www.access-board.gov

Access Board is a federal agency that develops minimum guidelines and requirements for standards issued under the Americans with Disabilities Act (ADA) and the Architectural Barriers Act (ABA). It provides technical assistance on those guidelines and standards, including the accessibility of buildings, transportation vehicles and telecommunications. It also provides enforcement of the Architectural Barriers Act, investigating complaints under the ABA. Access Board does not enforce the ADA, which is generally the responsibility of the Department of Justice. Access Board produces a number of publications, including *Access Currents*, a newsletter, and *ADA Accessibility Guidelines*, which provides detailed information on accessibility standards; this publication is also on its website at: www.access-board.gov/adaag/html/adaag.htm.

NOTE: Technical assistance questions sent by fax or e-mail should include a telephone number, and a good time to call if possible in order that the agency can provide interactive technical assistance.

Adaptive Environments Center

374 Congress Street, Suite 301
Boston, MA 02210 USA
Tel: (617) 695-1225
Fax: (617) 482-8099
E-mail: adaptive@adaptiveenvironments.org
Web: www. adaptiveenvironments.org

Adaptive Environments Center provides information and technical assistance regarding architectural accessibility and universal design standards. Its website includes links to other resources related to universal design.

American National Standards Institute (ANSI)
11 West 42nd Street
New York, NY 10036 USA
Tel: (212) 642-4900
Fax: (212) 389-0023
E-mail: info@ansi.org
Web: www.ansi.org

American National Standards Institute (ANSI) provides information on accessibility standards related to architecture.

Centre for Accessible Environments (CAE)
Nutmeg House
60 Gainsford Street
London SE1 2NY UNITED KINGDOM
Tel: (44-207) 357-8182
Fax: (44-207) 357-8183
E-mail: info@cae.org.uk
Web: www.cae.org.uk

Centre for Accessible Environments (CAE) is a technical information, training and consultancy resource committed to the provision of buildings and spaces that are accessible to all users, and to the enhancement of quality in design.

Center for Inclusive Design and Environmental Access
School of Architecture and Planning - University at Buffalo
Buffalo, NY 14214-3087 USA
Tel: (716) 829-3485 ext. 329
Fax: (716) 829-3861
TTY: (877) 237-4219 ext. 336
E-mail: idea@ap.buffalo.edu
Web: www.ap.buffalo.edu/idea/

Center for Inclusive Design and Environmental Access (IDEA) provides resources and technical expertise in architecture, product design, facilities management and the social and behavioral sciences to a broad range of people, including people with disabilities.

Center for Universal Design
North Carolina State University
School of Design
Box 8613
219 Oberlin Road (delivery address)
Raleigh, NC 27695-8613 USA
InfoLine: (800) 647-6777
Tel/TTY: (919) 515-3082
Fax: (919) 515-3023
E-mail: cud@ncsu.edu
Web: www.design.ncsu.edu/cud

Center for Universal Design's mission is to improve the built environment and related products for all users by effecting change in policies and procedures through research, information, training and design assistance.

Disability and Business Technical Assistance Centers (DBTACs)
Tel: (800) 949-4232
Web: www.adata.org

Disability and Business Technical Assistance Centers (DBTACs) provide information and technical assistance on the Americans with Disabilities

Act. There are 10 regional offices. Regional DBTACs can be reached automatically by dialing the national toll free number, or you may visit the website.

Disability Rights Education and Defense Fund (DREDF)
2212 Sixth Street
Berkeley, CA 84710 USA
Tel/TTY: (510) 644-2555
Fax: (510) 841-8545
E-mail: shenderson@dredf.org
Web: www.dredf.org
Contact: Susan Henderson

Disability Rights Education and Defense Fund (DREDF) is another resource to learn more about standards for accessible buildings. DREDF is a national, nonprofit law and policy center, dedicated to furthering the civil rights of people with disabilities. DREDF provides technical assistance, information and referral, and training to individuals and organizations on disability-rights laws and policies; provides legal representation directly and as co-counsel and amicus in cases of disability-based discrimination; educates people with disabilities; and trains law students through the Disability Clinical Legal Education Program. DREDF was key to the effort to pass the Americans with Disabilities Act and continues to provide expert training to individuals, businesses, etc. on that law.

Equal Access to Software Information (EASI)
EASI Corp
PO Box 818
Lake Forest CA 92609
Tel: (949) 916-2837
E-mail: info@easi.cc
Web: http://www.rit.edu/~easi/

EASI's mission is to serve as a resource by providing information and guidance in the area of access to information technologies by individuals with disabilities.

Planning for All
Ministry of the Environment
PO Box 8013
Dep, 0030 Oslo, Norway
Tel: (47-22) 24-90-90
Fax: (47-22) 24-95-60
E-mail: postmottak@md.dep.no
Web: www.miljo.no/pfa

Planning for All is a program run by the Ministry of the Environment of Norway. Its goal is to use planning as a tool to improve accessibility in the environment for people with disabilities.

Project Action
700 13th Street NW, Suite 200
Washington, DC 20005 USA
Tel: (202) 247-3066 or (800) 659-6428
Fax: (202) 347-4157 or (202) 737-7914
E-mail: nsmith@easter-sealsdc.org
Web: www.projectaction.org

Project Action is administered by Easter Seals and funded by the Federal Transit Administration. Project Action provides technical assistance and disseminates information regarding accessible transportation in the United States. Through the National Institute for Accessible Transportation (NIAT), a resource center and publications clearinghouse, it offers materials to the public free of charge. An online database of accessible transport in the United States is available on its website.

Trace Research & Development Center
University of Wisconsin-Madison
2107 Engineering Centers Bldg.
1550 Engineering Dr.
Madison, WI 53706
Tel: (608) 262-6966
Fax: (608) 262-8848
TTY: (608) 263-5408
Email: info@trace.wisc.edu
Web: http://trace.wisc.edu/

The Trace Research & Development Center is a part of the College of Engineering, University of Wisconsin-Madison. Trace's mission is to prevent barriers and capitalize on the opportunities presented by current and emerging information and telecommunication technologies, in order to create a world that is as accessible and usable as possible for as many people as possible.

World Wide Web Consortium
Web Accessibility Initiative (WAI)
E-mail: wai@w3.org
Web: www.w3.org/WAI

World Wide Web Consortium's Web Accessibility Initiative (WAI), in coordination with organizations around the world, pursues accessibility of the Web through five primary areas of work: technology, guidelines, tools, education and outreach, and research and development.

PUBLICATIONS

Inclusive Design: Designing and Developing Accessible Environments
By Rob Imrie and Peter Hall
Paperback - 208 pages (October 2001)
E & F N Spon; ISBN: 0419256202

Inclusive Design is a documentation of the attitudes, values and practices of property professionals, including developers, surveyors and architects, in responding to the building needs of disabled people. It looks at the way in which pressure for accessible building design is influencing the policies and practices of property companies and professionals, with a primary focus on commercial developments in the United Kingdom. The book also provides comments on, and references to, other countries, particularly the United States, Sweden and New Zealand.

WEBSITES

Accessibility for the Disabled —A Design Manual for a Barrier Free Environment **is an online manual prepared by the Lebanese Company for the Development and Reconstruction of Beirut Central District in cooperation with the United Nations and the Ministry of Social Affairs National Committee for the Disabled. The manual addresses urban and architectural design considerations for Beirut, and it may be useful for similar cities and countries.**
Web: www.un.org/esa/socdev/enable/designm

Equal Access to Software and Information (EASI) has a listserv on accessible technology and offers online course on universal design at:
Web: www.rit.edu/~easi

The Independent Living online library lists and links to hundreds of universal design resources at:
Web: www.independentliving.org/htdig/libsrch.html

Recommendations for transportation accessibility are available at the following website:
Web: www.independentliving.org/Mobility/

INCLUSION OF PEOPLE WITH DISABILITIES IN DELIVERY OF PROGRAMS/SERVICES

5

5

INCLUSION OF PEOPLE WITH DISABILITIES IN DELIVERY OF PROGRAMS AND SERVICES

> "Strategies for inclusion of women, children and men with disabilities integrated into each stage of the program from review of project proposals to implementation and evaluation." InterAction PVO Standards, Amendment 7.4.2

Dana Vion

Inclusion of people with disabilities is most effective if factors to promote inclusion are incorporated throughout the process of project planning and implementation. Including people with disabilities in the planning phase and integrating accessibility concerns into project design and proposals will save the organization time and resources in the long run. It is far easier and less costly, for example, to incorporate universal design concepts into building projects than it is to retrofit a building for accessibility after it has already been built (please see the Universal Design chapter in the Access section). Good planning creates a strong foundation for inclusion. Plan inclusively in order to become inclusive in your programs and services.

"Inclusion of people with disabilities is most effective if factors to promote inclusion are incorporated throughout the process of project planning and implementation."

PROJECT PLANNING AND PROPOSAL

- Involve people with disabilities during the design and writing of your project proposal. Parents of children with disabilities may also be important sources of information and ideas on inclusion.

- Plan for the participation of people with disabilities in each phase of the project. What outreach strategies will the project use to

reach and motivate people with disabilities? How will people with disabilities participate in outreach, budgeting, staffing, volunteers, transportation, resources, program venue, office space, or training methods? What accessibility issues will need to be addressed, to make facilities, materials, communication and activities accessible? What resources and strategies will the project use to address them?

- Incorporate flexibility into project plans. Recognize the different needs of people different types of disabilities, including physical, developmental, psychiatric, visual, hearing, health-related and other kinds of disabilities. There is no "one size fits all" approach to accessibility, but you can be effective by incorporating basic accessibility measures into the project design and communicating a willingness to make simple modifications as needed to address specific accessibility needs.
- Incorporate the unique perspectives and address the specific needs of women and girls with disabilities.
- Dedicate a line item of the project budget for costs related to disability-related access measures. (Please see the chapter on budgeting for inclusion in Section One of this manual).

For specific recommendations on making projects accessible, see the Checklist for Inclusion in the appendix.

EVALUATION

Incorporate questions, benchmarks and data collection tools into the evaluation design that will measure the success and impact of strategies for inclusion. MIUSA's *Gender and Disability* survey of InterAction member agencies (2001) pointed out that very few statistics are collected on the inclusion of people with disabilities in international development programs, and that the little data that are available are not gender specific.

Some questions that might be useful include:

- Was outreach effective in reaching and motivating people with disabilities to participate? How many people with disabilities

participated? How many women with disabilities? What types of disabilities were represented?

- Did people with disabilities feel welcome in your program?
- Were people with disabilities able to participate in all project activities and access the full range of services offered?
- What difficulties did people with disabilities have in participating in the program or accessing the services? What are recommendations for addressing the difficulties in the future?
- What impact has the program had on the lives of people with disabilities?
- How do people with disabilities participate in the program evaluation?
- Have the issues of women and girls with disabilities been considered and effectively addressed through the program?

For more recommendations on questions to ask in project evaluation, it may be helpful to review the Checklist for Inclusion.

One example of a data collection tool created specifically to provide baseline information on program inclusiveness is a questionnaire developed by Trickle Up and distributed to its partner organizations around the world. Please see the survey in this section.

PROGRAM SERVICES

Inclusive development practice looks different in different situations and contexts, reflecting diverse cultural contexts and geographical situations. For example, water aid programs may address the accessibility of village wells for people with mobility disabilities. Education programs may incorporate support and training to teachers on inclusion of students with disabilities. Disaster and emergency relief programs may address the needs of people with disabilities as they design systems that are responsive to the needs of vulnerable groups of people. Programs for maternal and child health may include women with disabilities in reproductive health outreach work and services.

Some strategies that may be common across sectors and regions include:

- Create linkages with disabled peoples organizations (DPOs) locally, regionally and internationally.
- Foster linkages between NGOs with which your organization works locally and local DPOs.
- Hold your meetings, events, and training activities in accessible locations. (See section 4.2)
- Hire people with disabilities in your field offices and encourage the local NGO's you work with to recruit qualified people with disabilities as well. (See section 1.2)
- Require all infrastructure projects to be accessible to all community members by incorporating universal design principles. (See section 4.6)
- Make simple adaptations to existing structures in order to make them accessible. (See section 1.4)
- Make sure that people with disabilities learn about your programs and services. (See sections 4.2, 4.4 and 1.7)

The following pages provide an expanded list of strategies to use for making your programs accessible to people with disabilities. In addition, this manual includes examples of Best Practices for inclusion of people with disabilities in development, and strategies for inclusion reflecting a variety of programs and issues. As more international development organizations take creative approaches to include people with disabilities in their programs and services, the range and diversity of Best Practice examples will reflect this commitment. MIUSA looks forward to including YOUR success stories in a later publication.

A note about technical support: Mobility International USA (MIUSA) is pleased to offer technical support for inclusion of men and women with disabilities to InterAction members at no cost. However, if your agency is NOT a member of InterAction, please feel free to contact us with your questions or requests.

Creative Ideas and Strategies for Including Women and Men with Disabilities

GUIDING PRINCIPLES

- ***Inclusive development*** makes use of the strengths and potential of **ALL** members of the communities, as partners and contributors as well as beneficiaries. Include people with disabilities at every level of the program.
- ***Outreach*** is essential. **ALL** development programs and projects must target people with disabilities in their outreach strategies.
- ***Universal Design*** benefits the whole community. Designing all programs from the start to include **ALL** members of the communities – including people with disabilities – is more efficient and cost-effective than making adaptations later!
- ***Include women and girls with disabilities*** in outreach, program design and implementation.

STRATEGIES FOR INCLUDING PEOPLE WITH DISABILITIES IN DEVELOPMENT

Make your own projects accessible.

Creative Ideas:

- Use low-tech, low-cost solutions to reduce accessibility barriers.
- Seek out the advice of community leaders who are people with disabilities and disability-led organizations to find solutions to accessibility problems.
- Arrange for your application processes, materials and training programs to be accessible. Use sign language interpreters, readers, note-takers, Braille materials, cassette tapes and other creative arrangements.
- Make your meeting places accessible. Meet in ground floor rooms, build ramps, add hand-rails to stairways.

- Find solutions to transportation barriers. Contract with taxis, private drivers, ambulance services, rehabilitation services; offer mobility aides to assist people with disabilities in using inaccessible transportation systems.

Go TO people with disabilities.

Creative Ideas:

- Reach out: invite people with disabilities to your meetings and ask for invitations to their meetings. (Don't wait for people with disabilities to come to you.)
- Conduct informational sessions, application processes and training at the places where people with disabilities meet.
- Hold meetings for your projects in the places where people with disabilities meet.
- Form partnerships with organizations led by people with disabilities.
- Incorporate your services into existing projects run by people with disabilities.
- Make sure that program information reaches people with disabilities in a format that they can use.

Support creative funding approaches to pay for disability related costs.

Creative Ideas:

- Attach a "conditional grant" to loans for individuals or organizations to purchase equipment or services for accessibility.
- Fund proposals that include disability-related items, such as mobility aids, wheelchairs, sign language interpreters or readers, adapted bicycles, ramps for buses or lifts.
- Fund business ventures run by people with disabilities that will empower disabled community members: such as wheelchair builing or crutch-making shops, accessible transportation ventures, sign language training and services.

Provide funding and technical support for projects by and for people with disabilities.

Creative Ideas:

- Economic empowerment programs run by and for women with disabilities.
- Small businesses organized by disability-led organizations.
- Literacy, health, peer support, community-based rehabilitation, programs led by and for people with disabilities.
- Ensure that women and girls with disabilities are included in disability-led projects.

Support capacity building for disability-led organizations.

Creative Ideas:

- Write letters of introduction, recommendations and support.
- Support businesses run by people with disabilities. Contract with disability-led businesses to provide services for your organization.
- Share your office, your mailing or e-mail address, computer, fax machine, copier.
- Provide matching funds or seed grants.
- Support women with disabilities to take leadership in disability-led organizations.

Make your OWN organization inclusive.

Creative Ideas:

- Collect data about participation of people with disabilities in every project.
- Hire qualified women and men with disabilities as field staff, consultants, trainers, administrators.
- Include people with disabilities on community advisory councils and Boards of Directors.
- Provide training and resources to headquarters and field staff on disability issues and inclusive programming.

- Seek technical assistance from qualified people with disabilities to assess inclusiveness of policies, staff and programs.
- Contact disability organizations to provide technical assistance, resource materials and solutions to accessibility problems.

Include people with disabilities in global dialogues on development and human rights.

Creative Ideas:

- Seek out people with disabilities to contribute their perspectives and concerns when developing policies on human rights and development issues.
- Provide support for people with disabilities to participate in conferences, leadership meetings and policy-development processes.
- Facilitate coalition-building between people with disabilities and other disenfranchised groups.
- Listen to and learn from people with disabilities.

Be a mentor.

Creative Ideas:

- Introduce disabled community leaders to potential funders and partners.
- Pass on relevant information, news, announcements.
- Take representatives of disability organizations to meetings and conferences.
- Listen, advise, and share your experience.
- Facilitate opportunities for women and girls with disabilities to have mentors – and to be mentors.

Include women and girls with disabilities at every level.

Creative Ideas:

- Include women with disabilities in every training, program or service.

- Hire qualified women with disabilities as staff, consultants, administrators.
- Reach out to women with disabilities. Ask community members to help you find disabled women. Make contact with parents groups, health clinics, schools for disabled children, adult clubs, churches, nursing homes and community programs.
- Invite women and girls with disabilities to participate in programs that target women. Take steps to make training, application and projects accessible.
- Support women with disabilities to join community and global dialogue on issues of importance to women: education, employment, parenting, agriculture, health, childcare and prenatal care.
- Provide support, training and access to technology for women with disabilities to succeed in business, parenting, family, literacy, and leadership.
- Facilitate coalition-building between women with disabilities and other disenfranchised women.
- Provide funding and technical support for projects by and for women with disabilities.
- Listen to and learn from women leaders with disabilities.

COORDINATOR SURVEY

Working with People with Disabilities

Trickle Up was recently chosen to be a Model Partner Organization by Mobility International USA, a US-based NGO that is working to foster collaboration between the US development community and people with disabilities working internationally for equal opportunities and human rights. Over the next three years we will work to improve the inclusion of people with disabilities in our program and among our staff and board members.

We know from our field trips and from entrepreneur profiles that many Coordinators already select people with disabilities as Trickle Up entrepreneurs, but we have never tried to collect data about how many people with disabilities our partners serve around the world. Therefore, we would be grateful if you would answer the following brief questionnaire regarding your agency's work with people with disabilities. Even if you have not worked with this target group before, we ask that you still return the questionnaire so we have complete information.

Thank you for your time.

Disability is defined as a physical impairment (for instance, the loss of or limited use of a limb, leprosy, or polio), mental impairment, sensory impairment (deafness or blindness) or psychological impairment that may result in activity limitations and/or restrictions on family, social, civic or economic participation. In some cases, the activity limitation results from the attitudes of others rather than the actual impairment

AGENCY FILE CODE: _____

DATE: _____

1. Does your organization only work with people with disabilities?
   ☐ Yes ☐ No

2. Do you employ people with disabilities or have volunteers with disabilities?
   ☐ Yes ☐ No

3. Does your organization offer any programs that specifically target people with disabilities?
   ☐ Yes ☐ No

4. In the past 2 years, has your agency selected a Trickle Up entrepreneur who has a disability?
   ☐ Yes ☐ No

4a. If Yes, please list the business number(s) of the entrepreneurs with disabilities and check if they are the business leader or other member.

Business No. _____ ☐ Leader ☐ Member

Business No. _____ ☐ Leader ☐ Member

Business No. _____ ☐ Leader ☐ Member

Business No. _____ ☐ Leader ☐ Member

Business No. _____ ☐ Leader ☐ Member

Business No. _____ ☐ Leader ☐ Member

Business No. _____ ☐ Leader ☐ Member

(add additional pages if necessary)

5. In the past 2 years, has your agency selected a Trickle Up entrepreneur who is a parent, caretaker or other family member of a person with disabilities?

☐ Yes ☐ No

5a. If Yes, please list the business number(s) of the parents of people with disabilities and check if they are the business leader or a member.

Business No. _____ ☐ Leader ☐ Member

Business No. _____ ☐ Leader ☐ Member

Business No. _____ ☐ Leader ☐ Member

Business No. _____ ☐ Leader ☐ Member

(add additional pages if necessary)

SUGGESTIONS FOR A GENDER-FOCUSED QUESTIONNAIRE:

Trickle Up's questionnaire offers an excellent example of a simple tool for collecting baseline data on involvement of people with disabilities. Including gender-focused questions would yield important additional information about differences in participation between disabled women and men.

Examples of gender -focused questions might include:

1. Does your organization only work with people with disabilities?
   ☐ Yes ☐ No

1a. If yes: does your organization only work with women with disabilities?
   ☐ Yes ☐ No

2. Do you employ people with disabilities or have volunteers with disabilities?
   ☐ Yes ☐ No

2a. If yes: do you employ women with disabilities or have volunteers with disabilities?
   ☐ Yes ☐ No

3. Does your organization offer any programs that specifically target people with disabilities?
   ☐ Yes ☐ No

3a. If yes: does your offer any programs that specifically target women with disabilities?
   ☐ Yes ☐ No

4. In the past 2 years, has your agency selected a Trickle Up entrepreneur who has a disability?
   ☐ Yes ☐ No

4a. If Yes, please list the business number(s) of the entrepreneurs with disabilities and check if they are the business leader or other member, and please indicate the gender of the member.
Business No. _____ ☐ Leader ☐ Member
☐ Female ☐ Male

5. In the past 2 years, has your agency selected a Trickle Up entrepreneur who is a parent, caretaker or other family member of a person with disabilities?
☐ Yes ☐ No

5a. If Yes, please list the business number(s) of the parents of people with disabilities and check if they are the business leader or a member, and please indicate the gender of the member.
Business No. _____ ☐ Leader ☐ Member
☐ Female ☐ Male

BEST PRACTICE

No Save the Children Fund (SCF) – supported programmes should only target able-bodied children/adults. Therefore it should be assumed that disabled children/parents are part of all target groups. The best way to ensure that there is a 'disability perspective' in all of SCF's work is to involve disabled people and their families in decision-making throughout the project.

'Disability' is primarily about the exclusion of people with impairments through attitudinal, physical, social and institutional barriers. All projects can aim to eliminate these barriers and meet ordinary needs (food, shelter, stimulation, friendship, love, etc.) of disabled children and their families. Disability project may focus on 'special' needs such as rehabilitation, correction of impairment and special education, but ultimately the goal is for everybody to be seen as having some common needs and some individual needs. In other words, for difference to be seen as normal.

From: Integrating Disability into Development Programmes, written by Sue Stubbs for Save the Children Fund

INTERNATIONAL AND REGIONAL RESPONSES

6

6.1

THE UN AND PERSONS WITH DISABILITIES

The following information is excerpted and reprinted with permission from the United Nations website. For a complete review of the UN and Persons with Disabilities please visit www.un.org/esa/socdev/enable

UNITED NATIONS COMMITMENT TO ADVANCEMENT OF THE STATUS OF PERSONS WITH DISABILITIES

More than half a billion persons are disabled as a result of mental, physical or sensory impairment and no matter which part of the world they are in, their lives are often limited by physical or social barriers. Approximately 80 per cent of the world's disabled population lives in developing countries.

"More than half a billion persons are disabled. Approximately 80 per cent of the world's disabled population lives in developing countries."

Disabled persons often suffer from discrimination, because of prejudice or ignorance, and also may lack access to essential services.

This is a "silent crisis" which affects not only disabled persons themselves and their families, but also the economic and social development of entire societies, where a significant reservoir of human potential often goes untapped. Considering that disabilities are frequently caused by human activities, or simply by lack of care, assistance from the entire international community is needed to put this "silent emergency" to an end.

"This is a 'silent crisis' which affects not only disabled persons themselves and their families, but also the economic and social development of entire societies, where a significant reservoir of human potential often goes untapped."

From its early days the United Nations has sought to advance the status of disabled persons and to improve their lives. The concern of the United Nations for the well-being and rights of disabled persons is rooted in its founding principles, which are based on human rights, fundamental freedoms and equality of all human beings. As affirmed by the United Nations Charter, the Universal Declaration of Human Rights, International Covenants on Human Rights and related human rights instruments,

persons with disabilities are entitled to exercise their civil, political, social and cultural rights on an equal basis with non-disabled persons.

The contribution of United Nations specialized agencies to advance the situation of disabled persons is noteworthy: the United Nations Educational, Scientific and Cultural Organization (UNESCO) by providing special education; the World Health Organization (WHO) by providing technical assistance in health and prevention; the United Nations International Children's Fund (UNICEF) by supporting childhood disability programs and providing technical assistance in collaboration with Rehabilitation International (a non-governmental organization); the International Labor Organization (ILO) by improving access to the labor market and increasing economic integration through international labor standards and technical cooperation activities.

"As a result of initiatives from within the community of disabled persons, the 1960s saw a fundamental reevaluation of policy and established the foundation for the full participation by disabled persons in society."

FIRST STEPS: EVOLUTION OF HUMAN RIGHTS OF DISABLED PERSONS

In the 1940s and 1950s the United Nations was active in promoting the well-being and rights of persons with physical disabilities through a range of social welfare approaches. The United Nations provided assistance to Governments in disability prevention and the rehabilitation of disabled persons through advisory missions, workshops for the training of technical personnel and the setting up of rehabilitation centers. Seminars and study groups were means of exchanging information and experience among experts in disability. Fellowships and scholarships were awarded for trainers. As a result of initiatives from within the community of disabled persons, the 1960s saw a fundamental reevaluation of policy and established the foundation for the full participation by disabled persons in society.

In the 1970s, United Nations initiatives embraced the growing international concept of human rights of persons with disabilities and equalization of opportunities for them. In 1971, the General Assembly adopted the "Declaration on the Rights of Mentally Retarded Persons". 1/This Declaration stipulates that mentally retarded persons are accorded the same rights as other human beings, as well as specific rights

corresponding to their needs in the medical, educational and social fields. Emphasis was put on the need to protect disabled persons from exploitation and provide them with proper legal procedures. In 1975, the General Assembly adopted the "Declaration on the Rights of Disabled Persons", 2/ which proclaims the equal civil and political rights of disabled persons. This Declaration sets the standard for equal treatment and access to services which help to develop capabilities of persons with disabilities and accelerate their social integration.

THE INTERNATIONAL YEAR OF DISABLED PERSONS

In 1976, the General Assembly proclaimed 1981 as the International Year of Disabled Persons (IYDP). It called for a plan of action at the national, regional and international levels, with an emphasis on equalization of opportunities, rehabilitation and prevention of disabilities.

WORLD PROGRAM OF ACTION CONCERNING DISABLED PERSONS

A major outcome of the International Year of Disabled Persons was the formulation of the World Program of Action (WPA) concerning Disabled Persons, adopted by the General Assembly in December 1982.

WOMEN AND DISABILITY

The WPA recognizes women's needs as requiring special attention. The consequences of disablement are particularly serious for women, because disabled women are discriminated against on double grounds: gender and disability. Therefore, they have less access to essential services such as health care, education and vocational rehabilitation.

Women are also specially affected by disability because they are often entrusted with the responsibility of caring for disabled persons in the community. Furthermore, women are more exposed to the risk of

becoming disabled because of neglect and certain forms of abuse and harmful traditional practices directed against them.

UNITED NATIONS DECADE OF DISABLED PERSONS

In order to provide a time frame during which Governments and organizations could implement the activities recommended in the World Program of Action, the General Assembly proclaimed 1983-1992 the United Nations Decade of Disabled Persons.

INTERNATIONAL DAY OF DISABLED PERSONS

Marking the end of the Decade of Disabled Persons, the General Assembly proclaimed 3 December as the International Day of Disabled Persons. The Day was initially established to commemorate the Anniversary of the General Assembly's adoption of the World Program of Action.

THE STANDARD RULES ON THE EQUALIZATION OF OPPORTUNITIES FOR PERSONS WITH DISABILITIES

Among the major outcomes of the Decade of Disabled Persons was the adoption, by the General Assembly, of the Standard Rules on the Equalization of Opportunities for Persons with Disabilities in 1993. The rules serve as an instrument for policy-making and as a basis for technical and economic cooperation.

RECENT DEVELOPMENTS AT THE UNITED NATIONS IN DISABILITY POLICY

Recent United Nations World Conferences reflect the growing awareness that persons with disabilities have both special concerns and needs that require serious consideration of the international community. All of the recent conferences - United Nations Conference on the Environment

(Rio, 3-4 June 1992), the World Conference on Human Rights (Vienna, 14-25 June 1993), the International Conference on Population and Development (Cairo, 5-13 September 1994), the World Summit for Social Development (Copenhagen, 6-12 March 1995), the Fourth World Conference on Women (Beijing, 4-15 September 1995), Habitat II (Istanbul 3-14 June 1996) - have addressed the situation of people with disabilities and made recommendations to rectify past discriminatory practices as well as to protect and promote their rights to participate fully in all aspects of the society as citizens of their countries.

"The work of the United Nations concentrates on improving the situation of disabled persons by promotion and monitoring the implementation of the Standard Rules and the World Program of Action."

The United Nations and the specialized agencies continue their efforts to assist Member States in attaining the equality of all people, including persons with disabilities, in social life and development. The work of the United Nations concentrates on improving the situation of disabled persons by promotion and monitoring the implementation of the Standard Rules and the World Program of Action. The United Nations continues to provide technical and financial support for national and international projects upon request. The Statistics Division of the Department for Economic and Social Information and Policy Analysis plays an important role in developing statistical concepts and indicators, gathering relevant country information and preparing technical manuals and publications on disability statistics.

"The work of the United Nations will increasingly focus on equalization of opportunities for persons with disabilities."

The work of the United Nations will increasingly focus on equalization of opportunities for persons with disabilities. One of the most important concerns is accessibility: to new technologies, in particular information and communications technologies, as well as to the physical environment. The notion of "mainstreaming" will also be given prominence, that is, including a disability dimension in policy recommendations covering a wide spectrum of social and economic concerns.

"The notion of "mainstreaming" will also be given prominence, that is, including a disability dimension in policy recommendations covering a wide spectrum of social and economic concerns."

6.2

INTEGRATING DISABILITY INTO MULTILATERAL DEVELOPMENT BANKS

by Pamela M. Dudzik, The World Bank

The Multilateral Development Banks (the Banks) include the following organizations: the African Development Bank, the Asian Development Bank, the European Bank for Reconstruction and Development, the Inter-American Development Bank, and the World Bank. This article draws upon knowledge of these Banks, and not other multilateral financial institutions or sub regional banks.[1] A short explanation of Multilateral Development Banks and other multilateral financial institutions or sub regional banks can be found at the World Bank web site.[2]

In recent years, there has been a growing awareness in donor organizations that the needs of disabled persons should be addressed since several papers have argued, and to the extent possible demonstrated, that disability leads to poverty and poverty leads to disability.[3] As multilateral development banks have the overarching goal of reducing poverty through promoting long-term economic growth, they should be addressing issues of disabled people. Some have begun,[4] and this paper will discuss the ways the Banks' work on disability issues potentially can be strengthened and increased.

"As multilateral development banks have the overarching goal of reducing poverty through promoting long-term economic growth, they should be addressing issues of disabled people."

One thing to keep in mind is that although one could argue that poor people are ultimately the clients of the Banks, the reality is that these institutions lend to and work with governments. This creates an interesting set of requirements to ensure that disability is integrated into work funded by the Banks. The three main players must each take an active role: the Banks, governments (borrowers), and Non Government Organizations (NGOs).

THE ROLE OF THE BANKS

As noted above, multilateral development banks lend to and primarily work with governments. While governments are the clients and ultimately have the final word on what is to be done with the money they borrow,

there is no denying that the Banks have a degree of influence in designing and implementing projects. The staff of these Banks are usually extremely knowledgeable in their field, and any recommendations are often listened to. Staff thus need to be aware of and knowledgeable about disability issues and be able to express the importance of ensuring that disabled people participate in and benefit from projects. A focal point usually is necessary to provide the necessary links to available information for staff use. The World Bank has led the charge in this area by appointing an Advisor on Disability and Development as of June 2002. Other Banks such as IDB and ADB have a staff person who spends a percentage of his/her time on disability issues. In addition to the important role staff of the Banks play, the Banks also serve as convening authorities, meaning that they are able to get various government ministries to talk together, an issue which is often important when working on disability issues.

"The World Bank has led the charge in this area by appointing an Advisor on Disability and Development."

Finally, the Banks are increasingly aware that there are many players in the development community, and are becoming increasingly open to working with NGOs. The World Bank for example "… welcomes the opportunity to work with NGOs and to share and learn from each other's experiences in improving the living conditions and in protecting the environment."[5] The Asian Development Bank notes that "... cooperation with NGOs is an increasingly important aspect of ADB operations in country programming processes, loan and technical assistance activities, and policy development activities."[6] The Inter-American Development Bank has an established program of working with NGOs and civil society, outlined in a brochure available on its web site.[7] The European Bank for Reconstruction and Development has an Outreach and NGO Relations Unit, which is meant to be an accessible first point of contact for NGOs and civil society and provides both NGO team contacts and local office contacts.[8] The Banks must work with NGOs concerned with disability issues. The Africa Decade of Disabled Persons may make a difference with the African Development Bank.[9]

THE ROLE OF NGOS

It is often the perception that governments and the Banks exclude outside participation in determining how funds are used. Yet NGOs and

civil society must have and can have some influence. In relation to a Lithuanian World Bank project, for example, Viltus, the Lithuanian Welfare Society for Persons with Mental Disability, organized 'the first demonstration ever in support of a World Bank loan.''[10] The demonstration resulted in disabled children and their parents being invited to meet with the Social Department in Vilnius, and since they were prepared with a written document outlining their proposals, they were able to achieve what they desired.

Both the World Bank and IDB web sites note the potential importance of working with NGOs. They can lend skills and experience to plan, implement and evaluate projects, and review and comment on draft strategies and guidelines for lending. NGO projects can serve as models for similar programs that will have a wider scope. NGOs can serve as agents of advocacy and participation by representing marginalized groups and communities, and can provide alternative perspectives on development issues. NGOs concerned with disability issues must make the effort to become active partners with both the Banks and their country governments.

"The Banks must work with NGOs concerned with disability issues."

THE ROLE OF GOVERNMENTS

Governments have limited funds to address the multitude of challenges facing the nation. Often the emphasis is on building infrastructure and serving the general population before attempting to address the needs of marginalized groups such as disabled persons, especially when countries must pay interest on the money they borrow (interest rates vary according to a country's GDP). As a result, they often depend on grants and zero interest loans to address the needs of specific groups such as persons with disabilities. Yet more frequently governments are instituting participatory processes, which will lead to a greater understanding of disability issues. Governments must make the decision that by addressing disability issues in the loan-supported projects they will be attacking the overarching issue of poverty in the nation.

WHAT NEEDS TO BE DONE

Awareness raising: Each of the three players – governments, Banks, and NGOs - must raise awareness of its roles, policies, and projects. Borrowing governments must be open to dialogue with civil society, including those organizations addressing disability issues, in order to understand the needs of the population and how elements can be incorporated into projects funded through loans. The Banks must develop an understanding of and commitment to disability issues, ideally hiring a staff member to advise on disability issues because it cuts across so many sectors, as well as hiring staff in individual sectors who have some knowledge of disability. This will help create an atmosphere in which individuals within the Banks who are supportive of the issue but do not necessarily have the experience can feel empowered to include disability in their activities.

"Once the Banks understand the need to address disability issues, they must communicate its importance to government officials."

As the Banks internalize the need to address disability as part of the development process, they must communicate the importance of these issues to government officials. Governments have a responsibility to communicate policies and services to disabled persons. Disability-concerned NGOs must stay informed about the actions of their governments as well as Bank activities either through web sites or interaction with local staff from the Banks. They also must create carefully planned, implemented and evaluated programs which will help persuade both governments and the Banks to tackle the issues, and make them aware of such programs. When NGOs provide information sessions on disability related topics, the information should be presented in a way that the Banks understand. For example, the Banks place a high degree of importance on data, and must understand the economic implications of tackling the issues.

Capacity building of NGOs concerned with disability: NGOs must seek out ways to build their own capacity by seeking funding from various donors. (SHIA in Sweden, Action on Disability and Development, and Japanese Society for Rehabilitation of Persons with Disabilities are examples of organizations working to help train leaders and build organizational capacity of disability NGOs in developing countries.) In addition, when Banks seek to improve the capacity of the NGOs that it work with, it should make an effort to include disability-related NGOs. The World Bank, for example, notes on its web site that it "…works with groups in

the region to strengthen their capacity to act as indispensable elements in democratic societies." This should include disability related organizations.

Partnerships/Participation[11]: A recent study of inclusion and disability at the World Bank noted that "despite a trend towards openness of working with NGOs and civil society, historically NGOs working on disability issues for the most part have been overlooked in partnership efforts and have not participated in Bank activities, either through consultation, as beneficiaries, and in decision-making."

"When Banks seek to improve the capacity of the NGOs that they work with, they should make an effort to include disability-related NGOs."

This report noted a list of strategies for consultation which included: establishing a role of disabled peoples' organizations (DPOs) as monitoring agents of government services in the area of disability; organizing seminars including DPOs; requiring consultation with disability experts as a condition for funding; and creating a registry of disability-related NGOs, with particular emphasis on organizations "of" disabled people.

NGOs can help foster their own participation by creating and maintaining contact with the Banks and with governments, in effect creating a role for themselves. The World Bank, for example, has an NGO and civil society web page that invites NGO input. This page also lists funding mechanisms available to all NGOs, and NGOs concerned with disability issues should consider themselves part of this. In addition, other lending mechanisms such as country-based social funds which make money available to local community organizations through a competitive process) could provide funding to disability-related NGOs.

Knowledge Management

Efforts are underway worldwide to include people with disabilities and address disability issues in all sectors, e.g. education, transport, health. Those undertaking this work must capture this knowledge and disseminate it so that as more efforts are undertaken lessons can be learned from the past. As a leader in information gathering and dissemination, the World Bank could serve as a broker of knowledge about addressing disability in international development. As a broker of disability knowledge, the Bank would also link one client government with another.

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CONCLUSION

The three players in the development arena, the Banks, NGOs and governments, each have their own responsibilities, but it is only through working together that disabled persons will obtain what they need to become active participants in society. The more that disability NGOs become involved in projects funded by the Banks and implemented by governments, the more the Banks are able to meet their mission of reducing poverty. And the more that disability NGOs become involved with both the Banks and their respective governments, the more their role is strengthened in society and the prevailing perception of invalidity or lack of capacity will be changed and ultimately improve the lives of disabled people.[12]

[1] Other multilateral financial institutions include: The European Commission and the European Investment Bank, the International Fund for Agricultural Development, The Islamic Development Bank, the Nordic Development Fund and the Nordic Investment Bank, the Opec Fund for International Development. Sub-regional banks include: the Caribbean Development Bank, the Central American Bank for Economic Integration, East African Development Bank, and West African Development Bank.

[2] http://web.worldbank.org/WBSITE/EXTERNAL/EXTABOUTUS/0,,contentMDK:20040614~menuPK:41699~pagePK:43912~piPK:44037,00.html

[3] See Elwan, *Poverty and Disability*, and DFID, *Disability, Poverty and Development*, and Dudzik, P., Elwan, A., and Metts, R. *Disability in Latin America and the Caribbean: A First Review of Policy, Statistics, and the Potential for Inclusionary Policies and Strategies.*

[4] The Inter-American Development Bank sponsored a conference in Chile in 2001, and supported the development of issue papers related to the Latin American context. The Asian Development Bank supported four country studies, the results of which were discussed in a regional conference with the goal of providing input to a strategy for the its work on disability issues. See the website: http://www.adb.org/Documents/Conference/Disability/default.asp. The World Bank hired an Advisor on Disability and Development and sponsored a successful seminar on Disability and Development on December 3rd, 2002 (see www.worldbank.org/disability for the webcast of the conference).

[5] http://wbln0018.worldbank.org/essd/essd.nsf/NGOs/home.

[6] www.adb.org/Documents/Policies/Cooperation_with_NGOs/default.asp?p=coopngos.

[7] www.iadb.org/exr/socciv/english.pdf

[8] www.ebrd.com

[9] For more information see www.un.org/esa/socdev/enable/disecn017e2.htm

[10] Spectrum, Page 11.

[11] As noted in *Inclusion and Disability in World Bank Activities*, participation measures the extent to which people with disabilities and their chosen representative organisations are given and able to use a voice in decisions that are made affecting their lives and the lives of their communities.

[12] See *Inclusion and Disability in World Bank Activities*.

SOURCES

Multilateral Development Banks

African Development Bank
www.afdb.org

Asian Development Bank
www.adb.org/NGOs

European Bank for Reconstruction and Development
www.ebrd.com

InterAmerican Development Bank
www.iadb.org

World Bank NGO and Civil Society site
http://wbln0018.worldbank.org/essd/essd.nsf/NGOs/home

Other Web Sites

Action on Disability and Development
www.add.org.uk/

SHIA (Solidaritet, Humanitat, Internationallet Arbete)
www.shia.se/englishshia.htm

Canadian Center on Disability Studies
www.disabilitystudies.ca

International Disability and Development Consortium
www.iddc.org.uk

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Elwan, A. (1999). Povety and Disability: A Survey of the Literature. Washington, DC: The World Bank. (Available on the World Bank Disability web site. See http://www.worldbank.org/disability)

Stienstra, D., Fricke, Y., D'Aubin, April, et. al. (2002) *Inclusion and Disability in World Bank Activities: Baseline Assessment.* Canada: Canadian Center on Disabiltiy Studies. (Available on the World Bank Disability web site http://www.worldbank.org/disability and on Canadian Center on Disability Studies web site http://www.disabilitystudies.ca)

Ms. Dudzik currently works with the World Bank on mainstreaming disability in its activities and policies, and serves as the Administrator for the Norwegian Trust Fund for Disability and Development. She has approximately ten years of experience working on disability issues, with positions ranging from teaching at a school for disabled refugees and ex-combatants in Zimbabwe to researching domestic education issues, and prior to becoming staff at the World Bank, served as a consultant to the World Bank and the Inter-American Development Bank on disability issues.

RESOURCES

The African Development Bank (AFDB)

Angle Des Trois Rues
Avenue Du Ghana, Rue Pierre De Coubertin, Rue Hedi Nouira
BP. 323, 1002 Tunis Belvedere, Tunisia
Tel: (216) 71 333 511
Fax: (216) 71 351 933
E-mail: afdb@afdb.org
Web: www.afdb.org

The African Development Bank is the premier financial development institution of Africa, dedicated to combating poverty and improving the lives of people of the continent and engaged in the task of mobilizing resources towards the economic and social progress of its regional member countries.

Asian Development Bank (ADB)

P.O. Box 789
0980 Manila, Philippines
Tel: (632) 632 4444
Fax: (632) 636 2444
Email: information@adb.org
Web: www.adb.org

ADB is a multilateral development finance institution dedicated to reducing poverty in Asia and the Pacific. Since ADB changed its overarching goal to poverty reduction in 1999, a significant amount of regional and country-based activities on disability have been developed such as ADB's Expanding Employment Opportunities for Poor Disabled Persons, implemented in the three largest cities of Mongolia. In late 1999, the first ADB Workshop on Disability was held in Manila and concluded with two main recommendations: strengthening ADB's capacity to address the disability dimension in its operations and strengthening developing member countries' capacity to mainstream disability.

The European Bank for Reconstruction and Development (EBRD)
One Exchange Square
London EC2A 2JN UK
Tel: (44) 20 7338 6000
Fax: (44) 20 7338 6000
E-mail: generalenquiries@ebrd.com
Web: www.ebrd.com/index.htm

The European Bank for Reconstruction and Development was established in 1991 when communism was crumbling in central and Eastern Europe and ex-soviet countries needed support to nurture a new private sector in a democratic environment. Today the EBRD uses the tools of investment to help build market economies and democracies in 27 countries from central Europe to central Asia.

Inter-American Development Bank (IDB)
Banco Interamericano de Desarrollo
Washington, D.C. 20577 USA
Tel: (202) 623-1000
Fax: (202) 623-3096
Web: www.iadb.org

The Inter-American Development Bank, the oldest and largest regional multilateral development institution, was established in December of 1959 to help accelerate economic and social development in Latin America and the Caribbean. The Bank was created in response to a longstanding desire on the part of the Latin American nations for a development institution that would focus on the pressing problems of the region.
In addition to the Bank, the IDB Group consists of the Inter-American Investment Corporation (IIC) and the Multilateral Investment Fund (MIF). The IIC, an autonomous affiliate of the Bank, was established to promote the economic development of the region by financing small and medium-scale private enterprises. The MIF was created in 1992 to promote investment reforms and to stimulate private-sector development.

The World Bank
1818 H Street, N.W.
Washington, DC 20433 USA
Tel: (202) 473-1000
Fax: (202) 477-6391
E-mail:disabilitygroup@worldbank.org
Web: www1.worldbank.org/sp/

The World Bank is one of the world's largest sources of development assistance. Its primary focus is on helping the poorest people and the poorest countries. This site provides an overview of how the Bank uses its financial resources, its highly trained staff, and its extensive knowledge base to help developing countries onto paths of stable, sustainable, and equitable growth. Increasing the quality of such projects is a high priority, and will be accomplished through the collection of information on good practice in development assistance for disabled persons and distribution of this information in project design. Internally, a working group has been established to identify initiatives to create a more supportive environment for staff with disabilities. In conjunction with this effort and to be more accessible to its disabled clients and partners, improvements are being made to Bank offices to increase access for people with disabilities.

The internationally recognized expert on disability and diversity issues, Judith E. Heumann, will lead the World Bank on the issue of disability. With Judith's assistance, the Bank will include disability issues as a segment of discussion with clients in the prospective countries in which the Bank works. For example, disability will be part of the country-based analytical work, support for improving policies, programs, and projects that allow people to live and work in the economic and social mainstream of their communities.

6.3

INCLUDING DISABILITY IN THE DEVELOPMENT POLICY AGENDA

By Rosangela Berman Bieler
President, Inter-American Institute on Disability

INTRODUCTION

As affirmed by United Nations reports and recently re-stated by Bengt Lindqvist, UN special rapporteur on disability and social development in his 2002 report, "it is obvious that in developing countries, as in more developed areas, persons with disabilities and their families are more likely than the rest of the population to live in poverty. It is a two-way relationship: Disability adds to the risk of poverty, and conditions of poverty increase the risk of disability. Prejudice and social stigma affect the lives of both children and adults with disabilities and lead to isolation and exclusion from the life of their communities."

"Disability adds to the risk of poverty, and conditions of poverty increase the risk of disability. Prejudice and social stigma affect the lives of both children and adults with disabilities and lead to isolation and exclusion from the life of their communities."

According to the World Bank's *latest World Development Report 2000/2001: Attacking Poverty*, to achieve major reductions in poverty, it is necessary to adopt a more comprehensive approach that directly addresses the needs of poor people in three important areas: opportunity, empowerment, and security. This most detailed-ever investigation of global poverty adds that economic growth is often not sufficient to create conditions in which the world's poorest people can improve their lives.

The report builds on the view that poverty means not only low incomes and low consumption but also lack of education and poor nutrition and health. Based on changes in thinking about poverty, the report expands the definition of poverty to include powerlessness, voicelessness, and vulnerability.

As expressed by World Bank Chief Economist and Senior Vice President Nicholas Stern, "We know that economic growth is crucial to sustained poverty reduction. But we also recognize the fundamental role of institutional and social change to the strength of development processes and the inclusion of poor people."

Even taking into consideration the fact that the World Bank has some experience in addressing disability issues and understands the importance of including the disabled population in the general poverty reduction agenda today, we still don't see the topic mentioned in its most recent general documents, such as the *World Development Report*, when describing measures to promote poverty alleviation and inclusion of all.

"Past development practice discloses a serious oversight or neglect of a disability perspective in program design and implementation. There have been major missed opportunities, for instance, in a number of post-conflict infrastructure and natural disasters reconstruction projects to achieve cost-effective accessibility. "

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PURPOSE OF THIS PAPER

This paper discusses the inclusion of disability issues into the development agenda, and suggests the establishment of political and economical partnerships for the advancement of inclusive public policy while focusing on poverty alleviation.

We will comment on the impact of the Standard Rules on the Equalization of Opportunities for Persons with Disabilities, an upcoming UN Convention, and the new approaches brought by the current human rights perspective (introduced to replace the former medical model) on the quality of life and dignity of persons with disabilities around the world.

Finally, we will consider ways of using these international human rights and disability related treaties to guide, support and monitor the development of inclusive projects and policies in an effort to build a society for all.

OVERVIEW OF DISABILITY AND DEVELOPMENT

Although the situation of disabled people in developing countries still has not improved to an acceptable level, we must acknowledge the many positive changes that have happened worldwide.

One of the most relevant changes was the shift from the medical to the social and now the human rights model to approach disability issues.

Historically and universally, the medical model has been applied on both national and international levels to consider disability issues. There are many definitions of the medical model, but in essence, it is an individual model, placing the responsibility on the individual with a physical or mental impairment to find the best way to adjust to or fit into society as it is.

"At the heart of the social model and of many disability rights campaigns is the recognition by the disability leadership that the actual impairments themselves cause far fewer problems than marginalization, exclusion and prejudice. "

In the last 30 years, the medical model has gradually been superseded by the social model, put forward by academics and activists to identify society as the main obstacle to the inclusion of disabled people in its midst. The social model articulates that both attitudinal and architectural barriers have been erected by society and must be dismantled by legal and educational means. At the heart of the social model and of many disability rights campaigns is the recognition by the disability leadership that the actual impairments themselves cause far fewer problems than marginalization, exclusion and prejudice.

Following the World Programme of Action Concerning Disabled Persons (1982), the Standard Rules on the Equalization of Opportunities for Persons with Disabilities (1993) brought a new dimension to our field – the human rights dimension. In their new report commissioned by the UN High Commissioner for Human Rights, lawyers Gerard Quinn and Theresia Degener explain that, "in essence, the human rights perspective on disability means viewing people with disabilities as subjects and not as objects. It entails moving away from viewing people with disabilities as problems to viewing them as rights holders." This shift is based on human rights values such as dignity, self-determination, equality and the ethic of solidarity.

With these concepts now being introduced and gradually accepted, it is time to explore new approaches to cover issues that have not been addressed or not sufficiently addressed under the existing international documents and initiatives.

WHERE WE ARE

The process of disability emancipation began in the North in the 1960s, and although the process in the South has only about a 20-year history, we have accomplished a lot. Since 1981, with the unprecedented stimulation given to the disability field by the International Year of Disabled People, we can now say that we are starting to be included in the self-image or concept of society. In most parts of the world, we now have specific legislation, and in some cases, constitutional protection, as well as some kind of government structure pertaining to disability. In my opinion, the most important achievement has been the conceptual shift that is gradually moving disability from the medical to the social and human rights model.

The advancements achieved during these last 20 years, in large part, were results of newly introduced international philosophical, institutional and financial support. These regional structures, such as special years and decades, while imperfect, provide a structure for setting goals and monitoring advancement. The multitude of demonstrations and public protests resulting from grassroots organizing in the South seem to also be progressing the disability agenda forward through advocacy and increasing civil participation.

From a sociological perspective, we have accomplished elevating the status of 600 million disabled people in the world to human beings and potential citizens. From a socio-economic perspective, this is still not the case.

Much more work needs to be done to integrate and accommodate disability concerns in development policies and programs.

INCLUDING DISABILITY

In developing countries, where there is an overwhelming lack of resources and money for infrastructure, sanitation, education; where there is no real widespread understanding of what citizenship or social and economic justice means; where legislation and public policies are not effective for the majority of the population and no monitoring practices are applied, the reality is that disability issues are still left at the bottom of the list of priorities. And it is difficult to change this situation without a long-term vision of a new society.

Among the main paradigms that have guided us through the past two decades, in opposition to exclusion, paternalism and marginalization, were the concepts of "empowerment," "equalization of opportunities" and "inclusion." All of these concepts were very important steps in helping us define the right ways of approaching disability issues, helping us understand a very complex issue that was not part of our knowledge-base as a society before.

We are entering this new century confident in our clear perspective that (1) disability must be addressed as part of the development agenda; (2) it is a horizontal, crosscutting issue involving all aspects of the human condition; (3) disability rights are human rights; (4) institutions or approaches that practice segregation or benign oversight must be eliminated and (5) the disabled population and disability issues must be mainstreamed.

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But when we take into consideration that there are and will always be specificities and special needs to be addressed, how are we to mainstream disability into development programs, projects and policies without creating special programs, projects and policies?

Three main relatively new concepts attempt to offer solutions for most of the cases: "respect for diversity," "inclusion" and "universal design." Does this mean that if we apply these concepts then we can completely mainstream people with disabilities into societal life? This is still to be proven and that's our challenge.

SEARCHING FOR DEVELOPMENT AS PART OF THE WHOLE

There was a time when it was important to build a whole identity for the population composed of people with disabilities. The World Health Organization (WHO) political data -1 in 10 (10%) of the world's population has a disability- was very important. The special measures, in the context of legislation, public policies and development-related projects were extremely relevant, because we were talking about "adapting" society to receive us. Now we are talking about changing society to include all.

"By definition, universal design is the design of products and environments to be used by all people and to the greatest extent possible without the need for adaptation or specialized design. "

With this thinking in mind, we now have a new challenge: instead of proving we are a 10%, we must convince society we are an irreplaceable part of the 100%. This may seem pure rhetoric but it is a very crucial switch in the disability field's approach for development.

We must no longer plan our physical spaces and our services for just the mythical average man anymore, but for real people, including elders, children, pregnant women, obese, people temporarily impaired, wheelchair users, blind or visually impaired, deaf or hearing impaired and so on. In this "reconstruction" project, we have to conceptualize a new society, inclusive, to be planned for all. The guidelines for this process should be the principles of universal design.

By definition, universal design is the design of products and environments to be used by all people and to the greatest extent possible without the need for adaptation or specialized design. The intent of universal design is to simplify life for everyone by making products, communications, and the built environment more usable by as many people as possible at little or no extra cost. Universal design benefits people of all ages and abilities.

SAFEGUARDS FOR DEVELOPMENT

If we are projecting a society for all, no development funds and loans should be spent in projects that are not accessible for all. The concept of "inclusive and universal design" should guide all new projects that receive

international financial support. This principle must be adopted by the international agencies as a safeguard for all money spent in development.

Today, international development institutions such as the World Bank and other bilateral and multilateral agencies are beginning to attempt to insert disability components into existing and future programs, projects, and structures, thus demonstrating that mainstreaming disability into all aspects of society, instead of creating special programs, institutions, or structures, is the process to be followed.

"The concept of "inclusive and universal design" should guide all new projects that receive international financial support. "

There have been some positive developments, but they tend to be ad hoc. If the World Bank can incorporate, for instance, gender considerations into its total structure (such as a gender and transportation policy or gender and infrastructure policy), it should also adopt an equivalent approach for disability concerns.

It is clear that disability issues must be mainstreamed and that any investment in the old medical and institutional models should be abandoned. However, to achieve such a challenging goal, society, governments, and organizations need to build capacity, provide information, stimulate and support civil society, and collect and monitor feedback from the community.

This kind of approach should be stimulated and supported by the disability community through the establishment of a proactive relationship in international, regional and country levels. We have to work with our governments, through the disability related agencies and grassroots organizations, and to educate our national development agencies about the need for inclusionary programs and projects. People with disabilities must participate in decision-making at all levels.

"There have been some positive developments, but they tend to be ad hoc. If the World Bank can incorporate, for instance, gender considerations into its total structure (such as a gender and transportation policy or gender and infrastructure policy), it should also adopt an equivalent approach for disability concerns. "

We should concentrate all our efforts to educate policy-makers and funding agencies on the concept that money used for construction, reconstruction or general infrastructure, if not applied within the basis of universal design, will be serving to create and perpetuate barriers to access for a large portion of the population, in present and future generations, and this is an inadmissible waste in a world where so many people live below the poverty level.

It has been estimated by the UN that approximately two-thirds of the world's disabled people live in developing countries. Taking into consideration that this is where international development financial resources are being directed, such an approach would have a tremendous impact in the short, medium and long terms.

For instance, countries such as Guatemala and El Salvador recently affected by natural disasters already had a high percentage of their population living in poverty and with disabilities. During the calamity situation generated by Hurricane Mitch, poor people were affected the most and, out of those people, more people acquired disabilities. It is crucial that from now on, reconstruction and poverty alleviation measures must address disability issues, including access.

The benefit of such kinds of projects/investments would result in a major positive impact on the quality of life and development for the whole population, including people with disabilities. Our common disability-specific projects sponsored by small and sporadic grants would never achieve or would require generations of effort to achieve such broad goals. If we start right now to implement such measures, we will be starting to construct the society of the future, a truly inclusive society.

In developing countries, where poverty and infrastructure problems are so dramatically difficult to solve in the short-to-mid term, I cannot help thinking that this approach would be a much easier and faster way of addressing disability needs at the same time as attacking other social and economic priorities; and probably it would be cheaper and more cost effective than convincing governments to invest in only special and isolated disability programs.

TRANSITION OF DISABILITY CONCERNS INTO MAINSTREAM DEVELOPMENT PROGRAMS

What about the specific needs that disabled persons have, such as special lifts in public transportation, special educational resources in regular schools, accessible clinics, immediate need for training and working opportunities?

Our first and most important paradigm to work with is "recognition of diversity," and concepts like inclusion and universal design serve almost as tools for us to find ways of putting this into practice. People are different and have different needs. The idea is not to see the population on a mass scale, eliminating unique qualities, but to be able to see each individual who composes the population. We need to acknowledge and include all specificities.

"The establishment of permanent enforcement and monitoring systems is our main challenge. "

The establishment of permanent enforcement and monitoring systems is our main challenge. At the same time that we work towards the goal of building an inclusive society, we – all the different actors - need to be (1) working on the creation and implementation of local, regional and international legislation and public policies; (2) actively participating in building local, regional and international capacity and structures to include disabled people; and (3) continuing to advocate for our rights - always.

A big challenge, though, is how to go through the transition process from exclusion to mainstream, without preventing people with disabilities from receiving immediate necessary assistance.

Since society has a cultural resistance to new concepts, many industrialized countries have started to acknowledge the need for a protectionist public policy, such as affirmative action in the USA, as a way of guaranteeing that some philosophical political advances are converted into practice. This approach has been and is applied in relation to other so-called "minority" groups besides disabled persons. This has been a controversial concept for many, but studies show that the practice can help to effect immediate positive responses and results in the process of social transformation.

Agencies such as the World Bank, the regional development banks, and other donor agencies, have a key role to play in the transition from segregation to inclusion, from the medical to the social and human-rights model of conceptualizing disability issue. Such a role would include the establishment of internal guidelines for inclusionary programs to be used in bi-lateral agreements and capacity support for the development of public policy and cooperation among the countries, the regions and the

international community. Certainly, this is not an easy role to play, and demands focus, capacity building, structure, investment, and consistency.

Because disability is such a complex issue, especially when considered alongside social, economic and cultural issues in the development world, all measures should be considered simultaneously. We should always keep the broad vision of what we want to achieve in the society of the future, but never grow complacent or ignore our current and cruel reality - society is far from being ideal.

"One of the key aspects of assuring effectiveness and quality in the process of including disabilities into development programs and policies is the involvement of disabled people in decision-making at all levels, from planning to evaluation."

PARTICIPATION OF PEOPLE WITH DISABILITIES IN DECISION-MAKING PROCESSES

One of the key aspects of assuring effectiveness and quality in the process of including disabilities into development programs and policies is the involvement of disabled people in decision-making at all levels, from planning to evaluation. The concept that guides and enforces this need is clearly explained by international disability organizations, through the statement "Nothing about us, without us." In all disability and development related projects, disabled people should be able to represent their interests, speak on behalf of themselves and to decide for themselves what is better for their lives and how to achieve their goals.

"Nothing about us, without us."

In discussions with development agencies, common explanations for the lack of such participation include:

1. People with disabilities are not interested in development activities.
   - Projects such as the MIUSA exchange programs and others that create international exchange opportunities for disabled people from around the world should be encouraged and supported in their development.

2. It is too difficult for people with disabilities from the North (where agencies are located) to travel to developing countries.
   - Agencies should include in their job announcements a specific request or encouragement for people with disabilities to apply for educational and working opportunities overseas.

3. It is too costly to have disabled people as project officers in the field because of reasonable accommodations.
   - These budget and accommodation excuses cannot be accepted as reasons to exclude people with disabilities from actively participating in development projects. Agencies should include a percentage in every project budget to cover costs such as personal assistance and other individual-specific needs to guarantee full participation. One good example has been the approach of the Swedish Agency for Disability and Cooperation, which includes 10% of its budget for reasonable accommodations.

EXPORTING THE MEDICAL MODEL

Another important aspect that we should pay careful attention to is the exportation /reproduction of old models that are now being questioned and replaced in the developed world. When missions of government and organizations from the global South come to visit the modern and more developed countries to learn the best disability-related practices that can be applied to their own countries, they are often taken to large, highly structured institutions. But they are rarely exposed to new models, such as independent living centers or community based/inclusive projects that also abound throughout those regions, and have proved to be effective in using the new model approaches.

Again, people with disabilities should be involved in the planning of visitors' programs to ensure that the social and the human rights model is being exported and disseminated adequately.

INTERNATIONAL CONVENTION

In December 2001 the UN General Assembly adopted a resolution calling for the creation of an ad hoc committee "to consider proposals for a comprehensive and integral international convention to protect and promote the rights and dignity of persons with disabilities."

Developments are following rapidly. In February 2002, the UN Special Rapporteur on Disability, Bengt Lindqvist, submitted to the UN Commission for Social Development (CSD) his report, *Monitoring the Implementation of the Standard Rules on the Equalization of Opportunities for Persons with Disabilities*. In his report, Mr. Lindqvist stressed the importance of the "twin-track approach" to human rights and social aspects of the problem: improved cooperation between United Nations bodies in the field of disability, and continued monitoring of policy development.

In the report, the special rapporteur also included a proposed supplement to the standard rules called "Reaching the most vulnerable" to address the remaining shortcomings and gaps in the original document, such as adequate standards of living, housing, disabled people in emergency situations, violence and abuse, gender issues, the situation of children, and elderly people with disabilities.

The entire discussion about a convention is leading to a consensus that a treaty must be an open, inclusive process and must be comprehensive, covering the full range of civil, political, economic, social, and cultural rights.

CONCLUSIONS

Since human rights must be followed by civil rights, including socio-economic development, we should finally consider ways of using these international human rights and disability related tools to guide, support and monitor the development and implementation of inclusionary projects and policies in an effort to build a society for all.

We must now apply the knowledge gathered and take action to integrate disability concerns into general plans and programs, to establish cooperation among governments, funding agencies and the disability-related organizations, and to help define and establish future options for UN involvement in disability policy development.

Besides the above-mentioned recommendations, some of the concrete measures that should be taken by government, non-profit and private sectors include:

- Establish a "disability desk" to build capacity within agency structures.
- Develop internal criteria and mechanisms for reporting, enforcing and monitoring progress toward mainstream versus special programs.
- Stimulate and promote the development, implementation and dissemination of best practices through mechanisms such as request for proposals on inclusive projects.
- Use experts with first-person experience of disability as consultants and employees within the agencies, especially in development-related positions.
- Maintain consistent pressure for the realization of inclusionary programs and projects.
- Create standards and criteria for internal or members' use on how to include people with disabilities (e.g. as currently adopted for gender policies).
- Provide support for special programs to go through the transition process into inclusion in order to guarantee that the disabled population does not stop receiving necessary assistance.

"Disability rights are human rights. "

Disability rights are human rights. Thus, disability should be part of the development agenda, as it is integrally linked to development objectives relating to poverty and social exclusion, as well as education for all and similar social change initiatives.

Our generation of disability leaders has had the privilege of helping to generate new paradigms for the future, within the universe of diversity. Now we have the chance and the challenge to contribute to their actual implementation. We will only be able to do this if, serving as individuals and institutions, we apply these new paradigms of this still-utopian inclusive society as the basis for our daily decisions and personal and professional actions.

ABOUT THE WRITER

Rosangela Berman Bieler is a Brazilian journalist, publisher, as well as a disability rights advocate. One of the founders of the Independent Living Movement in Brazil, she is also a founding member and former president of several disability related organizations. Rosangela is known internationally for her expertise on Latin American disability issues, especially disability and development, inclusive public policy, gender and media. Currently living in the USA, she is the founding-president of the Inter-American Institute on Disability (IID), a non-profit entity created to promote development and empowerment of people with disabilities through international cooperation. Berman-Bieler has been serving as a consultant for regional and international agencies such as UN, UNICEF, OAS, Inter-American Development Bank among others. Currently she is a full-time consultant on Disability and Development for the Human Development Department of the World Bank Latin-American and The Caribbean Region.

6.4

BEST PRACTICES BY INTERNATIONAL DEVELOPMENT ORGANIZATIONS

By Yutta Fricke, Disability and Development Consultant

In the context of research undertaken for the Canadian Centre on Disability Studies and the World Bank, I had the opportunity to speak with the coordinators of some of the world's leading non-government organizations dedicated to disabilities in international development. All of these organizations, located in the USA, Canada, Norway, Finland, Sweden, and Denmark, are led by people with disabilities. The following summary of best practices is based on their experience.

"According to the experts — that is, people with disabilities— disability in development is all about social change."

According to the experts —that is, people with disabilities— disability in development is all about social change. Gone is the medical model of disability, which would respond only to the physical impairment of an individual as the source of the problem. Instead, the social change model focuses on eliminating the societal barriers that keep disabled people from being full participants in and contributors to their communities and nations.

Best practices by international development organizations have in common a vision of equalizing the rights and opportunities of people with disabilities with their fellow citizens. There are four basic elements to best practices in disability inclusion, all beginning with the letter "C" (as in See, your agency could be doing this too!):

1. *Consultation*
2. *Capacity-building of disability organizations*
3. *Community mainstreaming*
4. *Commitment*

This chapter will explain what each of these elements means in development assistance, and will provide examples of how they influence project outcomes.

1. CONSULTATION

"People with disabilities will let you know what is most important; listen to them."

"By consulting with disabled farmers in Ghana, agricultural project organizers learned that blind women farmers could benefit from the agricultural assistance programs."

People with disabilities around the world are demanding to be involved in making the decisions that affect their lives. Consultation is an empowering process for not only the individual involved, but also for the population s/he represents. In acknowledging the inherent expertise of people with disabilities in matters concerning their lives, foreign aid agencies provide a direct message to the public and governments of the recipient countries. In this way, by using consultation to influence attitude change toward people with disabilities, the Northern project partner will have a much more enduring impact on social change than is possible for any single project initiative.

"Ideally, a national disabled peoples' organization should be contacted, including an open meeting to obtain input from its membership. Special attention should be paid to the participation of women and consideration given to the disabilities that are least likely to be represented, including deaf persons and people with mental disabilities."

Consultation also results in better projects. Consultation is key to learning the priorities of the affected population, as well as any challenges the project may present or secondary opportunities an outsider may not have considered. For instance, by consulting with disabled farmers in Ghana, agricultural project organizers learned that blind women farmers could benefit from the agricultural assistance programs. The one necessary concession to disability would be the extra funding required to pay for sighted assistance in seeding. *"An established farmer has the funds to do this, but a new disabled farmer does not have the funds."*

Because there are many different kinds of disabilities and an even greater variety of social circumstances, consulting with *one* disabled person is not enough. (Ideally, a national disabled peoples' organization should be contacted, including an open meeting to obtain input from its membership. Special attention should be paid to the participation of women and consideration given to the disabilities that are least likely to be represented, including deaf persons and people with mental disabilities.) However, if it is possible to have only one representative at a meeting, it is

important that there is enough lead time to allow the organization to democratically determine who is the most suitable participant. Ask what accommodations are required for the individual to participate fully.

Consultation should take place both North and South (noting that the economic division between peoples is not fully captured by latitude). Disabled peoples' organizations exist in almost all countries. Many have overseas programs. By building partnerships with organizations in the North, the transfer of knowledge can take place in either direction, thereby strengthening the development of our global community.

"An interesting examination of a cost-benefit analysis would be the added impact of having northern DPOs (disabled peoples' organizations) work with southern DPOs. Then you get much higher output, in comparison to other aid NGOs. The experience of the North is very valuable to the South. Through matching programs you get a lot from a little bit of money."

2. CAPACITY BUILDING OF DISABILITY ORGANIZATIONS

"Feed him a fish, and he will eat for a day. Teach her to fish, and she will eat for a lifetime."

Another interpretation of the same development philosophy:
Include disabled persons as project participants, and they will benefit until project funding runs sout. Teach them to organize, and they will not need you to introduce future projects; they'll do it themselves. (In some countries, like Uganda or South Africa, they will be officially elected or appointed to determine not only disability plans but national budgets.)

"Include disabled persons as project participants, and they will benefit until project funding runs out. Teach them to organize, and they will not need you to introduce future projects; they'll do it themselves. (In some countries, like Uganda or South Africa, they will be officially elected or appointed to determine not only disability plans but national budgets.)"

"Capacity building is vital because strong disabled peoples' organizations are essential for long term social change."

Consultation as a best practice is effective only if there are representative disability organizations with whom to consult. Unfortunately, in many countries these are still fragmented and without financial or human resources.

Capacity building must aim to strengthen disability organizations, including training for men and women in leadership skills, management and advocacy. Capacity building means direct involvement of the disability organizations at all stages of projects specifically designed for the benefit

of people with disabilities. It means invitations to national round tables on development, and opportunities to consult on any project directed at poverty alleviation.

Capacity building is vital because strong disabled peoples' organizations are essential for long term social change. According to disability organizations interviewed in the North, this is a universal truth. It is to their credit that we are discussing disability inclusive aid planning. Dr. Henry Enns, one of the founders of Disabled Peoples' International, recalls that when DPI first approached the Canadian International Development Agency (CIDA) in the early1980s, he was told that disability was not a development issue. Happily, Enns soon proved his point and CIDA has funded DPI ever since.

The Swedish International Development Agency (SIDA) is proud of its non-conventional aid projects through which it has assisted in both capacity building of organizations and political integration of disabled people in their societies. In a project entitled "Electoral and Political Enfranchisement of Citizens with Disabilities" SIDA is working with the International Foundation of Election Systems and disability organizations to assure the right of disabled persons to participate in elections through attitude change and accessibility measures (building access, Braille, avoidance of long lines). In addition, SIDA has helped provide the funding for the creation of the Parliamentary Office on the Status of Disabled Persons in the new South Africa. *"With 30 million kroners over a three year period, the impact of this funding has been tremendous."*

"Mainstreaming people with disabilities into their communities makes good development sense - not just for the disabled persons, but for the national budget."

3. COMMUNITY MAINSTREAMING

"Mainstreaming. This is how attitudes are changed, both among people with disabilities and able-bodied persons. People grow to respect one another. With mutual respect other advances are made more easily."

The noun "mainstream" means "the ideas, attitudes, or activities that are regarded as normal or conventional." (New Oxford Dictionary, 1998) When changed to a verb and used in the context of disability in development, it refers to the integration of disabled persons into programs or activities intended to benefit the broader public that is (non-disabled

peers) including in the school system and workforce.

Mainstreaming people with disabilities into their communities makes good development sense - not just for the disabled persons, but for the national budget. Special services generally cost a lot more. The majority of disability development aid, however, is still targeted to disability-specific projects. One risk is that these projects may reinforce segregation and isolation of disabled persons. Even community-based rehabilitation (CBR), which is a strategy chosen by many development agencies for promoting de-institutionalization and community mainstreaming of disabled persons, has been criticized by disability organizations for sometimes doing the opposite:

> *"Like the Bible, you can practice it in so many different ways. CBR has become a type of political segregation of disability matters. In most places in the North disabled people would not hear of having a national CBR program. It contradicts mainstreaming disability in education policy, employment policy etc. Furthermore, when the CBR people and their projects are gone, there is nothing sustainable left behind."*

"According to an official from Honduras' Ministry of Finance, not one of the international development or disability agencies that provided the country with millions of dollars for post Hurricane Mitch reconstruction stipulated accessibility measures. Today, schools, roads and public buildings have been reconstructed just as inaccessibly as the original post-colonial structures they replaced."

Another problem with thinking "special" projects and services are required by disabled persons, is that more often than not the result is that they are ignored altogether. In a rather chilling example, according to an official from Honduras' Ministry of Finance, not one of the international development or disability agencies that provided the country with millions of dollars for post Hurricane Mitch reconstruction stipulated accessibility measures. Today, schools, roads and public buildings have been reconstructed just as inaccessibly as the original post-colonial structures they replaced. With annual national debt repayments that are practically the equivalent of Honduras' GNP, the opportunity to retrofit (to add curb cuts, wider doorways, or ramps) is not only impractical, but financially impossible. Unfortunately, the better example of accessible reconstruction in Lebanon, post civil war, did not make its way to Central America. One obvious difference between the two situations is that Lebanon had a strong national disability movement.

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Mainstreaming disabled persons in development generally requires a re-vision of development practice by aid agencies. The current emphasis

in development assistance on "poverty alleviation" is leading to just such a revision. Aiming to increase the inclusion of the disabled poor, consultative meetings have been held, new research conducted, and commitments made by both governmental aid agencies and international development banks. At USAID, project partners are asked, "Do you include people with disabilities and what does it mean?" At SIDA, staff is encouraged to use a checklist of indicators determining disability inclusion. At the Ministry of Foreign Affairs of Finland, a national checklist is being adapted for international use. The Inter-American Development Bank is conducting research on people with disabilities in the workforce. The World Bank has recently hired a disability advisor and has conducted baseline research to be used in guiding and evaluating progress for disability inclusion.

"As more and more agencies include disability information in their data collection and disability components in their projects, eventually aid workers will not question whether disability is a development issue, but rather ask "Where are the disabled persons in this project?"

As more and more agencies include disability information in their data collection and disability components in their projects, eventually aid workers will not question whether disability is a development issue, but rather ask "Where are the disabled persons in this project?" Then, we will know that efforts to mainstream have been successful.

4. COMMITMENT

"Disability inclusion requires planning. It requires commitment."

"Commitment must be organization-wide to be effective."

Even development agencies that have adopted guidelines for disability inclusion, or perhaps hired an individual to lead their efforts (albeit part-time), find that commitment must be organization-wide to be effective. In other words, disability mainstreaming is required within the agency itself and not just in the projects. By using a "disability lens," agencies are able to review and address critical areas for disability inclusion. Some questions they ask are:

- Is there an organizational policy promoting disability inclusion?
- At what organizational level is the accountability for disability inclusion?
- Are mechanisms for monitoring or follow-up in place?
- Are the agency's premises and communications accessible to disabled persons?

- Are resources committed to disability inclusion for
  staff training?
  disability expert consultation?
  knowledge growth?
  disability accommodation expenses?
  disability components or pilot projects (with an emphasis on mainstreaming)?

"All programs should be inclusive, but because people with disabilities have been marginalized, there should also be special funds. This is affirmative action. Bring disabled people up to the base, and then you can make the case that remedial programming is not necessary. Generic projects should be made inclusive. Disability supports will not be there naturally."

To guide their work in the area of disability inclusion, many agencies rely on international conventions. Because most governments have signed onto the same principles, the instruments also provide important tools for promoting broader social change. They include:

1. The UN Standard Rules on the Equalization of Opportunities for Persons with Disabilities, 1993
2. The Convention on the Rights of the Child, 1989
3. The Convention on the Elimination of All Forms of Discrimination against Women, 1979
4. The Universal Declaration of Human Rights, 1948

But one of the best ways to assure sustained commitment to disability inclusion is often forgotten: Get to know someone with a disability by including a disabled person on the board of directors and in the workplace.

There is truth to the saying "out of sight, out of mind." By contrast, it seems that many of the disability movement's strongest non-disabled allies (whether among non-government agencies, government or business) know someone with a disability. The conclusion is that some of the most important lessons in life are not only learned by the mind,

"Some of the most important lessons in life are not only learned by the mind, but also the heart. The human destiny to fulfill one's life to the best of one's personal ability is just such a lesson. Inclusive policies and practices are a way for development agencies to transfer this philosophy to action."

but also the heart. The human destiny to fulfill one's life to the best of one's personal ability is just such a lesson. Inclusive policies and practices are a way for development agencies to transfer this philosophy to action.

ABOUT THE WRITER

Yutta Fricke was the Development Program Director of Disabled Peoples' International for ten years ending in 1999. Since then she has continued to work on disability and development issues as an independent consultant specializing in research and project management.

6.5

INCLUDING PERSONS WITH DISABILITIES IN INTERNATIONAL DEVELOPMENT INITIATIVES

A Case Study of North-South Disabled Peoples' Organization (DPO) Cooperation

By Venus M. Ilagan Chairwoman, Disabled Peoples' International

Persons with disabilities in the Asia-Pacific Region have, over the years, remained among the poorest of the poor. Women and girls in particular are always at a disadvantage compared to men and boys, not only on account of their disability but also because of their gender.

Poverty is an unacceptable human condition. Public policy and action can, and must, eliminate poverty. This is what development is all about. According to the publication, *Fighting Poverty in Asia and the Pacific: the Poverty Reduction Strategy of the Asian Development Bank*, close to 900 million of the world's poor (i.e. those who survive on less than $1 a day) live in the Asian and Pacific regions. Nearly one in three Asians is poor. Although the proportion of people living below the poverty line had been declining, the trends in poverty reduction have worsened in recent years as a result of the Asian financial crisis in 1997. Central Asian republics have slipped into poverty because of economic disruptions. Small countries of the Pacific, despite their relatively higher per capita income, remain vulnerable because they are remote, prone to natural disasters, and have limited ability to deal with external economic shocks.

The poor are not a homogenous group. Just as the nature of poverty is diverse, so, too, are its causes and victims. They may be denied access to assets for many reasons, or simply because they are women and disabled. Among the so-called most vulnerable sectors of Asian and Pacific societies, persons with disabilities remain to be the poorest, the most disadvantaged, the least served and the most denied in terms of entitlements and services.

Despite the emergence of international standards to promote the inclusion of persons with disabilities in development, as well as proclamations and in-country legislations and policies, integrating people with disabilities in mainstream development remains a major challenge for most governments in the region. Disabled people are disproportionately undereducated, untrained, unemployed and underemployed, and generally poor.

A vast range of issues, including physical and social barriers, must be considered and addressed within the context of full participation of people with disabilities in community life, if they are to be included in the development process. Without access to the full range of community services and experiences as a vital step, people with disabilities will not be able to confront barriers to inclusion in general.

"Without access to the full range of community services and experiences as a vital step, people with disabilities will not be able to confront barriers to inclusion. "

KEY BARRIERS TO PARTICIPATION

1. *Accessibility barriers*: such as the lack of access to the built environment like access to transportation, buildings and structures; lack of mobility aids and appliances; lack of access to technology and assistive devices, sign language interpreters and materials in Braille, among others.

2. *Institutional and attitudinal discrimination*. While all persons with disabilities suffer discrimination, women and girls face more discrimination at both the interpersonal and institutional levels because of negative perceptions regarding their abilities, potentials and even rights, as women and girls with disabilities.

3. *Low expectations and self-confidence*. Among the disabled, women and girls are generally least considered by their families for education, training and employment, even if they demonstrate stronger will to succeed compared with men and boys, simply because of their gender.

4. *The requirement to have higher skills*. While women with disabilities have few opportunities to develop skills to be productive, they need to demonstrate stronger qualifications compared to disabled men and to non-disabled women.

A woman with a disability may have to work twice as hard to earn half as much a non-disabled woman earns.

5. *General lack of organizational support.* Projects by and for women with disabilities are hardly supported by organizations run by a majority of men with disabilities.

As a result of the barriers faced by people that have disabilities, there has been a conscious shift in NGO responsibilities.

For examples of initiatives in support of disabled persons in developing countries of the South see: *From Charity towards inclusion: The Way Forward for Disability Support Through Danish NGOs* ***(A study of Danish NGO support to disability organizations in developing countries)***

A. An innovative step in bilateral development co-operation

In the early 1990s, a new dimension has emerged within Denmark's bilateral development co-operation with the increasing involvement of Danish disability non-government organizations (NGOs). The new focus on equal rights for persons with disabilities recognizes their strengths and need for inclusion within the wider society. The shift has highlighted disabled persons' right to inclusion in the development process. The Danish Council of Organizations of Disabled People (DSI), which is made up by a majority of the Danish disability NGOs representing an estimated 300,000 persons with disabilities, has been a driving force in this process, with support from the Danish Ministry of Foreign Affairs (DANIDA).

Under this initiative, DANIDA has made use of Denmark-based NGOs as entities through which resources to support disability-related undertakings in countries of the South were channeled. This example demonstrates how the experience and expertise of disability NGOs in a developed country like Denmark were used to provide funding and technical assistance and support to their counterpart organizations in developing countries.

"This example demonstrates how the experience and expertise of disability NGOs in a developed country like Denmark were used to provide funding and technical assistance and support to their counterpart organizations in developing countries."

As of 2000, 14 of the 29 member organizations in the Danish Council of Organizations of Disabled People (DSI) have been involved in providing financial support for persons with disabilities in developing countries. The Danish disability NGOs administer funds amounting to approximately DKK25 million annually (approx. US$ 3.5 million) to more than 20 countries to support disability initiatives.

Within a relatively short period of time, Danish organizations have established a substantial number of projects with significant variations in size, geography and development objective. They have also gained a lot of experience in a field that may have not been necessarily the same as the core activities of these Danish NGOs.

DANISH DISABILITY ORGANIZATIONS' INVOLVEMENT IN MAJOR DISABILITY PROJECTS, 1990-1999

Organization	Country	Project type	Budget in DKK	Period
Danish Hemophilia Society	India	Combination	10,250,000	1998-2001
Muscular Dystrophy Assn. of Denmark	South Africa	Service/Rehabilitation	2,910,081	1997-1998
The Danish National Association LEV	Bangladesh Albania	Service/Rehabilitation Organizational Dev't.	4,958,804 713,801	96-01 95-97
Danish Association Of the Disabled	Nicaragua	Service/Rehabilitation Service/Rehabilitation Combination Combination	3,000,000 4,998,821 3,084,849 12,005,000	90-93 92-95 95-97 97-02
National Society of Polio and Accident Victims	Philippines Lesotho	Combination Combination	6,506,000 2,772,713	95-97 97-00
Danish Association of the Blind	India Indonesia Ghana Bangladesh Nepal	Combination Combination Combination Service/rehabilitation Service/rehabilitation	1,722,570 960,340 4,448,191 4,154,236 2,450,692	94-95 94-97 94-99 94-02 95-99
Danish Association	Uganda	Combination	4,977,518	94-99
of the Deaf	East Africa	Service/Rehab	3,908,000	97-02

Federation of Hard of Hearing People	Nepal	Combination	14,300,000	94-97
The Danish Council of Organizations of Disabled People	Uganda	OD & Lobby	8,286,000	96-99
	South Africa	OD & Lobby	4,620,000	95-98
		OD & Lobby	4,700,000	97-98

OD = organizational development

LESSONS LEARNED

The majority of the Danish disability organizations, which were involved in international development initiatives for developing countries in the South, indicated that they had many positive experiences with their partner organizations. They said that their interventions had produced good results, not least when combining a number of activities (e.g. organizational development, lobbying, rehabilitation, direct service provision, income generation, etc.) within a project.

"Their experiences show that it was particularly difficult to work with small and often weak partner organizations in a different cultural context without extensive experience and skills in the field of development co-operation."

The organizations, however, also indicated that they had, to some extent, underestimated the problems involved in providing funding and developing partnerships with poor developing countries. Their experiences show that it was particularly difficult to work with small and often weak partner organizations in a different cultural context without extensive experience and skills in the field of development co-operation. Many of the organizations had very high expectations and became quite frustrated when they found out that their partner-organizations operated below par compared to how they ran their own organizations in Denmark. Many difficulties were encountered in day-to-day co-operation and these problems were usually related to issues of financial management, reporting and follow-up.

The Danish organizations learned that they must be more modest as far as goals and time frames are concerned. In the future, they would recommend undertaking more detailed investigations before commencing a partnership with a counterpart in the South, develop and set more concrete and measurable objectives, and establish more specific requirements for reporting.

The disability organizations also acknowledge that their hands-on knowledge about relevant issues, which people with no disability experience may easily overlook, is an advantage in doing international development work.

The potential of pursuing such initiatives is promising, in view of the broad base of the Danish disability movement that assures a strong foundation in Denmark for support to activities in the South, which generally takes the form of exchange visits, advocacy work and meetings. For many of the Danish organizations, development co-operation is an activity which enables them to learn from the experiences of their counterparts in the developing countries. Such insights learned enable them to bring new perspectives into the lives of their own members in Denmark.

"Disabled persons were involved in the planning, conception, and day-to-day running of BBP. "

B. A specific case study:

Engaging Filipinos with disabilities as catalysts for their own development

THE PROJECT

The **Breaking Barriers-Philippines (BBP)** project (1995-1998), a partnership of KAMPI –the National Federation of Organizations of Persons with Disabilities in the Philippines— and the Danish Society of Polio and Accident Victims (PTU), was the first project of its kind to be implemented in the Philippines. It was a pioneering effort at addressing the rehabilitation needs of children with disabilities – the most vulnerable yet least served among disabled persons in the country.

The manner by which BBP was conceived and implemented is far from the conventional way of implementing foreign-funded projects. Disabled persons were involved in the planning, conception, and day-to-day running of BBP. They recruited, screened and selected non-disabled professionals (e.g. physical and occupational therapists, social workers, teachers and other staff) who provided the specific technical expertise to run the project. The funds was provided for by the Danish Foreign Ministry (DANIDA) though the Danish Society of Polio and Accident Victims (PTU).

Such "revolutionary" approach to project implementation has been largely doubted in the beginning but was proven feasible, effective and sustainable by the project's end in 1998. In fact, BBP was continued and further expanded through **Breaking Barriers for Children (BBC)** project (1998-2003) because of its many fine results and achievements.

Under BBP, five Stimulation and Therapeutic Activity Centers (STAC) were established in five pilot regions of the Philippines from 1995-1998. The project overshot its goal of providing services to 1,000 beneficiaries by at least 50%, having served a total of 1,500 poor children with disabilities when the project was terminated in April 30, 1998. As envisioned, the beneficiaries of BBP were provided free rehabilitation services (e.g. physical and occupational therapy, training on activities for daily living, pre-school training, supplemental feeding for those who are malnourished), school placement services and referrals to other facilities (government and NGOs) mostly for medical, dental, surgical and other interventions which were not available in the STACenters.

"Such "revolutionary" approach to project implementation has been largely doubted in the beginning but was proven feasible, effective and sustainable by the project's end in 1998."

Other achievements of BBP include: launching of awareness campaigns on disability; policy research, formulation and advocacy in the areas of employment, accessibility, health care, legislation and education for persons with disabilities; continued piloting and development of concepts and action plans on integrating disabled children and young adults in mainstream services; provision of assistive devices and technical aids to beneficiaries in need, generating support from local government units who were eventually convinced to assume and take over the operation of the STACenters for sustainability when BBP ended in April 30, 1998; and provision of livelihood skills trainings and grants for small capital to augment the often limited income of parents of disabled children.

UNINTENDED PROJECT RESULTS

1. The STACenters established under BBP were accredited by the Philippines Department of Social Welfare and Development, as a government partners in the provision of rehabilitation and other services to persons with disabilities.

2. Some 25 colleges and universities in the Philippines have designated the STACenters as training facilities for graduating physical, occupational therapist-students, social work students and other students of allied medical courses. This partnership with colleges and universities has not only augmented the STACenters' manpower complement but also generated added revenues by way of donations from the student-interns. These revenues were used to meet expenses of disabled children which were not covered by the BBP funds from Denmark.

BUILDING ON THE SUCCESS

The Breaking Barriers for Children (BBC) 1998-2003 was implemented to build on the fine achievements of the BBP. It has not only continued the efforts of its forerunner but also expanded its services and added more features and components to make the services for children with disabilities much more comprehensive and sustainable in the long term. It has succeeded in fostering and nurturing the goodwill and social-civic mindedness of communities and the citizens at large. BBC to some extent, has made Filipinos become more conscious of and caring about the well-being of persons with disabilities.

"With the Danish support, Filipinos with disabilities under KAMPI have become both consumers and providers of rehabilitation services."

By end of 2001, the BBC served more than 7,000 children with disabilities in the five project areas – with clear indicators that it will overshoot its projected targets. From the original five pilot centers established in BBP, BBC services is now being used by beneficiaries from the original five main training and resource centers and 60 community-based rehabilitation centers spread throughout five regions of the Philippines.

DISABLED PERSONS EVOLVED FROM BEING CONSUMERS TO PROVIDERS OF SERVICES

The two projects – BBP and BBC- have demonstrated how disabled persons from a donor country like Denmark can be instrumental in supporting efforts of their counterparts in a developing country, like the Philippines, overcome barriers and stereotypes to become catalysts of change for their own development. With the Danish support, Filipinos

with disabilities under KAMPI have become both consumers and providers of rehabilitation services.

As BBP-BBC continue to produce fine results in their various efforts to build better lives for children in particular and persons with disabilities in general, KAMPI and PTU likewise continue to seek and explore possibilities to farther their mutually beneficial partnership beyond 2003. In spite of the challenges posed by shrinking resources, their potential is bright owing to the solid foundation and fine accomplishments that both BBP and BBC have established.

Another fine "unintended" result achieved by BBC is the emerging appreciation and willingness of local government units in the Philippines to be partners in this initiative of providing low-cost but quality services for the rehabilitation of children with disabilities. Involvement of the local government units is critical and is of prime importance to assure the sustainability and possible replication of the project in other parts of the country so that more beneficiaries can be served.

"Emphasis must be placed on the formation of strong, decentralized disability organizations which recognize and promote gender equality among disabled persons in terms of leadership development, among other considerations."

SUGGESTED STRATEGIES TO SUPPORT INITIATIVES OF PERSONS WITH DISABILITIES IN DEVELOPING COUNTRIES OF THE ASIA-PACIFIC REGION:

1. Support for disability initiatives in developing countries of the Asia-Pacific region must be implemented based on the framework of the UN Standard Rules on the Equalization of Opportunities for Persons with Disabilities, and in support of the goals and targets of the Asian and Pacific Decade of Disabled Persons, 1993-2002 and the follow-up decade, 2003-2012.

2. Priority for funding and technical assistance must be given to projects and activities that promote the establishment of strong, democratic and rights-based disability organizations.

3. Emphasis must be placed on the formation of strong, decentralized disability organizations which recognize and promote gender equality

among disabled persons in terms of leadership development, among other considerations.

4. "Positive discrimination" must be made in resource allocation in favor of disabled persons in countries of transition as well as disability groups who have difficulty organizing themselves including women and girls with disabilities.

" 'Positive discrimination' in resource allocation in favor of disabled persons in countries of transition as well as disability groups who have difficulty organizing themselves including women and girls with disabilities."

5. Support must be encouraged for pilot projects involved in service provision which takes the following into consideration: 1) the implementing organization has the capacity and the expertise to assure successful project implementation; 2) the project shows high potential for replication or up-scaling in a broader/national scope; 3) the project has clear monitoring, evaluation and documentation components; and 4) the project includes a mechanism for sharing examples of good practices and lessons learned for the benefit of others involved in similar initiatives.

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THE WRITER:

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6.6

A RIGHTS BASED APPROACH TO DISABILITY, DEVELOPMENT AND THE INTERGENERATIONAL BARGAIN

Beverly Ashton, Action on Disability and Development

This paper was originally published for the DSA Annual General Meeting at the Centre for Development Studies, University of Bath, 1999. MIUSA wishes to thank Beverly Ashton and ADD for permission to reprint the article.

DISABLED PEOPLE ARE EXCLUDED

There is no doubt that disabled people, particularly disabled women, are amongst the very poorest people in their communities, marginalised by their societies and continually forgotten in development work. As the Action on Disability and Development Bangladeshi Programme Manager has written:

> *Attitudes towards disability vary across culture and historical space. In our society, disability is often seen as a form of punishment: the disabled individual, his or her family or ancestor has violated a taboo, sinned, or been cursed by God. Disabling inherited traits are sometimes viewed as a family curses. Where disability is seen as a result of sin, the presence of a disabled child may be something of which the family is deeply ashamed. Religious teaching has provided some of the most negative attitudes towards people with disabilities. Similarly, language used by communities to describe disabled people and traditional role of people with disabilities reinforce negative attitudes. The negative response of most of non-disabled people to disabled people is based mainly on ignorance: they assume that disablement is a catastrophe, and they fear it; fear creates awkwardness, avoidance and prejudice (Coleridge 1993). The negative attitudes - physical and social barriers cause most of the problems faced by people with disability, not the disability itself. These barriers create blocks to development and integration in the society. The negative cycle of disability makes people with disabilities helpless and insecure.*
>
> ***Mosharraf Hossain: Inclusion of People with Disabilities in the Microcredit: The Dialect of Attitude and Aspiration 1999***

"Physical and social barriers cause most of the problems faced by people with disability, not the disability itself. These barriers create blocks to development and integration in the society. "

Disabled people are "poor" because they are excluded from facilities, services and resources which their peers have access to.

In February 1998 the "Guardian" newspaper published an article by Simon Maxwell from the Institute of Development Studies on Social Exclusion. Maxwell suggested that people become poor because they are excluded from social institutions, access to which is based on status, privilege, race and gender. Their exclusion results in them experiencing multifaceted deprivation - lack of resources, poor housing, low expectations, poor health, poor education etc. and they find themselves on the bottom of the proverbial heap.

"Disabled people are "poor" because they are excluded from facilities, services and resources which their peers have access to. "

This could be called the "Social Model of Poverty", mirroring the "Social Model of Disability". The Social Model of Disability states that disability is a form of social discrimination imposed on individuals who are identified as having some form of physical, sensory or psychological impairment. The disadvantages experienced by "disabled" individuals arise from a perception of their difference rather than as a direct result of their medical condition.

The Social Model identifies three types of discrimination faced by disabled individuals:

"The Social Model of disability states that disability is a form of social discrimination imposed on individuals who are identified as having some form of physical, sensory or psychological impairment. "

- Institutional discrimination: Institutional discrimination exists where disabled children are not required to go to school and there is no special provision for their needs if they do enroll. In many countries banks do not accept disabled customers, creditors will not advance them loans, employers will not consider them for jobs and families do not include them in the distribution of inheritance.

- Environmental discrimination: In most countries the physical environment excludes disabled people. Buildings with steps and narrow entrances, inaccessible "public" transport, a scarcity of information transcribed into braille or available on cassette tape and a lack of sign-language translators all serve to keep disabled people out, pushed to the margins and without the information they need to participate equally.

- **Attitudinal discrimination:** Prevailing attitudes are the third part of the conspiracy. There are many possible justifications for excluding and ostracising disabled people and their families. Some of the most common are beliefs that disability must be associated with evil, witchcraft or infidelity. There is a confusion between illness and disability which can lead to suffocating overprotection and exclusion of disabled people from everyday challenges. As people have low expectations of disabled people, disabled people often have low expectations of themselves.

Institutional discrimination builds and reinforces attitudinal discrimination and condones environmental discrimination. By this I mean that if people know that the law requires them to send their primary aged children to school, except their disabled children; if bus drivers can throw disabled passengers off the bus with impunity: and bank managers can refuse disabled people an account simply because they are disabled, the general perception is that these actions are valid. Together they have a logic and people use their fears, suspicions and prejudices to build a supporting rationale. Negative attitudes prevent spending on the necessary measures to overcome an inaccessible environment.

"People know that the law requires them to send their primary aged children to school, except their disabled children; if bus drivers can throw disabled passengers off the bus with impunity: and bank managers can refuse disabled people an account simply because they are disabled, the general perception is that these actions are valid."

MARGINALISATION OF INFANTS

Exclusion and marginalisation of disabled people starts very early. Infants who are noticeably impaired by illness or deformity are often simultaneously overprotected but yet offered a much less favourable start in life than their healthy siblings.

"Disabled children are likely to be fed last and may have to survive infections as best they can without medical intervention as their fate is seen to "be the will of god."

Disabled children have less demands placed on them. They may not be able to perform some of the simple household tasks other small children do to contribute to the household economy, but then their mothers may not teach or ask them to do others which they could. Disabled children are likely to be fed last and may have to survive infections as best they can without medical intervention as their fate is seen to "be the will of god". Later, disabled children are less likely to be sent to school for fear that they will not cope, will face ridicule or that their disclosure will affect the marriage prospects of their siblings.

Even at this early stage in life, a disabled child is often seen as the passive receipient of whatever fate delivers.

Having not attended school, disabled young people are at a significant disadvantage in obtaining apprenticeships and job training placements. This in turn makes it difficult for them to obtain work, earn an income or financially support a family. Even those who have been to school are not easily able to find paid work or gain access to the credit they need to begin a business.

As disabled girls are deemed unmarriagable, they are not able to secure their future through a husbands income.

"This early lack of investment in disabled children is not just a reflection of ignorance. In situations of poverty this is a desperate but rational economic decision by the family. Excluded from job-training, employment, and access to credit disabled young people are not in a position to financially support elderly parents. Indeed unmarriagable disabled women and their illegitimate children often remain dependent on family support themselves."

REDUCED CAPACITY TO SUPPORT THE FAMILY

As society excludes disabled people the pay-back, or social security, disabled children can offer their parents later in life is severely reduced. They are not seen as a worthwhile investment by the family, who speak of them as a "useless mouth to feed".

This early lack of investment in disabled children is not just a reflection of ignorance. In situations of poverty this is a desperate but rational economic decision by the family. Excluded from job-training, employment, and access to credit disabled young people are not in a position to financially support elderly parents. Indeed unmarriagable disabled women and their illegitimate children often remain dependent on family support themselves.

SELF-HELP APPROACH TO CHANGE

Disabled people want to change their situation. They have formed self-help groups to press for legislative protection of their rights. "Action on Disability and Development" (ADD) works with these self-help organisations of disabled people - from the newly formed village level groups finding their voice for the first time, through to the more power-

ful federations at national level who are engaging directly with their governments regarding inclusion of disabled people in poverty alleviation strategies and constitutional reform.

In Uganda we have seen what these organisations can achieve and the far-reaching measures which have been put in place as a result of their endeavours. I would like to look at ADD's work in Uganda as a case study.

UGANDA

"In areas where the disability movement is strong, self-confidence among disabled people has increased and marginalisation is decreasing."

In Uganda disabled people have achieved a greater level of political representation than in any other country. ADD has worked in Uganda since 1987. In the first phase of the programme we contributed to building the capacity of our main partner, the National Union of Disabled Persons of Uganda, (NUDIPU.) This group has since become independent of ADD and has successfully campaigned for political representation from village to parliamentary level.

In areas where the disability movement is strong, self-confidence among disabled people has increased and marginalisation is decreasing. Increasingly DPOs are lobbying for the rights of their members. Some district authorities (e.g.: Gulu, Soroti, Mbarara and Kabale) now have earmarked funds within their budgetary allocation towards work on disability. The government policy of providing free primary education to four children within each family offers priority to disabled children (although, in reality, many parents fail to comply with this prioritisation). Sign language is now constitutionally recognised. National television now broadcasts the news with a sign language interpreter.

"The disability movement has begun to have a real impact on the political scene."

Feedback within ADD's Uganda programme shows a general consensus among disabled people that there has been a marked improvement in most areas of their lives during the past few years. The disability movement has begun to have a real impact on the political scene. The new constitution provides for the representation of the disability movement at all levels of political administration. At parliamentary level five seats are reserved for disabled people, representing the four regions of Uganda and the interests of disabled women. In each local election, at all levels of government, there must be one disabled representative.

A recent participatory evaluation found that ADD's influence in the capacity building of partner organisations has contributed significantly to such achievements. However, much still needs to be done before disabled people realise full integration into Ugandan society. The improved attitudes at national decision-making level have yet to be reflected at the grass-roots.

Our work in Uganda has now expanded to all regions of the country and we work with more than 25 partner organisations, all set up and controlled by disabled people themselves. Disabled people are still marginalised, particularly women and children. They are still subjected to negative attitudes and are generally amongst the poorest of the poor. They have limited access to health care, education and mobility aids and are often treated poorly by public service providers. However, with a high political profile the DPO's are gradually changing this reality.

A RIGHTS-BASED APPROACH TO DEVELOPMENT

In tandem in the North, there has been a recent shift in emphasis that governments and development agencies are adopting towards poverty eradication, moving towards a human rights approach to development. ADD hopes that this shift will bring the rights and needs of disabled people onto the development agenda.

ADD believes that disabled people themselves are the most powerful advocates for changing attitudes and breaking down the barriers created by society. We continue to work with disabled people's organisations in Africa and Asia, supporting their campaign for the rightful inclusion of all disabled adults and children in society.

BEST PRACTICE: REGIONAL RESPONSES

Empowerment and the Young India Project, Andhra Pradesh

The Young India Project (YIP) provides a successful example of the kinds of empowerment activities required for strengthening the inclusion of people with disabilities in community life. YIP is linked to a federation of trade unions of agricultural and landless labourers (and their families) who advocate for access to existent government schemes, such as employment, income generation, housing, education and health programmes, as well as protest against injustices perpetrated against the rural poor.

YIP, in partnership with Action on Disability and Development (ADD), India, has included people with disabilities in all its work, the aim being to facilitate the access of people with disabilities to the services, equipment and opportunities they need to improve their own lives. Opportunities are created for people with disabilities, through union membership; to form supportive and campaigning self help groups and awareness building groups.

By early 1998, YIP had unions in 209 Mandals (group of 30-50 villages) with a total membership of more than 355,235. Work with people with disabilities makes up 25% of YIP's work. Well over 600 self-help groups of people with disabilities have been formed with a combined membership in 1998 of more than 11,000.

YIP has proved to be successful in linking disability issues into more mainstream debates. People with disabilities are forming their own groups as well as participating in the more general ones. They are increasingly aware of their rights and are able to claim and advocate for their entitlements.

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Department for International Development, 2000

BEST PRACTICE: REGIONAL RESPONSES

The post-Apartheid government in **South Africa** has published a comprehensive White Paper, putting forward an Integrated National Disability Strategy. This is based on the social model of disability and supports a rights-based approach. Government departments and State bodies have a responsibility to ensure that, in each line function, concrete steps are taken to ensure that people with disabilities are able to access the same fundamental rights and responsibilities as any other South African.

To co-ordinate this activity, the Office on the Status of Disabled Persons has been established in the Office of the Deputy President. This is charged with working together, and in parallel, with the various State bodies and departments and organisations in civil society to further the development of a disability friendly environment.

In **Uganda**, people with disabilities have achieved a greater level of political representation than in any other country. The disability movement has begun to have a real impact on the political scene. The new constitution provides for the representation of the disability movement at all levels of political administration. At parliamentary level five seats are reserved for people with disabilities, representing the four regions of Uganda and the interests of women with disabilities. In each local election, at all levels of government, there must be at least one representative who has a disability.

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6.7

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Action on Disability and Development has a vision of a world where all disabled people are able to participate as fully as they choose at every level of society. It works in partnership with networks of disabled people in some of the poorest communities in the world, to help them to campaign for the rightful inclusion of disabled adults and children in society. ADD is a British-based organization supporting rights based development work, exclusively with groups of disabled people in Africa and Asia. The aim is to see democratic, representative and active networks of disabled people who are campaigning for the rights of all their members whatever their disability. Through facilitating the growth of these organisations at local through national and international level, ADD aims to help promote a vibrant people's movement.

Canadian International Development Agency

200 Promenade du Portage
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Tel: (819) 997-5006
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E-mail: info@acdi-cida.gc.ca

CIDA supports sustainable development activities in order to reduce poverty and to contribute to a more secure, equitable and prosperous world. Working with partners in the private and public sectors in Canada and in developing countries, and with international organizations and agencies, it supports foreign aid projects in more than 100 of the poorest countries of the world. The objective: to work with developing countries and countries in transition to develop the tools to eventually meet their own needs.

Department for International Development UK (DFID)

1 Palace Street
London SW1E 5HE UK
Tel: (44) (0) 20 7023 0000
Fax: (44) (0) 20 7023 0016
E-mail: enquiry@dfid.gov.uk
Web: www.dfid.gov.uk/

The Department for International Development (DFID) is the UK government department responsible for promoting sustainable development and reducing poverty. DFID is committed to working towards the awareness of disabilities in development projects.

Disability Awareness in Action Network (DAA)

World Federation of the Deaf (WFD)
11 Belgrave Road
London SWIV 1RB UK
Tel: (44) (0) 20 7834 0477
Fax: (44) (0) 20 7821 9539
E-mail: info@daa.org.uk
Web: www.daa.org.uk

Disability Awareness in Action (DAA) is an international human rights network, run for and by disabled people. Primarily focused on people in developing countries, DAA is a collaborative project among Disabled Peoples' International, IMPACT, Inclusion International and the World Federation of the Deaf. DAA was established to provide a network for the exchange of information and experience between disabled people and their representative organizations, internationally. It supports disabled people's self-advocacy and promotes and protects disabled people's human rights.

Disabled Peoples' International (DPI)

748 Broadway
Winnipeg Manitoba R3G 0X3 Canada
Tel: (204) 287-8010
Fax: (204) 783-6270
TTY: (204) 284-2598
E-mail: DPI@DPI.org
Web: www.dpi.org

Disabled Peoples' International (DPI) is a worldwide organization that advocates the equalization of opportunities and the full participation of people with disabilities in all aspects of life. DPI is a grassroots, cross-disability network with member organizations in over 158 countries, over half of which are in the developing world.

DPI's goals are: to extend the principles of human rights to all people with disabilities, including the right to full participation in their families, their communities, their nations and in all spheres of their lives; to ensure that people with disabilities have control over their lives and input into the services that affect them; to achieve full integration of people with disabilities in their societies, with the same level of opportunity as their fellow citizens.

Disability World Web-Zine

www.disabilityworld.org/

Disability World is a new web-zine dedicated to advancing an exchange of information and research about the international independent living movement of people with disabilities.

Finnish Disabled People's International

Development Association (FIDIDA)
Kumpulantie 1 A
FIN-00520 Helsinki, Finland
Tel: (358) (0) 14 63 466
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E-mail: 358014614 33@faxaway.com
Web: http://66.201.75.104/Active2/rorg_a.asp

Acts as a cooperation and expert organization. Carries out development cooperation projects. Provides information on issues concerning people with disabilities in developing countries.

Inclusion International (II)

13D Chemin du Levant
Ferney-Voltaire 01210 France
Tel: (33) 45 040 0197
Fax: (33) 45 040 0107
E-mail: info@inclusion-international.org
Web: www.inclusion-international.org

Inclusion International is an international non-governmental organization committed to fighting discrimination, abuse and neglect of persons with intellectual disabilities. Emphasizing inclusive education, Inclusion International focuses efforts on anti-discrimination, family support, community based resources, self-advocacy, development partnerships, and social well being for people with mental disabilities. Il has close to 200 member organizations worldwide, and cooperates closely with the UN and several of its agencies. Il organizes international seminars, regional conferences and world congresses, and publishes an international newsletter, as well as various other publications.

International Development and Disability Consortium (IDDC)

c/o Handicap International
5 Station Hill
Farnham, Surrey GU9 8AA UK
Tel: (44) (0) 1252 821 429
Fax: (44) (0) 1252 821 428
E-mail: co-ordinator@iddc.org.uk
Web: www.iddc.org.uk/i

IDDC is a self-managing group currently consisting of 16 international non-governmental organizations supporting disability and development work in over 100 countries globally. IDDC's aim is to more effectively and efficiently promote the rights of disabled people through collaboration and sharing of information and expertise. To achieve this aim, IDDC believes development policy and practice should be inclusive.

Japan International Cooperation Agency (JICA)

6-13F, Shinjuku Maynds Tower
1-1, Yoyogi 2-chome
Shibuya-ku, Tokyo 151-8558 Japan
Tel: (81) 03-5352-5311/5312/5313/5314
Web: www.jica.go.jp/

Japan's Official Development Assistance (ODA) began in 1954, when it joined the Colombo Plan, an organization set up in 1950 to assist Asian countries in their socio-economic development. Today, Japan stands as the top donor in the world in terms of net ODA disbursement and in 1992, it was the major donor in 25 countries. JICA is responsible for the technical cooperation aspect of Japan's ODA programs. Technical cooperation is aimed at the transfer of technology and knowledge that can serve the socioeconomic development of the developing countries. JICA carries out a variety of programs to support the nation building of developing countries through such technical cooperation. JICA has about 1,200 staff members working both in Japan and at its more than fifty overseas offices.

Svenska Handikapporganisationers Internationella (Swedish Org. of Disabled International Aid Federation) SHIA
PO Box 4060
Stockholm 102 61 Sweden
Tel: (46) 08-462-3360
Fax: (46) 08-714-5922
TTY: (46) 08-714-5951
E-mail: shia@shia.se
Web: www.shia.se/

Svenska Handikapporganisationers Internationella (SHIA) or the Swedish Organization of Disabled International Aid Federations is a non-governmental affiliation of Swedish organizations of disabled persons involved in development projects around the world. SHIA serves to support the work being done by people with disabilities to achieve equality and full participation in their communities. Founded in 1981, today SHIA has over 20 member associations providing support to development projects in countries in Africa, Asia and Latin America.

United Nations Economic and Social Commission for Asia and the Pacific (UNESCAP)

Asian and Pacific Decade of Disabled Persons
Disadvantaged Groups Section, Social Development Division
United Nations ESCAP, UN Building
Rajadamnern Avenue
Bangkok 10200 Thailand
Tel: (66) 2-288-1345
Fax: (66) 2-288-1030
E-mail: spidgs@un.org
Web: www.unescap.org/decade

In order to address the major issues that disabled persons face and thereby enhance the quality of their lives, the governments of the Asian and Pacific region declared the period 1993 - 2002 as the Asian and Pacific Decade of Disabled Persons. The Economic and Social Commission for Asia and the Pacific (ESCAP) supports member and associate member governments in the ESCAP region on developing approaches that promote the participation of people with disabilities in the development process. This support is provided through operational activities, encouragement of networking and collaborative action, identification of examples of good practice, as well as advisory services on the implementation of the Agenda for Action for the Asian and Pacific Decade of Disabled Persons.

U.S. Agency for International Development (USAID)

U.S. Agency for International Development Information Center
Ronald Reagan Building
Washington, D.C. 20523-1000 USA
Tel: (202) 712-4810
Fax: (202) 216-3524
Web: www.usaid.gov/

USAID is an independent federal government agency that receives overall foreign policy guidance from the Secretary of State. The agency works to support long-term and equitable economic growth and

advance U.S. foreign policy objectives by supporting: economic growth, agricultural and trade, global health, conflict prevention and humanitarian assistance. The U.S. Agency for International Development (USAID) is committed to the inclusion of people who have physical and mental disabilities and those who advocate and offer services on behalf of people with disabilities. This commitment extends from the design and implementation of USAID programming to advocacy for and outreach to people with disabilities. USAID's policy on disability is as follows: To avoid discrimination against people with disabilities in programs which USAID funds and to stimulate an engagement of host country counterparts, governments, implementing organizations and other donors in promoting a climate of nondiscrimination against and equal opportunity for people with disabilities.

DEVELOPMENT TOPICS AND DISABILITY

7

7.1a

WOMEN WITH DISABILITIES: BRIEF GLOBAL OVERVIEW

Prepared by Harilyn Rousso, Girls and Women with Disabilities: An International Overview and Summary of Research. Oakland, CA: World Institute on Disability; and New York, NY: Rehabilitation International

OVERVIEW

Women are more likely to become disabled throughout the lifespan than men as the result of such factors as violence, armed conflict, aging and gender-biased cultural practices that limits their access to food, shelter, health care and a safe working environment.

"An estimated 10% of the world's population have disabilities and about 80% of these live in developing countries."

"There are more than 300 million women with disabilities in the world. In many societies they are consigned to the margins — not admitted to schools, rejected by employers, denied health care. We cannot afford this loss." Madeleine Albright, U.S. Secretary of State, 1997 address to International Leadership Forum for Women with Disabilities.

An estimated 10% of the world's population have disabilities and about 80% of these live in developing countries. (WHO Press Release, 3 December 1999)

Women and girls with disabilities face double discrimination based on disability and gender. As a group, they fare far worse than nondisabled women or disabled men on most indicators of financial, educational and vocational success. (Harilyn Rousso, "Girls and Women with Disabilities: an International Overview and Summary of Research," 2000, in publication by Rehabilitation International and World Institute on Disability.)

POVERTY AND ECONOMICS/EMPLOYMENT

There is a strong and cyclical relationship between poverty and disability: poor people tend to become disabled because of their living conditions, which makes them even poorer. When one is both disabled and poor, as hundreds of millions are, we are not talking about just lack of income — but also a lack of information, resources, influence and access to fulfillment of basic human needs. (Poverty and Disability: a position paper, Swedish International Development Authority, 1995.)

"All over the world, disabled women still rank at the bottom of every scale that measures progress. Recent studies show that disabled women are the least likely people to be employed, the most likely to live in dire poverty and among the people most likely to die young." Judy Heumann, U.S. Assistant Secretary for Education, "Education: Engine for Empowerment," 1997.

"The United Nations estimates that the literacy rate worldwide for people with disabilities is around 3%, with the rates for disabled women and girls hovering around 1%."

According to the UN, only a quarter of women with disabilities worldwide are in the workforce (Groce, 1997, as reported in Rousso, 2000, as noted above). They are twice as unlikely to find work as disabled men. (International Disability Foundation, 1999, as reported in Rousso, 2000.)

LITERACY AND EDUCATION

The United Nations estimates that the literacy rate worldwide for people with disabilities is around 3%, with the rates for disabled women and girls hovering around 1%. (*The United Nations Decade of Disabled Persons: A Decade of Accomplishment 1983-1992*, UN, New York 1992)

For girls and young women, disability bias in combination with gender bias keep them out of school, limit their number of years of schooling, or compromise the quality of their schooling. For example, in the U.S., disabled women are five times as likely as nondisabled women to have fewer than eight years of school. In some countries, schools are inaccessible or too far away, or there are formal policies to exclude disabled students. (Rousso, *Girls and Women with Disabilities*, 2000)

"In most countries of the world, sign language is not recognized as an official language for deaf persons and braille is not recognized as the official written language for blind and deaf blind persons. These are major barriers standing between these groups and their literacy and education." Kicki Nordstrom, Vice President, World Blind Union

SURVIVAL AND HEALTH

Partly due to male preference, women and girls often have less access to food, health and medical services; and therefore may survive disabling conditions less often than their male counterparts, are taken less often to receive immunization or treatment and may be more likely to have malnutrition. Thus, for females, curable conditions may worsen, leaving permanent disabilities. (Nora Groce, "Women with Disabilities in the Developing World," 1997, in *Journal of Disability Policy Studies*; Rousso, 2000, as above; and Elwan, World Bank as above.)

Worldwide, rehabilitation services reach only 3% of those who could benefit (Einar Helander, WHO, as quoted by Groce) and those services that exist are often inaccessible or unavailable to women and girls (Groce, as above).

On a regular basis, women and girls with disabilities around the world face inaccessible health care, refusal of service from mainstream health systems, lack of respect by the medical profession for their need for autonomy and privacy, and subjugation to medical procedures with unproven efficacy. (Rousso, as above.)

Concerning reproductive health care, in numerous countries disabled women are prevented from or pressured against having children through abortion or unauthorized sterilization and hysterectomies. If they do give birth, they may be forced to give up their children through adoptions or otherwise deprived of custody of their children. These actions are widely supported by health officials who, with no scientific basis, assume disabled women cannot be adequate parents or that they will invariably produce disabled children. (Disabled People's International & Interessenvertretung, 1998, as reported in Rousso, as above.)

VIOLENCE AGAINST WOMEN

Research indicates that women and girls with disabilities experience violence and physical and sexual abuse at significantly higher rates than their non-disabled counterparts. For example, the WHO estimated in 1999 that violence towards persons with disabilities occurs at three times the rate of such incidence among the general population. (*WHO Draft Policy on Disability*, unpublished manuscript by Groce, Eigner and Sandborg.)

"Women and girls with disabilities experience violence and physical and sexual abuse at significantly higher rates than their non-disabled counterparts."

The abuse against disabled women and girls takes place within families, institutions and communities and tends to be more chronic and severe, as well as taking unique forms, such as the withholding of essential care and medication. (Rousso, as above.)

It is not yet well recognized that abuse and violence is also becoming a significant cause of both physical and mental disabilities in women. (K. Raye, "Violence, Women and Mental Disability," paper prepared for Mental Disability Rights International; and B. Waxman Fiduccia and L. Wolfe, 1999, "Women & Girls with Disabilities: Defining the Issues," Center for Women Policy Studies, Washington, D.C.)

WOMEN, ARMED CONFLICT & LANDMINES

International statistics concerning the alarming rise in civilian deaths and disability caused by armed conflict are now well-known, as are the indicators that at least 70 people a day are now injured by landmines around the world. According to the International Disability Foundation (*World Disability Report 99*), there are now between 250,000 and 300,000 disabled survivors of landmines today, most of whom are amputees. It is less well-known that just as disabled civilians will have less access to prosthetic and rehabilitation services than disabled soldiers, disabled girls and women will have even less and, in fact often remain unserved.

THE GIRL CHILD

"The difficulties faced by disabled girls can start at birth, and if disabled girls are allowed to survive, they can face discrimination within the family, receive less care and food and be left out of family interactions and activities. They also have less access to health care and rehabilitation services and fewer education and employment opportunities. Disabled girls and women are at high risk of being abused mentally and physically, sometimes by those within the household. Abuse…is often unreported because of the additional shame to the family which is already stigmatized for having a disabled daughter." (Based on studies quoted by Elwan, "Poverty & Disability: a Survey of the Literature," 1999 World Bank, as above.)

"Discrimination starts at home, in the early years of the life of a disabled woman. This discrimination brings with it a reluctance on the part of…decision-makers within the families to make tangible and intangible resources available to disabled women, thus further undermining their life chances." L. Abu-Habib, *Gender and Disability: Women's Experiences in the Middle East*, 1997, Oxfam.

"Girls with disabilities are assumed to be unable to fulfill typical roles of wife, mother or worker and hence are deprived of opportunities to prepare for adult roles."

Often, girls with disabilities are assumed to be unable to fulfill typical roles of wife, mother or worker and hence are deprived of opportunities to prepare for adult roles. Low parental and community expectations, social isolation and lack of access to education and training place them at high risk for poverty and abuse.

Contact: **Rehabilitation International**
25 East 21st Street, New York, NY 10010
Tel.: 212-420-1500, Fax: 212-505-0871
E-mail: Rehabintl@rehab-international.org
Website: http://www.rehab-international.org

Rehabilitation International is a worldwide network of people with disabilities, service providers and government agencies working together to improve the quality of life for disabled people and their families. Founded in 1922, it now has more than 200 member organizations in 90 nations

7.1b

LOUD, PROUD AND PASSIONATE ® : INCLUDING WOMEN WITH DISABILITIES IN INTERNATIONAL DEVELOPMENT PROGRAMS

Cindy Lewis for ***Mobility International USA***

HOW WOULD THE DEVELOPMENT PROCESS CHANGE IF WOMEN WITH DISABILITIES WERE INCLUDED AT EVERY LEVEL?

"Disabled women's rights are women's rights are human rights!"

Women and girls with disabilities are estimated to represent up to 20 percent of the world's female population, the majority living in less economically developed countries, yet are under-represented and under-served in every aspect of the international development field.

The international community can no longer afford to overlook the immense resources that women with disabilities offer. Women with disabilities have knowledge, skills, and expertise, and with access to appropriate resources can join the development process as potent agents of change. International development and women's organizations must combat — not contribute to — marginalization, oppression and segregation of women with disabilities. Human rights organizations must apply their well-developed understanding of the oppression of women and poor people to the situation of women who are also disabled, and take proactive steps to counteract the many levels of oppression faced by disabled women.

"DISABLED WOMEN'S RIGHTS ARE WOMEN'S RIGHTS ARE HUMAN RIGHTS!" BEGINNINGS IN BEIJING

In 1995, more than 300 women with disabilities and allies from around the world made history at the Fourth UN World Conference on Women and the parallel Non-Governmental Organization (NGO) Forum. In spite of nearly overwhelming barriers, women with disabilities joined forces to form the largest ever international coalition of women with disabilities and make a powerful statement to the world's women: "Disabled women's rights are women's rights are human rights!" The actions of women with disabilities in Beijing, reported by international media, resulted in heightened awareness by non-disabled women's groups around the world of the situation and accomplishments of women with disabilities.

In Beijing, for the first time, the voices of women with disabilities were significantly reflected in an official, international agreement. The *Platform for Action*, the agreed-upon blueprint for action over the next decade to improve the status of women, mandates government and non-governmental organizations to include girls and women with disabilities in areas of economic development, education, leadership training, health, violence prevention, and decision making. The Platform for Action makes specific recommendations for community and international development programs:

> "Mobilize all parties involved in the development process, including academic institutions, non-governmental organizations and grass roots and women's groups, to improve the effectiveness of anti-poverty programs directed towards the poorest and most disadvantaged groups of women, such as ... women with disabilities".

WOMEN WITH DISABILITIES AND DEVELOPMENT: MAKING THE LINK

In spite of the fact that women and girls with disabilities are estimated to represent up to 20 percent of the world's female population, the majority living in less economically developed countries, women with disabilities

report that they are denied significant participation in community projects, human rights organizations and international development programs. Stated strongly by the Uganda Disabled Women's Union,

> "It is quite absurd that international development programs rarely address the needs of disabled women. Women with disabilities are harassed sexually, exploited by men, suffer abject poverty and social disrespect, malnutrition, disease and ignorance." (Mobility International USA, *Loud, Proud and Passionate ®: Including Women with Disabilities in International Development Programs*, 2002.)

Development policy makers and practitioners need to listen to women with disabilities as they identify the barriers that impact their ability to participate in the development of the community and achievement of their rights. Among the important problems articulated by women with disabilities:

- Women and girls with disabilities are denied access to education and vocational training, employment, transportation and housing, making it difficult or impossible to achieve economic self-sufficiency and contribute to our communities.
- Women and girls with disabilities receive inadequate — if any — rehabilitation services, because the very limited available resources are directed toward adult men with disabilities.
- Women with disabilities are less likely than non-disabled women to marry, but more likely to be abandoned with children, facing social stigma, loneliness, and poverty.
- Protection against violence, even the inadequate protection afforded to non-disabled women, is not available to women and girls with disabilities.
- Although women and girls with disabilities are more likely than non-disabled females to be physically, sexually, and emotionally abused, most battered women's shelters and rape crisis centers are not accessible to them.
- Involuntary sterilization, contraceptives, and abortion continue to be forced upon women with disabilities.

- Women with disabilities are denied access to reproductive health services by cultural attitudes, physical barriers, financial constraints, and unenlightened medical personnel and health care providers.
- In most countries, women and girls with disabilities have a higher mortality rate than do disabled males.
- Women and girls with disabilities are more likely to be malnourished than disabled males.
- Restricted to their homes by inaccessible environments, lack of mobility aids or transportation, family overprotection and shame caused by cultural biases, women with disabilities are often isolated and unaware of either their rights or their options.

Mobility International USA (MIUSA) has collaborated with women with disabilities from every region of the world since 1981, through international exchange programs emphasizing leadership training and human rights. Each year, we are excited by the determined and skillful efforts of disabled women who, in spite of immense barriers, are working to become full and equal participants in their communities. On the other hand, we are increasingly angered and frustrated by the continued exclusion of women with disabilities in development efforts that target economic and social empowerment of women.

"We are excited by the determined and skillful efforts of disabled women who, in spite of immense barriers, are working to become full and equal participants in their communities. On the other hand, we are increasingly angered and frustrated by the continued exclusion of women with disabilities in development efforts that target economic and social empowerment of women."

UNTAPPED RESOURCES

Women with disabilities around the world today are challenging old stereotypes by becoming involved in politics, leading organizations, entering the labor market, and participating in community life. Women with disabilities are taking remarkable action to fight the systemic gender and disability-based discrimination that results in poverty, inadequate health care, lack of education, violence and abuse of disabled women and girls. As women with disabilities work more cohesively across borders, they are developing networks of support and a culture of shared pride in their strengths and accomplishments.

Women with disabilities offer an untapped resource for international development, as partners, staff and beneficiaries. In 1999, MIUSA

conducted a survey of grassroots organizations led by and for women with disabilities in Eastern and Central Europe, Africa, Asia and the Pacific, and North America and the Caribbean. (Full results of the survey are published in MIUSA's *Loud, Proud and Passionate®: Including Women with Disabilities in International Development Programs, 2nd ed).* Among these:

"Women with disabilities offer an untapped resource for international development, as partners, staff and beneficiaries."

- 75% of the organizations surveyed offer leadership development opportunities to women with disabilities; most offer targeted training through seminars and workshops.
- 75% conduct some form of public campaign to raise community awareness of the issues, rights and potential of women with disabilities.
- 73% offer training programs and support for women with disabilities to participate in business or income-generation activities.
- 29% offer some kind of microcredit program for women with disabilities.
- More than half of the organizations conduct advocacy activities for improved rights of women with disabilities, many at national and regional policy levels.
- Nearly half of the organizations address educational and health needs of women with disabilities.
- 44% offer programs for young women and girls with disabilities.

GUIDELINES FOR GENDER APPROPRIATE INCLUSION

Lessons learned from efforts to incorporate gender perspectives throughout the development process offer useful guidelines toward the inclusion of women with disabilities. These include:

- *Inclusion of women and girls with disabilities must be comprehensive and take place at all levels of the development process.*

Full inclusion of women with disabilities in the development process must go beyond limited approaches that have traditionally offered separate programs for people with disabilities. While women with disabilities

may benefit from appropriate targeted interventions that enable them to maximize their skills and abilities, development assistance programs must support women with disabilities to access the full range of options available to all members of the communities.

- *Involve women with disabilities at all levels of development as implementers as well as recipients.*

In order to achieve full inclusion, women with disabilities must participate not only as beneficiaries, but also as administrators, consultants, partners and field staff. Increasing the involvement of women with disabilities as program planners, implementers and participants requires dedicated outreach efforts, modifications to increase accessibility, and changes in attitudes, assumptions and both gender and disability awareness by US and indigenous staff.

"Increasing the involvement of women with disabilities as program planners, implementers and participants requires dedicated outreach efforts, modifications to increase accessibility, and changes in attitudes, assumptions and both gender and disability awareness by US and indigenous staff."

- *Incorporate practical, appropriate strategies to make projects accessible to women and girls with disabilities.*

Inclusive programs must incorporate adaptive strategies and perspectives of women with disabilities in every phase of the development process, beginning with program design and continuing through implementation and evaluation of projects and policies. Women with disabilities must be involved in program planning to ensure that practical and effective adaptations are built in projects to facilitate full participation of women with disabilities.

- *Support and work in partnership with organizations led by women with disabilities.*

Grassroots organizations led by women with disabilities offer expertise and resources for technical assistance, problem solving and partnership to expand the participation of women with disabilities in development programs.

- *Adopt organizational policies and strategic objectives that address i nclusion of women and girls with disabilities.*

Systematic practices to include women and girls with disabilities require coherent policy and strategic objectives for implementation.

- *Collect data on involvement of women and girls with disabilities.*

Data collection is essential in order to accurately assess the extent of inclusion of women and girls with disabilities in the development assistance process, and design and evaluate effective strategies to remedy inequalities.

DEVELOPMENT AGENCIES: TOOLS FOR EMPOWERMENT

Development organizations can play a powerful role in counteracting the cycle of oppression through which disabled women are denied access to support and resources which would empower them to reach their potential and contribute to the community. Disabled women leaders in the MIUSA survey credit international assistance organizations and foundations with progress in the formation of successful disabled women groups and even small inroads for women with disabilities. As articulated by a leader of a disabled women organization in Nepal:

> "The important change has been in the NGOs. All organizations, old and new, are involving women with disabilities in decision-making in their organizations. As a result, more and more women with disabilities come to leadership".

In MIUSA's *Loud, Proud and Passionate ® :Including Women with Disabilities in International Development Programs*, women with disabilities from diverse countries and cultures call on NGOs working with women in development to share expertise, training and resources, to support the formation of disabled women's groups and to empower women with disabilities to participate in non-disability-specific groups. Their recommendations for international development programs, human rights, women's and other non-governmental organizations include:

- Leadership training and community development projects must conduct specific outreach efforts to include women with disabilities.

- Women with disabilities must be involved in all policy and decision making processes, and at every level of the projects: as staff, consultants, participants, and evaluators.
- Advice and expertise of women with disabilities must be utilized in designing programs and policies, research, conferences, and documentation of major social issues that affect women.
- Education, vocational training and rehabilitation programs must include women with disabilities, to prepare women and girls for careers and gainful employment.
- Rehabilitation and adaptive technology must be available for women with disabilities, and women with disabilities must be involved in the development and production of adaptive devices.
- Health service personnel must be trained to offer informed and sensitive service and education addressing the health needs of girls and women with disabilities.
- NGOs can support the efforts of women with disabilities by helping to reduce logistical obstacles, by sharing office equipment and meeting space, offering access to telephone, Internet and fax, and contributing to transportation solutions.
- Governments and non-governmental organizations must be pressured to effectively implement the many important recommendations that have been made over the years by various UN bodies and non-governmental organizations, particularly at the Fourth World Conference on Women in Beijing in 1995.
- Governments and non-governmental organizations in host countries must be educated to prioritize issues of women with disabilities in development efforts.

DEVELOPMENT FOR **ALL** WOMEN: A NEW PARADIGM

It is time to reach out to bring the perspectives and resources of women with disabilities into the development process. Human rights, women's and development organizations must support women with disabilities to achieve the full range of options available to women: to be workers, leaders, activists, mothers, partners, citizens. Development programs and

women's organizations must support women with disabilities to meet and work side by side with other women, to contribute to dialogues on gender and development, and to participate in global efforts to achieve economic justice, human rights and a peaceful world.

MIUSA is proud to join our sisters around the world, proud to be part of a culture of women with disabilities that crosses many boundaries. Women with disabilities are "Loud, Proud and Passionate®", in our work for the empowerment of all women, for all people with disabilities, and for all people. We will be heard!

REFERENCES

IMobility International USA (2002) Loud, Proud and Passionate® : Including Women with Disabilities in International Development Programs.

United Nations (1995). UN Platform for Action from the 4th World Conference on Women, Beijing China. United Nations, Department of Public Information.

7.1c

GENDER AND DISABILITY: A SURVEY OF INTERACTION MEMBER AGENCIES

Findings And Recommendations on Inclusion of Women and Men with Disabilities in International Development Programs

Mobility International USA (MIUSA) conceived and undertook the research project, ***Building an Inclusive Development Agenda: A Survey of Inclusion of People with Disabilities Among InterAction Member Agencies*** to document the extent to which people with disabilities, particularly women and girls with disabilities, participate in the international development assistance process. This research is the first systematic attempt to determine whether international development organizations based in the United States include eligible people with disabilities in policies, employment, programs and services, and what data, if any, they collect concerning participation by women and men with disabilities. Recognizing the need for such data and information, 104 member agencies of InterAction, a diverse coalition of more than one hundred sixty five US-based relief, development, environmental and refugee agencies working in more than 100 countries around the world, participated in the research in partnership with MIUSA.

Susan Detroy

The research confirmed that most organizations do not collect data showing the extent to which people with disabilities, in particular women and girls with disabilities, participate in the development assistance process. Almost one-third of organizations that participated in the research operate disability-specific services or programs such as care and treatment for HIV/AIDS, vocational rehabilitation, or provision of prosthetics. A few others are working actively to include people with disabilities in their general programs. However, according to available data and respondent observations, few women and men with disabilities are employed by respondent organizations or are served in field programs aimed at general populations.

"The research confirmed that most organizations do not collect data showing the extent to which people with disabilities, in particular women and girls with disabilities, participate in the development assistance process."

The new data presented in this report sound a clarion call for InterAction members to begin implementing the InterAction Private Voluntary Organization (PVO) Standards on Disability adopted in 2000. The presence of USAID (United States Agency for International Development) funding in 56% of respondent organizations also reinforces the importance of USAID's Disability Policy, which mandates that USAID grantees must: "avoid discrimination against people with disabilities in programs which USAID funds." Based on these new findings and recommendations, InterAction, its member organizations, MIUSA and others can begin designing appropriate and effective methods to promote inclusion of people with disabilities.

"One of the world's largest minorities, 600 million people with disabilities comprise almost one in ten of the world's population. Pity, misperception and prejudice serve to isolate and marginalize most people with disabilities from the community mainstream."

One of the world's largest minorities, 600 million people with disabilities comprise almost one in ten of the world's population. Pity, misperception and prejudice serve to isolate and marginalize most people with disabilities from the community mainstream. Women with disabilities experience literacy rates estimated to be less than five percent and unemployment that exceeds 75 percent. With little chance to achieve economic security, marry or inherit property, women with disabilities in most societies face severe economic hardship and even threats to their survival. In light of the extreme poverty and disenfranchisement experienced by most people with disabilities around the world, it is imperative that people with disabilities who are eligible to participate in development assistance programs be afforded an opportunity to do so.

PARTICIPATION OF WOMEN AND GIRLS WITH DISABILITIES IN INTERACTION MEMBER PROGRAMS

This research focused on inclusion of women and girls with disabilities in InterAction programs. Data highlight issues such as women with disabilities in InterAction members general programs, Women in Development or gender-specific programs, strategies used by InterAction member organizations to include women and girls with disabilities in programs, women with disabilities in disability-specific programs, programs for women and girls with disabilities, barriers or obstacles to inclusion of women with disabilities in programs, and inclusion of women and girls with disabilities in organization policies and strategic objectives.

PARTICIPATION OF WOMEN AND GIRLS WITH DISABILITIES IN INTERACTION MEMBER PROGRAMS

1. Respondent organizations collect little or no data about the participation of women and girls with disabilities in gender-specific, non-gender specific and disability-specific programs.

2. Very few respondent organizations refer to women and girls with disabilities in their strategic objectives, suggesting that this group and its particular needs are not yet recognized or identified.

3. Nearly half of participating organizations that operate Women in Development or gender-specific programs do not use any specific strategies to include women and girls with disabilities in such programs.

4. According to respondents, obstacles to inclusion of women and girls with disabilities include poor outreach, lack of training and information, lack of funds for disability-related accommodations and physically inaccessible facilities.

5. The 27 respondent organizations that conduct training on gender issues do not specifically address issues of women and girls with disabilities.

There are no data available to support assumptions that women and girls with disabilities are included in InterAction member programs. On the contrary, a presumption of exclusion may be more supportable based on the fact that very few respondents reported implementing outreach strategies or policies, or dedicating resources to facilitate inclusion of women with disabilities.

The following comments from participating organizations illustrate the widespread lack of data about participation of women and girls with disabilities in programs that are not gender-specific.

"We may have some women with disabilities in our programs operated by implementing partners, but we don't track the numbers."

"We don't collect this information. Anecdotally, we are aware of female microfinance borrowers who are supporting children or other dependents who are disabled. As mentioned earlier, I don't know if we have any disabled people who are direct borrowers."

"Our programs serve detained asylum seekers and immigrants; therefore whatever population exists in the detention facilities is who we serve. I don't know whether the people in the field make a special effort to search out detainees with disabilities.

"We assume that there are many women with disabilities served by our counterpart organizations."

WOMEN WITH DISABILITIES IN WOMEN IN DEVELOPMENT OR GENDER-SPECIFIC PROGRAMS

Fifty-three percent (39 of 74) of respondent organizations conduct gender-specific programs. These InterAction member programs address issues that are critical to women with disabilities. Table 9 illustrates some of these programs:

WOMEN IN DEVELOPMENT AND GENDER-SPECIFIC PROGRAMS OPERATED BY INTERACTION MEMBER AGENCIES

Types of Women in Development and Gender-Specific Programs	Number of Organizations Operating This Program	Percentage (n=39)
Microcredit/Economic	15	38%
Health	12	31%
Capacity-building	6	15%
Education	6	15%
Gender Equity	6	15%

STRATEGIES USED BY ORGANIZATIONS TO INCLUDE WOMEN WITH DISABILITIES IN WOMEN IN DEVELOPMENT AND GENDER-SPECIFIC PROGRAMS

Forty-three % (32 of 74) of participating organizations stated that they do not use any strategies to include women with disabilities. When organizations use strategies to include women with disabilities in women in development and gender-specific programs, these include encouraging participation in conferences and trainings, conducting programs at accessible locations, and outreach to the community in order to identify women who might participate.

Though organizations conducting gender-specific programs assume that women with disabilities participate, few could provide numerical data about their participation.
"We do not specifically target women with disabilities in our gender-specific programs, although they may benefit indirectly through our programs."

"Forty-three % of participating organizations stated that they do not use any strategies to include women with disabilities."

BARRIERS OR OBSTACLES TO INCLUSION OF WOMEN WITH DISABILITIES IN WOMEN IN DEVELOPMENT OR GENDER-SPECIFIC PROGRAMS

Most organizations did not identify specific barriers to inclusion. Among those that did, factors identified by respondents as obstacles to inclusion for women with disabilities in gender-specific programs did not differ significantly from those identified by general programs. This outcome suggests either that the barriers are actually the same or a lack of recognition of the specific needs of women with disabilities, or both. Participant organizations identified the following barriers: sixteen percent identified lack of outreach, eleven percent identified lack of knowledge about how to include women with disabilities, four percent identified lack of funds for providing disability-related accommodations and one percent identified physically inaccessible facilities. Fifty-five percent (41 of 74) of participating organizations reported that no funding is dedicated to programs that specifically address the needs of women with disabilities.

ORGANIZATIONAL POLICIES AND STRATEGIC OBJECTIVES

Ninety-five percent of respondent organizations indicated that their organizations do not specifically refer to women or girls in their strategic objectives. Only 4% (3 of 74) of the respondent organizations refer specifically to women and girls with disabilities in their strategic objectives, all three through program implementation. Of the organizations surveyed, 47% (35 of 74) have a gender policy but 97% of such policies do not specifically refer to inclusion of women and girls with disabilities. Of the 27 participating organizations that conduct training that specifically addresses gender issues, 96% do not address issues of women with disabilities.

Dana Vion

STRATEGIES TO ASSURE PARTICIPATION OF WOMEN AND GIRLS WITH DISABILITIES IN WOMEN IN DEVELOPMENT OR GENDER-SPECIFIC PROGRAMS

Respondent organizations that do not use any strategies to include women with disabilities were asked how they assure participation in Women in Development or gender-specific programs. Forty-six of 74 organizations (62%) responded that the question was not applicable to them, and 8 organizations did not respond to the question. Sixteen organizations (22%) do not take steps to ensure that women with disabilities are included in gender-specific programs. These organizations, as with the organizations that do not assure inclusion of people with disabilities in general programs, do not take specific steps to assure participation of women because of the inclusive nature of their policies and programs.

"We do not discriminate when sending out applications for our training programs. However, we are not as aggressive in inclusion as we could be – but we are changing that through our strategic planning process now."

"We do not specifically target women with disabilities in our gender-specific programs, although they may benefit indirectly through our programs."

Responding to a question about why no strategies are implemented to recruit women with disabilities, one organization said,

"We have enough to focus on already!"

DISCUSSION

Comparing issues for disabled women with those of other marginalized groups and poor non-disabled women, participant leaders with disabilities at MIUSA's 1998 International Symposium on Microcredit for Women with Disabilities identified many common issues. Included were a lack of acceptable collateral, low self-confidence, few resources for business, lack of experience and training, illiteracy, heavy family responsibilities, unmarried status or discouragement from husbands.

MIUSA Microcredit Symposium delegates identified obstacles that affect the abilities of women with disabilities to participate in microcredit activities. Structural and communication barriers include inaccessible meeting and market places, equipment, and modes of transportation; print-only materials, and lack of sign language interpreters. Other important barriers include disability stigma and discrimination in training, loan opportunities and the marketplace. These disability-specific obstacles can be extrapolated to other development programs, and they require specific responses to assure participation of women with disabilities.

"MIUSA Microcredit Symposium delegates identified obstacles that affect the abilities of women with disabilities to participate in microcredit activities. Structural and communication barriers include inaccessible meeting and market places, equipment, and modes of transportation; print-only materials, and lack of sign language interpreters. Other important barriers include disability stigma and discrimination in training, loan opportunities and the marketplace. These disability-specific obstacles can be extrapolated to other development programs, and they require specific responses to assure participation of women with disabilities. "

InterAction's CAW, describing successful approaches to incorporating gender perspectives in program planning, recommended:

"Consultation with local women's organizations and involving women participants in program planning is perhaps the best way to ensure a gender perspective in program design."

Women with disabilities must be involved in program planning to ensure that practical and effective methods for inclusion are built into projects from the outset.

"Women leaders with disabilities are the best resource for technical assistance and problem solving for inclusion of women with disabilities. All development organizations, microcredit programs and lenders must consult with women leaders who have disabilities for strategies to make all information, programs and services accessible for women with disabilities." (Mobility International USA: Resolution and Recommendations: Loud Proud and Prosperous: an International Coalition on Microcredit and Economic Development for Women with Disabilities, 1998.)

RESOURCES

The following are organizations and individuals that work with women and girls with disabilities. These contacts can be useful for international programs working to recruit women and girls with disabilities for inclusion in programs, and are a good source of information on resources available to women and girls with disabilities.

Association for Women's Rights in Development
96 Spadina Ave.
Suite 401
Toronto, ON M5V 2J6 Canada
Tel: (416) 594-3773
Fax: (416) 594-0330
E-mail: awid@awid.org
Web: www.awid.org

The Association for Women's Rights in Development (AWID) is an international membership organization connecting, informing and mobilizing people and organizations committed to achieving gender equality, sustainable development and women's human rights.

Center for Research on Women with Disabilities
3440 Richmond Avenue, Suite B
Houston, Texas 77046 USA
Tel: (713) 960-0505 *or* (800) 44-CROWD (800-442-7693)
Fax: (713) 961-3555
E-mail: crowd@bcm.tmc.edu
Web: www.bcm.tmc.edu/crowd/

The Center for Research on Women with Disabilities (CROWD) is sponsored by National Institute on Disability and Rehabilitation Research (NIDRR), Centers for Disease Control and Prevention (CDC), and National Institutes of Health (NIH). CROWD has conducted national U.S. studies of sexuality issues among women with disabilities, violence against women with disabilities, and health promotion for women with

disabilities. It offers fact sheets with statistics about US women with disabilities, conducts research, and develops and disseminates information to expand the life choices of women with disabilities, and offers leadership training for women with disabilities in English and Spanish.

Disabled Women's Alliance
PO Box 6008
Albany, CA 94706 USA
E-mail: corbetto@aol.com
Web: www.disabilityhistory.org/women

Disabled Women's Alliance offers a set of videos and a manual titled *Workshop in a Box: Disabled Women Speak Out on Mentoring, Violence and Relationships.*

Disabled Peoples' International (DPI) - Women's Committee
Marquardsenstr. 21
91054 Erlangen, Germany
Tel: (49-9131) 20-5022
Fax: (49-9131) 20-7351
E-mail: dinah.radtke@zsl.erlangen.de

DPI's Women's Committee assures the participation of women with disabilities within and outside of DPI. This committee has been involved in a variety of projects, including networking among other international disability organizations, participation in conferences and production of articles and publications on women with disabilities.

Disabled Women in Development (DIWODE)
PO Box 2284
Blantyre, Malawi
Tel:(265) 621-0001
Fax: (265) 624-014

The goals of Disabled Women in Development (DIWODE) in Malawi are to improve the socio-economic status of women with disabilities through economic empowerment and to mobilize women with disabilities to engage in economic activities. DIWODE currently works with local financial institutions to develop credit programs for women with disabilities to begin micro-enterprises.

Disabled Women's Reproductive Health Training

Great Plains Paralyzed Veterans of America Education Center
7612 Maple Street
Omaha, NE 68134-6502 USA
Tel/TTY: (402) 398-1424 *or* (800) 454-7782
Fax: (402) 398-1424
E-mail: pva@edcenter.org
Web: www.edcenter.org/health.html

Offers training to health care providers to effectively meet the health needs of their clients with disabilities, in particular disabled women and their reproductive health needs.

Ethel Louise Armstrong Foundation (ELA) Foundation

2460 North Lake Avenue, PMB #128
Altadena, CA 91001 USA
Tel: (626) 398-8840
Fax: (626) 398-8843
E-mail: info@ela.org
Web: www.ela.org

The ELA Foundation funds programs that enable women and girls with disabilities to enhance their education and training. ELA Foundation also offers a scholarship for women graduate students who are studying in the United States, or studying abroad as part of a U.S.-based study abroad program.

European Network of Women with Disabilities (DISWEB)
Mariankatu 24 E 40
Helsinki, Finland 00170
Tel: (358) 0-135-7925
Fax: (358) 0-160-4312
Web: www.stakes.fi/sfa/disweb0.html

European Network of Women with Disabilities (DISWEB) is a cross-disability organization serving as a bridge between women with disabilities in Europe. DISWEB seeks to provide a forum for the exchange of ideas and experiences among women with disabilities. In addition the Network works to promote interests and needs of women with disabilities, supporting them in starting local groups. DISWEB publishes an annual newsletter, written by women with disabilities. It contains articles about the personal experiences of disabled woman as well as general information concerning women's issues. DISWEB holds an annual conference to bring together women from throughout Europe.

Health Resource Center for Women with Disabilities
Rehabilitation Institute of Chicago
345 East Superior Street, Room 106
Chicago, IL 60611 USA
Tel: (312) 908-7997
Fax: (312) 908-4300
E-mail: jsparkle@aol.com
Contact: Judy Panko Reis, Co-Executive Director

The Health Resource Center for Women with Disabilities offers physical, psychosocial and emotional services to women with disabilities. It provides equipment, consultation, family planning and contraceptive care, mammogram referrals, preventive health care counseling, parenting support, peer counseling, psychological services and support groups. It publishes a quarterly newsletter, *Resourceful Women: Women with Disabilities Striving Toward Health and Self-Determination*.

National Women's Health Information Center
8550 Arlington Boulevard, Suite 300
Fairfax, VA 22031 USA
Tel: (800) 994-WOMAN (800-994-9662)
TTY: (888) 220-5446
Web: www.4women.gov/wwd/

This national organization provides health-related information for women and has specific resources for women with disabilities. National Women's Health Information Center has English- and Spanish-speaking information and referral specialists.

Whirlwind Women
San Francisco State University
1600 Holloway Avenue
San Francisco, CA 94132 USA
Tel: (415) 338-6277
Fax: (415) 338-1290
E-mail: whirlwind@sfsu.edu
Web: http://whirlwind.sfsu.edu/general_info/whirlwind_women/whirlwind_women1.html

Whirlwind Women is a project of Whirlwind Wheelchair, Inc. (WWI), a US non-profit organization that works internationally to develop grassroots wheelchair production, and to remove barriers to wheelchair travel through social and political change. Whirlwind Women's goals are to enable women with disabilities to take an active role in increasing their own and others' mobility, introduce women with disabilities to wheelchair production in developing countries; train women to maintain and repair their own wheelchairs while developing leadership and business skills, and expand the global network supporting women with disabilities in learning essential technology. Whirlwind Women conducts outreach and training, and offers support to women involved in WWI programs. In addition it offers technical information and resources on an international scale to women with disabilities.

WinVisible USA - Women with Visible and Invisible Disabilities
Crossroads Women's Center
PO Box 11795
Philadelphia, PA 19101 USA
Tel: (215) 848-1120
Fax: (215) 848-1130
E-mail: 72144-1055@compuserve.com

WinVisible USA is a grassroots network bringing together women with disabilities to campaign for economic, social and physical autonomy.

Women with Disabilities in Development of the Disabilities Action Council
PO Box 115
Phnom Penh, Cambodia
Tel: (855) 23-215-341
Fax: (855) 23-214-722
E-mail: dac@bigpong.com.kh

Women with Disabilities in Development of the Disabilities Action Council (WDDDAC) is a non-profit, women's organization in Cambodia that advocates the active participation of women with disabilities in development programs. WDDDAC's goal is that women with disabilities have equal rights and opportunities and improved quality of life from social recognition, encouragement and provision of social services. Objectives include communication and involvement of women with disabilities in development, access to income generation activities, access to social and health care services and raising awareness on the issues of domestic violence and discrimination against women with disabilities.

Women and Philanthropy
Tel: (202) 887-9660
Web: www.womenphil.org
Contact: Felicia B. Lynch

Contact this organization for proceedings, recommendations and participant lists from the "Funding All Women: Including Women and Girls with Disabilities" conference, which was held June 17-18, 1999.

Women With Disabilities Australia (WWDA)
PO Box 605, Rosny Park
Tasmania 7018 AUSTRALIA
Tel: (61-3) 6244-8288
Fax: (61-3) 6244-8255
E-mail: wwda@ozemail.com.au
Web: www.wwda.org.au

WWDA is an Australian disability organization for women and has a website with information on a variety of useful resources, including books, articles, websites and more.

7.2

DISABILITY IN THE CONTEXT OF CIVIL SOCIETY

Sarah Buckley: Mercy Corps International, Civil Society Program
Karen Heinicke-Motsch and Susan Sygall: Mobility International USA

This chapter explores ways to empower people with disabilities in international development programs, and stresses that greater societal impact can be had by doing so. It relies heavily on Mercy Corps' application of a civil society "lens" to its humanitarian work[1]. It recognizes that MIUSA and other disabled people organizations (DPOs) commonly employ a human rights approach in their work, and it shows how examining disability within a civil society approach is an effective way to build on this rights-based paradigm to assure inclusion of people with disabilities in international relief and development work.

The chapter first explores concepts of civil society and how they fit within international relief and development. It then illustrates how a civil society approach builds on a human rights paradigm. The bulk of the chapter presents Mercy Corps' civil society approach in detail and how it relates to people with disabilities. The final sections include practical strategies for building an inclusive civil society and illustrative examples from around the world.

CIVIL SOCIETY AND INTERNATIONAL DEVELOPMENT

Many international non-governmental organizations have civil society programs that aim to strengthen the peoples' voice in the countries in which they work. It is increasingly recognized that relief and development activities provide an important opening for the strengthening of civil society, a necessity for building communities that are more peaceful,

democratic and economically stable. At the same time, a healthy and functioning civil society reduces the need for repeated relief operations and leads to more sustainable development.

Emergency response and development activities related to health, recovery, agriculture, and economic opportunity have greater impact and sustainability if civil society strengthening activities are incorporated into project designs. Correspondingly, projects whose goal is to strengthen civil society, such as the development of the NGO sector, promotion of democratic elections or influencing policy reform, help develop the context in which sustainable economic and social development can thrive.

Whether an agency's approach to civil society programming concerns the NGO sector, democracy and governance activities or a methodology applied to all programming, it is critical that practitioners take into account people with disabilities when planning programs. Because a civil society approach to programming finds its basis in the active participation of all people in society, it is a natural starting point for considering the inclusion of people with disabilities in relief and development activities.

A CIVIL SOCIETY APPROACH AND THE HUMAN RIGHTS PARADIGM

On one level, this chapter describes the partnership between MIUSA, an organization that saw an opportunity to bring disabled peoples organizations (DPOs) into the mainstream of international relief and development work, and Mercy Corps, a humanitarian organization committed to working with vulnerable people worldwide. Just as MIUSA approaches disabilities from a human rights paradigm, Mercy Corps approaches international relief and development work through a civil society lens.

MIUSA and Mercy Corps find that these two paradigms complement each other well.

First, both organizations are committed to human rights and civil society strengthening. Where Mercy Corps' civil society approach rose out of its

early commitment to human rights and its civil society principles are derived from the Universal Declaration of Human Rights, MIUSA believes that the inclusion of people with disabilities is critical to building a strong civil society. Second, both Mercy Corps and MIUSA see the comparative value in each approach. A civil society approach provides a vehicle for, or operationalizes, the application of human rights concepts in relief and development programs, whereas human rights are a universally accepted and understood legal paradigm. Both approaches have at their core the active involvement of all citizens in society.

Since signing a partnership agreement with MIUSA in February 2002, Mercy Corps has deepened its commitment to including people with disabilities in its operations and programs. With limited resources, the goal has not yet been fully realized, but there have been numerous successes.

WHAT IS CIVIL SOCIETY?

Acknowledging that many definitions of civil society exist, Mercy Corps defines civil society as follows:

Civil society is both the process and result of civic organizations[2], government and business interacting in a way that is participatory, accountable and includes mechanisms for peaceful change, all of which contributes to the creation of more secure, productive and just communities.

A healthy and vibrant civil society empowers citizens to participate in the economic, political and social activities and decisions that affect their lives. By promoting the strengthening of and collaboration between civic organizations, the government and the private sector, the goal of creating secure, productive and just communities can be advanced.

The above definition refers to the relationship of three sectors, which includes the major forces that exist in any society and that influence social and economic development. What makes a society "civil" is the interaction of these three sectors in such a way that ultimately promotes positive social values and behavior and that empowers people to participate in decisions that affect their lives. The three sectors include:

- Government (the public sector) – i.e. a governance system or the state,
- Business (the private sector) – i.e. a market system and
- Civic Organizations (the civic sector or the third sector) – i.e. a system for the expression of citizens' voices in which citizens associate and represent their interests.

DISABILITY AND MERCY CORPS' CIVIL SOCIETY PRINCIPLES

Drawing language from the Universal Declaration of Human Rights, Mercy Corps identified three key principles that characterize healthy, vibrant societies: **participation, accountability** and **peaceful change.** These principles provide the basis for government, business and civic cooperation that results in secure, productive and just communities. They are also a good starting point for considering people with disabilities in development programs.

"An organization that employs a civil society approach seeks out people with disabilities to actively participate as staff, volunteers and beneficiaries in all steps of a program."

Participation. Participation refers to the ability of all people to actively engage in the processes and decisions that affect their lives. Participation requires concerted outreach to include traditionally marginalized parts of the population, such as women, people with disabilities, youth, the elderly and ethnic or religious minorities. Conditions necessary for effective participation include respect for basic human rights, freedom of peaceful assembly and expression, access to accurate, unbiased information and a culture of inclusion.

An organization that employs a civil society approach seeks out people with disabilities to actively participate as staff, volunteers and beneficiaries in all steps of a program. People with disabilities are involved in the design and implementation of services that address their needs, including any community projects such as the building of a school or a well. Development organizations should consider barriers to participation and work to break down these barriers in order to enable equal participation. This means anything from ensuring that people in wheelchairs get picked up so they can attend a town hall meeting to providing access to education and legal literacy services. Finally, the participation of women, youth, girls and boys with disabilities is an integral part of an inclusive development approach.

Accountability. Accountability refers to the ability of citizens to hold those with decision-making power responsible for the decisions that they make. It also refers to the willingness of those leaders, including government, business and civic leaders, to hold themselves responsible for the decisions they make on behalf of others. Finally, it means that citizens recognize their responsibility to play an active role in society. This type of behavior requires a culture of transparency that promotes the right of people to understand the roots of decisions that affect them, including the allocation of resources for critical social and economic services such as job development, housing, health care and education. In a society that values accountability, people have access to their leaders and confidence in the rule of law. This means a system in which laws, as well as administrative systems, rules and regulations are public knowledge, clear in meaning and apply equally to everyone.

Because people with disabilities are often disempowered in many societies, it is especially important that they be able to advocate for themselves. This includes being aware of their own potential, resources and responsibility to hold leaders accountable to their needs. To do this, people with disabilities need to know how to find information about their rights under the law and international standards. Political leaders have a responsibility to consider the needs of people with disabilities, as they are undoubtedly part of their constituency. NGOs that claim to work for people with disabilities need to be accountable to their beneficiaries by making sure that they gain input from their members/beneficiaries on a regular basis and that people with disabilities are active participants in the NGO. Ideally people with disabilities would play key leadership roles in any such organization. In other words, people with disabilities should make choices about their lives and potential not based on preconceived notions of what other people and organizations think they can do, but based on their own experiences. As an integral part of society, people with disabilities should be empowered to challenge others in society to be accountable to their needs.

Peaceful Change. Peaceful change refers to the process and manner in which communities and societies manage, react to, live with and/or influence change. Some level of conflict exists in every society. A

functioning civil society has mechanisms for solving conflict without resorting to violence. Promoting peaceful change means providing people with tools and mechanisms to work collaboratively and solve problems peacefully at all levels – from the community level to the national level.

Although disability is a common thread of concern for all communities, it can carry special meaning in communities affected by conflict where peoples' disabilities may have resulted from land mines and fighting. Post-war societies provide opportunities to mainstream people with disabilities in which they may have traditionally been viewed as invalids. In the same way that women, elderly people or the clergy often have the credibility to provide a bridge for communication and empathy across conflict lines, people with disabilities can play this role as well, uniting communities under the common cause of disability or of rejecting violence because of their personal struggle as a result of conflict.

People with disabilities are critical stakeholders in the process of conflict transformation, part of the diversity and breadth of opinions necessary for sustainable peace.

For international relief and development work to be successful, people with disabilities must be included in all components and levels of the project cycle.

Inclusive development is, in the long term, the most effective way to promote full human development, reduce poverty, equalize power and increase stability. An inclusive civil society model provides a framework for bringing silent voices into the public dialogue.

"Simply put, people with disabilities are enabled to have a voice in public decision making. "

STRATEGIES FOR BUILDING AN INCLUSIVE CIVIL SOCIETY

While this chapter posits that all relief and development work should include disability and civil society considerations, the reader may still be asking, what are some practical civil society approaches that humanitarian

organizations can consider in their work? And how do these relate to people with disabilities? In reading the following strategies, development practitioners should think about how these approaches can be incorporated into their programs, from economic development to health to agriculture to civil society, etc :

1. **Strengthening the civic voice:** This means helping people build a stronger voice in issues that affect them and their geographic or interest-based community. It means that people with disabilities and disabled peoples organizations are targeted for and included in community empowerment and mobilization activities. It includes leadership training for people with disabilities. It also means helping grassroots disability groups and disability NGOs to identify their challenges and solutions to those challenges, and to collaborate with other civic organizations, government and business actors to build coalitions, networks and alliances that advocate for specific systemic changes. Simply put, people with disabilities are enabled to have a voice in public decision making.
2. **Raising public awareness:** This means tackling the disengagement in civic life that often stems from low levels of awareness and lack of hope in regard to social problems and laws. People with disabilities should be made aware of their rights and responsibilities in a democratic society. Likewise, it is critical that the general public be aware of the rights and responsibilities of their fellow community members with disabilities. International non-governmental organizations can aid people with disabilities in collecting their own data and information on their rights in order to conduct awareness campaigns regarding these issues. Posters, TV documentaries, radio public service announcements, billboards, information leaflets and community fairs are just a few ways to raise public awareness.
3. **Sharing tools and mechanisms for peaceful change:** Conflict exists in all societies on many different levels; initiatives should always be aware of tensions in society and strengthen local mechanisms for dealing with conflict without violence. When conducting conflict analysis, international NGOs should speak with disabled peoples organizations (DPOs). DPOs should be considered as potential allies in peace movements and coalitions campaigning for peace. When sponsoring conflict management workshops, DPOs should be included as

"People with disabilities should be made aware of their rights and responsibilities in a democratic society. Likewise, it is critical that the general public be aware of the rights and responsibilities of their fellow community members with disabilities. "

"When sponsoring conflict management workshops, DPOs should be included as participants. "

participants. People with disabilities have often had to overcome challenging situations through negotiating for their needs. These lessons are useful in conflict management efforts. People with disabilities might be a voice for peace in the midst of disability-inducing violence.

4. **Promoting cross-sectoral collaboration:** For many reasons, government offices, civic organizations, and business people don't communicate and collaborate. Building trust and working relationships among these actors is a key civil society strengthening activity. People from these sectors have a common interest in an active and educated citizenry. People with disabilities can be coordinating their activities with other civic organizations, and government and business to build alliances that achieve their goals. International non-governmental organizations often have the contacts to initiate this cooperation. They can also aid DPOs in figuring out available and effective avenues for communicating with receptive government ministries, lawmakers or district level officials.
5. **Localizing initiatives:** Most relief and development programs aim for eventual full management and ownership by a local partner in order to assure sustainability of an initiative. Localizing means more than building skills—it means empowering leadership and encouraging vision. One effective localizing role that an International non-government organization (INGO) can play is to link community based organizations of people with disabilities to national level DPOs. These types of relationships can legitimate advocacy organizations by connecting them with the community; they provide an opportunity for local level organizations to have a voice in decision-making. Likewise, institutional capacity building of DPOs and the DPO sector is essential to sustain the life of these organizations.

PUTTING INCLUSION INTO PRACTICE

Many practitioners find it helpful to have examples of how organizations are programming with people with disabilities in mind. Below are a few examples from Mercy Corps to inspire the imagination.

Mercy Corps: Working with local partners to assure inclusion

Mercy Corps has always been committed to working with vulnerable

groups including people with disabilities. Since initiating its partnership with MIUSA, Mercy Corps has deepened its commitment to working with people with disabilities by employing expanded and creative approaches, as well as tracking and promoting this work. Below are some examples and successes related to working with people with disabilities. Mercy Corps' ultimate goal is to mainstream the inclusion of people with disabilities as a regular part of all of its programs.

Because an integral part of Mercy Corps' civil society approach is working with and through local partners to promote ownership and sustainability, many of the examples below reflect the dedicated work of community-based organizations and local NGOs with Mercy Corps acting as facilitator, catalyst and technical and financial supporter.

BEST PRACTICE

In **Georgia,** Mercy Corps, with assistance from USAID, has supported over 30 projects through local NGOs that address issues related to people with disabilities. Many of these local NGOs have pioneered the promotion of integrating people with disabilities in education and other spheres of their communities. Because of the negative perception of people with disabilities in Georgia, public awareness-raising through the media has been an important part of Mercy Corps Georgia's commitment to working with disabled adults and children. These activities help to promote positive images of disabled children and adults – and overcome negative stereotypes from the past. They also result in legitimization of NGOs as true supporters of positive social change, resulting in critical community support.

One such NGO, a library and cultural center for people with disabilities called Tanadgoma, produced a video with Mercy Corps' assistance. The video was made in response to resistance from parents who did not want their children in the same school, classroom or activity with disabled children. Tanadgoma considered the importance of media on public opinion and had the video, which emphasized the challenges faced by people in wheelchairs, aired daily on an influential TV station free of charge. Their efforts paid off and drew lots of attention and comments from viewers, including: "I have never thought about these children before", "It is so important for healthy children to know that people with special needs really need their assistance," "I have never seen a child in a wheelchair," "I hope the girl in the film with be happy," "That's what we all need...this film changed me."

Another local partner, Fund New Life, established a mixed (i.e., children with disabilities and children without disabilities) school for vulnerable children in 1996. At the time there was not much support for the school because people were hesitant for children with disabilities to attend school with other vulnerable children who were not physically or mentally disabled. The next year, a local newspaper journalist published an article generating interest and raising important public debate around the issue. Following the article, a TV station produced a 45-minute program

on the school, providing valuable coverage and legitimizing this work. In 1996 only seven children attended the school; in 2003 there are more than 60 students. Parents, and Georgian society in general, are seeing that these children can be educated and play an active and participatory role in society. The school has established a positive image among the public, donors and local governments, who are now more willing to give support.

The Association of NGOs Assisting Children with Speech and Hearing Disorders also saw the need for attitudinal changes in Georgian society. As part of a Mercy Corps funded project for disabled children in Tbilisi, the association produced a video emphasizing the children's many abilities, showing that it is possible to create vocational opportunities for people with disabilities. As a result of the program, a number of journalists wrote follow-up articles for local newspapers.

Mercy Corps Georgia's experiences with these NGOs and Mercy Corps' partnership with MIUSA have motivated them to go back and fund access ramps on schools and other community-managed infrastructure projects. Disability considerations will also be a requirement for future infrastructure projects that result from the community mobilization process in its East Georgia Community Mobilization program. Furthermore, Mercy Corps explicitly planned and budgeted for disability considerations in its new British Petroleum-funded Community Investment Program in Georgia.

In **Montenegro**, Mercy Corps' local NGO partner, Alter Modus, provides in-kind grants such as equipment to vulnerable individuals and families to aid in self-employment. In the past, more than half of the recipients of these grants had physical disabilities. More recently, Alter Modus has come to recognize that there is a much larger group of people with disabilities needing assistance than originally thought. According to the World Health Organization (WHO), there are approximately 60,000 such persons in Montenegro, where they are widely discriminated against in education, employment, transport and access to public buildings. Furthermore, people with disabilities are not empowered or encouraged to participate actively in the social, economic and political life of the

country, partially due to negative perceptions and partially due to a lack of representation in the civic sector. Recent legislation cut off government aid to NGOs, making the situation worse for people with disabilities. In recognition of this need, Alter Modus has identified people with disabilities as one of two target groups for its grant and microcredit programs in its 2003-2005 strategic plan.

Mercy Corps Tajikistan**'s activities, funded largely by the USDA and USAID, include working with a number of local NGOs and citizens groups that assist and empower people with disabilities.**

Dilsuz, the National Association of Disabled People, has seven staff, 38 branches across the country and 83,000 registered members. This organization, run by people with disabilities, supports people with disabilities through farms - by employing them to work at the farms, by selling the farm produce at subsidized rates and by donating the produce to vulnerable people. They have worked with Mercy Corps to distribute food aid to institutions such as orphanages and homes for the elderly. Mercy Corps has also provided Dilsuz with training in strategic planning and organizational development. The planning has resulted in a more participatory organization, as it involves volunteers, all staff and the branch offices in the planning process. Staff at Dilsuz have also learned group facilitation techniques as part of the training, and employed them in Mercy Corps Tajikistan's planning processes.

Dilsuz has good links with the government and is able to access resources in kind, land, buildings and so on. As a result of their close collaboration with Mercy Corps' civil society program, they now play an advocacy role, collaborating with the Ministry for Social Protection to make changes in the law to assist the disabled. In a recent evaluation of the impact of Mercy Corps' civil society approach on their work, one Dilsuz staff had this to say: "After our work with the civil society program and drawing up a business plan, our organization radically changed our work. Our organization tries to pay more attention to the protection of rights of people with disabilities, make our members more active so they participate in work of our organization and building of the state more actively."

The local NGO, Avrora, which provides assistance to blind children and those with poor vision to assure equal opportunities in education and childhood development, has received a grant from Mercy Corps to assure access to information through the creation of a "talking books" library. Mercy Corps also helped Avrora to implement educational programs on legal issues and economical, cultural and professional education. Nadejda, a community based organization, provides legal literacy and humanitarian assistance to people with disabilities. It also builds mutual understanding and tolerance among children and youth. Mercy Corps supported public awareness raising activities including seminars and roundtables that explored ways for people with disabilities to actively participate in public life. Mercy Corps also supported the publication of legal booklets designed to educate people with disabilities about their rights.

Mercy Corps **Serbia**'s Community Revitalization through Democratic Action (CRDA) program is currently funding a project through a Serbian NGO called Educational Humanitarian Organization (EHO). This project is addressing access for people with disabilities in the city of Prokuplje by improving tollgates and sidewalks. EHO is also working with the media to familiarize residents of the needs and rights of people with disabilities. If successful, Mercy Corps is already discussing expanding the project to several other towns. This project and the MIUSA partnership have inspired Mercy Corps Serbia to ensure that all efforts are made to provide wheelchair and disability access on infrastructure projects. This is a major commitment for a $40 million USAID grant spanning five years. Because this project is implemented through mobilizing communities to identify their needs and implement and match their projects with the help of the greater community, government and business, Mercy Corps' commitment to funding disability modifications is a strong catalyst for community awareness-building and social improvement.

In **Russia's Far East**, between 1999-2002, Mercy Corps implemented the USAID funded Assistance to Russian Orphans (ARO) project. ARO gave small grants and technical assistance to local NGOs preventing the abandonment of children, offering family-based alternatives to institutional care and working on social adaptation issues for children and youth

exiting institutional care. Because they are over-represented in institution populations, children with disabilities were beneficiaries of a number of projects.

One such NGO partner, Smile, in Spassk, a village in Primorsky Krai, started the *Rehabilitation and Education Program for Disabled Children*, a Montessori kindergarten, which integrates children with special needs with other children from the community. In addition to educational services, the center provides social work services to families with children with special needs. For the first time, families with children with disabilities can receive support and education services at home. Formerly this option did not exist and children were institutionalized.

During the first year of the project, Smile collaborated closely with government agencies, developing strong relationships with and receiving considerable support from the municipal authorities. The municipal department of education was so impressed with the results and success of the program that it decided to provide on-going funding for the Montessori kindergarten and asked Smile to expand its activities into other schools.

In Vladivostok, ARO partner NGO Voice of Help, a membership organization made up of parents with disabled children, implemented two projects, *Special Needs Child and Mainstream School* Project and *Parental University* Project. When Voice of Help began the first project, the main implementers were specialists who were not members of the organization. One of the reasons for this was that parents were certain that their children could be helped only by highly qualified specialists such as doctors, specially trained teachers and psychologists. Parents could not imagine themselves as the primary experts and teachers of their children. However, through their work on both projects, parents began to learn how to care for, teach and advocate on behalf of their children. Now parents are confident about their important roles as caregiver, teacher and expert. Parents are the driving force behind Voice of Help's continued work in supporting families with disabled children, changing attitudes of parents, teachers, government workers and community members about their disabled children's ability to learn and transferring their "expert" knowledge to the specialists.

To build on the work of ARO, Mercy Corps continues to work with two ARO partner organizations, Fund Danko and the Chernigovka branch of the All-Russia Women's Union, to implement the EU Tacis funded *Capacity Building and Coordination of Social Sector NGOs in Russia Far East* project. The project aims to expand the role of NGOs from that of social services providers to that of advocates for social reform for people with disabilities through training, study tours and technical assistance.

Mercy Corps has brought together NGOs working with adults and children with disabilities on a number of occasions to learn new skills in lobbying, working with the media and building coalitions in an effort to advance the cause of people with disabilities in Primorsky Krai. The groups have been encouraged to incorporate civil society principles into their programs and to promote active participation of the disabled. These groups, which have had a history of animosity and non-cooperation, have agreed to come together based on a common goal of promoting the rights of the disabled. Mercy Corps feels a major success has been accomplished as this newfound cooperation has provided the foundation for a locally driven coalition of DPOs in Russia's Far East.

[1] Mercy Corps is an international relief and development organization operating in over thirty countries. At Mercy Corps, civil society is seen as both the process and result of civic organizations, government and business interacting in a way that is participatory, accountable and includes mechanisms for peaceful change, all of which contributes to the creation of more secure, productive and just communities. This definition differs from the standard definition of civil society as the civic sector. Mercy Corps not only approaches all programs through this "civil society lens," but it also implements "civil society program" designed to strengthen the ability of civic organizations to influence positive social change.

[2] Civic organizations include formal and informal voluntary associations that are organized around common interests. These can include, for example, national level non-governmental organizations advocating for policy reform, small business associations providing business development services to local entrepreneurs, women's groups working to decrease levels of domestic violence in their communities, and even social clubs for soccer, knitting or reading, since these clubs increase a social sense of "belonging" and can act as forums for discussion and cooperation.

CIVIL SOCIETY AND THE RIGHT TO VOTE

The Global Initiative to Enfranchise People with Disabilities

The following information is from the International Foundation for Election Systems(IFES) and the International Institute for Democracy and Electoral Assistance (IDEA) press releases and from the IFES website as well as from an interview with Jerry Mindes, Disability Adviser for IFES. MIUSA wishes to thank Jerry Mindes for his advice and guidance on the issue.

Bengt Linqvist calls the initiative "…the first ever comprehensive gathering of disability, electoral and intergovernmental organizations to address the fact that a substantial proportion of citizens in every country – usually estimated at around 10 percent – have not had their rights to participate in the electoral process respected."

On September 17, 2002, disability rights experts and activists, senior election administration officials and international parliamentarians from more than 24 countries launched the Bill of Electoral Rights for People with Disabilities. The Bill of Rights defines and promotes the fundamental rights of people with disabilities in relation to all aspects of the electoral process. Specifically, the bill includes the right to a secret vote, full physical accessibility of polling stations and full and equal electoral rights for people with mental disabilities.

The draftees of this important Bill of Rights included: Bengt Lindqvist, UN Special Rapporteur on Disability, senior election officials from Canada, Ghana, Indonesia, Lesotho and Jamaica and members of Parliament from South Africa, Sri Lanka and Namibia. The drafting of the bill was co-organized by International Foundation for Election Systems (IFES) and the International Institute for Democracy and Electoral Assistance International (IDEA). The Swedish International Development Cooperation Agency (SIDA) sponsored it.

Bengt Linqvist calls the initiative "…the first ever comprehensive gathering of disability, electoral and intergovernmental organizations to address the fact that a substantial proportion of citizens in every country – usually estimated at around 10 percent – have not had their rights to participate in the electoral process respected".

Access to the electoral process for people with disabilities is an issue in both established and developing democracies. Election observers around the world cite inadequate physical access to polling stations as the biggest factor limiting disabled people's ability to participate in elections.

The bill is both the beginning of an international movement to guarantee that people with disabilities have the opportunity to exercise their political and electoral rights and a result of work around the globe, which continues today, to monitor the accessibility of the electoral processes. IFES, a US-based democracy organization, has been instrumental in supporting and documenting much of this global initiative to enfranchise people with disabilities

IFES works to extend the reach of democracy through technical assistance and support to governmental and non-governmental organizations in new and emerging democracies. IFES manages the clearinghouse for information on the participation of people with disabilities in the electoral process. It is the first mainstream democracy organization committed to ensuring that people with disabilities have free and equal access to electoral systems.

The following stories, written by people with disabilities, illustrate the work being carried out to enfranchise people around the world funded by IFES with grants from the governments of Sweden and Finland. These stories and additional information can be found at the IFES website: www.electionaccess.org.

Ghana

Since 2000, IFES and Ghanaian disability and electoral organizations have worked in partnership to promote the full participation of people with disabilities in Ghana's elections. Ongoing activities include election monitoring by 80 Ghanaians with disabilities (the first observation effort of its kind in the world), and the design and pilot testing of a tactile ballot to allow blind voters to vote in secret. Nicholas Halm, an election observer and the director of the Ghana Society for Persons with Disabilities, writes:

Only a few people with disabilities voted in the Adenta constituency. While many constituencies had similar low participation from people with disabilities, my constituency's participation rate was particularly low for the following reasons:

Architectural barriers: *At some polling stations, there were gutters and steps, clearly an inconvenience and a deterrent for voters with disabilities.*

Lack of awareness among election officials: *Some people were not sure why people with disabilities were there and why they would want to vote. However, once informed, voters and officials generally welcomed the observers.*

Limited access to information for blind voters: *There was virtually no voter education material available either in Braille or on cassette.*

The observation initiative uncovered the obstacles to people with disabilities present in Ghana's electoral procedures. By being exposed to election observers with disabilities, election officials and government leaders were provided with the opportunity to explore solutions to fostering inclusiveness in the election process.

"Through the observer training process, people with disabilities who had never participated in elections nor thought about their rights began to think of themselves as citizens. Media coverage noted that including people with disabilities as observers was a measure of increased democracy in the country, and other voters recognized as discriminatory what they had neglected to see in previous elections."

Nicaragua.

The Nicaraguan Association for Community Integration (ASNIC), an affiliate of Inclusion International, organized an election monitoring effort by 115 citizens with disabilities, 12 of whom had intellectual disabilities, for the November 2001 presidential elections in Nicaragua. This event marked the first time in any nation where citizens with intellectual disabilities served as election monitors.

Diane Richler of Inclusion International and Roberto Leal Ocampo of Inclusion InterAmericana wrote: *Through the observer training process, people with disabilities who had never participated in elections nor thought about their rights began to think of themselves as citizens. Media coverage noted that including people with disabilities as observers was a measure of increased democracy in the country, and other voters recognized as discriminatory what they had neglected to see in previous elections.*

Bangladesh

During 2001, Action on Disability and Development (ADD) of Bangladesh identified, trained and deployed over 300 citizens with disabilities to serve as election observers for the October 2001 elections. ADD/Bangladesh also served as a full member of the alliance of domestic election observation organizations, participating in the development of the election observation form and other key activities.

Mosharraf Hossain, program manager with ADD/Bangladesh, writes: *In addition to overseeing the deployment of the observers with disabilities, I had the opportunity to join the Election Monitoring Working Group (EMWG), an alliance of 29 NGOs facilitated by the Asia Foundation. Having "a seat at their table" was the key to the inclusion of disability issues in the mainstream election process.*

By raising the issue of people with disability to the NGO alliance, the issue of disability became a concern to the alliance as a whole. For example, the standard election observation form used by all of the 149,000 domestic election observers of the NGO alliance included two questions pertaining to the electoral participation of people with disabilities. The same checklist was used by the Fair Election Monitoring Association, which deployed 80,000 domestic observers throughout the country.

The participation of people with disabilities in the election created waves in the attitude of the society to break barriers. The disability community is now planning to raise its demands with the newly formed Parliament to establish their rights as equal citizens.

RESOURCES

International Institute for Democracy and Electoral Assistance
International IDEA,
Strömsborg, S-103 34
Stockholm, Sweden
Tel: (46) 8 698 3700
Fax: (46) 8 20 24 22
E-mail: info@idea.int
Web: www.idea.int/

IDEA, an intergovernmental organization with member states across all continents, seeks to support sustainable democracy in both new and long-established democracies. IDEA draws on comparative experience, analyzes democracy trends and assistance, and develops policy options, tools and guidelines relating to political participation, especially among those who are under-represented; electoral systems, management and observation; political parties – law, management and financing; and post-conflict democracy building and dialogue.

International Foundation For Election Systems
1101 15th Street, NW
Third Floor
Washington, DC 20005 USA
Tel. (202) 828-8507
Fax (202) 452-0804
E-mail: jmindes@ifes.org
Web: www.electionaccess.org

The International Foundation for Election Systems (IFES) provides professional advice and technical assistance in promoting democracy and serves as clearinghouse for information on the participation of people with disabilities in the electoral process.
IFES offers an extensive website with valuable resources and links.

Mercy Corps International
3015 SW First Avenue
Portland, OR 97201 USA
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Web: www.mercycorps.org

Mercy Corps exists to alleviate suffering, poverty and oppression by helping people build secure, productive and just communities. Mercy Corps believes humanitarian assistance must meet basic needs while laying the foundation for more democratic and economically strong societies. Our relief and long-term development programs help people build small businesses, grow more food, protect their environment, improve health care, and advocate for their communities.

7.3a

MICROFINANCE

"Credit is a need and a right: Inclusive policy and practice in microfinance"

INTRODUCTION

The terms "microcredit" and "microfinance" are used somewhat interchangeably, leading to confusion and lack of precision in terminology, and blurring the real distinctions in the scope of each term. "Microcredit" refers to very small loans targeted to the poor, particularly in developing countries, to help them start or expand a business and work their way out of poverty. The term "microcredit" was popularized by the success of various solidarity and peer group lending models in the 1980s and 1990s, such as the Grameen Bank, and by the Microcredit Summit Campaign, established in 1997. The Summit's current goal is to reach "100 million of the world's poorest families, especially the women of those families, with credit for self-employment and other financial and business services by 2005." The addition of "financial and business services" acknowledges the growing number of services available for the poor, which are better conveyed by the term "microfinance." The term "microfinance" embraces a range of financial and business services and tools, and continuing innovations from the field, that are being designed and implemented to serve very poor families. These services include microcredit; individual and group savings programs, some of which are based on local traditions; the use of micro-grants as seed capital for business start-up; business training; business development services that include marketing and other forms of technical assistance; micro-insurance; financial services linked

with other community development programs such as literacy and health education; village banking; and new approaches being pioneered for families affected by HIV/AIDS, and for the poorest of the poor who are living on less than a dollar a day. While the article below focuses specifically on microcredit, people with disabilities should be given the opportunity to benefit from all forms of microfinance.

The Trickle Up Program

7.3b

CREDIT IS A NEED AND A RIGHT: INCLUSIVE POLICY AND PRACTICE IN MICRO FINANCE

Policy and Practice of Leonard Cheshire International (UK)

Sarah Dyer, Assistant International Director, Leonard Cheshire International (UK).

POVERTY AND DISABILITY – A REALITY

There is an indisputable causal and consequential link between poverty and disability. Poor people are at greater risk of experiencing disability personally or within their family. Disability tends to impact negatively on the economy and earning power of an individual and his / her family members.

"It is surprising that mainstream development initiatives focusing on poverty alleviation continue to exclude disabled people as a target group in their policies and practice."

The extent of the problem has been well documented. Stark figures, such as 1 in 5 of the world's poorest people are disabled people (Elwan, 1999) and more than half a billion disabled people are amongst the poorest of the poor (Metts, 2000), demonstrate the size of the problem. Given this context, it is surprising that mainstream development initiatives focusing on poverty alleviation continue to exclude disabled people as a target group in their policies and practice. The implementation of economic empowerment programmes for disabled people continues to largely be the responsibility of organisations of and for disabled people.

STRATEGIES TO SOLVE THE PROBLEM

Since the 1970s, micro finance services have been one of the major approaches used in trying to fight poverty. By making a range of financial products, including savings, loans and insurance accessible to poor people, some positive gains have been made. Unlike women, who have been defined as a marginalised group and targeted by the

micro finance programmes, disabled people have largely been ignored and have remained excluded from their work.

Because the economic needs of poor and disabled people cannot be ignored, organisations of and for disabled people have rightly established their own initiatives in economic empowerment, including micro finance and credit programmes. There are many examples of successes and positive changes in the economy of poor disabled people. However, it has also been the experience of many disability organisations that their work in credit has detracted and diverted their limited resources from other priority areas of their work. In the words of one disability organisation, they " became focused on debt collection rather than social change".

"Unlike women, who have been defined as a marginalised group and targeted by the micro finance programmes, disabled people have largely been ignored and have remained excluded from their work."

Because of resource constraints, conflicting interests and priorities and limited technical knowledge and experience, the finance programmes operated by disability organisations have had limited success. "Good" loan repayment rates are often reported to be as low as 65 percent. The rate expected and needed for sustainability by successful mainstream providers is at least 90 percent. As a result, many if not most credit programmes operated by disability organisations struggle to achieve self sustainability let alone growth.

If disability organisations continue to implement micro finance programmes, many of which are not viable, it not only diverts resources, it also reinforces the larger problem of mainstream providers not seeing disabled people as a group they have a responsibility to target.

THE EXPERIENCE OF LEONARD CHESHIRE

Leonard Cheshire is a UK registered organization, working globally with disabled people. In our international work with over 250 partner projects in 57 countries, issues of poverty and the need for economic empowerment programmes have been identified as a major priority.

In 1997, like many other disability organisations, our first reaction was to set up our own credit facility for small business entrepreneurs who needed

capital to either set up or expand their own small enterprises. This was one part of our four-pronged approach to economic empowerment, which also included support of skills and vocational training, production unit development and access to employment by disabled people.

A review of the credit component during the second year of its operation showed some positive impacts of the work. Disabled people had been able to set up and expand their enterprises and some had improved their earning power. The impact in terms of numbers reached and the rate of success was disappointingly low. Additionally, the administrative costs of implementing the programme were disproportionally high in relation to the outcomes achieved. It was clear that if the programme was to be more successful in terms of reach, and making real and positive changes to the economy of the beneficiaries, we would need to invest more human, financial and technical resources. To properly monitor and expand the work would require long term and significant investment by the organisation and this would be at the risk of diverting resources from other priority areas of our work.

REDEFINING THE POLICY

Because of these findings and in line with our policy of working for recognition of and inclusion of disability as a mainstream development issue, Leonard Cheshire redefined its policy for promoting access to credit for poor and disabled people.

We decided that we would not act as implementors of micro finance or credit programmes. Instead we would focus on developing partnerships with established micro finance mainstream providers with experience and proven expertise. Our role as a disability organisation would be to raise awareness and understanding of the mainstream providers in disability issues and to work with them to develop programmes where disabled people would be successfully targeted and included in their work. By taking this approach we felt we could better use our experience and expertise in disability and maximise rather than divert our limited resources and achieve greater impact.

"Our role as a disability organisation would be to raise awareness and understanding of the mainstream providers in disability issues and to work with them to develop programmes where disabled people would be successfully targeted and included in their work."

IMPLEMENTING THE POLICY – THE STEPS TAKEN

The first step was to put the needs and potential of poor disabled people in the minds of micro finance providers. This was done through a series of formal and informal meetings, presentations and discussion forums. Initially we targeted those responsible for policy development and through them management and programme staff.

We found that most had not had contact with disabled people and were unaware and ignorant of the real problems faced by poor people experiencing disability. Common responses and misconceptions were that disabled people needed "welfare and charity" and questions of the potential of disabled people to be economically active and successful were raised. However, a number of micro finance programme staff could give examples of successful inclusion of disabled people in their own work and were interested to include more.

"Most organisations were positive about seeing disabled people being included in their programmes, as long as they were able to fulfil the criteria they had for any potential borrower."

Most organisations were positive about seeing disabled people being included in their programmes, as long as they were able to fulfil the criteria they had for any potential borrower. There was a readiness to consider adapting the programme to facilitate inclusion, but if this required additional resources, the mainstream provider would be looking for us to provide this.

A positive outcome of these meetings was that many micro finance providers started to look more closely at the needs of disabled people when establishing or extending their programmes and the meetings certainly positively sensitized and raised awareness of disability as an important issue in their mind.

To strengthen our links with a mainstream micro finance provider and to increase our own capacity for and knowledge about micro finance, Leonard Cheshire International in the UK formed a partnership with the micro finance network Opportunity International. A part time job share with one of their staff has been established. Through this our staff and partner projects can access technical support. Opportunity International and its partners also have access to personnel with experience and knowledge in disability who will be able to give training and advice on how to

include disabled people in their micro finance practice. A similar part time partnership has been established in the Philippines for our South East Asia programme.

Another challenge faced was changing misconceptions and increasing understanding of disabled people and staff in our projects about micro finance. Because the main source of support had been more welfare based and previously in the form of grants rather than loans, many were doubtful and fearful of entering a loan scheme. Others had negative experiences of lending schemes. Some had been refused credit or had been unable to meet the repayments. There was need to increase understanding by providing information about and exposure to the work. Additionally and importantly we have started to implement preparatory training programmes in business and basic financial management.

THE PRACTICE

In the Philippines a partnership has been formed with the registered micro finance provider Alalay sa Kabuhayan Foundation Inc. (AKAY). AKAY's mission is to fight poverty and focuses its work in metro Manila targeting poor women, disabled people and their family members through group lending programmes. It was established and is mainly staffed by disabled people, but operates fully inclusive programmes.

In 2001, Leonard Cheshire provided US$50,000 to AKAY for an inclusive group-lending programme. US$9,500 was a grant for social preparation and capability purposes. US$41,500 was given as a loan, repayable over four years at 7 percent interest. The target is 1800 borrowers of which 20 percent (360) will be disabled people or their family members. Additional technical support has been provided by Leonard Cheshire through a locally based micro finance consultant and administrator.

In September 2002, 47 centres had been established and are operated by 10 staff of whom seven are disabled people. One thousand and forty four borrowers have taken out loans and of these 151 are disabled people and 75 are relatives of disabled people. The repayment rate is currently 93%. The programme is now looking at how it can expand to both reach

more borrowers and also to meet the demand for larger loans needed by borrowers who are successfully expanding and extending their businesses. The aim is that the funds granted as a loan by Leonard Cheshire will be used to extend this programme and over time to help establish other partnerships. In this way our initial capital input will have a multiplying impact.

Lconard Cheshire

There are many personal success stories from the AKAY programme. Lisa is a member of one of the groups. She is married to Luoloi, who was disabled as a result of gunshot wounds and because of this cannot walk long distances. Lisa has taken out a second loan and has successfully expanded her sari sari store and now operates a hot snack store. Luoloi works on the store with her. They are now better able to support their children and have set up a savings account.

In Ndola, Zambia the Leonard Cheshire project has provided vocational and skills training to young disabled women. The challenge for many of the graduates of this programme is how to earn an income that will enable them to be financially independent. Most of the young women currently do not have sufficient experience in small business enterprise to meet the criteria set by the local micro finance provider. Many also lack experience and confidence to try to join a mainstream micro finance programme.

Anne Chibesa Mweemba operates a successful tailoring business in Ndola and as a disabled woman, appreciates and understands the challenges faced by disabled women in starting and succeeding in their own business enterprise. Anne is working as an animator and supporter with the graduate trainees. She is helping them to develop further their dress making and business skills. The aim is that with greater experience and confidence, they will be better prepared and able to enter the money earning economy. It is expected that for some this will be by establishing their own businesses with the support of micro finance.

THE IMPACT SO FAR

The impact of our practice in terms of numbers of disabled people and relatives accessing mainstream micro finance programmes is still relatively low, about 330 people worldwide since implementing our inclusive policy. However, we believe that significant and important steps have been taken towards achieving long term access and inclusion of disabled people in high quality mainstream micro finance programmes. This has been from relatively small human and financial inputs by our organisation.

Awareness and greater understanding of the needs and rights of disabled people to access and participate in quality and relevant micro finance programmes has been put in the minds of policy makers and implementors of mainstream micro finance organisations. The indicators are that there is interest and commitment to implement more inclusive programmes in the future through partnerships and alliances with disability organisations.

"Awareness and greater understanding of the needs and rights of disabled people to access and participate in quality and relevant micro finance programmes has been put in the minds of policy makers and implementors of mainstream micro finance organisations."

The capital that we have invested as a loan is now being repaid, which gives the opportunity for reinvestment by either expanding the current work or initiating new programmes. Ongoing investment in high quality and successful programmes means our resources can multiply and our reach can continue to grow.

The examples of positive changes in the lives of disabled people who participate in the programmes demonstrate that disabled people can succeed in small business enterprise using loans, and this acts as a motivator for both micro finance organisations and for other disabled people.

Through effective partnerships, it means that the respective partners are using their skills and resources in the area of work that they know best. Disability organisations can provide training and expertise in disability as required and the micro finance providers can focus on quality micro finance provision. Again this means resources are being focused and maximised, not diverted and weakened.

Leonard Cheshire International is committed to this inclusive practice and plans to expand our work in inclusive micro finance as one of our strategies towards economic empowerment with disabled people. Over

the next three years it is expected that we will develop new programmes in South and South East Asia, Southern, East and West Africa using the experience and knowledge gained from the first projects we have i mplemented. Resource and training materials based on our practice will be developed and made available for wider use.

To find out more about the work of Leonard Cheshire International look at our web site www.lcint,org or contact Sarah Dyer (Assistant International Director, Training and Development) at: T&Dadmin@london.leonard-cheshire,org.uk, or write 30 Millbank, London, SW1P 4QD, U.K.

To find out more about the work of Opportunity International look at www.opportunity.org.

Thanks to Veronica Mendoza and Penny Mharapara of Leonard Cheshire International for their contributions to this work and the article.

STRATEGIES FOR INCLUSION

Poverty and lack of economic opportunities were identified as major barriers to disabled women's empowerment in the 1995 research article "*Leadership Development Strategies for Women with Disabilities: A Cross-Cultural Survey*" by Laura Hershey and Robin Stephens. In 1997, Mobility International USA (MIUSA) hosted the Women's Institute on Leadership and Disability (WILD). WILD participants identified access to and successful participation in micro credit programs as key strategies for addressing poverty endemic among women with disabilities. People with disabilities have been left out of micro finance programs and women with disabilities have been doubly marginalized.

The following strategies for including people with disabilities, and especially women with disabilities, in micro finance programs are drawn from the WILD Institute proceedings and recommendations. For more information on inclusive micro credit strategies for women with disabilities visit the MIUSA website at: www.miusa.org or email us at development@miusa.org.

KEY STRATEGIES FOR INTERNATIONAL DEVELOPMENT PROGRAMS:

Make your own projects accessible:

- Reach out specifically to marginalized groups, (which includes people with disabilities) when identifying borrower participants.
- Bring people with disabilities to your projects and facilitate relationship building with other participants through formal and informal activities.
- Use low tech, low cost solutions to accessibility barriers.
- Seek out the advice of people with disabilities (and especially women with disabilities) to find solutions to barriers
- Provide sign language interpreters, readers, and Braille materials for your application processes, training programs and services.
- Make your meeting places accessible: meet in ground floor rooms, build ramps, and add handrails to stairways.
- Find solutions to transportation barriers: contract with taxis and private drivers, ambulance services, rehabilitation services, offer mobility aids to assist people with disabilities in using inaccessible transportation systems.

Go to people with disabilities:

- Invite people with disabilities (especially women) to your meetings and ask for invitations to their meetings.
- Conduct informational sessions, application processes and training at the places where people with disabilities meet.
- Hold meetings of YOUR projects in the places where people with disabilities meet.
- Make sure that information reaches people with disabilities about training, partnership, business and funding opportunities, and that it is in a format they can use.

Support Creative Funding Approaches:

- Attach conditional grants to loans for individuals or organizations to purchase equipment or services for accessibility.

- Accept proposals for funding that include disability related items, such as mobility aids, wheelchairs, sign language interpreters or readers adapted bicycles, ramps for buses or lifts.
- Fund business ventures run by women with disabilities that will also empower wwd, such as wheelchair repair, production and/or sales of mobility aids (crutches, braces), sign language services or accessible transportation services by wwd.

Support leadership and capacity building:

- Write letters of introduction for people with disabilities to facilitate networking and cooperation
- Support businesses run by people with disabilities (especially women) to provide services to your organization
- Seek out other ways in which you can cooperate and mentor to build capacity— through training, through sharing resources and space, through networking.

Engage women with disabilities in the global dialogue on microfinance and economic empowerment of women:

- Actively include organizations led by women with disabilities in l ocal and regional networks of microcredit programs.
- Facilitate conference participation: Provide support for women with disabilities to participate in regional and international conferences.
- Support women with disabilities to go online: donate used equipment, provide technical support and training. Share resources and pass on information.
- Facilitate coalition building between women with disabilities and other disenfranchised women.
- Listen to and learn from women with disabilities.

Make your organization inclusive:

- Collect data about participation of people with disabilities in every project.
- Hire qualified people with disabilities into your organization as field staff, consultants, trainers, and administrators.

- Include people with disabilities (especially women) on community advisory councils and boards of directors.
- Learn and implement disability policy (for instance, programs receiving funding from USAID should refer to the USAID Disability Policy).
- Provide ongoing opportunities for people with disabilities and development workers to build relationships that will lead to changed attitudes and real partnerships.
- Make your office and training facilities accessible.

MORE BEST PRACTICES:

Life is difficult for women in Namangan where women marry early in life and their worth is judged by their fertility. Few women in Namanan are educated, and the average monthly salary of $30 is barely enough to cover food for a family of five, and rarely enough to clothe children appropriately for school. But there is something about the women's Micro Credit Program that has a way of attracting the most determined, unstoppable women in the country. The deaf women's borrowing group is just such an example. During Soviet rule these six women worked in a factory that made special clothes and bed sheets for hospitals. Like so many businesses, the factory was unable to function in a market economy, and the women lost their jobs.

Jamila Abdullaeva, a woman who has a number of deaf family members and is therefore considered "deaf," found out about Mercy Corps's micro credit program from friends who are borrowers. She gathered several deaf friends who had fledgling businesses and visited the micro credit office in Namangan to see if they could borrow money to improve their businesses. Acting as translator, Jamila asked questions and used sign language to convey the information to the group members.

The women in this group of deaf borrowers are now well respected at the micro credit program office. They have increased their profits more rapidly than other borrowers, are always on time for their meetings with loan officers, and are always prepared for repayment with their money counted out beforehand.

From a report to Mercy Corps headquarters, 2002

She is 34 years old and lives in Kyehumburwa village in Buhesi sub country. She stays with her eight children. The husband was dead since the children very young. The mother work very hard to see that the children come out. She has a disability of the arm and poor sight. She got Trickle Up funds that helped her very much to sustain her family.

In addition she enjoyed very much the skills she gained through the training she got from KDA (The Trickle Up local counterpart). Now she is growing crops. The profit she got she used on medical care, clothes, books. The husband left no kitchen. She managed to construct one and to renovate the house her husband left unfinished. In addition she start to encourage some widows also to unite and form a small group where by they start a small savings and credit scheme. The group grows and some men want to join them. She is pleased with the program because it changed her life to normal status.

From a field report sent to Trickle Up

Women from Southern Africa Talk about the impact of a micro credit program run by Disabled People's Organizations in their countries (SAFOD, NCDPZ, and ZNADWO)

WOMEN WITH DISABILITIES TALK ABOUT THE IMPACT

"Before I couldn't manage to do anything. I thought I was a failure in life. Even my relatives didn't consider me as a normal person like they. They thought maybe I just came in this world doing nothing. But after I started business my relatives started to consider me as a person like them."
Christine Kumwenda, Zambia

"We work hard because we don't have other sources of income. We don't have any other jobs, so when we get money and embark on these projects we really do that with all our hearts, with all our efforts."
Lizzie Longshaw, Zimbabwe

"I'm able to bank some of the money… My daughter used to have only one pair of shoes…now she's got another pair".
Catherine Chuma, Zimbabwe

"Before they thought I would never prosper. But now when they see that I have prospered now they have given me respect. Anything that happens in the family [they say] 'Go and call Mary, we can't leave her out."
Mary Mwenda, Zambia

RESOURCES

Action on Disability and Development
Vallis House, 57 Vallis Road
Frome, Somerset, BA11 3EG UK
Tel: (44) (0)1373 473064
Fax: (44) (0)1373 452075
E-mail: add@add.org.uk
Web: www.add.org.uk

Action on Disability and Development (ADD) is a non-profit organization working to improve the quality of life for people with disabilities in Uganda. Founded on the principle of self-advocacy, ADD offers leadership training, educational programs and micro-credit loans in order to empower people with disabilities to improve their lives.

Disabled Women in Development (DIWODE)
PO Box 2284
Blantyre, Malawi
Tel: (265) 621-0001
Fax: (265) 624-014

The goals of Disabled Women in Development (DIWODE) in Malawi are to improve the socio-economic status of women with disabilities through economic empowerment and mobilize women with disabilities to engage in economic activities. DIWODE currently works with local financial institutions to develop credit programs for women with disabilities to begin microenterprises.

Foundation for Independence of Women with Disabilities
Central Council of Disabled Persons
PO Box 5 Kinigama Road
Bandarawela 90100 Sri Lanka
Tel: (94) 57-22-698
Fax: (94) 57-22-701

Formed out of a need for women with disabilities to speak for themselves, FIWD advocates for the full inclusion of girls and women with disabilities in society. To this end FIWD conducts public education and awareness campaigns. FIWD provides counseling and training to rural women with disabilities, providing them with the knowledge and skills they need to access social services and achieve greater social integration. In addition, FIWD works with women to secure micro-credit loans through local financial institutions. FIWD works to improve literacy rates among girls and women while encouraging girls with disabilities to attend general education.

Global Fund for Women
1375 Sutter Street, Suite 400
San Francisco, CA 94109 USA
Tel: (415) 202-7640
Fax (415) 202-8604
E-mail: gfw@globalfundforwomen.org
Web: www.globalfundforwomen.org

The Global Fund for Women is a grant making foundation supporting women's human rights organizations around the world that are working to address critical issues such as gaining economic independence, increasing girls' access to education and stopping violence against women.

Leonard Cheshire International
30 Millbank
London SW1P 4QD UK
Tel: (44) 207-802-8224
Fax: (44) 207-802-8275
E-mail: l.spickova@london.leonard-cheshire.org.uk
Web: www.lcint.org

Leonard Cheshire International (LCI) is an international arm of the charitable organization Leonard Cheshire based in the UK. LCI works within economic, social, and cultural contexts to break down barriers faced by people with disabilities. The work of LCI includes projects in

education, employment, economic empowerment, rehabilitation and day care services, short and longer-term residential care, and community programs.

Opportunity International

2122 York Road
Oak Brook, Illinois 60523 USA
Tel: (800) 7WE-WILL (793-9455)
Fax: (630) 645-1458
Web: www.opportunity.org

For over 30 years, Opportunity International has been a leader among nonprofit organizations in the global fight against poverty. A pioneer in microenterprise development, Opportunity is committed to solving poverty instead of merely treating its symptoms. By providing loans and basic training in business practices for the poor, Opportunity is able to break the cycle of poverty and foster social and spiritual transformation.

Pan African Federation of the Disabled Persons (PAFOD)

PO Box 2609
Bamako, Mali
Tel: (223) 211-972
Fax: (223) 23-1523

Pan African Federation of the Disabled Persons (PAFOD) is a coalition of disability-rights organization founded on the premise that people with disabilities are best able to address their own needs. Created to promote the rights of people with disabilities in Africa and Asia, PAFOD has been active in organizing conferences and symposia on the inequalities faced by people with disabilities. PAFOD works in conjunction with other international bodies in order to advance its agenda. PAFOD organizes leadership trainings and educational outreach programs. As a result of lobbying efforts by PAFOD the Organization of African Unity declared 2000-2009 to be the African Decade of Disabled People.

Trickle Up Program
104 W. 27th Street, 12th Floor
New York, NY 10001-6210 USA
Tel: (212) 255-9980 or (866) 246-9980
Fax: 212.255.9974
E-mail: info@trickleup.org
Web: www.trickleup.org/

Founded in 1979, the Trickle Up Program's mission is to help the lowest income people worldwide take the first step up out of poverty, by providing conditional seed capital and business training essential to the launch of a microenterprise. This proven social and economic empowerment model is implemented in partnership with local agencies.

7.4a

DISASTER, EMERGENCY RESPONSE AND DISABILITY

International organizations committed to disaster response developed a code of minimum standards based on years of experience in providing humanitarian assistance. These standards are set forth in the Sphere Project: Humanitarian Charter and Minimum Standards in Disaster Response. The agencies involved invite humanitarian actors, including states themselves, to adopt these standards as accepted norms.

The agencies involved in the Sphere Project commit themselves to make every effort to ensure that people affected by disasters have access to at least the minimum requirements (water, sanitation, food, nutrition, shelter and health care) to satisfy their basic right to life with dignity. Key indicators accompany the minimum standards, to measure impact or results along with guidance notes to consider when applying the standard in different situations.

In each of the areas — water, sanitation, food, nutrition, shelter, and health care— indicators relate to the needs of at-risk and vulnerable groups. In some instances these particularly vulnerable or at-risk groups are identified. This identification often specifically mentions people with disabilities. The second edition of the Sphere Project: Humanitarian Charter and Minimum Standards in Disaster Response will be published in 2003. The second edition draft incorporates a disability lens for each of the areas.

The particular needs and concerns of people with disabilities should be taken into consideration in disaster response programs. Emergency and disaster situations lead to disability and also create situations in which

people with disabilities are particularly at risk. International development organizations are beginning to recognize the importance of including people with disabilities in the planning and development of emergency response programs for these reasons.

"International development organizations are beginning to recognize the importance of including people with disabilities in the planning and development of emergency response programs."

In the following article, Marion McNamara discusses aspects of emergency preparedness and disaster response from an organizational point of view. Many organizations that may plan for the inclusion of people with disabilities in their programs may not have planned for accommodations in emergency situations.

This chapter ends with strategies and some best practices in emergency response excerpted from the *EPI Guide for Emergency Managers, Planners and Responders* from the National Organization on Disability as well as a best practice example from Church World Service.

For further information on specific aspects of humanitarian assistance as it relates to refugees with disabilities, please see the "Refugees and Disability" chapter of this book.

7.4b

A MOZAMBIQUE EXPERIENCE

Well, I think you heard about the cyclone in Southern Africa, hoe it destroyed Mozambique. At first I kept quiet. I said, "Well, they cover everybody … so they will really come up with something for people with disabilities." Then I said, "Oh, that is a mistake! No one will think of us if you do not come out." And for sure, I tried to organize a workshop in Mozambique and asked, "What have you done for people with disabilities … the people who were affected, the victims?" You know what they were doing? They were giving food and other things but they were in place whereby people with disabilities won't have access to go and get benefits from whatever they were giving. So when we heard that issue about how many people with disabilities are really benefiting from the program we told the government. The government apologized and said, "We're going back to the drawing board and see how best we can help people with disabilities" because most of them, they lost their wheelchairs, they lost their hearing aids, canes, what have you. Everything was washed out but no one thought about … those things, because the government just thought of giving food and clothes. They didn't even think that someone who lost (an assistive device) really needs that wheelchairs or cane or whatever. Then they said "We're going to sit back and see how we can best help people with disabilities."

Dorothy Musakanya

7.4c

DISASTER AND EMERGENCY RELIEF

Marion McNamara: Oregon State University

The purpose of this chapter is twofold. The first is to highlight the need for NGOs to have in place emergency preparedness and business continuity plans that include people with disabilities to help mitigate the effects of disaster, help your organization survive an event, and recover to assure continued delivery of services after disasters take place. The second is to stress the importance of involving people with disabilities in planning and mitigation activities.

Disaster, unfortunately, is a growth industry. Worldwide, natural hazards such as earthquakes, droughts, floods, storms and tropical cyclones, wildland fires and volcanic eruptions cause an estimated loss of 100,000 lives each year, set back or destroy economic and social infrastructure, and cause environmental damages and severe economic loss (UN 2002). Population growth, migration into hazard-prone areas, and human activities have added to the list of disastrous events such as the intentional and unintentional release of chemical, biological, or radiological toxins; intentional or unintentional damage to essential infrastructure such as power, water, and communications; and, of course, war. Complicating the picture are factors such as poverty, gender, age or physical ability, geographic or cultural/social isolation, all of which increase vulnerability to the effects and after effects of natural and human- caused disasters.

Although NGOs that specialize in disaster relief may have sophisticated plans for dealing with the immediate and long-term effects of disasters in the field, some don't have equally sophisticated plans for the home office. And many NGOs whose primary focus is on other areas may not have given much thought to planning and preparedness for emergency events.

Even organizations with good plans in place may have overlooked the additional health and safety issues that will impact their employees, volunteers, or clients with disabilities.

There are steps that NGOs can take to increase the survivability of everyone who enters their organization, steps they can take to ensure they can continue to operate after a disaster, and steps individuals can take to make themselves and their homes less vulnerable in case of a disaster. This chapter will look at ways that NGOs can include people with disabilities in developing safer environments and insuring quicker recovery.

"Many of the reasons that people with disabilities do not participate in emergency planning and preparation are the same whether people have disabilities or not."

BARRIERS TO PEOPLE WITH DISABILITIES

Many of the reasons that people with disabilities do not participate in emergency planning and preparation are the same whether people have disabilities or not. Research indicates that people tend to think that preparing for a possible emergency is not a good use of resources, particularly when those resources are scarce. There is a tendency to think that: 1) a disaster won't happen; 2) if it does occur, it won't happen to them; 3) if it does happen to them, it won't be really bad/they'll deal with it then; 4) if it is really bad, there's nothing that can be done to prepare anyway (Conducting Disaster Education Activities in Your Community).

This attitude can affect both individuals and institutions, creating a culture of denial about emergency planning and preparation. This attitude puts all populations at risk, but is most risky for people with disabilities, because their health and safety concerns may be the most heavily impacted by an emergency. People with a mobility disability may have difficulty evacuating a multi-storied building in the event of fire or earthquake, when elevators are not operable and debris creates barriers. People with medical needs, such as oxygen or insulin, may find themselves cut off from their supply in the event of widespread flooding, fire, or extensive earthquake damage. Assistive technologies, such as synthetic speech machines, TDYs or CCTV, may become unusable in the wake of a large event that disrupts power supplies.

OVERCOMING INDIVIDUAL BARRIERS

Just these few examples indicate why it is critical that people with disabilities be actively engaged in planning for emergency situations and connected to the community to receive communication in an appropriate format in case of an emergency. It is, likewise, critical that NGOs with employees, volunteers, or clients with disabilities engage in planning with the primary objective of protecting the health and safety of all the people associated with their organizations, and the secondary objective of continuing to deliver services after an emergency event.

As indicated above, one of the biggest barriers to individual engagement in planning and preparing for emergency situations is denial. But once that barrier is breached, the scope of the task of planning can be overwhelming. Planning for people with disabilities includes all the tasks that people without disabilities must undertake, plus extras: extra emergency supplies to be collected, extra procedures to be planned, additional people to be involved. The standard recommendation of having a 72-hour emergency kit with you at all times (at home, work, and in the car) is even more difficult to execute when the extras get added in such as food and water for a service animal, medications, extra canes for the visually handicapped, wheelchair tire patch kits etc. Added to the sometimes overwhelming scope of emergency preparations may be lack of knowledge about emergency services that are available locally, lack of communication with emergency services, and lack of resources, both material and social.

One of the key activities in transforming the overwhelming task of preparation is to provide the information to link people with disabilities with community resources, perhaps through a staff training program requested from your local Red Cross chapter. Such training could serve as a springboard to developing an organization-wide effort to do one activity a month, at home and at work, to prepare for emergencies. Connecting employees with community resources and dividing preparation into a series of manageable tasks will go a long way to helping individuals overcome their barriers to being prepared.

"It is, critical that NGOs with employees, volunteers, or clients with disabilities engage in planning with the primary objective of protecting the health and safety of all the people associated with their organizations, and the secondary objective of continuing to deliver services after an emergency event."

"One of the key activities in transforming the overwhelming task of preparation is to provide the information to link people with disabilities with community resources."

OVERCOMING INSTITUTIONAL BARRIERS

The first step in overcoming institutional barriers is to increase awareness of the problem. In this case, awareness building may need to be two-fold; NGOs need to develop awareness of their risk and what they can do to plan for and mitigate against disaster, and they need to build awareness of the needs of their employees, volunteers, and clients with disabilities. It is critical to include all employees in the development of emergency plans and procedures, to insure that everyone's needs are met. Many actions can be taken that have little or no cost associated with them, such as posting lists of emergency phone numbers, compiling contact information for employees, establishing a meeting point outside the office, etc. Keep in mind that this information should be available in all appropriate formats (such as large print, Braille, audio), so all members of your organization have access to it.

"Many actions can be taken that have little or no cost associated with them, such as posting lists of emergency phone numbers, compiling contact information for employees, establishing a meeting point outside the office."

Many NGOs plan for inclusion — they strive to create barrier-free environments, and recruit women, minorities, and people with disabilities to work and volunteer in their organizations. As they develop their awareness of natural and technological hazards that put their organization at risk, NGOs need to consider their human and physical resources, and their plans for serving their clients after an emergency. NGOs should have in place policies and procedures to assure the safety of all the people in the organization, taking into account the needs of a diverse workforce and client base.

"One of the most effective strategies in developing inclusive plans is to help the people with disabilities who are part of your organization develop their advocacy skills."

One of the most effective strategies in developing inclusive plans is to help the people with disabilities who are part of your organization develop their advocacy skills. The plans and adaptations adopted by your organization should take into account the wide diversity of people with disabilities; don't adopt procedures or adaptations that accommodate one group to the disadvantage of people with different disabilities. An example of the unintended consequences that can result from focusing solely on one disability is the sidewalk curb cuts that made sidewalks more accessible for people in wheelchairs, but that became an obstacle to people with visual impairments, who were no longer able to judge where the sidewalk ended and the road began. A later modification, adding a different texture to the curb cut, assured that the needs of both populations could be met.

Don't reinvent the wheel. Although nothing can take the place of training

your own people to know what to do in an emergency, there is an extensive body of information that your organization can use to get started (see references at end of chapter). Many of these publications have the advantage of drawing on experts on a wide range of disabilities for their advisory committees and outside reviewers, and can form an important part of the core training and preparation that should take place in the workplace and at home.

The secret to success in any venture is to plan the work and then work the plan. The same is true in planning for emergencies. As you initiate planning, your organization will undoubtedly identify gaps in knowledge or skills that can be addressed through training. Training needs may range for the very general, such as CPR and first aid, to more specific, such as how to use an Evacu-Chair, perform a two-person lift, or assist people with animal guides. Practice sessions will give you and your staff an opportunity to test how well your plan is working, and to adjust it to meet the many different contingencies that may arise. For example, you may find out what happens if an emergency occurs on a day when the "buddy" or "buddies" are absent from the office, or if the emergency occurs after regular working hours, or if the specified emergency calls for "sheltering in place" rather than evacuation. Practice gives you a chance to refine your plan, increasing the safety of your staff. It allows you to learn what you don't know, and take corrective action before there is a real emergency. And finally, practice allows you and your staff to become more comfortable with responding to emergencies, increasing the likelihood that you will be able to remember what to do in the event of a real emergency.

"Many of the mitigation activities suggested in preparedness guides will be neutral in their impact on people with disabilities. However, some modifications, may need to be adapted in order to remain accessible to everyone."

MODIFYING THE PHYSICAL ENVIRONMENT

Many of the mitigation activities suggested in preparedness guides will be neutral in their impact on people with disabilities. However, some modifications, such as installing latches on drawers and cabinet doors, may need to be adapted in order to remain accessible to everyone. Some procedures, such as shutting off utilities, may need to be adapted so that people with disabilities can perform them. Notification devices such as alarms need to include both visual and auditory signals. It may be necessary to purchase evacuation equipment that allows people with

long-term or temporary mobility disabilities (such as a broken leg) or with conditions such as asthma or heart disease, to be safely evacuated down stairs by one person.

Your organization will certainly want to include adaptations that address the needs of staff with disabilities. The adaptations to the emergency plan are apt to be most thorough when the people who will be immediately affected are involved. However, adaptations for people with all types of disabilities must be included in the plan, since it is impossible to know just who will be present when an emergency occurs. People with chronic or acute health conditions who are not usually identified as having a disability, such as those with asthma, heart disease, or with a broken leg, may have difficulty following emergency plans without some adaptation. Information about the plan should be available in appropriate, alternative formats, whether that be in other languages, closed captioned, audio, or other. Resources from the American Red Cross, the Federal Emergency Management Agency (FEMA), the National Organization on Disability, and Independent Living Centers throughout the country provide excellent strategies that enable the needs of people with disabilities to be addressed in developing an organizational emergency plan.

ASSURING CONTINUITY OF SERVICES

The work of your organization is important. In the case of a widespread and/or persistent emergency, your organization may find it difficult to operate, even if your employees are safe and your physical resources are relatively unharmed. Power and telephone lines may be knocked out, you may not have access to your offices, or your employees may have difficulty getting to and from work. Although reports vary, it is thought that between 25 percent and 40 percent of businesses that experience a sustained disaster never reopen. Creating a business continuity plan is far from a trivial exercise, but in many respects it is simply organized common sense. Because every organization is vulnerable to incidents such as a serious computer malfunction or information security breaches, it makes sense to conduct regular back-ups of critical data, and to store backup tapes or disks off site, so you can re-establish your operations quickly. Establishing a plan for communicating with employees and clients

is essential, especially if your organization has field-based operations in other regions (see the Red Cross publication "Preparing Your Business for the Unthinkable"). Many excellent guides to business continuity planning are available free of charge, and can help your organization be more resilient in the face of unexpected events. One reason many businesses in the World Trade Center were able to rebound after September 11 was that they had already prepared for an emergency that never happened—the Millennium Bug of the year 2000. As with other aspects of emergency planning, it is essential to include people with disabilities in continuity planning. Communication strategies, alternative workspaces, and back-up equipment rental should all be accessible and useable by all members of your staff.

CONCLUSION

Even organizations with policies that encourage active participation of people with disabilities in their normal operations may, in the heat of an emergency event, fail to take the needs of those with disabilities into account. The time to consider those needs and plan to accommodate them is well before an event. Good planning can protect lives, conserve resources, and facilitate continuity of services. We all hope that our emergency plans will never need to be used, but it is far better to have a plan that is never needed than to need a plan that was never made. NGOs can increase their organizational resiliency by including people with disabilities in the planning and practice of emergency response, by encouraging all employees to have a personal emergency plan, making appropriate modifications to the physical environment, training staff for emergencies, and making plans for continuity of operations after an emergency event.

ABOUT THE AUTHOR

Marion McNamara is Co-Director of the Office of International Research and Development at Oregon State University. She has worked on and managed international programs in agro forestry, agriculture, environmental management and education, leadership and community building, and HIV/AIDs education. She has worked in Latin America, Southeast Asia, Sub-Saharan Africa, and Eastern Europe and the Newly Independent States. Her work for this book grew out of a State Department-sponsored citizen exchange program that focused on organizing neighborhood networks to respond to emergencies in Uzhgorod, Ukraine. The Ukrainian program participants were inspiring in their attention to inclusion of people with disabilities in planning for emergencies.

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7.4d

EMERGENCY PREPAREDNESS INCLUSIVE STRATEGIES

This information is excerpted and reprinted with permission from The National Organization on Disability's Emergency Preparedness Initiative Guide on the Special Needs of People with Disabilities. Although this guide is written for emergency managers, planners and responders in the US, many of the strategies are applicable in other settings. We urge you to read these strategies with an eye to both domestic and international application.

Americans are not well prepared for emergencies. A National Organization on Disability (NOD)/ Harris Poll survey commissioned in November 2001 discovered that 58 percent of people with disabilities did not know whom to contact about emergency plans in their community. Some 61 percent had not made plans to quickly and safely evacuate their homes. And among those who were employed, 50 percent said that no plans had been made to safely evacuate their workplaces. All of these percentages were higher than for people without disabilities.

The survey also found that people with disabilities were far more anxious about their personal safety. Eighteen percent of those with disabilities were extremely or very anxious, compared with just eight percent of the non-disabled population. Another 44 percent of people with disabilities were at least somewhat anxious.

These statistics should improve over time with continued emphasis on preparedness for all people, along with a focus on the special needs of those with disabilities.

- What is it like to be a person with a disability during and after an emergency?
- Can one hear or understand the warnings?
- Can one quickly exit a home or workplace?
- Can one move about the community after escaping?
- Are there special necessary or even vital daily items (medicines, power supplies, medical devices) that are not likely to be available in emergency shelters?
- Are basic services like restrooms and showers available and accessible to people with disabilities?

"Involving and listening to people with disabilities assures the best insights for addressing their needs. Emergency planners should."

These questions are not always easy to answer. That is why it is imperative to analyze the various needs and form meaningful partnerships with the disability community.

Partnership with the Disability Community: Opportunities and Benefits

"Customize awareness and preparedness messages and materials for specific groups of people."

Involving and listening to people with disabilities assures the best insights for addressing their needs. Emergency planners should:

- Identify those in the community who might have special needs before, during and after a disaster or emergency. Doing so ahead of time results in an improved emergency plan, a better determination of resource needs, and more informed actions and decisions.
- Customize awareness and preparedness messages and materials for specific groups of people, thereby increasing the ability of these individuals to plan and survive in the event of an emergency. Such preparedness allows appropriate allocation of critical personnel, equipment and assets during the response period, and reduces 911 call volume.

"Educate citizens with disabilities about realistic expectations of service during and after an emergency."

- Educate citizens with disabilities about realistic expectations of service during and after an emergency even while demonstrating a serious commitment to their special needs. Such education re sults in a more cooperative relationship with local authorities and enhances their appreciation of the concerns of people with disabilities. It also leads to improved response by the entire community.

- Learn and gain from the knowledge, experiences, and non-traditional resources the disability community can bring to a partnership effort with emergency professionals. By utilizing and embracing members of the disability community as partners in the planning process, emergency personnel often discover creative solutions before they are needed during an emergency. These solutions may benefit not only the disability community but also the general population.
- Work with institutional and industry-specific groups that are not typically considered to be emergency service resources but that can offer valuable and timely support to emergency professionals. Identifying and marshaling these groups ahead of time leads to a better-prepared service community that is able to take on responsibilities during an emergency. It also leads to a unified team able to quickly assess and communicate service gaps during an emergency, and to a host of additional equipment, materials, and skilled personnel.

"Learn and gain from the knowledge, experiences, and non-traditional resources the disability community can bring to a partnership effort with emergency professionals."

COMMUNICATION IS THE KEY

Communication is the lifeline of emergency management. This is especially true for people with disabilities, many of whom are unemployed, socially isolated, or in other ways less connected to society than their non-disabled counterparts. Fortunately, most emergency communication can be undertaken at minimal cost, and most disability-targeted communication can be implemented as a simple adjunct to more general strategies.

"Communication is the lifeline of emergency management."

Communication with members of the disability community must be viewed differently depending on the point at which it is initiated. This can be done:

- Well before an event, as part of a preparedness outreach effort;
- Prior to an event, as an emergency warning or notification;
- During an event, as emergency information and instruction; or
- Following the event, as recovery information.

The medium used to reach people may change at different points in the timeline. In addition, the technology employed may vary, and the amount of labor required to complete the task may change. In general, however, there are some important considerations to keep in mind when directing communication on one's own or in partnership with the media:

"Those setting up emergency hotlines during an event should include TTY/TDD numbers when available, or the instruction "TTY callers use relay."

- Television stations must be responsible to all viewers and not run a text message "crawl" across a television screen in any area reserved for closed captioning as this will make both sets of messages unintelligible for deaf or hard of hearing viewers.
- Camera operators and editors need to include the sign language interpreter in the picture if one is interpreting next to the official spokesperson presenting emergency information.
- Those setting up emergency hotlines during an event should include TTY/TDD (text telephone, also known as telecommunication device for the deaf) numbers when available, or the instruction "TTY callers use relay." Make sure the same information is provided by the official spokesperson and is used on television and radio.
- Frequently repeat the most essential emergency information in a simple message format those with cognitive disabilities can follow.

"Repeat the most essential emergency information in a simple message format."

- When posting information on a website, make sure the website is accessible (see details on web accessibility in the Access section of this manual).
- Provide information in alternative formats (e.g. Braille, cassette, large font, etc.) whenever possible ahead of time based on the needs of the population. (For more information see Section 1: Alternate formats of this manual).

"Provide information in alternative formats."

Buildings, Residential Facilities and Other Tall or Large Structures with Relatively Permanent Residents

As part of emergency planning efforts, it is important to work with the administrators of these facilities to ensure that each structure has a workable evacuation plan in place. Administrators should undertake regular drills so residents or employees within their structures are familiar with these plans. These drills, of course, should pay adequate attention to the special

needs of all people with disabilities, not just those in wheelchairs and with other mobility impairments, but also those with visual, hearing, or mental impairments. Work with groups that represent smaller organizations, like home health care regulators or local business associations, to encourage each of their members to undertake these same activities.

"People with disabilities who experience a disaster may be deprived of vital connections to attendants, guide animals, neighbors, local business owners, and even family members."

Unfortunately it is often too late at the moment of disaster to educate people, already confused and harried by a crisis, about how to escape or to help individuals with disabilities do so. Some cities are already taking the lead in pre-disaster planning. The City of Chicago, for example, in 2002 promulgated new local standards requiring evacuation plans for people with disabilities to be put in place in any commercial or residential structure over 80 feet high.

INCLUDE DISABILITY NEEDS IN THE RECOVERY PHASE

The recovery phase of an emergency typically is the longest and most difficult aspect of a disaster for a community's residents, and this can be especially traumatic for people with disabilities. In addition to coping with any personal losses or injuries that they may have suffered, **people with disabilities who experience a disaster may be deprived of vital connections** to attendants, guide animals, neighbors, local business owners, and even family members. **They may no longer be able to follow their accustomed routines.** The disaster may also cause psychological distress by forcing individuals with disabilities to confront the limitations imposed by their disability on a more or less continual basis, or to relive traumatic hospitalization experiences from their past.

OTHER FACTORS TO CONSIDER

Several potential problems can be particularly stressful or confusing during planning and response phases of a disaster. They require added attention.

- It is commonplace in post-disaster situations for many services to be dispensed by volunteers. It is therefore important, where feasible, to **train volunteers ahead of time** in the basics of dealing with their fellow residents with disabilities. Such training is important so that the volunteer workers treat neighbors with disabilities with dignity and respect. These volunteers must also recognize and respond to requests that might appear to be luxuries in time of crisis, but for people with disabilities, may be essential to their day-to-day living. (MIUSA adds that having people with disabilities as volunteers is an excellent strategy).

"train volunteers ahead of time."

- **Federal, state and local regulatory codes address special needs issues**, and it is important to understand when such codes can help in the context of emergency planning. If no codes are in place, it is worth the effort to lobby for changes that can strengthen the ability of emergency professionals to incorporate special needs issues into plans and response capabilities. Examples of code-re lated questions that each locality must resolve include: Are nursing homes required to have an onsite source of redundant power? Can nursing students be used in a medically managed shelter? What level of emergency plans are home care agencies required to put in place for their clients with disabilities?

"Shelters must meet minimal accessibility levels so that all members of a community can find safety."

- **Shelters must meet minimal accessibility levels** so that all members of a community can find safety. The level of medical oversight to be provided must be determined well in advance of an emergency. Whether or not there will be different classes of shelters (e.g., medically managed or designated for special needs) must also be established in the planning phase. By making these determinations ahead of time, the needs of those with disabilities using the shelter system will be properly identified and addressed.

"It is vital to make accessible transportation available during and after a disaster."

- It is vital to **make accessible transportation available** during and after a disaster. Because transport fleets with wheelchair lifts or ramps may not be available or might be called into service in other areas, it is helpful to include non-emergency vehicles in disaster plans. Door-to-door pick-ups have been employed in some localities and should be incorporated into emergency plans if applicable.

- During the planning and preparedness phase, it is important to make sure that organizations and groups providing services to the

disability community are informed about the **importance of proper business continuity planning** as a means of assuring ongoing care to their client base of people with disabilities after a disaster.

- There are many types of **emergency equipment for use by people with disabilities during a disaster.** These include specialized evacuation chairs, transfer-height cots, communication boards, and reverse 911 notification systems. Unfortunately, there are no federal minimum safety or review standards for this equipment, and therefore "buyer beware" remains a necessary caution. To assure the use of only the highest quality equipment, emergency professionals should rely on appropriate members of the disability community to help research and "test drive" equipment before such items are written into plans or purchased by municipalities.

"There are many types of emergency equipment for use by people with disabilities during a disaster."

The planning and preparation efforts that are specially devised for people with disabilities are likely to benefit the general population as well, particularly those who may be traumatized or disoriented by a disaster. People with disabilities, whose very lives depend on thorough planning for emergencies, must be involved in this planning. We urge officials at all levels to recognize the innate resourcefulness, ingenuity and determination gained through the daily challenges of disability that can help the community at large and enhance the effectiveness of emergency operations.

"We urge officials at all levels to recognize the innate resourcefulness, ingenuity and determination gained through the daily challenges of disability that can help the community at large and enhance the effectiveness of emergency operations."

The mission of the National Organization on Disability (N.O.D.) is to expand the participation and contribution of America's 54 million men, women and children with disabilities in all aspects of life. By raising disability awareness through programs and information, together we can work toward closing the participation gaps.

The complete guide The National Organization on Disability's Emergency Preparedness Initiative Guide on the Special Needs of People with Disabilities is available at ***www.nod.org.*** *Emergency management professionals may receive up to three free printed copies of the guide. Other requests may include charges for shipping and handling. Requests should be made to epi@nod.org or by fax to (202) 530-0727.*

RESOURCES

Christoffel Blindenmission International (CBMI)
Christian Blind Mission International
Nibelungenstrasse 124
64625 Bensheim
Germany
Tel: (062) 51-131-131
Fax: (062) 131-122
E-mail: Hans-Peter.Kuhlmann@cbm-i.org
Web: www.cbmi.org

Christian Blind Mission International is the world's leading agency working towards the prevention and cure of blindness and towards the enablement of people with disabilities in developing countries. Founded in 1908, CBMI works with more than 1,000 projects in over 100 of the world's poorer countries. CBMI has affiliate offices in Australia, Austria, Belgium, Canada, Czech Republic, Germany, Italy, New Zealand, Switzerland, UK and USA.

Handicap International
ERAC - 14 av. Berthelot
Cedex 07
Lyon F-69361 FRANCE
Tel: (330) 47-869-7979
Fax: (330) 47-869-7994
E-mail: contact@handicap-international.org
Web: www.handicap-international.org

Handicap International (HI) is a non-governmental association working to assist all people in a vulnerable situation, such as poverty, exclusion, violence or violations of basic rights. It works particularly with persons with disabilities. HI focuses its efforts in countries where armed conflicts have destroyed existing systems of assistance and solidarity, as well as in countries where there are severe economic problems, or where the association's expertise in prevention and socio-economic development is requested. Technicians offering expertise in the creation and fitting of

prostheses, physical therapy, psychomotor therapy, psychology and the anti-landmines campaign, as well as health care professionals, agronomists, architects, engineers and educators are today conducting projects in rehabilitation, prevention, rural development and emergency programs in Africa, Middle East, Asia, South America and several European countries.

7.4e

BEST PRACTICE: DISASTER PREPAREDNESS

BEST PRACTICE: DISASTER PREPAREDNESS

Church World Service responds to natural and human-caused disasters worldwide by supporting local partners with consultation, technical assistance, training, funding, and material resources. The Emergency Response Program of Church World Service developed the following brochure for its domestic response program. This brochure helps member congregations develop disaster plans that include people with disabilities as members of the planning team. This resource, as well as information available through the Church World Service website, was developed by a team of experts which includes people with disabilities.

Form a disaster-preparedness committee That includes persons with disabilities.

Church World Service—"Prepare to Care" Training Manuals
<www.cwserp.org>: (212) 870-3151;
Fax: (212) 870-2236

Determine the most likely disasters in your area and learn how to prepare before, during, and after each emergency.

Federal Emergency Management Agency
<www.fema.gov/pte/prep.htm>: (800) 480-2520;
Fax: (301) 362-5335

Network to locate and inform those with disabilities. Encourage persons with disabilities to self-identify. Ask church folk, local support groups, grocery deliverers, or state organizational contacts.

National Organization on Disability
<www.nod.org>
Emergency Preparedness—Locating People: (202) 293-5960;
TDD (202) 293-5968

Form Partnership to connect with personal-support networks—an all church all persons preparedness project.

National Mental Health Association
<www.nmha.org/reassurance/coping_faith.cfm>; (800) 989-6642;
TTY (800) 433-5959

Complete general readiness chechlist.

Independent Living Resource Center
<www.ilrcsf.org/Publications/prepared/HTML/>; (415) 863-0581;
TTY (415) 863-1367
<www.ilrcsf.org>
Emergency Preparedness Multilanguage Formats
<www.prepare.org/prepare.html>

☐ Using Life Support Systems
<www.preparenow.org/pwsmn.html>
(408) 993-7156

☐ Communication Disabilities
<www.pueblo.gsa.gov/crh/disabilitytips.htm>
(800) 877-0996

☐ Serious Brain Illness
<www.pathways2promise.org/family/symptoms.htm#information>
Fax (314) 644-8834

☐ Chemical Sensitivity
<www.redcross.org/servicesdisaster/beprepared/html>

☐ Cognitive and Developmental Disabilities
<www.ilresf.org/Publications/prepared/HTML/Tips_Sheet07.html>

☐ Visual Disabilities
Audio Tapes; local Red Cross;
Braille/Large-Type Tip Sheets;
(451) 543-6222
TTY (415) 543-6698

☐ Mobility Disabilities
<www.jan.wvu.edu/media/emergency.html>

☐ Deaf or Hard of Hearing
<www.preparenow.org/deaf.html>
TTY (415) 863-1367

☐ Service Animals
<www.preparenow.org/fa-anim.html>;/eqtanpet.html>
Fax (415) 863-1290

7.5a

REFUGEES AND DISABILITY

This chapter draws on articles writen by Sue Stubbs of the International Disability and Development Consortium who wrote about refugee work while employed by Save the Children.

MIUSA wishes to thank Sue for permission to reprint her words.

According to the United Nations High Commissioner for Refugees (UNHCR) there are 50 million uprooted people in the world. Seventy-five to eighty percent of them are women and children. Of these 50 million people, 12 million are refugees. Among these twelve million refugees are people with disabilities who have also been forced to flee. In addition eighty percent of casualties by small arms are women and children who far outnumber military casualties.

"The needs of disabled refugees are first and foremost the needs of any other refugee; safety, health and nutrition needs."

Organizations providing humanitarian assistance to refugees are committed to ensuring that refugees have access to at least the minimum requirements to satisfy their basic right to life with dignity. Guidelines for such humanitarian assistance such as those published by the UNHCR and those contained in the Sphere Project's "Humanitarian Charter and Minimum Standards in Disaster Response" refer often to the need to ensure that such assistance reaches groups at risk and particularly vulnerable populations.

Sue Stubbs of the International Disability and Development Consortium writes:

In refugee situations, disabled children and adults are particularly vulnerable. If they do not have independent mobility, families may be forced to abandon them. Despite the difficulties, many disabled people do manage to reach camps. The refugee situation in itself also gives rise to an increase in causes of impairment through poor nutrition and health conditions, injuries relating to conflict, accidents, burns, torture and trauma.

The needs of disabled refugees are first and foremost the needs of any

other refugee; safety, health and nutrition needs. Yet in order for disabled refugees to benefit from nutrition and health programs, their existence needs to be acknowledged, and the programs need to ensure that they can benefit.

Disabled adults will often be able to help themselves and suggest ways to make programs accessible, given the chance to be heard. Mothers with disabled children will not always bring their disabled children forward unless there has been positive encouragement from camp organizers and professionals. Disabled children and adults can benefit greatly from access to ordinary educational, social and health services. Responding to the basic needs of disabled people in a refugee situation should not be an optional extra, but integral to all programs.

Disability inclusion is not the responsibility of one particular sector, but should form part of everybody's awareness.

KEY POINTS

- Disabled adults and children should have access to all health, social and educational programs.
- Disabled people can help themselves and others and should be involved in program planning and rehabilitation.
- The main problems for disabled people are often attitudes and lack of awareness of other people rather than their impairment.
- Rehabilitation knowledge and skills can be made available with very basic training and locally available resources. Community based rehabilitation programs have a range of experience which can be relevant to refugee situations.
- Disability is currently an invisible issue in refugee situations; making it visible will require risk and experiment.

BEST PRACTICE

Jhapa Refugee Program: Save The Children UK
From reports by Gauri Giri, summarized by Sue Stubbs in 1997.

The Jhapa Refugee program is a good example of addressing needs of people with disabilities within a refugee context. The following is a summary of the history and key components of the project that contribute towards its quality, impact and sustainability.

PLANNING THE PROGRAM:

- Disabled people were identified from a health review (1994) as part of a particularly vulnerable group whose needs were not being met.

- An inter-agency meeting (1995) established a working group of agencies involved in the social sector to develop a collaborative approach to responding to the needs of disabled people.

- From the start, the approach was collaborative and aimed to be sustainable, integrated within the community, and promoting self-reliance, not dependency.

- Save the Children Fund (SCF) (UK) agreed to implement a pilot project. This began with a Focus Group Discussion (FGD) to expose staff to issues and identify a future course of action; participatory approaches and an action-research approach were used from the start.

- The FGD was carried out with disabled children, their parents and SCF staff. The team focused on children with physical, sensory and speech impairments, so made effort to look at different types of disability.

- The results of the FGD gave the team information about attitudes, impact on the work-load and lifestyle of mothers; the children spoke about how they helped their parents, but were withdrawn about going outside because they got teased.

- Education was a unanimous priority for both parents and children. Parents were over-protective and the children were not getting opportunities for play and interaction.

- SCF allocated a full-time member of staff (who was not previously a disability specialist), recognizing that this was important to support the project. This staff member had a strong community development perspective and so was keen not to increase dependency providing 'special' programs.

- The pilot program as a result of the FGD focused on home visiting support, referral, integration of children into schools, and orientation for staff and the community.

PROGRAM COMPONENTS:

Home visiting systems varied from camp to camp, some were neighbors, and others were teachers and women volunteers. It was felt that the neighbor-to-neighbor support worked best.

- The action-research approach continued to be used in order to develop an appropriate and effective program. The pilot program was evaluated after six months. The evaluation highlighted good social integration, good parent support, good inter-agency collaboration and active community participation. But there was a need for more information about addressing communication problems, more work on helping parents be involved in planning rather than just implementing and more awareness raising in the community.

- The program continues to research and address the issue of attitudes in the community using multi-media activities, drama, song, story, and visual aids.

- More than 700 children have been integrated into mainstream schools, and a pilot integrated pre-school is operating.

- Low-cost aids and toys are being produced.

- Sign-language training has been conducted in all camps and both hearing and deaf children are actively signing.

- Other issues being addressed are: vocational training opportunities for older children, production of awareness-raising materials, more training for health workers and teachers and day care for children with severe disability.

- Maximum use has been made of national and international resources and contacts; visits have been exchanged from other disability programs, trainers have visited, resource persons have given input.

SUMMARY:

This program is an excellent model of approach to integrating disability with the following criteria of success:

- Participatory, action-research approach used from the start including gaining perspectives from consumers, disabled children and parents.

- Focusing on integration by targeting activities and resources at removing the barriers to participation such as negative attitudes, over-protectiveness, awareness levels in the community etc.

- Assuring sustainability from the start through supporting and involving parents and promoting self-help and self-reliance; it would be easier and quicker to establish a "service" without parent/community

involvement, but would just increase passivity and would not provide any useful skills/ownership for the future.

- Balancing practical and visible models with more general advocacy and influence at policy level; e.g. the integrated pre-school met with a lot of resistance from the United Nations High Commission for Refugees, but the model is very successful, and the aim is to promote it in other camps.

- Not focusing on disability as the problem of the individual child, but seeing disability in a broader development and rights context.

- Particular examples of pioneering activities such as sign-language training, respecting the mother tongue of deaf children, and developing an appropriate model to improve communication.

- Good management and support at all levels, and good choice of full-time coordinator; a disability specialist is not as important as a person with a good understanding of the community and how to involve them.

7.5b

INCLUSION OF PEOPLE WITH DISABILITIES IN EMERGENCY SITUATIONS

The case of the Sierraleonean refugee camps on the Guinea border

By, Nick HEEREN[1], Operational Director of Programs, HANDICAP INTERNATIONAL[2]

BEST PRACTICE

EMERGENCIES AND PEOPLE WITH DISABILITIES (PWDS)

Although HANDICAP INTERNATIONAL (HI) is mainly working in development situations (primary prevention, rehabilitation and inclusion of people with disabilities (PWDs)), the state of the world also obliges us to intervene in emergency situations. Unfortunately more and more emergency situations occur. And, again unfortunately, many civilians become victims, because they are caught between warring fractions. Unable to flee as quickly as able-bodied persons, disabled persons can get trapped, so they are often more exposed to the risk of war.

Second, what can be added to this bleak picture is the fact that arms such as anti-personal mines produce new people with disabilities among civilians, even after peace has been signed. This is the case in many countries (Mozambique, Kosovo, Afghanistan, Angola, Bosnia, Macedonia, Sri Lanka. The list is tragically long). These victims are often children who play with mines and unexploded cluster bombs, but also adults going to the water-pump, working their fields, etc.

Third, tragic conflicts like the one in Sierra Leone in the 1990s, have created special groups of people with disabilities (mutilated by the rebel forces) whose physical and psychological trauma is very deep indeed.

War and emergency situations can thus produce many more people with disabilities. I feel, Handicap International feels, that we need to address this topic. The exclusion of people with disabilities in emergency situations is even stronger than in "normal" situations.

Handicap International's experience in this area could be interesting for others. Indeed the experience in the camps of Sierra Leone refugees on the Guinea border and in other crisis or emergency situation (Nicaragua, Gujarat India, Afghanistan, Albania) shows that defending the people with disabilities situation in refugee camps can be achieved through two type of approaches[1] :

- a direct approach, with and for immediate relief of suffering of persons with disabilities (specific services);
- an indirect approach through all the other many players involved in emergency situation (High Commission on Refugees, international and local non-government organization).

This article puts forward some of the lessons[2] learned from working in this complex context in the refugee camps of Sierra Leone at the end of the 1990s and the beginning of 2000 on the Guinea border in West Africa.

THE SIERRA LEONE / GUINEA CONTEXT

Refugees arrived by hundreds of thousands from inside Sierra Leone in various waves. Many had gone through atrocious circumstances, notably the nefarious "short sleeve" and "long sleeve" mutilations in which hands or arms were cut off with machetes by drugged and drunken rebels. These mutilations were inflicted, not only on captured soldiers, but also on civilians, be they women, children, elderly persons and even babies.

Although figures have been exaggerated, which as such poses an ethical question on the need to worsen the picture in order to obtain financial support for refugees, the suffering and trauma these persons went through are beyond belief.

The Guinean authorities and the UNHCR, already experienced by the influx of refugees from Liberia in the early nineties, settled the overall majority of 350,000 refugees in several big camps, but mainly a larger

number of smaller camps[1] . These proved to be fairly permanent settlings as the conflict in Sierra Leone entered into a sustained instability. International aid therefore took the form of help in semi-permanent housing (mud block houses), wells, food distribution, schools and vocational training centers, access to micro-credit, etc. destined to refugees only[2] .

Ethnically speaking, many of the people across the border were of the same cultural background. Language and culture were not really a problem. But this very similarity made the "refugee-specificness" of the international aid difficult to comprehend for the local population.

Indeed, what was identified as a problem[3] , and amplified the complexity of emergency and development situations existing next to each other, was the difference in the objective living situation of the refugees (with access to housing, water, food, education, training and micro-credit[4]) and the local Guinean population which did not benefit from international aid and certainly lacked all these services. That did not stop the local population, nor the refugees, from developing subtle strategies to benefit from the aid-flow, and thus, in a way, redistribute the wealth.

However, that is not the topic of this article, although interesting as such and indeed part of HI's worries as a player in both the refugee camps and the Guinean society.

HI METHODS AND ACTION WITH PEOPLE WITH DISABILITIES: INCLUSION OF DISABILITY ISSUES IN MAINSTREAM EMERGENCY WORK

As mentioned, HI developed two strategies in this complicated context: Direct action in favor of people with disabilities, especially in our specific domain of rehabilitation and appliances, but also indirect action through the existing players in the camps.

Indeed many organizations, be they NGOs or UN, local or international, work in refugee camps and emergency situations. Our question was, should HI be another of those many players, fundraising among a similar public, with yet another, specific target group? Or could we and should we find newer and more efficient solutions, defending people with

disabilities interest but much more through an i*nclusive approach*?

The answer, once we had thought the problem through, was clear. Inclusion strategies can be implemented, even in emergency situations - let's call it **inclusion of disability issues in mainstream emergency work**.

Also, from a multi-player perspective, many more dynamics are being developed by involving many players in the disability issue, especially as HI itself was not seen as a competitor, as we didn't implement any concrete activities, except those directly linked to our technical sector and not provided by any other player.

When HI stopped its activities and set-up its program in Sierra Leone once the refugees went home, all our local staff had found a job in the various organizations with which we had worked and which continued to work in other emergency contexts. The sustainability of the on-the-job-training we've given our staff will thus be used to continue to defend people with disabilities interests.

Here are some examples from our practice:

Physical rehabilitation of mutilated refugees and people with disabilities *(direct approach)*

HI worked directly with the target group of refugees through setting up physical rehabilitation services for both those who suffered from the terrible mutilations inflicted on them by the rebel forces, and those whose disability was caused by disease or malnutrition, in order not to create discrimination. Three hundred fifty two persons benefited from HI's services, of whom half were victims of the war.

For physical rehabilitation, this included close co-operation with the National Orthopedic Central Workshop (NOC) of the Guinean Ministry of Health in the capital Conakry, ensuring that Sierraleonean refugees had access to these services. Upgrading of the premises and the equipment and training of the local staff were identified as needs, and responded to by HI, which was ultimately beneficial to both the people with disabilities in the Guinean population and the refugees. Specific research on appropriate appliances was necessary, as mutilation was often followed by bad amputation.

Transport from the camps to the capital (distances over 10 hours by 4WD vehicle) were guaranteed by HI as part of the refugee program. This would under normal circumstances be an issue of debate linked to the sustainability of such a transport service and thus the economic access of people with disabilities to rehab services. In Guinea, the local transport system is rather correctly developed, and one could hope for a fairly even access to the capital.

Capacity building for Disabled Peoples' Organizations (DPOs) in the refugee camps *(direct approach)*

Supporting 14 associations of people with disabilities in refugee camps, through capacity building, small grants, distribution of appliances or wheelchairs, etc. was another direct activity with the beneficiaries. Interestingly many "normal" people with disabilities had been able to flee from their villages. One can but admire their persistence and the solidarity of their families. However, the people with disabilities population amounted to only 1.5% of the total camp population (of more than 80,000), indicating that many, many people with disabilities had been left behind or had died in the Sierra Leone conflict.

One thousand ninety one persons with disabilities were organized in 14 *Disabled Peoples' Organizations*[1] or DPOs. This approach shows that even in the difficult circumstances of refugee camps, self-organization of people with disabilities is possible and necessary in order to become a player and weigh in, in the complex field of players involved in an emergency work.

A number of these people with disabilities had been organized in DPOs in Sierra Leone before. HI could build on the existing experiences, but had to face also the existing subtle strategies of DPOs leaders to use the funds for their personal aims. It would be naive to think that power struggle and personal rather than collective interests did not occur in the difficult settings of refugee camps and self-organizations.

Another part of the DPOs was less spontaneous in origin and they seemed to respond basically to the offer of HI to work with people with disabilities. In emergency situations, and in sometimes in a development context, what I would like to call supply-side driven processes, rather than

demand driven, can lead to the creation of less sustainable responses. In this case, HI's strategy envisaged disabled peoples' organizations, accepting that more important investment in accompaniment was no doubt necessary.

What should also be mentioned was a certain degree of difficulty of integration of mutilated people with disabilities in the disabled peoples' organizations of "normal" people with disabilities. Indeed the very recentness of the disabling trauma (and the extreme violence often associated with that experience) made mutilated persons into a specific category. HI tried to work on this acceptance aspect with the disabled peoples' organizations, and if some successes were made, it wasn't easy.

But in the end, many people with disabilities found their interests in the disabled peoples' organizations, as they said during the interviews: *I'm not alone anymore, we're now a community, we're more respected, I've more courage as a* people with disabilities*, we've received walking aids.* Indeed attitude and behavior of other people (family and other members of the community, but also local authorities) changed because of the group's very existence.

Psychosocial support to traumatized refugees/people with disabilities *(direct approach)*

The mutilated refugee population, but also abused women and children who witnessed mutilation of their parents or family members, had suffered great psychological trauma during their flight to the safer border areas. HI set up counseling sessions in the camps. These were individual at first, in small groups later on, and based on HI's experience in Rwanda (psychological "explicitation" for traumatized children through drawings) and Algeria. Training of 20 local counseling staff was also part of the HI psychosocial activities.

These activities proved difficult but absolutely necessary. Later they continued in Sierra Leone, once the Sierra Leone program opened through a more organized approach in phase with the Ministry of Social Services, for example, training of future social workers on psychosocial issues.

HI's advocacy and UNHCR's Extremely Vulnerable Individual (EVI) logic *(direct approach)*

In the Guinea/Sierraleonean context, HI was able to work with the UNHCR on "Extremely Vulnerable Individual", or EVI, ID cards for people with disabilities, giving right, in theory, to prioritized treatment. For example, faster distribution of food aid should be one of the advantages of the EVI card.

Indeed, for many people with disabilities the EVI card is an essential issue (38% of the persons interviewed mentioned this as their priority).

In practice it was a hard uphill struggle for HI to defend rights of people with disabilities or other vulnerable groups (one-parent families, pregnant women, the elderly, etc.) and obtain the EVI cards. Much time and energy was consumed by this activity. But ongoing working relations with the HCR helped obtain the necessary cards.

In one case, it was the fact that the HI-supported disabled peoples' organizations existed that made the HCR see this group as interlocutor for EVI card distribution.

However, convincing distribution agencies to actually use the EVI cards for prioritized distribution remained extremely difficult. Food distributing agencies preferred the straightforward alphabetical order of surnames, thus obliging people with disabilities to wait for hours for their turn.

Social integration and disability awareness building in the camps *(direct approach)*

Just because people with disabilities are in a refugee camp, prejudice and traditional beliefs don't cease to exist. HI stimulated the disabled peoples' organizations in the camps to organize awareness-building activities (for example theatre plays, traditional dances with people with disabilities on a regular basis with "awareness" messages in local language and traditional proverbs.) One hundred fifty five people with disabilities have been involved in these activities in the different camps where HI was working.

Education: inclusion of children with disabilities and special classes *(indirect approach)*

The IRC, International Rescue Committee, was responsible for education in the camps managing many schools for a total of 80,000 pupils with 2,000 teachers. Rather than to setup our own special schooling system, HI's objective was to include as many children with disabilities or non-disabled children whose parents have disabilities into the educational system run by the IRC.

The inclusive education issue was largely raised by HI, and it proved possible to include three hundred forty four children with disabilities in the IRC schools. It was even possible to set up a special class for 12 deaf children inside the school compound in one of the camps. However, one objective which remained to improve was the school-going rate for girls with disabilities (half of that for boys).

In one case, the Association of Disabled People in a camp asked for literary classes for its adult members. There too, HI tried to make a local NGO (Vulnerable refugees Working Group, VWG) respond to this important demand.

Vocational training *(indirect approach)*

With the German GTZ and their PROFOR program, responsible for vocational training in the camps, HI was able to include seven young prople with disabilities in their training programs that amounted to 5% of the total intake, which is much more than the actual percentage of people with disabilities among the camp population (1.5%).

Once training finished, these youth will try to start or get employed in small businesses (carpentry, metal work) which will obviously not be easy, but at least they have the technical skills necessary. In the case of return to Sierra Leone, the skills are not lost.

Small credit and small businesses (*indirect approach)*

Rather than setting-up a specific credit scheme for people with disabilities only, HI opted for an inclusive approach, starting with awareness building

among existing micro-credit NGOs active in the refugee camps (American Refugee Committee, ARC). Thus small credit for Income Generating Activities (IGA) of groups of people with disabilities in the camps including the necessary training was made possible.

In one or two specific cases, notably long term (10 years[1]) people with disabilities refugees settled in towns rather than camps and so having no access to the micro-credit NGOs specifically working in the camps, HI decided to set up a special credit service. But this remained an exception to the rule.

Two hundred thirty eight persons with disabilities benefited from grants and loans to set up businesses as varied as blacksmithing, bread making, tie dye, tailoring, carpentry, petty trading and soap making for the markets in the camps and also for the local Guinean markets.

However, the fact that people with disabilities had to compete with all other non-disabled refugees in business, or with the local population[2] when it concerned out-of-camp sales, indicating that the results were not as ideal as one might wish for. In actual fact, the success depends a lot on the objective one gives to income generating activities: *Income* (but for whom, the trainees, the trainer, the DPO?), *Training* or *Social Integration*. Depending on each objective, results vary.

In terms of income, the most interesting approach was to generate income for the Disabled Peoples' Organization. Sums were important (the equivalent of 45 kilograms of rice per month) and could be used, if rules are transparent, to help individual cases objectively needing help (i.e. pay the school fees of a child with disabilities). This also strengthened the economic sustainability of the DPO.

Analysis of the activities in terms of individual income showed only a limited impact, as margins are too small to really be significant.

In terms of *Training*, gains were made. But especially in terms of *Social Integration*, the disability specific IGAs permitted people with disabilities to be viewed as active productive and economic members of the camp community. Here impact was very positive.

Health *(indirect approach)*

With the Guinean Red Cross, which had a post in each camp and which was responsible for the intake of all refugees, collaboration was strong in order to have early detection of mutilated people or persons with disabilities. Special medical assistance to people with disabilities in the camps was possible, thanks to this co-operation. Nevertheless, HI put in place a direct monitoring system for extremely vulnerable individuals and people with disabilities.

Habitat and accessibility (*indirect approach)*

With the NGOs responsible for the (adobe) housing of the refugees in the camps, HI discussed and proposed accessibility issues for persons with disabilities. Indeed for those using tricycles for mobility, door openings and access-ramps had to be included in the design. The disabled peoples' organizations agents also carried out regular visits to help improve the housing situation for people with disabilities through defending their situation with the responsible NGOs.

CONCLUSION

I've evaluated the HI inclusive approach in 2000 when I was working at the University in Lyon. If certain aspects could certainly be improved, I was indeed impressed by the original and efficient approach. Rather than trying to do it all themselves, except the specific technical rehabilitation fields, the HI approach is one of networking, lobbying and putting active forces, be they private or public, together to improve the perspective for all, including people with disabilities.

I believe that such should be the way forward for the coming years, and HI believes that such can be a collective platform for disabled peoples' organizations, disability-specific NGOs, development NGOs, governments and UN bodies.

[1] The author has been involved in development action for 20 years for Dutch, British and French NGOs and was a university lecturer in development studies and an international consultant at the International Study Center for Local Development (CIEDEL) at the Catholic University of Lyon (France).
[2] Handicap International (HI) is a French development NGO. HI has been working for 20 years and in more than 50 developing countries on all continents to further activities with people with disabilities and excluded groups.
[3] This approach based on our actual practice reflects DFID's "twin track" approach.
[4] The author evaluated the HI project in July 2000 when he was attached to the CIEDEL Institute. See also the report *How di bodi? Evaluation/Appui-conseil, Volet réadaptation, projet de réfugiés sierraléonais handicapés et victimes de violence, Ciedel, 2000*.
[5] HI worked in 14 camps, and planned to increase to 18 camps out of a number more than 30 camps. The choice for smaller camps by the UNHCR and the Guinean authorities seems to have been an intelligent one from a feasibility perspective.
[6] The UNHCR mandate is very clear on this point. The funds given to them by governments can only be used in favor of refugees and not for the local population (even though suffering from the influx of refugees, e.g. through massive deforestation).
[7] In the author's evaluation cited above (note 3).
[8] Obviously the trauma many refugees went through cannot be compared to the situation of the local Guinean population.
[9] Association of Disabled People was the name chosen by the PWD members themselves for their DPO.
[10] This is in Macenta town, where refugees from the fighting in Liberia, which started in the early 1990s, are settled.
[11] The local population does not benefit from the specific support services for refugees and is often in a disadvantaged position compared to the refugees (a sewing machine paid for by the local tailor, while a refugee might have one free). The intermixing (local and refugee) of the outlet-markets creates in fact an unfair situation.

RESOURCES

Action on Disability and Development

Vallis House
57 Vallis Road
Frome, England BA11 3EG UK
Tel: (44) 373-473-064
Fax: (44) 373-452-075
Email: add@add.org.uk
Web: www.add.org.uk

Action on Disability and Development (ADD) is an international development organization providing support to organizations controlled and run by people with disabilities. ADD works in partnership with organizations whose members are seeking to: take control of their own lives and set up self help initiatives; access basic human needs such as food, health care, education, and livelihoods; campaign and advocate for equal opportunities at all levels of society; or establish sustainable self help organizations.

The Center for Integration of People with Disabilities

Kicelj 18
Tuzla 75000 Bosnia
Tel: (387) 75-231-176
Fax: (387) 75-283-049
Email: tip.tz@irc-bh.tel.hr
Contact: Selma Sakic

The Center for Integration of People with Disabilities (Centar za Integraciju sa Onesposoblijenjem) (CIOO) is a non-profit organization working for the full integration of people with disabilities into all aspects of society. In order to achieve this goal CIOO seeks to establish and strengthen links among civil society, municipal agencies and private organizations with regards to people with disabilities. Through advocacy trainings and networking with other disability organizations, CIOO has helped to create a network of people with disabilities empowered to advocate on their own behalf. These trainings have brought together people of

diverse ethic and religious backgrounds who collaborated to write a declaration of non-discrimination for people with disabilities.

Handicap International

Nick Heeren, Operational Director of Programmes
Department of Programmes
14 Avenue Berthelot
F-69361 Lyon Cedex 07 France
Tel: (33) 4-78-69-79-79
Fax: (33) 4-78-69-79-94
E-mail: contact@handicap-international.org or
nheeren@handicap-international.org
Web: www.handicap-international.org

Handicap International (HI) is a non-governmental association working to assist all people in a vulnerable situation, such as poverty, exclusion, violence or violations of basic rights. It works particularly with persons with disabilities. HI's mission is to promote human development by: reducing the risk factors that generate incapacity or worsen a situation of vulnerability; developing people's aptitudes and autonomy; adapting environmental, social, or physical factors in order to improve services and access to services for people in need; developing social participation in order to reduce disability situation, vulnerability or exclusion. The association works in partnership with all the different national and international, governmental and civil, institutional and community actors.

Save the Children UK

Public Enquiry Team
Save the Children
17 Grove Lane
London SE5 8RD UK
Tel: (44-020) 7703-5400
Fax: (44-020) 7703-2278
E-mail: Go to this page and fill in a form to submit for an e-mail response:
www.savethechildren.org.uk/functions/indx_contact.html
Web: www.savethechildren.org.uk

Save the Children works in the UK and across the world, offering emergency relief, long-term development and prevention work to help children, their families and communities to be self-sufficient. Save the Children also works to educate and advise other organizations and individuals on these issues. An important publication that is produced by Save the Children UK is *Promoting Psychosocial Well-Being among Children Affected by Armed Conflict and Displacement.*

United Nations High Commissioner for Refugees (UNHCR)
Case Postale 2500
CH-1211 Genève 2 Dépôt, Switzerland
Tel: (41) 22 739 8111
E-mail: Go to this page and fill in a form to submit for an e-mail response: www.unhcr.ch/cgi-bin/texis/vtx/contact
Web: www.unhcr.ch/cgi-bin/texis/vtx/home

The United States Association for UNHCR (USA for UNHCR) was created to assist the heroic efforts of those who help the world's refugees. Its mission is to build support in the United States for UNHCR through education and advocacy on behalf of those who are forced into flight for their lives or liberty. USA for UNHCR's goals are to educate the American people about the work of UNHCR, to disseminate information concerning the needs and circumstances of refugees, and to raise private funds for UNHCR's programs. UNHCR is committed to working towards more inclusion of people with disabilities in services to refugees and in 1996 published *Community Services Guidelines on Assisting Disabled Refugees: A Community-based Approach.*

7.6

DOMESTIC VIOLENCE AND WOMEN WITH DISABILITIES

Evelyn Anderton

The problem of domestic violence and women with disabilities is one that we need to deal with on an international level. The solutions and interventions vary greatly in different cultures and in different political systems, but there is no country in the world where domestic violence is not a serious problem for all women and an even worse problem for women with disabilities.

Domestic violence is the use of violence or the threat of violence in an intimate relationship to maintain power and control over another person. Domestic violence includes physical, psychological, sexual, or financial abuse. In the cases of women with disabilities, the definition of the abuser is expanded to include an attendant, an interpreter, an advocate, a family member, a paid caregiver, or anyone whom the woman relies on for support or assistance.

"In the cases of women with disabilities, the definition of the abuser is expanded to include an attendant, an interpreter, an advocate, a family member, a paid caregiver, or anyone whom the woman relies on for support or assistance. "

Since an abuser looks for a person who is easily victimized in order to gain a feeling of power and control, a woman with a disability is seen by many abusive men as an easy target. In fact, while one in four non-disabled women is a victim of abuse, the number rises dramatically for women with a disability. "The World Health Organization estimated in 1999 that violence towards persons with disabilities occurs at three times the rate of such incidence among the general population[1]." "Women with an intellectual disability are ten times as likely to be assaulted as other women[2]."

It can be even more difficult for women with disabilities to leave a violent relationship or to demand that the violence stop than non-disabled women because they are more often physically and/or financially dependent on their abuser:

- Jane from Zimbabwe tells that her "husband takes my wheelchair or crutches and puts them on top of the wardrobe because he fears I might go somewhere else."
- In most countries, at least two-thirds of disabled people are unemployed. In Tunisia, 85% of disabled people aged 15-64 are unemployed.
- Disabled women find it four times harder than disabled men to get work. In Zimbabwe, less than 1% of disabled people contribute actively to the economy. The situation is not much better for women with disabilities in more developed countries.
- In the UK and USA, 67% of disabled people are unemployed. Considering that the unemployment rate for all people in the USA is usually between 4% and 7%, this is a shocking difference.

Recommendations for decreasing the incidence of domestic violence among women with disabilities:

1. Educate women with disabilities about what domestic violence is and their rights within their own culture and political system. This will vary greatly from one country or culture to another, but information is available through international organizations' websites about the laws that have been enacted in recent years around the world.
2. Form coalitions between the international disability movement and the international domestic violence movement.
   - Work locally to devise effective alternatives to the violence for women with disabilities. Again, this will vary greatly from country to country.
   - Work together to change the attitudes and laws about domestic violence in the local community and the country. Include workshops in all domestic violence conferences that deal with the issue of violence and women with disabilities. Actively recruit women with

disabilities to attend the conferences and provide scholarships and attendants when necessary.

3. Educate all workers in the disability movement and those working in any capacity with people with disabilities about the prevalence of domestic violence so they not only recognize it when they see it but also look for when it is being hidden by the victim.

   - Contact local domestic violence experts to provide training. Remember that the nearest experts may be in the provincial or national capital far from your program. Seek these people out.
   - Remember that expertise about domestic violence is present wherever there is a group of women willing to talk about their life experience and/or the experiences of the women in their family or their friends. The most effective advocates are not necessarily professionally trained but are grassroots activists who understand the oppression of all women, including women with disabilities.

4. Educate workers in domestic violence about the myths and stereotypes that keep them from being effective advocates for women with disabilities, such as:

   - A man who would be in a partnership with a woman with a disability must be a wonderful person, so any stories about abuse must be made up.
   - Women with a disability are seen as asexual so they are not believed when they say they have been raped.
   - Women with psychiatric or intellectual disabilities are seen as promiscuous.
   - Women with disabilities are seen as unfit mothers, so when the abuser uses the common threat that he will take the children away if she reports the abuse, she is even less likely to tell about the abuse.
   - Women with disabilities who speak out or make complaints are seen as troublemakers or crazy or led on by irrational advocacy groups.

5. Educate the international medical community about the prevalence of domestic violence during pregnancy and the need to intervene once recognized. It is very typical for domestic violence to start during pregnancy because it is a time when the abuser feels he is losing control.

6. Plan for accessible services in domestic violence programs.
   - When starting or moving a program or shelter, locate it in an accessible building. (For information about planning for everyone see the Universal Design chapter in the Access section. For information on adapting an already existing facility see the Guidelines for Accessibility in the first section of this manual.)
   - When devising a strategic plan for services, consider how women with disabilities will participate. See the disability inclusion checklist for planning, implementing and evaluating programs and services.
   - Maintain a list of available interpreters for deaf women/people.
   - In addition to incorporating a disability accommodation line item, organizations may also create a supplemental fund, perhaps dedicated to expenses such as personal assistants. Service clubs, foundations, corporations and private donors interested in reaching underrepresented minorities are particularly responsive to appeals for donations earmarked for making programs accessible to people with disabilities. Contributions could also come from earmarking a percentage of participant fees to the fund, thus ensuring that each participant shares in the costs of making the project inclusive. Of course, whenever possible, it is always easier to include these funds in your original budget requests rather than relying on possible outside funding. (Please see the Budgeting for Inclusion chapter in the first section of this manual).

7. Hire people with disabilities and sign language interpreters as paid staff and volunteers in domestic violence programs and budget for accommodations.
   - By having a person who uses a wheelchair or a person with another disability on staff, the likelihood of a person with a disability contacting the program increases, as does the ability to serve that person effectively.

- Hiring people with disabilities as staff and interns is one of the most effective strategies for expanding the diversity of participants.
- MIUSA also recommends incorporating a disability accommodation line item of 1-5% in the administration budget to make reasonable accommodation to ensure that any employees with disabilities can do their jobs effectively in any project. (See the Budgeting for Inclusion chapter of the Management and Human Resources Development section.)

8. Recognize that domestic violence causes disabilities and work to prevent them.
   - Maria from Mexico tells of a friend who "became blind when she was pregnant because her husband hit her a lot."
   - Julie from the USA is deaf and blind because she "was born prematurely due to her father beating her mother during pregnancy."
   - Beverly from the USA tells that 90% of the men in the head injury program she was a part of became disabled from accidents while 70% of the women in the same program were disabled from beatings.

9. Ensure that any training or program your organization undertakes concerning domestic violence includes women with disabilities.

The foundation of both the domestic violence movement and the disability movement is the belief that all people deserve equal rights and opportunities. Moreover, both movements believe that the dominant culture cannot be allowed to deny those rights through discriminatory practices, including violence. Each of the movements can gain great strength from the other by working together. Both movements were started by people effected by the issue, not by outside experts. The expertise about how to work together is held by those active in each of the movements. The separation of the two groups is artificial and needs to end.

Evelyn Anderton worked for eight years as a vocational trainer and case manager for adults with developmental disabilities, followed by eleven years as the director of a domestic violence program. She has volunteered for Mobility International USA in a variety of ways, including helping to

organize and lead a trip to China in 1989 and writing a book in collaboration with Susan Sygall on traveling in China for people with disabilities. She is currently the development director for a non-profit organization that provides services for adults with mental illness, adults with brain injury, and homeless families

[1] WHO Draft Policy on Disability, unpublished manuscript by Groce, Eigner and Sandborg.
[2] Disabled Women: An International Resource Kit.

RESOURCES

The Daphne Program, Information Kit
Disabled Peoples' International- European Union Committee, DPI Italia ONLUS Via A. Reillo,
5 - 88046 Lamezia Terme CZ
Tel: (39) 0968-462419 – (39) 348-3208070
Fax (39) 0968-462520
E-mail: donned@dpi
Web: www.dpi.it/donne/testoVe.htm

The disabled women in DPI, and more in particular in DPI-Europe, decided to attack vehemently the problems related to all kinds of violence, especially to sexual violence. They set up a commission of disabled women within the organization which, through denunciations, promotions of debates, meetings and confrontations, as well as elaborating and experimenting instruments of protection and self-defense, have brought to the surface a reality that was present but hidden. They stimulate the growing awareness of many other disabled women in Europe and in the whole world. The main aim of the Information Kit was to promote a process of empowerment, which offers every disabled woman the opportunity to gain full awareness of her own humanity and her rights, through which she can develop a growing sense of selfesteem. It is only through selfawareness that one can take action to obtain the right social, cultural and political changes.

Disabled Women's Network Canada (DAWN)
200 Bay Street, Suite 301
Ottawa, ON K1R 7W8 Canada
Tel: (613) 235-4242
Fax: (613) 235-3881
E-mail: kathy@dawncanada.net
Web: www.DAWNcanada.ne

Disabled Women's Network Canada (DAWN) is a national, chapter-based organization of women with disabilities in Canada focused on advocacy and social justice on behalf of disabled women. Their goal is to

end the poverty, isolation, discrimination and violence experienced by women with disabilities. DAWN produces many resource materials for and about women with disabilities. DAWN Ontario: Disabled Women's Network Ontario is a progressive, feminist, cross-disability organization dedicated to social and economic justice. It works for access, equity and full participation of women with disabilities through public education, coalition building, lobbying, self-advocacy, resource development and information and communication technology.

Escape: A website for battered women who have disabilities
http://www.geocities.com/finexhouse/housing.html

The website contains a comprehensive listing of resources, legal policies, safe housing, and definitions of abuse for women with disabilities. Also available is FINEX House publication: *Escape: A Handbook for Battered Women Who Have Disabilities.*

Women With Disabilities Australia (WWDA)
PO Box 605, Rosny Park
Tasmania 7018 Australia
Tel: (61-3) 6244-8288
Fax: (61-3) 6244-8255
E-mail: wwda@ozemail.com.au
Web: www.wwda.org.au

WWDA is an Australian disability organization for women and has a website with information on a variety of useful resources about domestic violence and disability, including books, articles, websites and more. The objective of WWDA is to actively promote the participation of women with disabilities in all aspects of social, economic, political and cultural life.

7.7

WOMEN WITH DISABILITIES AND HEALTH CARE

Jane Maxwell, Hesperian Foundation

Most women with disabilities do not get basic and needed reproductive health services. There are many reasons why. For example:

- The health-care facilities may be far away or expensive.
- The facilities and/or services may not be accessible.
- The health workers are rarely trained to understand special health needs women with disabilities may have.
- Attitudes health workers may have about disability make it uncomfortable and hard for disabled women to seek health care.
- Women with disabilities and their families may themselves not believe disabled women can get health problems such as breast or uterine cancer.

Dana Vion

"Most women with disabilities do not get basic and needed reproductive health services."

Like women everywhere, however, women with disabilities need to have regular reproductive health exams every three to five years from a trained health worker - even if they feel fine. All women should start to have these exams when they are about 20 years old, or sooner if they start to have sex. These exams should include:

- a pelvic exam.
- a breast exam.
- a Pap test (to test for cancer of the cervix).
- an exam for sexually transmitted infections (STIs).
- a test for weak blood (anemia).

Like women everywhere, women with disabilities also need good information about, and access to, family planning (including emergency contraception), and advice and care during pregnancy and birth. A woman with diabetes may need ongoing injections of insulin, but her other needs are no different from any other woman's.

Many women with disabilities have experienced de-humanizing exams as children when their "disability" was used as a teaching tool and they were forced to undergo naked, public exams in front of classrooms full of nursing and medical students. This experience can lead a disabled woman to feel her body does not belong to her and that she does not have the right to make decisions about her own health care needs. Health care workers can help alleviate this situation by learning as much as possible about disability, and by working with disabled women in their community to make sure that disabled women feel welcome and that they will be treated with respect when they go to a clinic or hospital for medical care.

"Like women everywhere, women with disabilities also need good information about, and access to, family planning (including emergency contraception), and advice and care during pregnancy and birth."

Health care workers should:

- Learn as much as possible about how disability may or may not affect reproductive health.
- Realize that a woman with a disability will understand more about her body, and about what is "normal" for her, than anyone else — including the health worker.
- Remember that women with disabilities can have loving sexual relationships and become good, caring mothers and wives.

"Realize that a woman with a disability will understand more about her body, and about what is "normal" for her, than anyone else — including the health worker."

With the right information, health-care providers and women with disabilities can both work to make health-care services more "user-friendly." This chapter gives general information about appropriate reproductive health services for women with disabilities and also lists resources that provide more detailed information.

THE PELVIC AND BREAST EXAMS

If you are a health worker, do not wait for a disabled woman to ask about pelvic and breast exams. Each time you see a disabled woman for a health problem, make sure she knows what these exams are for, and why they are important for ALL women.

For women who are deaf or cannot hear well
Let the woman bring a friend with her to the exam. The friend can use sign language to explain the exam and can help you communicate with the woman. Where possible, have sign language interpretation available.

For women who are blind or who cannot see well
Let the woman bring a friend with her to explain and describe the exam. Explain to the woman what you will be doing BEFORE you touch her. Do not expose her body any more than you would for any woman having this exam. Just because she cannot see does not mean that she will not be embarrassed or feel uncomfortable.

"If you are a health worker, do not wait for a disabled woman to ask about pelvic and breast exams."

For women who are mentally slow
A pelvic exam can be frightening for women who are mentally slow. You will probably need to do more preparation and education, and be extra patient during the exam. Here are some things you can do that will help:

Talk about the exam in advance: Ask a family member or friend to help you explain the exam to the woman. Together you can help her to understand that this exam is important for her to be a healthy woman. Describe what will happen during the exam and answer any questions she has.

Let her visit the clinic in advance: The day before she is to have the exam, let her come with a friend to the clinic or the place where the exam will be done.

Let the friend stay during the exam: If the woman wants, let a friend or family member stay with her during the exam. If the health worker is a man, a woman she trusts should stay with her the whole time.

Explain the exam again right before: Before starting the exam, explain again what will happen. Ask her if she has any questions. She will probably be less afraid if she can ask questions before the exam starts.

Show her any instruments you will use, such as the speculum. Make sure she knows what a speculum is before the exam so that it does not surprise her, and let her touch it if she wants to.

Talk to her during the exam: Explain what is happening at each step. Tell her what you need to do next. Ask her if she is ready and wait for her to agree. That way she will have control over what happens.

For women with physical disabilities: Exam tables close to the ground are best for women with a physical disability. There are special exam tables that can be raised or lowered, depending on a woman's needs. These can be expensive, but are very useful if a clinic or hospital can buy one. The pelvic exam, however, does not need to be done on a special table. It can be done on any clean, firm surface — even on a clean floor.

Any woman with a physical disability will know best how to move from one position to another. Ask her how you can help her. Or let a friend come with her to the exam to help her if she prefers. Before the exam begins, make sure she is well balanced and feels safe and comfortable.

The pelvic exam can easily make the muscles of the bladder and bowel open and urine and stool can come out. So when you make an appointment for the woman to come for her exam, ask her to pass as much urine and stool as possible ahead of time. But even if she does this, it is still possible for some urine and/or stool to come out. Do not be surprised if this happens so that the woman will not be embarrassed.

If she uses a catheter all the time (a fixed catheter), she does not need to remove it. It will not affect the exam. If she has a urine bag tied to her leg, ask her to remove it and place it either beside her or across her belly. Make sure the tube does not bend, and that it continues to drain properly.

For women with stiff or tight muscles: Muscles can suddenly get tight and stiff (spasm) during an exam. This happens mainly to women with a spinal

cord injury or cerebral palsy. Sudden stiff muscles can happen when:

- the woman moves onto the exam table.
- she is in an uncomfortable position.
- an instrument like a speculum is put into her vagina – especially if it is cold.
- during a "hand" or "bi-manual" exam.

Ask a woman with a physical disability if she has tight muscles, and go slowly if she does. This will give her more time to relax. If a spasm happens during the exam, stop and wait until she tells you her muscles are relaxed or soft again. You or her friend can gently hold or support the affected place until the muscle is soft again.

The exam will be much easier for the woman if she can find a comfortable position where she can relax and does not have to make her muscles tight to hold herself in place. A friend or family member can help to hold her body during the exam. Or it can also help to roll up blankets or cloth and put them underneath her knees.

Dysreflexia (sudden high blood pressure with pounding headaches): Dysreflexia is common to people with spinal cord injury. It is the body's reaction to something that would normally cause pain or discomfort, but which the person does not feel because of the injury. Dysreflexia can be caused when something touches or stimulates the bowel, urine system, the skin in the lower body and genitals, or the breasts.

Signs:

- severe, pounding headaches
- sweating, especially of the head
- stuffy nose
- reddish or dark skin patches above the level of the spinal cord injury
- feeling sick (nausea)
- high blood pressure (up to 240/150)

During the woman's pelvic exam, dysreflexia can be caused by:

- a woman's body touching a hard exam table or surface (even if she cannot feel it).
- pressure in the vagina or rectum from an instrument (like a speculum), especially if the speculum is too cold, or from the hands of the person doing the exam.
- cold temperature in the clinic or place where the exam is being done.
- a urine tube (catheter) that has become bent or twisted.

Treatment:

Act quickly to remove the cause and lower the blood pressure. **Dysreflexia is a medical emergency.** The high blood pressure can cause fits or deadly bleeding inside the brain. **Do not leave a person with dysreflexia alone.**

- Stop the exam and remove the speculum or hand from the vagina.
- Loosen any tight clothing, including tight socks or stockings.
- Change the woman's position so she is sitting up. Make sure she is supported. Move her legs so they hang down over the side of the table. She should sit up until the signs go away.
- If the signs do not go away in 10 minutes, make a small hole with a needle or pin in a 10 milligram *capsule* of nifedipine and put it under the woman's tongue. This will make the blood pressure go down in 5 to 10 minutes.
- If you have only 10 milligram *tablets* of nifidipine, give the woman one tablet in a glass of water. The blood pressure will go down in about 40 to 50 minutes.

Prevention:

- If possible, rub lidocaine gel, 2 to 4% into the vagina and rectum before the exam begins.
- Make sure the room and the table where you do the exam is not cold. Warm the speculum in clean warm water before putting it into the vagina.

- If the weather is cold, have the woman wear warm socks. Cover her with a cloth or blanket during the exam as much as possible

THE BREAST EXAM

Women with disabilities, like all women, should be given information about the importance of examining the breasts once a month to make sure she is healthy. If she can examine her breasts once a month, she will learn the way her breasts feel and will then be more likely to know when something is wrong.

If a woman cannot examine her own breasts, someone she trusts, such as a sister or friend, can do it for her. It is best to have the same person to help each time so that the helper will know if something changes.

If a woman cannot feel well with her fingers (such as someone who has been burned, or whose fingers are worn away by Hansen's disease), teach her that she may be able to use another part of her hand. She can use her thumb, her palm, or the back of her fingers.

If a woman has weak muscles or her hands shake, show her how to use her other hand to guide her fingers. Or someone else can guide her hand. A helper can hold the woman's hand up to her breast and keep the woman's fingers in the right place.

If a woman cannot reach across her chest, she can use the hand that is closest to her breast. If her breasts are large, she may need help examining some part of her breast.

PREGNANCY

Every woman should have the right to decide for herself if and when she wants to become a mother. And this includes women with disabilities. There are precautions that women with some disabilities must take when they are pregnant, and some women will need more assistance than

others. But there is no reason why most women with disabilities cannot have a safe pregnancy and give birth to a healthy baby.

Here are some possible problems for a health worker to discuss with a disabled, pregnant woman:

- Which will be the safest place for her to have her baby: at home, a birthing clinic, or hospital?
- Will she have transport available if she needs it to take her to a hospital or clinic?
- If she takes medicines regularly, will they have any effect on the developing baby?
- Will her disability affect her health and the health or development of the baby?
- Is her disability likely to cause problems during labor or delivery?
- Could complications be prevented or treated safely?
- Does she know how to stay healthy during her pregnancy (eating well and exercising)?
- Does she have family members or friends to help her through the whole pregnancy and birth?

" There is no reason why most women with disabilities cannot have a safe pregnancy and give birth to a healthy baby."

If a woman has lupus, her risk of miscarriage can be higher than for most women. Lupus can cause antibodies in the blood to attack and damage the placenta and kill the developing baby. Or the growing baby itself can be damaged by the antibodies in the womb and may be born with cerebral palsy.

Most women who have lupus when they get pregnant are likely to have even worse problems as the pregnancy goes along. The problems caused by lupus come and go, so if a woman with lupus wants to get pregnant, it is best if she waits until she has had no lupus problems for 6 months before trying. This way she will be healthier and the baby is more likely to survive.

If a woman has multiple sclerosis (MS), there is no way to know ahead of time how her disability will be affected by pregnancy. She may have no

changes at all. Or she may get so tired, her ability to move around will be affected from the beginning of the pregnancy. She may have to start using a stick or wheelchair to get around. For some women with MS, the difficulties that come with the disability get worse during pregnancy and do not go away after the baby is born. This is especially true in hot climates.

If a woman has fits (seizures, convulsions, epilepsy), it is hard to say whether she will have more or fewer fits while she is pregnant. A woman who gets fits will know best how often she gets them and how severe they are. Many of the anti-fit medicines, especially phenytoin (diphenylhydantoin, *Dilantin*) may increase the risk of birth defects when taken by a pregnant woman. But the woman should not stop taking anti-fit medicines while she is pregnant because this can make the fits worse and even kill her. Phenobarbital (phenobarbitone, *Luminal*) is probably the safest anti-fit medicine to take during pregnancy.

If a woman has sugar sickness (diabetes) and becomes pregnant, she will probably already know how to control her diabetes and she should continue to do so during her pregnancy.

Some women get diabetes only when they are pregnant, and it goes away after the birth. But during the pregnancy, the diabetes can cause problems for the developing baby: it may die before birth, or may grow very large and get stuck in the pelvis, causing it to have a disability like brain damage.

Signs of diabetes for a pregnant woman:

- Her wounds heal slowly.
- She is thirsty all the time.
- She has to pass urine more often than other pregnant women.
- She is more hungry than other pregnant women.
- She gets frequent vaginal infections.
- Her womb or belly is unusually large for her month of pregnancy.
- She had diabetes with a past pregnancy.

- One or more past babies was born very big (more than 4 kilograms or 9 pounds), or was ill, or died at birth from unknown causes.

A pregnant woman with diabetes should plan to have her baby in a hospital. If this is not possible, she should try to eat well, avoid sweets, and eat small, frequent meals.

OTHER PROBLEMS DURING PREGNANCY

Problems of the Urine System
In pregnancy, all women are more likely to get an infection of the urine system than at other times.

Women with physical disabilities like limited muscle control, and paralysis or loss of feeling in the lower body, seem to have even more problems than other women with leaking urine and infections of the bladder and kidneys during pregnancy. If possible, their urine should be tested for infection each time they see a health worker during the pregnancy.

Prevention:

- Drink plenty of water or fruit juices – at least 10 to 12 glass a day.
- Keep the genitals clean.
- Wash the hands and clean the equipment when a catheter is used to empty the bladder.
- Watch for signs of infection (passing more urine than usual, fever). The woman may need to take antibiotics.
- Watch for signs of dysreflexia (sudden high blood pressure, sweating, and pounding headaches). **Bladder problems are the most common cause of dysreflexia.**

As the baby grows and the mother's belly gets bigger, it pushes against the bladder and leaves less room for urine. This can make urine leak out all the time, especially when the woman coughs or sneezes. Because of this, many women who usually use a catheter several times a day to pass urine change to a catheter that is left in all the time (a "fixed," or Foley catheter). If possible, the woman should try not to do this, because it will

be very difficult for her to change back after the baby is born. Her muscles that control the bladder will "forget" how to hold the urine inside.

Instead, she can use thick pads – which can be made from folded cloth – to catch the leaking urine. If pads are used, the woman should watch for signs of a rash or skin irritation around her genitals, which can happen when the skin is warm and wet. The pads should be changed often, then washed and rinsed well in soap and clean water, and hung in the sun to dry. The pads should be clean and dry before they are used again.

Movement and Balance

Because the belly is getting bigger during the second trimester of pregnancy, women begin to notice changes in how they can move about. They may start to lose their balance and fall easily. Or they may have problems with bending and picking things up. Because of this, many women start to use aids to help with walking and moving about until the baby is born.

What to do:

A 'walker' can be made from cane, rattan, bamboo or wood. The joints can be tied with any strong string, twine or ribbon, or with strips of car or bicycle inner tubes. A walker with 2 front wheels is easier to move than a walker with no wheels, and is more stable than a walker with 4 wheels.

For other examples of aids, such as a cane or walking stick made from forest plants, or crutches made from tree branches, see *Disabled Village Children* listed in the resources.

Some women will have to use a wheelchair while pregnant. They may find it difficult at first to use a wheelchair, but they will find it more comfortable than trying to get around without one.

Muscle spasms

These are uncontrolled tightening or pulling of muscles that make it difficult for a person to control her movements. This happens most often to people with a spinal cord injury or cerebral palsy. The muscles will be tight all over, and not just in one place.

What to do:

- Do not pull or push directly against the tight muscles. This will make them worse.
- Gently hold and support the affected part until the muscle relaxes.
- If the woman's back or whole body is affected, put something under her head and shoulders, bend them forward a little. This will help to relax stiffness in the whole body.
- Apply warm soaks to the tight muscles, or, if possible, have the woman sit or lie in warm water. Tell her to be careful not to burn her skin or overheat her body. Too much heat will harm the unborn baby.

IMPORTANT *In some countries, therapists and other people, use massage or rubbing to relax spastic muscles. Although massage often helps relax muscle cramps, or tight muscles from other causes, in spasticity, massage usually increases the muscle tightness. As a general rule: DO NOT MASSAGE SPASTIC MUSCLES.*

Back Pain

Most pregnant women get back pain, especially in the weeks just before the baby is born when the belly is very big and heavy. Women with disabilities seem to get back pain that is more severe and that happens earlier in the pregnancy. Even women who have no feeling in the lower body often notice back pain while they are pregnant.

What to do:

- Exercise before, during, and after pregnancy will stretch and strengthen the muscles in the lower back and keep the muscles in the belly strong.
- The woman should sit in a straight-backed chair.
- Rest, heat and massage on the painful area can help reduce back pain.

Breathing Difficulties

As the baby grows, it pushes against the mother's lungs and she has less

room in her chest to breathe. This is normal in pregnancy. But women with some physical disabilities, like small body size (short stature, *dwarf*) or paralysis of the chest muscles, can get short of breath earlier in the pregnancy than other women. The baby gets its supply of oxygen from the mother's lungs, so a pregnant woman must keep her lungs clear and healthy so that the developing baby will get all the oxygen it needs.

What to do:

- If possible, the woman should sleep sitting up a little. She will be more comfortable if she puts something under her knees.
- She should drink water often – at least 8 glasses a day. This will help the mucus in the lungs to stay loose so it is easier to cough it up. If the mucus stays in the lungs it can cause an infection.
- If the woman starts to cough up mucus with pus (phlegm), she may need to take an antibiotic that is OK to use during pregnancy.

Aches and Pain in the Joints

Many pregnant women get aches and pains in the hip joints, especially during the final three months (third trimester). But for women with disabilities like lupus and arthritis, the aches and pains can start during the second trimester and can also affect the shoulders, elbows, wrists, knees and ankles as well as the hips.

What to do:

- Rest the painful joints. Move a little from time to time so the joints will not get stiff, but the movements should be gentle.
- Applying cold or heat to the painful joint often reduces pain and makes movement easier. Usually cold works best on hot, inflamed joints, and heat on sore, stiff joints. Tell the woman to experiment to see which works best for her.

  For cold: use ice wrapped in a cloth or towel for 10 to 15 minutes.
  For heat: use a thick cloth that has been soaked in clean hot water (squeeze out the extra water) and wrap it around the sore joint. Cover the cloth with a piece of thin plastic, and wrap with a thick dry cloth or towel to hold in the heat. When the wet cloth starts to get cool, put it back in the hot water and repeat.

- Give paracetamol (acetaminophen) for pain, 500 mg every 3 to 4 hours.

Constipation

Many pregnant women have trouble with hard stools. For women with disabilities who have to remove their stool manually, they will probably need to remove the stool more often while they are pregnant. For example, if a woman usually does it every other day, she should start doing it every day. And if she usually does it once a day, she should start doing it twice a day. This is important because hard stool that is not removed can cause dysreflexia.

LABOR AND CHILDBIRTH

The length of time it takes for a woman with a disability – any disability – to give birth is no different from any other woman, usually from 3 to 24 hours. What may be different is how she can tell that labor has begun, and the position she may need to be in during the delivery.

Most women have some discomfort while they are in labor and giving birth. Women who still have feeling in the belly will notice cramps as these are usually very strong. Even women who are paralyzed and have no feeling in the belly can usually tell when the baby is ready to come out. Although they may not have real pain, the belly will feel different enough for them to know that something is changing. They may be able to feel with their hands as their belly changes from soft to hard during a contraction.

What to do:

- Make sure the woman has passed urine. A woman with a spinal cord injury is less likely to get dysreflexia if a catheter is left in place all during the labor and delivery so that urine can drain out.

- Make sure the woman changes position several times, at least once an hour. The more comfortable and relaxed she is, the more relaxed her muscles will be, and it is less likely they will cramp or

spasm. Also, she will be less likely to develop pressure sores from sitting or lying in one position for too long.

There are many positions that can be used during both labor and delivery:

- A wheelchair rider can sit in her chair.
- A woman with little or no leg or arm control can sit on someone's lap.
- Or she can rest on cushions in a half-sitting position.
- With help, a woman with some leg control can usually squat.
- A woman with some leg and arm control can try resting on her hands and knees. This position sometimes also helps prevent and control muscle spasms.
- A woman who is blind or who has poor balance may feel safer lying on the floor. Someone she knows well – a friend or family member – should be able to stay with her all the time.
- A woman who is deaf should be able to have a friend or family member stay with her all the time – especially if there is no one at the birth facility who knows sign language.
- Most hospitals and health centers have special beds for women giving birth. These beds have knee supports and can be useful for women with poor leg control.

A woman with little or no leg control can lie on her side while someone holds her top leg, with her legs bent …

… or straight.

Possible Problems During Labor and Birth

Some of the problems a woman may have with her disability when she is not pregnant can also happen while she is in labor and giving birth. For example, muscle spasms can start, or she can get pressure sores from lying in the same position for too long.

Muscle cramps and spasms (sudden stiff muscles)

Women with cerebral palsy, spinal cord injury, or who are paralyzed from polio can get cramps or tight spastic muscles at any time during

labor and delivery. Tight muscles in any part of the body are affected by the position of the head and body. Pulling or pushing directly against the spastic muscles will cause them to tighten more. But sometimes you can use 'tricks' to release or 'break' the muscle spasm.

What to do:

- Do range-of-motion exercises between contractions throughout labor. The exercises will keep muscles loose and help prevent cramps and spasms.
- Sitting in a bath of clean warm water will help the muscles relax.
- Cloth soaked in clean warm water will also relax the muscles.
- Do not try to pull a woman's legs apart at the ankles. This will make her legs pull together more tightly. Instead, lift her head and shoulders, and then bend her legs and slowly separate them. If you hold them above the knees, they will open more easily.
- Put something under the woman's head and shoulders to bend them forward. This will help to relax the stiffness in the whole body.

Sudden High Blood Pressure with Pounding Headaches (Dysreflexia)

When labor first starts, women with a fairly high spinal cord injury (usually at T-6 level and above) can get a sudden, dangerous increase in blood pressure with severe pounding headaches. This is called dysreflexia. Sometimes having the signs of dysreflexia is the way a woman knows she is in labor.

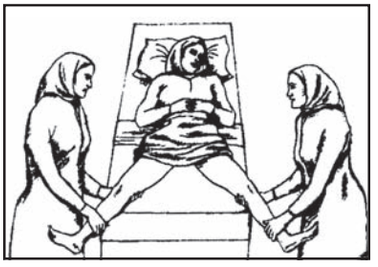
Dysreflexia is a medical emergency. The high blood pressure can cause fits or deadly bleeding inside the brain. Because of this, **before her labor starts,** it is best for a pregnant woman with a spinal cord injury to go to a hospital or clinic that can take care of the medical problems she may have during labor and birth. She must have an injection in her spine (epidural) of a very strong pain medicine (anesthesia) that will stop dysreflexia before her contractions start. In the meantime it is important to:

- Make sure she is not left alone.
- Make sure she is not lying down flat, and that her head and shoulders are supported and her knees bent.

- Measure her blood pressure frequently, at least once every 10 minutes.
- Make sure she does not need to pass stool, but do not give her an enema to remove the stool. This can start dysreflexia.
- Keep her bladder empty. If necessary, put in a catheter to drain the urine. Apply xylocaine gel (2% to 4%) to the urine hole (urethra) before putting in the catheter.

Birth by Operation (cesarean section, c-section)

Most pregnant women with physical disabilities, especially those who are paralyzed, are told by doctors and other health workers that they MUST have a c-section. This is not always true. With a little help, it is possible for most women who have a physical disability, or have no feeling in the belly, to give birth through the vagina. No matter what sort of disability a woman has, the muscles of the womb will still contract by themselves to push the baby out. Here is an example:



Fatuma Akan, who lives in Uganda, is paralyzed in both legs from having polio as a child. When she was pregnant, she built a "birthing stool" which enabled her to stay in a squatting position so her baby could be born through the vagina. Even though her legs are paralyzed, Fatuma's womb is still strong and can squeeze itself (contract) to push out a baby. And the position of her body on the birthing stool helps the baby drop down gently out of her body through the vagina, just as it does for other women who squat during birth. Fatuma had 4 healthy babies born through normal labor and delivery with the help of her birthing stool.

TAKING CARE OF A BABY

Most new mothers have family members to help take care of a new baby. But a disabled woman's family members must be careful not to help a disabled mother so much that they prevent her from taking care of her baby herself. She may need some assistance, but she should be free to be a mother to her child. All mothers need help sometimes.

Feeding and comforting are the two most important things a new mother

can do so that she and the baby will feel close and secure. When a disabled mother feeds and comforts her baby, she must:

- make sure the baby is safe.
- make sure she does not injure herself and cause another disability.

Feeding:
If possible, all new mothers should try to breast-feed their babies. And while most disabled women can do this, some will need help to hold the baby in a good position. Some may not produce enough milk. Others may become too weak and tired. The disabled woman herself can decide whether or not she can breast-feed her baby. She may need to find alternative feeding methods.

Comforting:
For a baby to feel safe and close with its mother, it is important for the mother to be the person who provides comfort when the baby is unhappy. If the baby of a disabled mother starts to cry and the mother cannot get to it quickly, someone else can bring her the baby. Then the baby can see the mother's face and hear her voice saying comforting words – even if the mother herself cannot hold the baby.

For a mother who cannot hear well: A healthy baby usually makes a lot of noise when he or she is hungry or not feeling well. So a woman who does not hear well will need to stay close to her baby as much as possible so she will know when the baby needs her attention. At night she can sleep with the baby as close to her as possible so she can feel the baby move.

Changing and Dressing the Baby:
A healthy baby becomes an active, wriggling baby very quickly. So as a baby grows, changing the baby's clothes can become more and more difficult. It helps to use clothes that are easy to take on and off. Or use strips of Velcro instead of buttons to keep the baby's clothes shut.

For mothers with physical disabilities: Many women with physical disabilities can safely change and dress their babies on a table or bed without injuring themselves, especially if they can sit down. But if a woman does not have enough body strength to do this, a simple wooden table can be made that will hold the baby safely and will also not hurt the mother's body, or will allow her wheelchair to fit underneath. The table can be made to the height each woman needs.

Cleaning the Baby:

It is important to clean the baby off each time it passes urine and stool. How well a woman can do this will depend on how well she can use her hands or can see.

For a mother with limited use of her hands: She may have to rely on a family member to clean and change her baby. If this is the case, the place where the baby is changed should be close beside the mother so that the baby can always hear her voice and see her face as it is being changed.

For a mother who is blind: If there is enough water available, the mother can hold the baby securely with one hand and wash the stool off the baby's bottom in a bucket or bowl of clean water. Or, she can hold the baby securely over the edge of a table and pour clean water over the baby's bottom.

Carrying and Moving About with the Baby

For a mother who uses crutches or a stick: She can probably best carry her baby on her back. At first her balance will be affected by the weight of the baby. But if she starts when the baby is small, she will get used to the feel of the baby, and her body and balance will adjust to the increase in weight.

For a mother who uses a wheelchair: It can be difficult for a woman who uses a wheelchair to hold a baby in her arms or on her lap if she is using both arms to push her chair. But if she can wear a sling around her neck, she can hold the baby safely in it as she rolls. She should tie the sling to her waist with a strap so that the sling does not bump around.

For a mother who uses sign language: A mother who is deaf can also use a sling to hold her baby. This means her hands will be free to sign.

Keeping Up with the Baby

For a mother who cannot move quickly: Small babies can move around with great speed, and it is easy for them to get hurt. If a mother cannot run after her baby to save the baby from a dangerous situation (like running in front of a car, or into a fire), she can tie a string around the baby's waist so that she can quickly pull the baby back to safety.

For a mother who is blind: As the baby grows and starts to move about by itself, the mother can tie something that makes a noise onto the baby's ankle or wrists (like a small bell or a seed-pod). This way the mother can always hear the baby and know where it is.

FAMILY PLANNING

Women with disabilities need information about and access to family planning methods, because:

- they are sexually active.
- they are able to get pregnant.
- they will not have disabled babies (unless their disability is genetic).

Using a family planning method should always be a choice ANY woman makes for herself and should not be forced on her. And becoming a mother should also be her choice. No woman, whether or not she has a disability, should be prevented from becoming pregnant if she wants to.

Which method a disabled woman chooses will depend on:

- how well she can use her hands.
- how much she can move her body (how paralyzed she is).
- whether she has had a stroke, or cannot walk, and must sit or lie down all the time.

- whether her disability changes over time.
- whether she is taking other medicines.
- any health problems members of her family may have (for example, a family history of breast cancer).
- whether she has difficulties dealing with monthly bleeding (menstruation).
- whether she can remember to use the method she chooses.

Choosing a Method

For women who are blind or deaf:
They can use all family planning methods.

For women who are unable to walk, have no feeling in the belly, but do have good hand control:
They can use: the condom for men, condom for women, diaphragm, cervical cap, spermicides, breast-feeding, mucus method, rhythm method, sterilization.
They should not use: pills, IUDs, injections, implants.

For women unable to walk, no feeling in the belly, and limited or no hand control:
They can use: condom for men, breast-feeding, rhythm method, sterilization.
They should not use: *condom for women, diaphragm, cervical cap, spermicides, pills, IUDs, injections, implants, mucus method.*

For women able to walk, with or without assistance, have feeling in the belly, and have good hand control:
They can use: all family planning methods.

For women able to walk, with or without assistance, have feeling in the belly, but have limited or no hand control:
They can use: condom for men, injections, implants, breast-feeding, rhythm method, sterilization.

They should not use: condom for women, diaphragm, cervical cap, spermicides, mucus method.

For women who are of small size (little people):
They can use: condom for men, cervical cap, diaphragm, spermicides, pills, injections, implants, breast-feeding, mucus method, rhythm method, sterilization.
They should not use: condom for women, IUDs.

For women with an on-going (chronic) disease (diabetes, epilepsy, lupus):
They can use: condom for men, condom for women, diaphragm, cervical cap, spermicides, progestin-only pills, injections **(see note*),** implants, IUDs, breast-feeding, mucus method, rhythm method, sterilization.
They should not use: any pills or other methods containing estrogen.
***Note:** women with diabetes should also not use injections.

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RESOURCES

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HealthWrights is a non-profit organization committed to advancing the health, basic rights, social equality, and self-determination of disadvantaged persons and groups. Some of its publications include: David Werner's *Questioning the Solution, Nothing About Us Without Us,* and *Disabled Village Children. Disabled Village Children* is a guide for community health workers, rehabilitation workers, and families. Containing more than 4,000 line drawings and 200 photos, it is especially for those who live in rural areas where resources are limited. But it is also for therapists and professionals who assist community-based programs or who want to share knowledge and skills with families and concerned members of the community. Publications from Health Wrights are available in several different languages and alternative formats.

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The Hesperian Foundation promotes health and self-determination in poor communities worldwide by making health information accessible. Hesperian publications are written simply and include many illustrations so people with little formal education can understand, apply and share medical information. Its first book, *Where There Is No Doctor*, by David Werner, is considered to be one of the most accessible and widely used community health books in the world. Other books included: *Where*

Women Have No Doctor, by A. August Burns, Ronnie Lovich, Jane Maxwell, and Katharine Shapiro*; Helping Children Who Are Blind: Family and community support for children with vision problems*, by Sandy Niemann and Namita Jacob; *Helping Health Workers Learn* by David Werner and Bill Bower. Topics of current and future publications include: women with disabilities and health, midwifery, dentistry, environmental health, mental health worker training, rehabilitation, HIV/AIDS, children with disabilities, workers' health and safety. Hesperian Foundation publishes in English and Spanish.

Source

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Source is an international information support center designed to strengthen the management, use and impact of information on health and disability. It is a collaborative venture of the Centre for International Child Health, HealthLink Worldwide, and Handicap International. The combined center is designed to meet the information needs of individuals and organizations working in health, disability and development worldwide.

World Health Organization

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The World Health Organization, the United Nations specialized agency for health, was established on 7 April 1948. WHO's objective, as set out in its constitution, is the attainment by all peoples of the highest possible level of health. Health is defined in WHO's constitution as a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity.

7.8

PARENTING WITH A DISABILITY

Judith Rogers, Through The Looking Glass

Through the Looking Glass (TLG) is the National Resource Center for Parents with Disabilities (NRC), funded by NIDRR, U.S. Department of Education.

INTRODUCTION

The National Resource Center for parents with Disabilities (NRC) provides information nationally and internationally for parents with disabilities or deaf parents and for professionals who are involved with them. The NRC provides a national clearinghouse of information, parent-to-parent network, technical assistance, publications, and professional training regarding custody, pregnancy and birthing, parenting adaptations, adoption, and appropriate intervention for parents with developmental disabilities. Increasingly the NRC has been providing technical assistance and training to support the development or improvement of services and policy regarding parents with disabilities and their children.

"The National Resource Center (NRC) provides information nationally and internationally for parents with disabilities or deaf parents and for professionals who are involved with them."

The following information, provided by Judith Rogers, a Through the Looking Glass (TLG) occupational therapist and mother with cerebral palsy, is an example of some of the expertise provided by the NRC regarding parenting adaptations for parents with physical disabilities. This discussion is drawn from and excerpted from publications by the team of TLG occupational therapists, researchers and psychologists in which Judith has participated. These publications are referenced at the conclusion of the article. Please contact the NRC for more information before developing the described adaptations.

For the past 13 years TLG has been doing research as well as providing adaptive equipment and direct service to parents who have a physical disability. In our research we learned that it is important for disabled parents, particularly new parents, to have a visual history of other disabled parents. A "visual history" is the accumulation of mental images of the

various ways in which parents with physical disabilities successfully perform baby care tasks. Most disabled parents have never seen another parent with a physical disability doing basic baby care tasks – such as dressing, diapering, feeding, bathing, carrying or transferring a baby. Yet most people have an idea of how nondisabled people care for babies because they have observed that care. From our work at TLG we realized that we needed to expand these images to include parents with disabilities doing baby care tasks.

Disabled parents need to know that they are not alone, and also to know that there are parenting solutions. By seeing other disabled parents doing baby-care tasks, newly disabled parents can assess whether those tasks will be easy or hard for themselves.

"Most disabled parents have never seen another parent with a physical disability doing basic baby care tasks – such as dressing, diapering, feeding, bathing, carrying or transferring a baby. "

Just as a parent with a disability needs an expanded visual history, so does the non-disabled professional. TLG has produced both a video and a book that have images that will help expand the visual history. (See Resources section at the end of chapter)

When a person without a disability does not have an expanded visual history, s/he will have an outsider's perception. This can lead to the wrong impression; i.e., the impression that a parent with a disability is having more difficulty doing a baby-care task than is experienced by the parent. In TLG's research investigating the impact of adaptive baby care equipment on baby care activities for parents with disabilities, we showed occupational therapists videos of the parent doing baby care tasks. We asked the professionals to rate the level of difficulty that they perceived for each parent on the video. The non-disabled occupational therapists tended to rate the level of parent difficulty as greater than the parents' self-ratings of the same task and greater than that of the disabled occupational therapist.

TLG is developing a clinical evaluation tool for occupational therapists that are assessing parents with physical disabilities. We have been using a non-pathological approach when doing such an evaluation. This means that we see the problem in terms of environmental barriers, such as those that contribute to the parent's fatigue or difficulties. Decreasing or eliminating the barriers will make the baby care task less demanding and

thus more joyful for parent and child. We see these environmental barriers as a mismatch with the parents' abilities.

A "mismatch" is defined as a physical element in the environment (including anything outside of the parent and their mobility aid) that does not match the functional abilities. Mismatches are common obstacles that families struggled with prior to our intervention.

An example of a mismatch would be either a too-low or too-high diapering surface for a parent using a wheelchair. Having an inappropriate diapering surface makes transferring (moving) the baby onto and off of the surface difficult. A solution for this mismatch would be to create an appropriate clearance for the parent's wheelchair, and to have the surface at a level that makes it easier for the parent to lift the baby on and off. Moreover, this modified table would place the parent's body in an optimal position for both transfers and diapering.

Although there are a number of baby care tasks, like diapering, feeding, and putting to bed, most of our interventions have been centered on certain aspects of these activities. We call this type of activity "transitional tasks." Transitional tasks are the essential links between and within most of the baby-care activities. They are the physical activities that begin and end a baby-care activity. The transitional linking tasks are:

- holding, carrying and moving
- transfers
- position change.

Carrying and moving is one of the most critical activities, because without it the parent would be stuck in one location with a baby. If the parent is using a manual wheelchair, there are only a few choices to use for carrying the baby when s/he is an infant. For parents who have limited use of one arm, a shallow sling, designed or made so it is easy to lift the infant in and out, could work. We have found a few commercially available front packs that may assist a few parents. In most cases, we have used our own designs. TLG has devised several different models which are described in our books, Adaptive Baby Care Equipment: Guidelines,

Prototypes & Resources and The Idea Book. It is beyond the limits of this article to describe these designs. Please see the resource page at the end of this chapter to contact Through the Looking Glass about these books.

One of the most difficult transitional tasks can be carrying and moving a baby while using a manual wheelchair. Until their child is two years old, many parents struggle with keeping the baby on their lap. This can be because of the child's lack of sitting balance or because they don't want to stay on the lap. The front pack may work until the child is two years old, but there are simpler options that can be devised. Again, these are described in the books.

"One of the most difficult transitional tasks can be carrying and moving a baby while using a manual wheelchair."

There are several versions of commercially available combination front/lap ("bum or fanny") packs. These are helpful for parents who may have limited lap space when using a wheelchair or for parents with upper extremity pain or the use of only one arm. One is from Basic Comfort called Pac N' Ride ™; the other one is from Arms Reach called Porta Pak ™. The web addresses are:
www.armsreach.com and www.basiccomfort.com.

A parent who uses crutches or a cane will need a four-wheeled walker with a seat to carry the baby. TLG has used several different seats that can be attached to the walker's seat: infant & child car seat, bouncy seat, or booster seat. Bungee cords have been used to connect the seat to the walker.

Transfers, or moving the baby from one surface to another, are generally difficult for parents who have limited use of one or both arms. Using a lifting harness makes it possible. A lifting harness is a child's vest with straps. These straps allow the parent to lift the child with a secure grasp. There are two different styles, both of which are available through the internet and may be adapted for use as a lifting harness. The web addresses are:
www. babybair.com and www.onestepahead.com.

- The Baby B'Air is the vest portion to which straps need to be added. To make the vest widely useful, the fasteners should be changed from buckles to Velcro.

- A walking harness from One Step Ahead can also be used. A crotch strap needs to be added to this harness in order to stabilize both the harness and baby during the lift.

The lifting harness can also help with positional change. An example of positional change happens during the burping of a baby. First a parent feeds the baby, then burps the baby, and then feeds the baby again. During feeding, the baby is in a reclining position. During burping, the baby is moved to resting on the shoulder, or sitting up on the lap. Whatever the burping position, the parent needs to do a positional change. The harness makes it easier for the parent to move the child from one position to the other. (Through the Looking Glass, 1995).

Adaptive techniques are alternative ways of doing tasks and can be used in conjunction with equipment. One technique is to have the child assist with the task. This encourages the child and parent to work as a team. This technique works when the child is developmentally ready. Working as a team produces positive results because it allows development to flourish and children enjoy it. It gives babies an opportunity to practice their newly gained skills.

Another functional technique is to have the parent do the task in a different way from how it is performed by non-disabled parents. For instance, parents who have use of one arm, limited upper extremity strength and coordination and may have difficulty transferring and transporting babies. Examples of techniques that can assist with transferring are:

Breaking down the task: To conserve energy and reduce task demand during transfers and transporting, mothers are encouraged to take time to rest and break the task down into smaller segments. Pausing between segments may also be beneficial.

Cueing: The parent is encouraged to cue the baby that a positional change or lift is about to occur. This can be done either verbally (e.g., saying the baby's name and counting "1, 2, 3") or by touching the baby to get his or her attention. This allows the baby to prepare for the lift or upcoming positional change. It has been shown that cueing some babies will cause

them to become more still and compact (e.g., curl in a ball) to ease the lift for the parent.

If a lifting harness is not available or the infant cannot hold up his/her head then this is a good technique.

One armed lift: If the baby is lying supine with feet closest to the mother's chest, the mother leans forward and wraps her arm around the baby with support under the baby's head and neck. The mother then brings the baby to her chest and straightens up. This works best for a person with the use of one arm and without back problems.

Parents who cannot reposition or hold their babies up on their shoulders for burping can consider an alternative position and technique:

Sit & Lean: The parent holds the baby on her lap and faces the baby away from her body. Supporting the baby by placing one arm across the baby's chest, the parent then gently leans forward. This puts pressure on the baby's stomach and facilitates a burp.

Positioning the baby for diapering may be very challenging. The following techniques can assist with placing the diaper under the baby's bottom:

Cueing Bottom Up: As early as one month old, some babies can begin to be taught to lift their bottoms up to assist the parent in placing the diaper under the baby's bottom. Initially, the parent cues the baby by moving the baby's bottom up and down and saying "up, up, bottom up." Young babies seem to enjoy having their bottoms moved up and down. Developmental changes such as the baby's discovery of his or her feet and increasing response to verbal cues, can decrease the need for the mother to actively assist in lifting.

Rolling to the Side: Rolling the child to the side instead of lifting his or her legs to place the diaper can decrease the mother's need to lift the baby's legs.

Slide and Lift: This technique is helpful for donning the diaper one handed. With the baby's feet facing the parent, the parent places her palm up on an opened disposable diaper. While sliding the diaper under the baby, the parent lifts up the baby's bottom using the hand. The parent simultaneously cues the baby, "up, up, bottom up." This cueing begins to teach the baby to assist the parent during diapering.

It is important to interview the parent(s) about which tasks they want help with, or which task is hardest. If they say "everything," start with one of the transitional tasks. This will help focus the intervention.

Some parents will say, "Everything is fine." This may be evidence of "disability accommodation" which is when parents feel they are doing the best that is possible and are unaware that there may be an easier method. Disability accommodation seems to be second nature to parents with disabilities because most people with disabilities are used to overcoming obstacles in their everyday lives. They do not understand how the adapted equipment can make it better until they have tried it.

Dana Vion

It is important to be aware that some parents may feel defensive about getting help because at times professionals have threatened to remove children from their disabled parents. Some parents feel they are under a microscope and are being judged. It is critical to make the parent feel safe about learning how to do successful and easy baby-care tasks.

PARENTING TODDLERS

The physical demands of baby care have decreased by toddlerhood because of the toddler's ability to help. However, there are other problems during this time.

Discipline can be the main problem during the "terrible twos." Having problems with discipline is not only caused by natural development but also by the parent's lack of visual history — the lack of images of disabled parents caring for their children. One of the classic ways to discipline a child who is having a tantrum is to pick up and carry him or her to

another room. It is very difficult for parents without disabilities to move an angry child to a different room. But for parents with disabilities, it is almost impossible to complete the task.

An adaptive technique for handling a temper tantrum is for the parent to separate from the angry child by going into a separate room or space. When the child realizes the parent is not there, he or she will try to find the parent. To do this, the child has to calm down.

BEST PRACTICE

At Through the Looking Glass there are several essential elements when considering best practice for developing parenting adaptations for parents with a physical disability. These include:

- working in the home
- having several follow up appointments
- using universal design when adapting or designing equipment
- keeping the adaptation or design simple
- remembering child development
- using adaptive techniques
- incorporating safety features
- considering the parent/child relationship
- respecting choice about roles in parenting (Rogers, 1999)

1) By going into the home, one will have an understanding of both the physical layout of the home space restrictions, as well as understanding the family dynamics. This helps in understanding what type of equipment will be needed.

2) Doing a follow up is crucial for equipment that is customized or is a prototype. Screws can become loose. The equipment could become a little unstable, yet the parents may be so happy to have the equipment that they do not call to complain. Since such breakdowns are common, it is necessary to go into the home or call to check with parents.

3)Finding commercial products that can be used and adapted for a parent who has a disability is the easiest solution. It is important to use "universal design" in adapting baby care equipment. A universal design is a design that can be used by both parents with and without disabilities. It is also a design that requires the least amount of physical function from a parent. By making a piece of equipment that can be used by almost anyone including a person with a significant disability, it becomes usable to the greatest number of parents.

4) Another important feature is that the adaptation should be easy to use and understand, regardless of the user's experience, knowledge, or language level. If the adaptations are simple, there will be fewer breakdowns.

5) An important area that is crucial in the design of baby care equipment is the child's development. Since the first year of life has changes in both growth and abilities, the baby care equipment should mirror and anticipate those changes. Anticipating development will allow enough time to have equipment adaptations made before the baby reaches that developmental milestone. For example, diapering can take longer for a parent whose upper extremities have a limitation. Most babies do not have any patience in lying still. When the baby is able to roll over, he/she will try to roll over during the diapering activity, making the diapering task difficult for both the parent and baby. Having a toy mobile with interactive toys will keep most babies entertained. If the toy mobile is in place before the baby starts rolling over, it can alleviate the impending frustration. It is also important to remember the weight and size of the baby when designing equipment.

6) Adaptive baby care equipment and techniques are vehicles that can facilitate the parent/child relationship. Such equipment can allow eye-to-eye contact, providing a way to soothe and play with the baby. Being able to soothe, feed and play with the baby are key activities in a good parent/child relationship.

Adaptive baby care equipment and techniques can provide parents with disabilities a chance to achieve their dream of participatory parenthood.

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RESOURCES

Disability, Pregnancy and Parenthood International (DPPI)
National Centre for Disabled Parents
Unit F9, 89-93 Fonthill Road
London, N4 3JH UK
Tel: (44) (0) 20 7263-3088
Fax: (44) (0) 20 7263-6399
E-mail: info@dppi.org.uk
Web: www.dppi.org.uk

Disability, Pregnancy and Parenthood international (DPPI) is an organization, controlled by disabled parents, which promotes better awareness of and support for disabled people during pregnancy and as parents.

Through the Looking Glass
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Through the Looking Glass (TLG) is a non-profit organization providing services and information for families in which a parent or child has a disability or medical issue. TLG provides in-home services, peer counseling and support groups, training, and technical assistance. It coordinates with social workers and developmental specialists in order to improve access to care for their clients. The TLG newsletter, *Parenting with A Disability*, is published three times a year. TLG serves as the National Resource Center for Parents with Disabilities, an information and referral center for parents and professionals, providing resources on a wide variety of topics including custody issues, adoption, pregnancy and birthing, and adaptive child care equipment.

Women with Disabilities in Zimbabwe Talk About Parenting:

When asked about how the experience of caring for a child was for them as women with physical disabilities many responded that their mothers or other female relatives were on hand to help them with lifting and carrying as well as going along on visits to the clinic for well baby checks. The young mothers soon developed their own adaptations:

"I used the bed as a changing table as it was a good height for me"

"I changed the bathing bowl so that it was slanted and I was better able to hold and lift my baby while bathing her"

"I birthed 11 children at home. I just crawled around the house in order to feed and bathe them".

"Most women in Zimbabwe tie their babies on their backs with a cloth sling. I tied my baby on my chest".

"I had one child and then had twins. All were born at the clinic. The community health nurse visited me at home to see how we were doing".

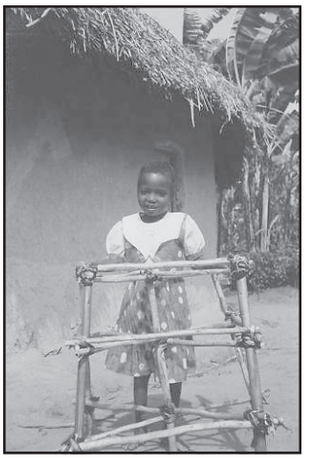
"I took in my brother's children when he died. One was two and a half years old and the other just a baby. Their mother didn't want them and left to return to her family. I was the oldest sister, so it was my responsibility to look after them. I bathed and changed them seated on the floor. When they were sick I asked my helper to stay with them in the hospital because I could not lift the babies from the cribs. Now they are big and studying in secondary school".

7.9

COMMUNITY BASED REHABILITATION

by Karen Heinicke-Motsch, Mobility International USA (originally produced by author in affiliation with CBMI)

Community Based Rehabilitation (CBR) is a strategy for ensuring that people with disabilities are included in community life and have access to the services they need. Over the years CBR has grown from a World Health Organization (WHO) initiative designed for the primary health care system to a strategy for inclusive community development based on a human rights model.



International Disability Foundation

In the 1980s, the WHO and other UN agencies began promoting community-based rehabilitation services as a means of delivering basic rehabilitation services at the community level through the primary health care system. The methodology soon came under criticism, primarily for its focus on disability as a medical issue, a perspective which resulted in prescriptive and therapeutic solutions. In addition, CBR was criticized for its top-down approach.

Already in the 1980s various organizations and people with experience in the field began to propose alternative methods for addressing the needs of people with disabilities on a community level. David Werner in Mexico and Mike Miles in Pakistan were two proponents of alternate solutions.

Criticism did not come only from people in the rehabilitation field. People with disabilities actively rejected the concept of disability as a medical issue with good reason. Disability is more closely linked with development issues, both in terms of causes and in terms of solutions, than it is with medical issues.

POVERTY IS THE MAJOR CAUSE OF IMPAIRMENT AND DISABILITY

The Department for International Development (DFID) in Britain estimates that more than 50% of the impairments that result in people being included in current disability prevalence rates are preventable and directly linked to poverty.

"The World Health Organization estimates that only two percent of people with disabilities in developing countries have access to services."

Poverty increases the risk of factors that lead to impairment and disability: malnutrition, lack of access to services and information, and environmental risks.

IMPAIRMENT, DISABILITY, AND HANDICAPPING CONDITIONS CREATE POVERTY

The World Health Organization estimates that only two percent of people with disabilities in developing countries have access to services. In Latin America, access percentages vary from about five percent in wealthier countries like Mexico, Chile, and Argentina, to one percent in poorer countries like Bolivia, Honduras, and Peru.

"70 to 80 percent of expressed needs of people with disabilities and their families revolve around access to community life and generic services rather than access to special services."

Denial of access to health, education, and work opportunities results in high levels of unemployment for people with disabilities. In general, 70 to 80 percent of expressed needs of people with disabilities and their families revolve around access to community life and generic services rather than access to special services. Lack of access, then, has a major impact on the quality of life of people with disabilities.

Societal attitudes towards disability based on a lack of knowledge and awareness, cultural barriers, and a lack of powerful role models perpetuate the myth that the needs of people with disabilities revolve around specialized care issues. People with disabilities are routinely marginalized.

As Maya Thomas reports in the Asia Pacific Disability Rehabilitation Journal, the situation for women and girls with disabilities from developing countries is even worse. Children with disabilities are less likely to get schooling. Girls with disabilities have less access to school as boys in

similar circumstances. Women with disabilities are less likely than men with disabilities to have access to health care, find employment, or get married. Although self help groups and associations of people with disabilities have been established in many countries, leadership in these groups tends to be dominated by disabled men. Likewise, women with disabilities are hardly represented in women's organizations because they are seen as "different" or "disabled", and not as women.

"Societal attitudes towards disability based on a lack of knowledge and awareness, cultural barriers, and a lack of powerful role models perpetuate the myth that the needs of people with disabilities revolve around specialized care issues."

CBR'S SHIFTING FOCUS

The medical model of disability simply did not address the predominant issues of access and empowerment. The shift to a human rights paradigm in the disability field has provided the framework for a more effective approach to the issues that people with disabilities face, and resulted in a major shift of focus in community based rehabilitation (CBR) programs in the 1980s and 1990's. CBR programs moved away from a medical model and developed a comprehensive approach based on a human rights model. This shift resulted in a range of new service and advocacy issues, encompassing prevention of disability, inclusive education, vocational training and job placement, social integration, attitudinal change, family and community support mechanisms, and advocacy of rights — all within the context of the family and community.

"Women with disabilities are hardly represented in women's organizations because they are seen as "different" or "disabled", and not as women."

In 1994 the International Labor Organization, UNESCO, and the World Health Organization formalized this shift of focus with the establishment of a joint definition of CBR:

Community-based rehabilitation is a community development strategy by which to achieve the rehabilitation, equalization of opportunities, and social integration of all people with disabilities.

Community-based rehabilitation is carried out through the combined efforts of people with disabilities, their families and communities, and the generic services of health, education, social welfare, and employment.

IN PRACTICE, COMMUNITY BASED REHABILITATION FOCUSES ON FOUR BASIC COMPONENTS:

1. Social inclusion of people with disabilities, including sharing of responsibilities and decision-making powers.
2. Involvement of community leaders in community development initiatives that support poor and vulnerable populations.
3. Simplified technologies using local resources, skills, and materials.
4. Appropriate and accessible services.

COMPREHENSIVE COMMUNITY BASED REHABILITATION PROGRAM ENCOMPASSES THE FOLLOWING AREAS:

"CBR programs moved away from a medical model and developed a comprehensive approach based on a human rights model."

1. Prevention of impairment: Information about the principal causes of disability and healthy lifestyles, motivation to participate in immunization programs, prenatal care and healthy births, accident prevention, etc. as well as secondary level prevention through proper diagnosis and timely intervention.
2. Development of positive attitudes towards people with disabilities (tertiary level prevention) through the active participation of people with disabilities in the planning and implementation of projects and through community awareness activities.
3. Reduction of the disabling effects of impairment through early detection and early intervention services.
4. Basic rehabilitation services (tertiary level prevention) through the use of trained community rehabilitation workers.
5. Collaboration with special services for referral of persons with disabilities whose needs cannot be addressed at the community's basic service level.
6. Access to education through early intervention, inclusive education, non-formal education, training in daily living activities, and alternative forms of communication.

7. Training and income-generating activities through access to local training options and microcredit systems.
8. Opportunities for care of persons with severe and profound multiple disabilities.
9. Management aspects for planning, monitoring, and evaluating programs and impact.

Not all CBR programs are comprehensive in scope. Some programs limit themselves to a specific age range or specific areas of work.

CHALLENGES

A NUMBER OF CHALLENGES HAVE BEEN ENCOUNTERED ALONG THE WAY.

- Disability continues to be seen as a "specialist" issue. Organizations and community groups are hesitant to include people with disabilities in their programs due to this preconception. Years of community level work in many parts of the world have failed to dispel this view. Service agencies for people with disabilities have contributed to this view when they operate in relative isolation on the basis of a medical model rather than cooperatively on the basis of a human rights model.

- People with disabilities are generally recognized only by their disability and not by any other characteristic (gender, poverty level, ethnic status, etc). This labeling process results in the exclusion of people with disabilities from services and programs that are available to the wider community.

- People with disabilities often lack mobility, education, and work skills. This is a result of years of discrimination and lack of access. This same lack of access prevents people with disabilities from participating in community development programs and further increases marginalization. Years of exclusion from generic services and community development initiatives combined with the predominant view of disability as a specialist issue results in low levels of self-motivation and expectations of charity. This cycle of marginalization is self-perpetuating.

- CBR, although it has been able to reach the poorest populations, has generally failed to include people with disabilities within its management and decision-making structures. In general, strategies for empowering poor and marginalized people with disabilities have not been developed and employed by CBR programs. As a result, in many instances CBR continues to be a strategy employed by one group to help another group.

- CBR is in the difficult position of balancing between advocating for full inclusion and support for special needs. Programs that continue to operate using a medical model concentrate their efforts on therapeutic and equipment needs of people with disabilities. These programs generally fail to address issues of advocacy and full inclusion and therefore the benefit is short term. Programs using a human rights model address the comprehensive rights of people with disabilities and therefore have a long-term benefit. They run the risk, however, of glossing over the needs of people with disabilities who require specialized services.

"Programs that continue to operate using a medical model concentrate their efforts on therapeutic and equipment needs of people with disabilities. These programs generally fail to address issues of advocacy and full inclusion and therefore the benefit is short term. Programs using a human rights model address the comprehensive rights of people with disabilities and therefore have a long-term benefit."

CBR PROJECTS WHOSE EXPERIENCE MAY BE HELPFUL:

The Simon of Cyrene Children's Rehabilitation and Denelopment Foundation

The Simon of Cyrene Children's Rehabilitation and Development Foundation in the Bicol region of the Philippines is an example of a traditional medical model, center-based service that has successfully made the transition to a comprehensive community based rehabilitation program. Simon of Cyrene began working with children with physical disabilities after an outbreak of polio in the area. In the late 1980s the program was providing services to children with physical disabilities and their families and had moved beyond a strict medical rehabilitation focus to a holistic approach including school placement, family planning, health and nutrition, small-scale loans for food production and income generation, advocacy and empowerment.

By 1987, faced with the fact that the center's services were reaching only a small percentage of the people with disabilities in the area, the project moved to a community-based focus. It trained community rehabilitation

workers to provide direct services at home and expanded its services to include all children with disabilities. It began concerted coordination with the government health, education, and social welfare sectors to advocate for the inclusion of people with disabilities within regular government programs. It began leadership training to help people with disabilities and local village councils plan and provide services seen as necessary on the local level.

Today, Simon of Cyrene provides comprehensive community based rehabilitation services to a large area of the Bicol region. It has become a strong advocate for the rights of people with disabilities both among NGOs and government agencies. It has done this, not alone, but in concerted effort with NGOs working in the health, community development, and education fields as well as with corresponding government agencies. This process has been facilitated by the creation of national, regional, and municipal councils (during the International Decade of Disabled Persons) composed of local government authorities, relevant government agencies and non-government agencies concerned with people with disabilities themselves.

Christoffel Blindenmission International and AUSAID have supported the Simon of Cyrene project.

WHAT CAN WE LEARN FROM THE EXPERIENCE?

1. The medical model limited the scope and impact of the work being done.
2. Low-tech service delivery is meeting the needs of large numbers of people with disabilities.
3. Establishment of a coordinated effort among NGOs and government agencies resulted in increased inclusion of people with disabilities in generic services.
4. The creation of local councils resulted in grass roots level planning and decision-making.
5. The empowerment of people with disabilities, family members, and interested community members can lead to organized and

effective service delivery as well as generate positive community response to disability issues.

6. An NGO within the field of disability can provide valuable support to government services and community development NGOs working towards the inclusion of people with disabilities within their programs.

Contact information: Amy Bolinas, Director, Simon of Cyrene Childrens Rehabilitation and Development Foundation. Email: amy@globalink.net.ph.

FACES (FUNDACIÓN DE APOYO COMUNITARIO Y SOCIAL DEL ECUADOR)

FACES (Fundación de Apoyo Comunitario y Social Del Ecuador) is a community development organization operating in the Loja region of Ecuador. The agency works in the fields of health, women's rights, and economic development.

In 1998 the agency, seeing that people with disabilities were not included in its programs and not participating in other development programs, began a community based rehabilitation program. This program has added a project coordinator and a CBR promoter to the staff and has trained a network of village CBR workers. The disability component of the work focuses on three main areas: prevention of disability (in conjunction with the agency's health component), rehabilitation (using the network of trained community workers and a network of secondary level services), and inclusion through work with local schools and assuring that other components of the FACES program are accessible to people (and especially women) with disabilities in the area. Since people with disabilities and parents of children with disabilities began to be included in the FACES small- scale loan program, results show this subgroup to have a higher loan repayment rate than the general population of loan recipients.

The inclusion of a rehabilitation component within the agency's structure has caused some friction among staff. The disability section has had to learn to broaden its perspective and the general section has had to learn about disability and disability issues.

This mutual learning process has not always been easy. FACES, however, remains committed to ensuring that people with disabilities not only have access to its community development programs but also that individual needs that fall beyond the scope of the agency's development program are met through trained local workers and close coordination with other agencies and government services.

Christoffel Blindenmission International supports this project.

WHAT CAN WE LEARN FROM THE EXPERIENCE?

1. People with disabilities have been historically denied access to community development initiatives.
2. Community development organizations can include people with disabilities in programs without changing the vision or fundamental structure of the agency.
3. The inclusion of people with disabilities within an agency's program can result in increased levels of coordination with other NGOs and with government sector services.
4. People working within the disability sector can and do learn to broaden their perspectives and assure proper accountability within a community development organization's mandate.

Contact information: Luis Palacios, FACES director; Olmedo Zambrano, CBR project coordinator. Email: olmedoz@yahoo.es.

SAVE THE CHILDREN CANADA (SCC) IN BOLIVIA

Since 1985 Save The Children Canada (SCC) in Bolivia has made a clear commitment to children from the poorest areas of Bolivia. SCC believes that children and youth from subsistence farming communities can become advocates for the transformation with dignity of their communities. SCC and local partner organizations in the poorest rural areas of the country work together, introducing a focus on childhood into integral community development. Using the child-to-child method, the agencies involved work side by side with children and youth forming leaders and catalysts

that in turn work with children in their communities on health, rights, and community development issues. In 1996, Save the Children in Bolivia established an advisory board to the agency composed of children and youth.

Save the Children Canada in Bolivia, throughout its many years of experience working with village children and youth, began to notice a phenomenon they had not expected. Children and youth with disabilities were among their strongest, most creative leaders and self advocates. As a result of this phenomenon, SCC formally developed an inclusive policy for its work in Bolivia.

This work is supported by Save the Children Canada.

WHAT CAN WE LEARN FROM THE EXPERIENCE?

1. Inclusion of children and youth with disabilities enriches youth programs.
2. Children with disabilities can and do have an impact on community development.
3. A willingness to assess what is happening on the ground leads to healthy policy change within an agency.

Contact Information: Save the Children Canada in Bolivia, director Patricia Erbe, Cochabamba, Bolivia.
Email: sccbo@savethechildrenbo.org.

VIDA BRASIL

VIDA BRASIL is an NGO established in 1996 and based in Salvador de Bahía. Its primary objective is the promotion of local development through active community participation and the involvement of solidarity networks. The agency focuses on four major areas: promotion of human rights and civil society participation, food security, inclusion of people with disabilities, and small-scale business development. Throughout its programs, the agency actively promotes the participation of people with

disabilities. In its efforts to create a better awareness of the rights of people with disabilities and to point out the flaws in urban planning, the agency investigated the accessibility of the transportation system, the communication system, parks and public buildings.

The results of this investigation were disseminated through a citywide conference and a program on a local television station titled: "Salvador: a Deficient City?" The purpose of the title was to draw attention to the handicapping conditions which municipal planners and other general service providers have created by not adhering to the Brazilian accessibility laws and by not considering disabled people in the design of public use systems. The study and subsequent campaign resulted in the creation of a citywide task force to bring the various sectors into compliance with accessibility laws.

Another of VIDA Brasil's programs is an annual entry in the carnival parade. VIDA Brasil, with the involvement of local artists, musicians, and teachers, uses its spot in the parade to give voice to children living in difficult circumstances including children with disabilities. The entry is a joyous presentation and does not attempt to provoke pity. Rather it aims to celebrate children who have traditionally been marginalized.

VIDA Brasil, in its small-scale business development program, has concentrated its work in one of the poorest slums of the city. Through its work they discovered that one of the most marginalized groups in the slum area is people with Hansen's disease (Brasil's prevalence of Hansen's disease ranks second to India). After its experience including people with Hansen's disease in its small scale business development program, VIDA Brasil, in response to the felt needs of this sub group, supported the group in developing an expanded program using a CBR model which includes self advocacy for inclusion and solution of specific problems in the population alongside its traditional small-scale business program.

This agency receives support from: Handicap International, UNESCO, and Christoffel Blindenmission International

WHAT CAN WE LEARN FROM THE EXPERIENCE?

1. NGO's with human rights focus can and do successfully address issues of disability.
2. The inclusion of disability issues enriches the NGO's programs.
3. The civil society framework is conducive to addressing disability issues.
4. Local NGO's can and do identify funding sources to support a range of programs based on the felt needs of the communities they work with.

Contact Information: Damien Hazard, general coordinator, VIDA Brasil.
Email: vidabsal@terra.com.br.

CENTER FOR DISABILITY IN DEVELOPMENT

Issues related to disability, as in many countries, were widely overlooked in Bangladesh. Disability was not recognized as a crosscutting development issue. Inadequate attention to disability issues resulted in the exclusion of people with disabilities from development initiatives and a minimal flow of resources for rehabilitation services.

In 1996, the Center for Disability in Development (CDD) was established to advocate for the recognition of disability as a crosscutting development issue. CDD operates with the conceptual understanding that the needs of persons with disabilities are fundamentally a question of human rights and the responsibility of a nation and its citizens. Inclusion demands that people with disabilities be able to access services available to the general population. The process requires addressing misconceptions and subsequent negative attitudes about disability. It also requires, depending on the type and degree of disability, rehabilitative interventions.

CDD began partnerships with a number of development NGOs working across Bangladesh within the framework of Community Approaches to Handicap in Development, a strategy for implementing

CBR. The process strives for the recognition of the existence of people with disabilities and the inclusion of people with disabilities in society and the subsequent provision of services to meet their needs.

The program focuses on attitudinal change of people and organizations for a more equitable distribution of resources, change in societal environments for the reduction of barriers that exclude people with disabilities; and finally the reduction of the impact of impairment and disability through prevention activities and the provision of adequate services.

CDD provides training to development NGOs across the country and trains Community Handicap and Disability Resource Persons (CHDRPs) for these NGO's. The trained CHDRP's become part of the organization's community development worker staff.

SINCE IMPLEMENTATION, CCD REPORTS THE FOLLOWING RESULTS:

- Changes in attitude that started with the NGOs involved and the communities in which they work have resonated at the national level.
- 120 community development organizations are now providing primary rehabilitation therapy through trained CHDRPs. Access to assistive devices and access to referral information and services have increased.
- Thousands of people with disabilities and family members have been included in development programs such as education, credit programs, savings associations, and health services.
- A focus has grown on accessibility features for public buildings and the homes of people with disabilities.
- Networking and advocacy work have resulted in increased interest on the part of other development NGOs, government sectors and international donors.

This project has been supported primarily by Handicap International and Christoffel Blindenmission International.

WHAT CAN WE LEARN FROM THE EXPERIENCE?

1. Partnerships between organizations for people with disabilities and community development organizations can facilitate change in the lives of disabled people.
2. Disability is a development issue and requires inclusive strategies, public awareness, and practical solutions.
3. Inclusion and access to rehabilitation services as needed requires a combination of strategies and actors.

Contact information: A.H.M. Noman Khan, executive director, Center for Disability in Development. Email: cdd@bangla.net.

KEY COMPONENTS TO PARTNERSHIP FOR INCLUSION:

- Know who you want to work . Assure compatible philosophical framework. Organizations with distinct areas of work can and do collaborate successfully when they share a common vision.

- Investigate partnership options. Do not limit yourself or your organization to partnerships with organizations you already know about.

- Enriching your vision is beneficial. Distorting your vision is detrimental. Be clear about who and what you are and do not distort your vision in an attempt to accommodate funding trends or other organizations.

- Be specific about what each organization brings to the collaboration and what specific responsibilities are.

- Don't bite off more than you can chew. In general, when launching into a new area of work, start with the easy tasks. The experience you gain along the way will allow you to meet more difficult challenges. Define your target area clearly and realistically.

- Make sure the population you wish to work with is involved in all phases of the process from initial planning to evaluation.

- Remember you don't need to do it all. In fact you should NOT do it all. Successful collaboration means shared responsibility. Successful implementation may well require bringing in other organizations/ persons/groups to help with certain tasks (training or secondary level services for instance). Think this through ahead of time.

- Collaborating for the provision of CBR services requires partnerships at many levels: disabled people and their families; local community organizations, schools, places of business, and local health and other public services; a network of secondary level specialized services, tertiary level collaboration for policy and macro initiatives.

- In general, services for people with disabilities are few and far between in developing countries. Do not let too much time pass between your investigation and training phase and your implementation phase. People with disabilities who have been identified in the investigation phase will be expecting that something will come of the information they gave you. Doors will close in your face when you get to the implementation phase if you have not provided a timely and appropriate response.

- Make sure what you plan to do is not duplicating but rather complementing or supporting work already being done in the geographic area.

INTERNATIONAL NGOS WORKING IN THE FIELD OF DISABILITY:

ADD (Action on Disability and Development)
Vallis House, 57 Vallis Road, Frome, Somerset BA11 3EG , U.K.

AIFO (Associazione Italiana Amici di Raoul Follereau
Via Borselli 4, I-40135, Bologna, Italy

CBMI (Christoffel Blindenmission International)
Nibelungenstrasse 124, D-64625 Bensheim, Germany

DPI (Disabled People International)
101-7 Evergreen Place, Winnipeg, Manitoba R3L 2T3, Canada

DSI (Danish Council of Organizations of Disabled Persons)
Klovervej 10B, 2650 Hvidovre, Denmark

FIDIDA (Finnish Disabled People's International Development Association)
Kumpulantie 1A, 00520 Helsinki, Finland

Handicap International
18 Rue Gerland, 69007 Lyon, France

Healthlink Worldwide
Cityside, 40 Adler Street, London E1 1EE, U.K.

HealthWrights
PO Box 1344, Palo Alto CA 94302, USA

Hesperian Foundation
PO Box 1692, Palo Alto CA 94302, USA

International Development and Disability Consortium
Coordinator, Sue Stubbs
Co-ordinator@iddc.org.uk

Leonard Cheshire International
30 Millbank, London SW1P 4QD, UK

NAD (Norwegian Association of the Disabled)
PO Box 9217, Gronland, N-0134 Oslo, Norway

PHOS (Platform Disability and Development Cooperation)
46 avenue Huart-Hamoir, B-1030, Brussels, Belgium

Save the Children UK
17 Grove Lane, London SE5 8RD, UK

SHIA (Swedish Organization of Disabled Persons)
International Aid Association, PO Box 4060, S-102 61 Stockholm

Stichting Liliane Fonds
St Catharina Straat 1, PO Box 75, 5250 AB Vlijmen
The Netherlands

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http//www.unescap.org/decade/cbr.htm.

ABOUT THE WRITER

Karen Heinicke-Motsch is a special educator with a Masters degree in early intervention. From 1983 to 2002 she worked in SE Asia and Latin America. For much of that time she worked exclusively in the CBR field with Christoffel Blindenmission International (CBMI) where she serves on the CBR advisory working group. Karen currently works for Mobility International USA (MIUSA) as the Manager of the International Development and Disability department.

7.10

INCLUSIVE EDUCATION

This chapter draws heavily from "Inclusive Education: Where There Are Few Resources" by Sue Stubbs. MIUSA wishes to thank Sue for her generosity in allowing us to use her words.

ACCORDING TO UNESCO, LESS THAN 2% OF DISABLED CHILDREN ATTEND SCHOOLS.

The Situation:

Children have, in general, been relegated to the margins of development work. Children with disabilities are marginalized even further. Children with disabilities, although shown to be more likely to be in vulnerable situations, are left out of programs that focus on the sexual exploitation of children, child labor, and street children. Disabled children are everywhere and yet are denied their basic rights. By implementing inclusive policies and programs, international development organizations can enable children with disabilities to realize their rights. One of the fundamental rights of the child is the right to education and yet according to UNESCO, only two percent of children with disabilities are able to exercise that right.

"Children with disabilities, although shown to be more likely to be in vulnerable situations, are left out of programs that focus on the sexual exploitation of children, child labor, and street children. "

Legal Framework

Education as a right for ALL children has been enshrined in international instruments since the Universal Declaration of 1948. Subsequent instruments pointed out that particular groups, including disabled children, were especially vulnerable to exclusion. The right to be educated within the mainstream system and not to be discriminated against was highlighted in more detailed instruments such as the Jontien declaration[1] and the UN Convention on the Rights of the Child[2]. However, the right to education does not automatically imply inclusion. The right to inclusive education is most clearly stated in the Salamanca Statement

and Framework of Action[3], which emphasizes that schools need to change and adapt. The importance of proper resourcing for inclusion is highlighted in the UN Standard Rules for the Equalization of Opportunities for People with Disabilities[4]. More recently, the UN instruments have been given a reality check by international NGOs who claim that Education for All (EFA) has not worked, and will not work unless there is more grass-root participation and real allocation of resources. Poverty alleviation is the current donor global priority, and there is an acknowledgement that EFA and therefore inclusive education (IE) will not work unless measures are taken to reduce poverty simultaneously.

What is Inclusive Education?

Inclusive education was born of two movements: school improvement and special needs education. School improvement is an excellent preparation for IE, but often falls short of actually including the most marginalized groups. Special education has provided some very practical expertise and some very strong advocates for inclusion, but can also be an obstacle, as the underlying philosophy does not provide the right foundations for sustainable IE. Other influences such as primary stakeholder activist groups (disabled people, parents, women), community based initiatives and actual practical models of success and failure have also made contributions to the development of IE.

Inclusive education:

- Is broader than formal schooling. It includes the home, the community, non-formal and informal systems
- Acknowledges that all children can learn
- Enables education structures, systems and methodologies to meet the needs of all children
- Acknowledges and respects differences in children: ages, gender, ethnicity, language, disability, HIV/TB status, etc.
- Is a dynamic process that is constantly evolving according to the culture and context
- is part of a wider strategy to promote an inclusive society.

So what's the difference between integration and inclusion?
Integration starts from the premise that in order for the child with a disability to succeed in the regular classroom, his or her "special needs" must be taken into account and addressed. Inclusion starts from the premise that in order for the classroom to succeed in the education of all children, the system must respond to diversity in ways that allow all children to participate.

Strategies for Inclusion

The framework:

- Make schools physically accessible and positively friendly towards diverse groups.
- Provide children with alternative formats to enable children to access learning.
- Promote a school culture which supports the conviction that ALL children have the right to attend.
- Promote a school culture in which bullying, name-calling and discrimination are not tolerated.
- Involve the whole school, not just the classroom in order that all aspects of inclusion be addressed.
- Problem solve with school, family, child and community involvement. Start from the premise that the school has a teaching difficulty, not that the child has the problem.

J. Maillard, ILO

Establishing a framework for inclusion is an essential initial step. Additionally programs moving towards inclusive education need to assess the situation, identify the resources available, and identify cultural factors and contexts that influence inclusion. Finally, in order for inclusion to work stakeholders must be participants in the planning, implementation, and evaluation of the process and a good system of monitoring and support need to be in place.

Is inclusion for everyone?

Providing children who are deaf and unable to use hearing aids contact with other deaf people in order to develop sign language is vital. The dilemma is that in many countries the only options for this to occur are segregated residential schools for the deaf that do not foster family and community inclusion. The solution lies in using the resources available: deaf adults are the most obvious human resource for assuring that deaf children are provided with the means to learn sign language fluently. Bi-lingual communication needs to be explored in ways that go beyond the traditional notion of school and involve families and communities creatively and effectively.

Children with profound and/or multiple impairments are often considered to be unable to be included in schools. In many South countries, inclusive strategies encompass home support for learning options and other non-formal and informal methods. In the North, inclusive education tends to means inclusion in the school setting and there are excellent examples of how children with profound impairments are included at all levels of the education system.

"Deaf people need a strong deaf community. Once this has been strengthened, deaf people can enjoy a full share of the benefit of living in a hearing society."
Raghav Bir Joshi, Director of the Kathmandu Association of the Deaf, EENET newsletter No. 2)

Best Practices

School inclusion is happening all over the world. Some of the best examples of IE are based in poorer countries of the South. IE is far more practical than segregated education. It is far more practical than simply excluding groups of children and then having to deal with the consequences of high rates of illiteracy and dependent citizens.

Inclusive Education Linked to School Improvement in Laos

In the early 1990s, Laos underwent a reform of its education system to a more active-teaching and child-focused methodology in order to improve the quality, and yet keep costs low, in its efforts to educate all children. Providing education for disabled children was part of the national goal of Education for All (EFA), and the pilot inclusive education program was successful because it was totally linked into the reform of the system. Janet Holdsworth writes in the EENET newsletter: "Laos has no special schools for disabled children, which is an enormous advantage for the Ministry of Education as it builds a system which reaches out to all children."

(EENET newsletter No. 2) The experience in Laos shows that with planning, support and monitoring, the goals of EFA and IE can be met.

Active Learning in Zambia

"Everyone teaches and everyone learns from one another." Paul Mumba, a primary school teacher in Zambia, used Child-to-Child methods to help encourage children to be more active learners. Some of the activities included:

- Developing teaching and learning materials that explore issues of disability and inclusion
- Investigating the role of group work to support inclusion in the classroom
- Developing simple assessment tests that can be used by children and teachers in their homes and communities
- Pairing non-disabled and disabled children together so that they can work to support each other within their school and community to promote inclusion. (Paul Mumba, EENET newsletter No. 3)

"Laos has no special schools for disabled children, which is an enormous advantage for the Ministry of Education as it builds a system which reaches out to all children."

Activists take the lead in India

In south India, disabled activists work with communities to promote social inclusion which in turn paves the way for educational inclusion. They do this by:

- Creating positive role models – disabled students were trained as change agents and shared valuable health information with the community. They began to be seen as valuable resources in the community
- Encouraging families to let their disabled children come out of the house and play in inclusive playgrounds.

"These events provided a platform for disabled and non-disabled children and their parents to mingle, paving the way for acceptance and inclusion. Familiarity breeds the seeds of inclusion. (B. Venkatesh, EENET newsletter No. 4)

Overcoming Racism through Inclusion in the Czech Republic
The Czech Republic mainstream schools are not conducive to diversity. There is a strong racism towards Romany people, who are considered to be inferior and best suited to special schools. Over 50 percent of Romany children attend special schools. An NGO has begun to have success in helping Romany children to be included in mainstream schools. They have done this by:

- Building the self-esteem of Romany children
- Challenging the attitudes within schools
- Working with families
- Placing Romany classroom assistants in schools to work with Romany children
- Focusing on improving learning of Romany adults. (Alison Closs, EENET newsletter No. 3).

Community Based Rehabilitation as a Catalyst for Inclusion in Honduras:
In Honduras, community based rehabilitation volunteers and mothers of children with disabilities joined together to work with the village elementary school to improve school inclusion. The strategies used by these women benefited the entire school. The rate of repetition of first grade (a common problem in many South countries) was dramatically lowered by this coalition of women by:

- Providing after-school tutoring help to children having difficulties at school (both disabled and non-disabled children were involved)
- Fund-raising in the community to purchase school supplies for children and active learning materials for the classroom
- Meeting with first grade teachers at the school and with parents to ensure that children received the support they needed.

The steps taken jointly by the school, the community based rehabilitation project, the parents, and the teacher-training program implemented by the project served as a model for inclusion. Many of the teachers involved in this pilot program are now involved in educating primary school teachers for inclusion on a national level. (internal reports CBMI)

International Development Organization Advocates Inclusion

Development organizations working specifically in the field of disability have been generally quick to support school inclusion. Development organizations without a disability focus, on the other hand, have traditionally seen this as a "disability issue' and not part of their mandate. This is beginning to change as the link between Education For All and Inclusive Education becomes clearer. At the same time, as the world becomes increasingly aware of the link between poverty and disability, the focus on poverty alleviation begins to encompass inclusive strategies. Some international development organizations have already established a track record of inclusive strategies. One such organization is Save the Children UK.

"Development organizations without a disability focus have traditionally seen this as a 'disability issue' and not part of their mandate. This is beginning to change as the link between Education For All and Inclusive Education becomes clearer."

Save the Children UK developed guidelines for inclusive education to be used by the organization's education staff as well as by partner organizations. By taking a stand in support of inclusion and providing resources to help partner organizations in South countries practice inclusion, the agency plays a leading role in ensuring that children around the world have access to education.

[1] 1990 Jomtien Conference World Declaration on Education For All
[2] 1989 UN Convention on the Rights of the Child.
[3] 1994 Salamanca Statement on Principles, Policy and Practice in Special Needs Education
[4] 1994 UN Standard Rules on the Equalization of Opportunities for Persons with Disabilities

BEST PRACTICE

Inclusive Education

In India, the state government of Andhra Pradesh is supporting the inclusion of children with disabilities and special needs in mainstream schools. The integrated education of children with disabilities has been implemented as a pilot project (covering 30-40 schools) under the District Primary Education Programme (DPEP)25 with Department for International Development (DFID) support.

Children identified as having difficulties in the areas of gross motor, fine motor, communication and social development are evaluated and assessed both medically and socially, with the help of appropriate specialists. Following these assessments, and individual education programmed is prepared by the team for every child with a disability. Teachers are then prepared and sensitized to the needs of the children in question through focused training programmes. Free aids (mobility, hearing etc.) are also provided where required.

Through this pilot project, children with disabilities are given the opportunity of receiving an education. They share their classes with children who have no disabilities, and are therefore included in mainstream school life. Children without disabilities are themselves increasingly aware of the capabilities and potential of their fellow students. The pilot project will therefore have a two-fold benefit; providing an education for children with disabilities while challenging stigma and negative stereotypes too often attached to these children.

(DFID)

BEST PRACTICE

Uganda has adopted a Universal Primary Education (UPE) policy which illustrates a good way of providing children with access to the minimum educational package. The policy, actively supported by DFID through a major investment programme, provides free primary education to four children per family. It is specified in the policy that at least two of the children should be girls (where there are girls) and any children with a disability. The law states that children with disabilities take priority, on the assumption that parents are less likely to pay for them on for girls than for boys who do not have a disability.

(DFID)

RESOURCES

Enabling Education Network (EENET)
EENET, Educational Support and Inclusion
University of Manchester, Oxford Road
Manchester M13 9PL UK
Tel: +44 (0) 161 275 3711
Fax: +44 (0)161 275 3548
Email: info@eenet.org.uk

EENET is an information-sharing network that supports and promotes the inclusion of marginalized groups in education worldwide.
EENET was initiated by Save the Children - UK, in partnership with UK and international non-governmental organizations, and research institutions.
EENET provides access to a unique and broad-based body of expertise and experience in the practice of inclusive education world-wide.

Inclusion International (II)
13D chemin du Levant
Ferney-Voltaire 01210 France
Tel: (33) 45-040-0197
Fax: (33) 45-040-0107
E-mail:info@inclusion-international.org
Web: www.inclusion-international.org

Inclusion International is an international non-governmental organization committed to fighting discrimination, abuse and neglect of persons with intellectual disabilities. Emphasizing inclusive education, Inclusion International focuses efforts on anti-discrimination, family support, community based resources, self advocacy, development partnerships, and social well being for people with mental disabilities. II has close to 200 member organizations worldwide, and cooperates closely with the UN and several of its agencies. II organizes international seminars, regional conferences and world congresses, and publishes an international newsletter, as well as various other publications.

Save the Children
17 Grove Lane
London, SE5 8RD UK
Tel: (+44) 020 7703 5400
Fax: (+44) 020 7703 2278
Web: www.savethechildren.org.uk/education/

Save the Children helps children get access to good quality education by: Supporting governments, local authorities and communities to provide appropriate and useful education for children; training teachers and other adults who work with children to use creative teaching methods and understand the process by which children learn; strengthening the involvement of local communities, children, parents and teachers to ensure that education meets the needs of disadvantaged children; developing education policies and curricula that take into account children's needs, and teach them useful skills; supporting flexible learning schemes for marginalized children and those (such as working) children who don't go to school. Supporting good early years provision to ensure that disadvantaged children get the best possible start in life; providing education for children caught up in conflicts and natural disasters; campaigning for more aid to basic education through the Beat Poverty campaign.

UNESCO (United Nations Educational, Scientific, and Cultural Organization)
United Nations (UN)
7, Place de Fontenoy
Division of Basic Education
Paris 07 SP 75352 FR
Tel: (33) 14-568-1195
Fax: (33) 14-568- 5626
E-mail: k.eklindh@unesco.org
Web: www.unesco.org/education/educprog/sne

UNESCO'S Section for Combating Exclusion in Education provides a platform for dialogue, exchange and development. It seeks to promote better understanding, networking and co-operation among the different partners, agencies, organizations and institutes working toward inclusion

of people who are marginalized and excluded.

The objectives of UNESCO'S action in inclusive education are developing national capacities for policy making and system management in support of inclusive education, and bringing forward the concerns of people with disabilities as well as other marginalized groups on the agendas of international organizations and agencies.

7.11

AGRICULTURE AND DISABILITY

This chapter discusses disability as it relates to agricultural workers and farmers in developing countries and in the United States. In any country, people with disabilities who farm or are involved in rural agricultural enterprises are best served through rural agricultural or rural development programs. The tendency in the past to exclude disabled farmers from rural development programs has resulted in their increased marginalization. This chapter highlights examples from around the world of organizations working to end this marginalization.

Christian Foundation for the Blind in Thailand

IN DEVELOPING COUNTRIES:

Disability is a cause of poverty and hunger, especially in rural areas, where people are far from services and have very limited economic opportunities. "Disabled people are marginalized; they are not considered economically active and this leads them very often into the hunger trap," explains Lawrence Jacobson, Food and Agriculture Organization (FAO), Focal Point for Disability Matters. The FAO estimates that between 70 and 80 percent of people with disabilities in SE Asia are farmers and rural workers. Yet people with disabilities are routinely excluded from programs intended to alleviate rural poverty or enhance local farming techniques.

"Disabled people are marginalized; they are not considered economically active and this leads them very often into the hunger trap," explains Lawrence Jacobson, Food and Agriculture Organization.

Boosting food production, improving nutrition and including disabled people into sustainable rural development programs are good development practices. They end marginalization and alleviate hunger and poverty. Two pilot projects implemented by the FAO of the United Nations,

FAO in Thailand and Cambodia demonstrate how this can be done.

In the northeast of Thailand, the poorest part of the country, FAO has been working to enhance the skills of disabled farmers, and make them successful entrepreneurs with income-generating activities. The FAO Regional Office in Bangkok developed an innovative training program based on mushroom cultivation. Mushrooms are part of the daily diet of Thai people and thus offer good market opportunities, and their cultivation can be started at a very low cost while generating income within a short time.

''Mushroom cultivation has restored their self confidence,'' explains Mr. Jacobson. ''These people have acquired the skills and means to lead better and more productive lives. They can stand on their own and, most important, they can teach other people within their community. This acquired ability to lead and to teach other people is an important aspect of the success of this project.''

''People have acquired the skills and means to lead better and more productive lives. They can stand on their own and, most important, they can teach other people within their community. ''

In Cambodia, the war and land mines have resulted in a per-capita rate of disability that is one of the highest in the world. A joint program between Handicap International and the FAO Integrated Pest Management Program is giving rural people with disabilities additional skills to integrate into their communities, to improve incomes, to manage their crops better and to regain their self-esteem.

''The project focuses not just on treating marginalized or disabled farmers as special,'' explains Robert Nugent, FAO Integrated Pest Management Country Officer. ''There is no point developing special programs just for disabled farmers. You have to look at the farming community as a whole and how networks of farmers can come together as trainers, as organizers, as scientists. This model is replicable anywhere where there is a need to place farmers at the center of the learning rather than production and technical delivery.''

Lawrence Jacobson comments: ''Fighting hunger in the world means fighting to feed all hungry people. The rural disabled in developing countries are a particularly vulnerable group who are all too often invisible. It is essential that development programs take account of their special needs.''

For information about these and other FAO programs, contact Nuria Felipe Soria, FAO Information Officer, email: Nuria.FelipeSoria@fao.org tel: 39 06 5705 5899, or FAO Media Relations Office, tel: 39 06 5705 3625
All project and contact information above has been taken from and is available on the FAO website.

Community Based Rehabilitation (CBR) programs, which work predominantly in poor, rural areas, have a wealth of experience working with local farmers and agricultural workers with disabilities. This includes adapting planting and harvesting techniques in order to accommodate people who are blind and providing mobility aids to farmers with physical disabilities. The majority of these programs provide training in adaptive farming techniques, use appropriate technology to ensure that rural people with disabilities are able to go about their daily tasks, and provide or facilitate the provision of small scale loans for farmers and agricultural workers with disabilities. It has long been realized by many in the field of Community Based Rehabilitation that technical support from the agricultural sector is much more useful to farmers with disabilities than support from a disability specialist. The current trend in community-based rehabilitation is to include people with disabilities in community development initiatives (see CBR chapter). Community development programs, which have historically excluded people with disabilities, are being asked to redress their exclusionary practices.

"Fighting hunger in the world means fighting to feed all hungry people. The rural disabled in developing countries are a particularly vulnerable group who are all too often invisible."

Now more than ever, people with disabilities are poised to make their presence felt in rural communities. Partnerships among organizations of people with disabilities, their allies and rural development organizations can and should provide the basis for advances in the fight against rural hunger and poverty as well as assure a place at the table for people with disabilities who live and work in rural areas.

IN THE UNITED STATES:

According to the U. S. Department of Agriculture (USDA), over 200,000 farm-related accidents occur every year, and of this number, five percent result in permanent physical disabilities. Aging and health conditions such as arthritis, health disease or terminal illnesses take their toll on the

occupational activities of farmers as well. Farmers rely on agricultural production as their financial mainstay. The onset or worsening of a disability threatens their livelihood and potential to support their families financially.

Since 1979, Purdue University in Indiana has been known as the nation's foremost provider of adaptive technology and community support for farmers with disabilities. Purdue's Breaking New Ground (BNG) Program reports that physical disabilities affect over 500,000 persons in the agriculture community. The Breaking New Ground Outreach Program offers opportunities for farmers with disabilities to become educated in the use of adaptive and modified farming equipment in order to maintain their agricultural activities.

"One of the most difficult transitional tasks can be carrying and moving a baby while using a manual wheelchair."

The BNG Program encourages community involvement through competitions that present opportunities for community groups to participate in designing creative adaptations and modifications of farm equipment to assist disabled farmers in going about their daily activities without major challenges. The BNG Program has produced an equipment resource magazine, *The Toolbox*, featuring modified agricultural tools, equipment, machinery and buildings for the farmer with physical disabilities.

Examples of successful adaptations designed by local community groups include:

Building additional steps and handrails on a tractor so that an older farmer can climb into his or her tractor cab easily.

Designing and building a portable chore chair for a farmer who could not stand for extended amounts of time while servicing his machinery.

Installing a clutch/brake hand control so that a person with limited leg use can operate a lawn mower.

Another organization involved in providing support for farmers with disabilities is the National AgrAbility Project. The United States Department of Agriculture (USDA) 1990 Farm Bill first authorized AgrAbility. One of the goals of the UDSA's commission to small farmers is to "provide just

and humane working conditions for all people engaged in production agriculture." Over the last five years, AgrAbility has assisted over 9,000 farming families. The AgrAbility Program thrives on the mutual support from a network of professionals and volunteers who share expertise and experience to promote sustained success for farmers with disabilities within the farming community.

Like the Breaking New Ground Program, the AgrAbility Project provides technical support and education to the community of farmers with disabilities. Assistance provided by these programs includes information on locating adaptive technology and farming equipment, training, technical reports, manuals and awareness promotional programs. Both organizations work towards promoting the continued occupational well-being for the community of farmers with disabilities.

CONTACT INFORMATION FOR US ORGANIZATIONS:

National AgrAbility Program
www.agrabilityproject.org

Breaking New Ground Outreach Program
Purdue University
1146 ABE Building
West Lafayette, IN 47907-1146
The toolbox mentioned above is also available through Purdue University.

Resource Center for Farmers with Disabilities
101 Nob Hill Road, Suite 301
Madison, WI 53713

BEST PRACTICE

AGRICULTURE AND DISABILITY

This story is available on the FAO website. MIUSA wishes to thank FAO for permission to reproduce the information.

Mushroom production training for disabled people: a progress report

Summary

Thailand offers enabling policies for people with disabilities, and the royal family has always actively supported government projects involving disadvantaged people. The Food and Agriculture Organization of the UN (FAO) decided to join the Thai government in a commitment to improve the livelihoods of rural disabled in a step towards poverty alleviation and sustainable development. The FAO-initiated project Mushroom Production Training for Disabled People is located in the Northeastern Training Center for People with Disabilities in Ubon Ratchathani. Mushrooms were favored because they offer good market opportunities, as they are part of the daily Thai diet. Furthermore, they can be cultivated by physically and mentally disabled people and can be started at a very low cost while generating income within a short term.

One of the main objectives of the project was to establish economic self-reliance for rural disabled as entrepreneurs. FAO assisted in strengthening capacity of the local institution for training rural disabled people. The purpose of the training was to prepare people with disabilities for equal participation in social and economic development at the family and community levels. Training further offered the opportunity for disabled people to prove their ability.

Specific selection and training methods were developed to fulfill specific needs and to assure replication and sustainability following training. Alternative ways of accomplishing certain tasks needed to be developed

to cater to specific disabilities. Motivational sessions as part of the training contributed to personal development.

Every step involved in mushroom cultivation was reviewed during training, including entrepreneurship and environmental protection. Forty-seven trainees successfully completed the 60 days training. Trainees, upon completing their training, went home and transferred acquired know-how to their family and community. All trainees have already set-up their mushroom houses, and are now assured of daily food and income. They have gained self-reliance and self-sufficiency to become active participants in their community. Five trainees returned to the center to become trainers and assist the five trainers who work under the Department of Public Welfare. Trainers acquired new skills for enhancing capacities of rural disabled people as entrepreneurs. Appropriate construction designs were introduced for trainees to set-up their mushroom enterprise, using readily available materials thus lowering set-up costs substantially. As a demonstration of self-confidence, six disabled trainees married and established their joint enterprise.

This project's success can be attributed to the commitment of the Thai government, FAO, consultants and project team members. The Department of Public Welfare already indicated the intent to replicate this training program at its center in Nong Khai. FAO is preparing monitoring and evaluation tools along with training manuals to ensure feasibility, sustainability, and successful replication in future local and regional projects.

- Related reading: Empowering the Rural Disabled in Asia and the Pacific.
- Browse the FAO database on the rural disabled for further information.

BEST PRACTICE

BLIND FARMERS IN UGANDA

This story is summarized from an article written by Paul Emong, Action on Disability and Development (ADD) Uganda

During the Teso insurgency in Uganda from 1986 to 1995, many people were displaced. People with disabilities were among those displaced by the insurgency. The Soroti Agricultural and Crafts Association of the Blind (SACAB) was formed by a group of displaced and resettled blind people in the Soroti district of Uganda. With support from Action on Disability and Development (ADD), the organization was able to establish homes and provide the group with support for agricultural means to assure food security. From the initial support in 1995, which included two oxen, an ox plough, seeds, and cassava cuttings, the farming work of the SACAB group has grown steadily. By 1998 SACAB had acres of cassava, millet, sorghum, groundnuts (peanuts), cowpeas, and potatoes as well as a goat-rearing business. Neighbors in the area now purchase such staples from SACAB. This agricultural project run by the SACAB now helps members to pay for school fees for their children.

ADD has also supported capacity building for the association. As a result SACAB has now developed a vocational training program for adults who are blind. Local authorities and Sight Savers International now support this vocational training. Since 1999, SACAB has produced 40 graduates. Some of these graduates have taken up leadership positions in the local councils in their villages.

RESOURCES

Breaking New Ground Outreach Program
Purdue University
1146 ABE Building
West Lafayette, IN 47907-1146 USA
Web: http://abe.www.ecn.purdue.edu/ABE/Extension/

In 1979, a severely disabled farmer contacted Purdue's Department of Agricultural and Biological Engineering and requested assistance on how to modify his tractor to enable him to continue farming. This initial contact led to the establishment of the Breaking New Ground (BNG) Resource Center, which has become internationally recognized as the primary source of information on rehabilitation technology relating to agricultural worksites. The program operates as part of Purdue's Cooperative Extension Service and has become a model of service for this traditionally underserved population. In 1990, the Outreach Program became a part of the USDA AgrAbility program that supports similar projects in approximately 20 other states.

The Food and Agriculture Organization of the United Nations (FAO)
FAO Headquarters
Viale delle Terme di Caracalla
00100 Rome ITALY
Tel: (39 06) 57051
Fax: (39 06) 570 53152
E-mail: FAO-HQ@fao.org

The Food and Agriculture Organization of the United Nations was founded in 1945 with a mandate to raise levels of nutrition and standards of living, to improve agricultural productivity, and to better the condition of rural populations. Since its inception, FAO has worked to alleviate poverty and hunger by promoting agricultural development, improved nutrition and the pursuit of food security — defined as the access of all people at all times to the food they need for an active and healthy life.

International Labour Office
4, route des Morillons
CH-1211 Geneva 22 Switzerland
For further information, please contact the Communications and Files Section (DOSCOM)
Tel: (41)-22-799-6111
Fax: (41)-22-798-8685
E-mail: ilo@ilo.org
Web: www.ilo.org/public/english/index.htm

The International Labour Organization is the UN specialized agency which seeks the promotion of social justice and internationally recognized human and labour rights. It was founded in 1919 and is the only surviving major creation of the Treaty of Versailles which brought the League of Nations into being; it became the first specialized agency of the UN in 1946.

National AgrAbility Program
Montana State University
220 Roberts Hall
Bozeman, MT 59717 USA
Tel: (800) 523-4342 (Bozeman, Montana)
E-mail: umets@gemini.oscs.montana.edu
Web: www.montana.edu/wwwplow/index.html#index2

The Montana-Idaho AgrAbility Project is part of a nationwide network of USDA-Extension Service Programs commonly known as AgrAbility. The project is a joint effort of the Extension Service and the Easter Seal Society. The individualized services, designed to promote independence and self-sufficiency, are available to farmers, ranchers, business professionals and other rural people making a living through agriculture. The general public also receives education on disability-related issues through information, awareness programs, and presentations provided by AgrAbility staff.

7.12a

MENTAL DISABILITY, HUMAN RIGHTS, DEVELOPMENT: PROMOTING COMMUNITY INTEGRATION

Throughout the world, children and adults with mental disabilities are segregated from society in institutions. This may include placement in orphanages, boarding schools, psychiatric hospitals, mental retardation facilities, nursing homes, or other social care facilities. Even in societies without institutions, individuals with mental disabilities may be segregated from society by being literally "closeted" in their own homes. As a practical matter, community integration of individuals with mental disabilities will require the creation of a broad range of community-based service and support systems. Educational programs must be made accessible for children with disabilities. The establishment of civil rights laws and protection systems are also essential to promoting effective community integration.

This section begins with an abridged version of an article by Chris Underhill of BasicNeeds Trust, a development organization that works in partnership with local organizations to promote an innovative model of community mental health and development. In his article Chris draws on practical experience at local and regional levels to champion the potential for mentally ill people to be involved in the development process. He uses evidence from India to show that stigma disbars mentally ill people from development processes and that this is a human rights issue.

This section is followed by selections from two reports by Mental Disability Rights International (MDRI), a human rights organization dedicated to promoting the international recognition and enforcement of the rights of people with mental disabilities. MDRI has documented

the conditions of individuals with disabilities in 17 developing countries, and has published reports with detailed recommendations for reform in Hungary Kosovo, Mexico, Russia and Uruguay (see MDRI's website at www.MDRI.org for full reports). The following excerpts from MDRI reports on Russia's orphanage system and Kosovo's mental health service system provide examples of the challenges faced by international development organizations in responding to the needs of people with mental disabilities. Following the factual overview is a series of recommendations directed to international development organizations. While these recommendations are taken from reports on specific countries, the general principles proposed by MDRI are the same in any country that is making the transition from institution-based care to community integration.

Note that the term "mental disability" used here incorporates a broad range of different disabilities – including individuals with psychiatric disabilities and people with intellectual or developmental disabilities. Individuals with these different disabilities may need very different accommodations and services in the community. However, these individuals are often lumped together in institutions and face many of the same challenges to community integration. Thus, development organizations should be prepared to develop programs tailored to the needs of these different disability groups. For more information on the development of such programs, consult MDRI reports available at www.MDRI.org. For further reading on the topic of mental health and development see the e-journal at www.mentalhealthanddevelopment.org, a publication of BasicNeeds Trust.

7.12b

MENTAL HEALTH AND DEVELOPMENT

From the local to the global - the involvement of mentally ill people in the development process.

Chris Underhill, BasicNeeds Trust

This article is an abridged version of an article originally published in "Selected Readings in Community Based Rehabilitation, Asia Pacific Disability Rehabilitation Journal, Series 2, Disability and Rehabilitation Issues in South Asia". MIUSA wishes to thank Chris Underhill for permission to abridge and reprint the article.

SUMMARY

From practical experience at local and regional levels the author champions the potential for mentally ill people to be involved in the development process. Insisting on the right of mentally ill people to be consulted in development work of all kinds, the author underlines failures and successes in the support of mentally ill people. He uses evidence from India to show that stigma disbars mentally ill people from development processes and that this is a human rights issue.

Drawing on substantial, recently available statistical evidence, the author considers the global implications of the prevalence of mental illness in relation to the poor provision of community facilities in the years to come. The author concludes that, as with any marginalized group, people with mental illness will only take their place in the development process by finding ways of achieving knowledge, leadership and resources through self-help and by creating appropriate alliances with other groups in society.

INTRODUCTION

A group of women and men gather in a village agricultural co-operative store. The room has been lent for the purpose of the gathering. People wait for the bus to bring some participants to the meeting. Staff from SACRED, a small community based organisation (CBO), hurry to fetch

others on their motorbike. Shivanna, an elderly man, is invited to give a song at the beginning of the workshop. His quavering voice rises up like tendrils of sound into the rafters. As he gives new meaning to a well-known mythological tale, we discern beauty held in the air like the grain dust caught in the morning sunlight. The facilitator starts to work with the group and they agree on the ground rules for the morning. All agree that a process writer may record the events of the day. A man, Sonykuty George, unobtrusively pulls out his pad. Like the start of hundreds of such meetings of people that occur all over the South Asian region, an animation session is starting in a small village outside Anantapur, Andhra Pradesh, India.

After some time when the group is feeling more at one, when it has learnt to laugh together, to sort out its translation needs common to any mixed language meeting (Telegu, Tamil, Kannada, occasional Hindi and English), some realities begin to emerge[1] :

> *Lakshmana of Gotkur village did not have a carer with him and was joined by Yellamma a 'SACRED' staff. He said, "I have a brother and a sister. My job is cattle grazing. My family weaves silk sarees. I had fits and am under medication". The staff then explained that since he had created some problem in the village his parents had tied him to a pole and beaten him up. Lakshmana said, "I get angry with my parents because they do not listen to me. They are not taking care of my desire to get married. I am asked to do cattle grazing while my brother works on the loom. They do not let me weave since they fear that I will get fits and will thus destroy the saree being woven. I can make incense sticks. But they do not let me do it saying that it is not profitable."*

The group is composed of mentally ill people, carers and staff members from SACRED. Whilst many animation meetings do take place all over the region it is true to say that very few of them are run with mentally ill people as the main participants.

In talking to mentally ill people living at home we have found that they are almost never part of community based rehabilitation schemes, development programmes or income generation projects. Certainly they very rarely seem to take their place in such programmes as full

participants. Sometimes they are involved as the "done to". They are the recipients of both charitable kindness and, indeed, of cruelty. Like an enclosing institution, the community contains them but does not allow them to participate in the full rituals of society.

TALKING TO MENTALLY ILL PEOPLE – LOCAL ACTION OF GLOBAL IMPORTANCE

In September 2000 a small team assembled in Bangalore for a series of field visits that would permit us to talk directly with mentally ill people, their carers, family members and so on. The team, before leaving for the visits, finalised the topic guide to be followed in the field:

1. Introductions (brief introduction about the programme for the day)
2. Introduction game for participants – (variations to be experimented based on the group size)
3. Permission to process document (intro of Sonykuty George) and permission to photograph.
4. Setting of ground rules for the conduct of the programme for the day.
5. *Constituency mapping* of the people (and institutions) who interact with people who are mentally ill and their carers in an ongoing manner. The exercise was planned to identify the proximity of people with mental illness to various community stakeholders. It was also agreed that the exercise would be conducted in small groups giving every participant an opportunity to take an active part in the exercise. The exercise came to be called "my world ".
6. Exploration of mapping exercise (clarifications, understanding, consequences)
7. Needs discussion. Needs of the mentally ill people, carers etc (in small groups – flip charts prepared)
8. Exploration of needs discussion (whole group).
9. What next? The discussions were initiated to get a commitment from the group as to what they could do on their own and to identify

areas where they needed external help. This would be indicative of the possible areas of intervention that can be supported by BasicNeeds. Further, would provide a discussion point with the CBO's.

Once the total meeting had agreed on the topic guide, mentally ill people, carers and CBO staff worked in separate groups for all the small group exercises, usually within the same hall or room. Only when the larger group came together again were mentally ill people, carers and CBO staff reunited. Occasionally the facilitator asked a staff member to assist with some process.

Four day-long workshops were conducted: two under SACRED's auspices and two under that of the Narendra Foundation. As we worked with the two CBO's a parallel process of discussion leading to partnership creation emerged and this process too was documented.

Thus, in effect, between September 2000 and February 2001 the BasicNeeds team found itself working on two fronts that slowly wove together. Consulting so as to establish a viable programme and locating appropriate partners so as to carry out the work on the ground[2].

To take the example already quoted, Rachanapally Village (near Anantapur), at the start of this paper. We are in a hall of approximately 20ft x 20ft – it is the village co-operative building meant for storage of agricultural products. All sit on the floor covered by dharis – mats made of cotton. To undertake the topic guide three groups form – the first being of mentally ill people, the second of carers and the third is made up of staff and volunteers from SACRED. The process writer[3] reports:

Group 1 sat in a circle and was at once on the job. Building consensus, valuing individual opinions and active participation was observed. Lakshmana took on leadership role and guided the process. The constituency mapping done by Group 1 had the following constituents: Mother, father, friends, elders, school, SACRED, agricultural work, weaving, marriage, hospitals and doctors, cultural events etc.

The day wore on with the three groups reporting and then going off to work on a needs analysis. In due course an all group discussion occurred. Voices arose from mentally ill people and carers alike[4]:
One of the participants had gone out of the room angrily and was brought back to the group. The facilitator asked him to sit opposite to him at the centre of the group. He did so and stated that he disliked the drinking habit of his father and the family environment. His mother was asked to join into the small group and a dialogue was initiated. The larger group keenly observed the processes and the tension that had appeared dissipated.

One of the mothers said,"'if we are not able to deal with the problems, we will consume pesticides and die". (This is the common form of suicide among the farming community due to the availability of the pesticides.) Four others expressed their approval vigorously shaking their head.

Another Mother said, "I will make my son join me in Bamboo basket making. He does a good job of it."

Mother said, "We want people to know our problems and understand us and behave properly."

"We want proper medication and guidance."

"We want to come together and share problems. This process is helping us to relieve a lot of our tensions. We would like to continue to do the same".

At this point Lakshmana confronted his mother who had joined the group 15 minutes earlier. He told her,"You should treat me the way you treat my elder brother. You should let me weave at the loom and not let me go and do cattle grazing. You are worried about my fits and fear that I will spoil a saree if I faint while doing the job. Please remember that even a millionaire eats rice not gold. Do let me work. Humanness is more important than money".

Adinarayan (son, and carer, of the singer who opened the meeting) summed up the discussion saying, "people with mental illness have their problems, parents and carers have their own problems so do the community. We need to come together, place these problems in the open and solve them together."

As I often do, I struggle with the strength of what has transpired at the meeting, with my own location[5] within the meeting and my interpretation of this most local of meetings within the local/global continuum. So much that is momentous seems to confront mentally ill people on a daily basis:

1. That mentally ill people want to take part in the big events of their community as others do around them. So, a good looking young man longs to marry with the help and advice of his family, according to tradition[6], but in this case the support is not forthcoming.
2. That their choices can be very limited compared to others around them. Further, that decisions affecting their life choices are taken for them and without reference to them.
3. That they can be abused with relative impunity and that their civil and human rights can be arbitrarily limited or denied them.
4. That they want to work. To work for money for the family, for the work itself, for the pride of it.

PUTTING OUR CONVERSATION INTO PRACTICE

Working with just over one hundred mentally ill people and their carers together with the Narendra Foundation, SACRED and GASS, we have slowly originated a five module programme:

1. *Capacity building*
2. *Income generation*
3. *Community mental health*
4. *Research*
5. *Administration*

TWO STRANDS OF THE CONSULTATION ENTWINE

In the wider context the method of implementation will be for a partner, known as a Facilitation Partner, to consult and then deliver a development programme after appropriate training and capacity building. The delivery will normally be through Community Based Organisations working within the same coverage as the Facilitation Partner. Thus, the large organisation Nav Bharat Jagrithi Kendra (NBJK) situated in Bihar and Jharkand envisages working through six CBO's operating within some of the thirty six districts that they currently cover.

In order to understand the work better and to have an intimate knowledge of the issues, BasicNeeds will work in the role of Facilitation Partner with three partner CBO's within reach of its base in Bangalore. They are SACRED, Anantapur District, Andhra Pradesh, Narendra Foundation, Tumkur District, Karnataka and, more latterly, Gramina Abdyudaya Seva Samstha (GASS) of Bangalore District, Karnataka.

Thus the two strands of the consultation entwine as the views are gathered from mentally ill people and we learn to work with those who will deliver long term the programme on the ground. In the process so far we have developed many of our ideas about the use of topic guides, process writing, animation technique and the primacy of the voice of mentally ill people in the consultative process. We have come to value expert help from specialists at NIMHANS[7] whose encouragement has been very appreciated.

OUR LEARNING AT LOCAL LEVEL

In the process undertaken from April 2000 until now we have come to realise that:

1. All five modules of a Community Mental Health and Development Programme need to be implemented if the work is to go ahead effectively. Much of our learning is incorporated in these modules.

2. CBO staff felt disempowered to work with mentally ill people mainly because of the substantial mythology built up around mental illness. They have come to realise that many of the techniques they already practice (whether drawn from the field of CBR or development) would be helpful to mentally ill people.

3. There are many people being missed out of basic CBR and development programmes because it is assumed that they are unable to take part because of their mental illness.

4. Above all talk to mentally ill people! When you do you realise that they have the ability to take the decisions necessary to operate development work in their own communities. The logic of this realisation is that their own community must accord mentally ill people their rightful voice. Development, the pursuit of basic needs, leads painfully slowly to basic rights.

REGIONAL PERSPECTIVES FROM INDIA – NEGOTIATING THE LOCAL / GLOBAL GAP

In thinking about the conversations with mentally ill people described above we see both how the world looks from their perspective, and how difficult it is going to be for them to survive when we know already of the problems faced by those who are not mentally ill. The phenomenon of globalisation can be described as being as much within countries as between countries, particularly in the differential between the rich and the poor. The access to knowledge, leadership and resources[8] often defines the differential most tangibly. Further, does access to these assets serve to connect the poor to the wider world beyond the immediate village or community?

Imagine then an "ordinary" struggle against fierce unremitting poverty made a hundred times worse (choose a figure) by the stigma of mental illness attached to you by society itself. Originally seen by the ancient Greeks as a derogatory physical mark such as a cut or burn on a slave, stigma today applies to the disgrace felt by, in this case, the label of mental illness[9]. Stigma not only labels people often long after the mental illness has to all intents and purposes disappeared, but also results in very

poor service being supplied to those so labelled. One would have thought that a hospital would have been the ultimate sanctuary of the mentally ill person yet Murthy (2000)[10] argues that in India:

> *The services provided by the mental hospitals have been very unsatisfactory. Most of the mental hospitals have remained undeveloped and unsatisfactory in terms of the services provided and the facilities for care .A recently completed survey of the mental hospitals, by the National Human Rights Commission (NHRC, 2000) presents a picture of neglect and low level of care to the mentally ill persons.A large part of the stigma about mentally ill people comes from the poor conditions of the mental hospitals.*

The institution of the hospital and the *institution* of the community seem to both provide such conflicted arenas as to require mentally ill people to have the negotiation skills worthy of a UN peacekeeper and the temperament of a saint! Why should anyone have to put up with such poor service? And how wonderful must the atmosphere feel when the programme is just a little bit right.

Who then stands with our sisters and brothers in the Herculean struggle against poverty *and* mental illness? Historically the burden has fallen on a medical and social service establishment who are very pressed in overall patient load and financial resourcing. Even as early as 1946 when India's total population was quite a lot smaller, the Bhore Committee[11] dryly noted:

> *Even if the proportion of mental patients is taken as two per 1,000 population in India, hospital accommodation should be available for at least 8,00,000 mental patients, as against the existing provision of a little over 10,000 beds for the country as a whole. In India, the existing ratio is of one bed to about 40,000 population, while in England, the corresponding ratio is approximately one bed to 300 population.*

Out of a total population exceeding one billion Murthy (2000)[12] reports that in India there are:

> *About 3000 qualified psychiatrists are working in different centres in the*

country. The number of psychiatric social workers is estimated to be around 600. The number of trained psychiatric nurses is around about 600.

And that:

Of the 140 medical colleges in the country, about three quarter of the colleges have an academic department of psychiatry. In another quarter a psychiatrist functions as part of the general medicine department with no additional staff.

He opines that:

The actual amount of training is grossly inadequate, as the minimum amount of training required as per Medical Council of India rules is only two weeks of training.

In conducting the work in India described at the beginning of this piece I came to understand how much pain many parents suffered in their roles as carers.

The role of parents coming together as a self-help group is a very powerful instrument for supporting mentally ill people and their families and there is an important example of this in the Bangalore based group called AMEND[13] led by Dr. Nirmala Srinivasan[14].

Generally, however, the most striking thing about mental illness in India, and I suspect in other parts of the region, is the extent to which the state medical and social service sector dominates the subject. In countries where the voluntary sector has a proud and plentiful tradition, the presence of NGO's (Non Governmental Organisations) is really quite extraordinarily slight in India[15].

It is noticeable how few mentally ill people seem to be involved in Development or CBR programmes. If there is a criticism to be levelled in relation to this state of affairs, it has to be at the voluntary sector (my own sector) for not getting much more involved much earlier. With very few notable exceptions[16] we are faced with the uncomfortable feeling that perhaps we too forgot to talk to mentally ill people in the same way

that we did to other groups within society such as landless labourers, dalits, women and disabled people.

So then, who does stand proudly beside our sisters and brothers, as asked above? Well, clearly the medical and social service professions, mostly from the state sector, have done the most in an organised fashion but equally clearly it is parents, families and communities who have taken on the greatest burden of care and associated anxiety. Almost all involved agree that it is the community based traditional healer who often sees the patient first, long before any other intervention is considered.

The voluntary sector has provided a limited number of residential models in India but it now needs to place its considerable experience in community development at the disposal of mentally ill people, and those who already care for them. Mentally ill people need to be invited, to be encouraged, to be motivated to become part of the development process. Clearly they need to be part of CBR programmes but they should also be part of agricultural schemes, income generation programmes and the whole gamut of programmes currently on offer to other citizens.

GLOBAL KNOWLEDGE – LOCAL ACTION

There is persuasive evidence that in the developing world non-communicable diseases such as depression and heart disease are fast replacing communicable diseases as the leading causes of disease burden[17]. Prof. Rachel Jenkins in assessing the mounting awareness of the importance of mental disorder cites[18] three influential collaborative reports:

1. A collaboration between WHO and the World Bank entitled *Investing in Health* (World Bank 1993) calculating that the global burden of neuropsychiatric disorders was 8.1% as measured by DALYS – Disability Adjusted Life Years.

2. *World Mental Health* (Dejarlais et al 1995)[19] which after presentation to the UN in 1995 resulted in the WHO of the UN setting up a major initiative known as "Nations for Mental Health" with the aim of improving mental health in developing countries.

3. *The Global Burden of Disease* being a five year data compilation by the Harvard School of Public Health, the World Bank and WHO.

With respect to this last report Prof. Jenkins goes on to point out that:

> *Five of the ten leading causes of disability worldwide in 1990 (measured in years patients have had to live with a disability) are psychiatric conditions: unipolar depression, alcohol use, bi-polar affective disorder, schizophrenia and obsessive compulsive disorder.*

With regard to future projections she concludes:

> *…the contribution of psychiatric disorder to the global burden of disease in 2020 is expected to be immense. The projections show that psychiatric and neurological conditions could increase their share of the total global burden of disease from 10.5% of the total burden to 15% in 2020. This is a bigger proportionate increase than that for cardiovascular disease.*

Since 1946 and the days of the Bhore Committee in India a paradigm shift has taken place in how, and where, the population of mentally ill people should be cared for. Generally the community has been perceived as being the best place for the vast majority of people with mental illness attended to by a limited but strategic medical intervention[20]. This shifts the model or models away from large hospital buildings and institutional care to a methodology that can cater for the numbers implied by Jenkins looking, as she does, into year 2020.

The implications on health policy and health spending are very significant if mentally ill people are going to be cared for in an effective and positive way in the community. This affects, for example, the demand on primary care facilities as mental health becomes an integral part of primary health care[21]. It also implies a heavy demand on CBR programmes and last, but not least, a new and somewhat untested demand on development projects.

Further, there will be a need to experiment with multisectoral approaches, e.g. integration with primary health care, income generation and self help group development. This will need to be tied with a willingness to

import into the region forms that have been successful elsewhere, e.g. ideas in community social enterprise and social firms as operated successfully by the state and voluntary organisations in Italy[22].

RESPONDING TO THE GLOBAL CHALLENGE - MENTALLY ILL PEOPLE AS PART OF THE DEVELOPMENT PROCESS

"Let me work" Lakshmana cried in a clear understanding that it is only by being productive that a family and a community accept you and that you can accept yourself. The distress of mental illness is so much the more when you are denied the chance to do something about it.

Those of us who have worked hard to construct the five modules described at the beginning of the piece hope that we are first and foremost responding to the needs epitomised by Lakshmana and his fellow group members. We hope that the mental health and development model will be flexible and will continue to respond to demand and need. We sit in time-honoured fashion and watch as the animator plies his Freirian[23] trade and the group slowly grows in confidence beneath his watchful eyes.

As we watch we become aware of the potential of two traditions blending. On the one hand there is the tradition of community development that grows the group so it may carry out its task in income generation, land clearance – whatever job is needed for the community. On the other hand there is a tradition that sees the growth of the group as part of a psychotherapeutic dynamic that has proved very encouraging for so many people. It is not that these two traditions must flow together. It is more that we just need to appreciate that there are two watercourses laying side by side and be aware of the proximity of these two traditions. In fact there will be natural opportunities for a satisfying exchange between the two water flows and we will all be the richer when it happens.

If mentally ill people are to take their place in the development process they are, perforce, taking their (in my view) rightful place in the fight against poverty. It is the human right of any person to do battle against

poverty and much of the work implied in the process of mental health and development is about winning basic human rights through hard work for the community. Simply through the observation I have made to date I feel that to be poor and mentally ill is very tough. Equally it is true to say that many mentally ill people are poor and homeless[24].

To me it is clear that mentally ill people can contribute to the development process. They will do it as does any other marginalized group seeking success or upward mobility. They will have to find ways of achieving knowledge, leadership and resources through organisation. They will need to stand apart from others so as to identify themselves as a group with needs, but they will also need to make alliances with others so as to fight poverty and injustice on, for example a joint community basis.

Those of us who work with various groups of marginalized people will of course see amongst them mentally ill people. After all mental illness is the province of us all – it is quite definitely not something that only happens to other people. It happens to us – that is why it is so perplexing that "we" should stigmatise ourselves. At one moment we are accepted – at another we are not. The hurt of such a palpable injustice can be felt like a stinging whip even in these dull words. The link between human rights, justice and mental illness is very clear, very much part of the development process and requires any development programme involving mentally ill people to have a large advocacy and community education component.

Shivanna was asked to sing a song to mark the close of the session. As he had opened the session would he like to close it; asked the animator? Slowly Shivanna stood – a little stiff, as any elderly man would be from sitting in the group for a long while. Lacking, for the moment, the finger cymbals that performers normally use he flicked his fingers open and shut in time to the music as it vibrated in the hot stillness of the little stone barn. What did Shivanna sing about? Hope of course, love and the connectedness of all things in the universe. In rendering a well-known mythological tale in a well-known musical form he was immediately understood by his own community. Yet, in singing of things that matter to all of us he reached all of us – wherever we may have been. The local and the global shimmering as one, held in an old man's voice in rural Andhra Pradesh.

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For further reading on the topic of mental health and development BasicNeeds Trust announces its new e-journal available at www.mentalhealthanddevelopment.org.

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7.12c

NOT ON THE AGENDA: HUMAN RIGHTS OF PEOPLE WITH MENTAL DISABILITIES IN KOSOVO

Although this article describes an institution in Kosovo, the situation is not unique to the institution described nor is it unique to Kosovo.

The following excerpt is reprinted with permission from the full report written by Mental Disability Rights International (MDRI). MIUSA wishes to thank Eric Rosenthal of MDRI for permission to reprint the summary and recommendations of the full report. To read the full report please visit www.mdri.org

Not on the Agenda: Human Rights of People with Mental Disabilities in Kosovo describes the findings of an investigation by Mental Disability Rights International (MDRI) on the human rights of people with mental disabilities[1] in Kosovo. MDRI conducted seven fact-finding missions to Kosovo between September 2000 and July 2002. MDRI teams investigated conditions at inpatient and community facilities, including: two social care facilities; two psychiatric wards at general hospitals; the psychiatric ward of the Lipljan jail; two group homes for children with disabilities; a special school for children with disabilities, and two recently established community mental health centers. The largest social care facility we visited is Shtime, a 285-bed facility designated for individuals with mental disabilities. Shtime currently has approximately 230 people under its authority. The other social care facility is known as the Elderly Home, a 165-bed facility housing people of all ages (as young as 17 when we visited). This report particularly focuses on Shtime and Prishtina University Hospital's psychiatric ward, a 75 bed short-term facility.[2] In addition to documenting abuses within institutions, this report examines policies and programs for reform of the mental health and social service system adopted by the United Nations Mission in Kosovo (UNMIK) and inherited by the new government of Kosovo.

International intervention in Kosovo by NATO and the United Nations was inspired by the worthy goals of protecting the human rights of people in Kosovo. Despite extensive international funding for the development

of democracy and the support for civil society in Kosovo, this report finds that people with mental disabilities have been left off the human rights agenda. Serious human rights abuses against people with mental disabilities are taking place in Kosovo and continue unabated. While some valuable community mental health programs have been established to serve a small number of individuals, internationally funded programs to refurbish Shtime are likely to perpetuate an outmoded and inappropriate system of services that segregates people with mental disabilities from society.

In Kosovo's social care facilities and psychiatric wards, people are being illegally and improperly detained in institutions in violation of domestic and international law. Once detained, people are deprived of meaningful treatment and habilitation, and they are subject to physical, sexual and psychological abuse. For the great majority of patients, life in Kosovo's facilities is one of mind-numbing boredom and inactivity in an environment devoid of privacy and dignity. Despite internationally funded programs to fix up buildings at Shtime, staff is inadequate to provide basic cleanliness or hygiene. Many residents live in filth, surrounded by the smell of urine or feces. Medical and psychiatric care is inadequate and unsafe; a cursory review of medical records at Shtime shows that non-professional staff is authorized to administer powerful psychotropic medications without review by a psychiatrist for months or years. MDRI received reports from international and Kosvar staff and patients about cases of sexual harassment, exploitation, rape, or other forms of violence at Shtime, Prishtina University Hospital, and the Elderly Home. Institution and UNMIK authorities have been informed about cases of abuse at Shtime, yet they have done nothing to remove known abusers from day-to-day contact with former victims. At Prishtina University Hospital, MDRI has received reports about sexual abuse of women by staff. There is no system at any institution MDRI visited to conduct independent investigations of abuses or to protect the privacy or safety of witnesses who may come forward. MDRI has encountered both staff and patients who are afraid to come forward with evidence about abuses they have experienced or observed.

Many people are inappropriately placed at Shtime, yet UNMIK continues to direct limited international resources to refurbishing Shtime rather than creating community-based alternatives According to an analysis by UNMIK's "Deinstitutionalization Team," the majority of people at Shtime

have no medical reason for being at the institution. UNMIK has stated that the main obstacle to their integration into the community is the lack of services and support systems in the community. Despite these findings, UNMIK has proposed a new program to the Dutch Government to rebuild and rehabilitate the Shtime institution. No funding has been set aside to create community alternatives for residents of Shtime.

The World Health Organization (WHO) and the Ministry of Health have created aprogram to provide community services to a small fraction of people with psychiatric disabilities in Kosovo. Adults with intellectual disabilities have been entirely left out of any plans for a community-based service or support system. Thus, policies and programs established under UNMIK authority will result in lifetime institutionalization for most people now detained in mental health facilities. The great majority of individuals with mental disabilities – approximately 40,000 such individuals – live with their families or on their own and receive no support from the government. Anecdotal reports suggest that such individuals and their families live in impoverished conditions. Due to lack of resources, lack of accessible public services, and the stigma associated with mental disabilities, many of these individuals remain closeted at home and cannot participate in any form of public life. The failure to create an integrated system of community-based services and support for these individuals also leaves them abandoned and segregated from society.

We find that the lack of respect for human dignity, the danger due to unhygienic conditions, inappropriate medical care, and lack of protection from physical and sexual abuse renders detention in Shtime for anyone a form of "inhuman and degrading" treatment in violation of the United Nations' International Covenant on Civil and Political Rights (ICCPR). Shtime is so dangerous and destructive to the mental and physical health of its residents that the UN should plan for its closure at the soonest possible date – as soon as alternatives can be created in the community. The lack of protections against physical and sexual abuse or exploitation at the Elderly Home and the psychiatric wards of general hospitals also constitute inhuman and degrading treatment under the ICCPR. The lack of protections against improper civil commitment in these facilities renders detention in these facilities a form of arbitrary detention under the ICCPR. For people capable of living in the community, the provision of services

exclusively in the segregated and inappropriate environment of institutions is a form of discrimination under international law.

For any democracy to function effectively, people must be in a position to represent their own interests, to demand rights enforcement, and to advocate for responsive government policies. The United Nations' own "Standard Rules on Equalization of Opportunities for Persons with Disabilities" (the "Standard Rules") call on all governments to create opportunities for people with disabilities to participate in public life. In addition to developing social services and support systems that promote community integration, the Standard Rules call on all governments to include people with disabilities in policy-making and program implementation on matters that affect them. UNMIK programs in Kosovo do not conform to the UN's own disability rights standards, given a service system that segregates them from society in institutions or abandons them in the community. International civil society programs have not provided training or support to organizations made up of people with mental disabilities or real opportunities for people with mental disabilities to participate in Kosovo's democracy.

MDRI calls on the UN Secretary General to direct UNMIK to:

- Act immediately to protect people detained in institutions from further violence or sexual abuse, create safe living conditions, and separate abusers from patients;
- Create a system of human rights oversight and accountability to ensure rights enforcement in institutions and community-based programs; this should include the creation of a mechanism to investigate abuse that will protect the privacy and safety of witnesses and victims;
- Establish a comprehensive plan to create community-based services for people with mental disabilities that (1) does not exclude people with intellectual disabilities (2) provides services for people now detained in institutions who are capable of living in the community (3) builds on the support of Kosovar non-governmental organizations and families and (4) creates independent community supports for individuals without families or with abusive family situations;
- Create a time-table for the closure of Shtime as soon as community-based alternatives can be created for its residents;

- Ensure participation by organizations of people with mental disabilities in policymaking, human rights advocacy, and program implementation through the creation of targeted outreach, training, and civil society support programs for people with disabilities and their families;
- Report to the UN Human Rights Commission on steps taken to end abuses against people with mental disabilities in Kosovo, in accordance with the Human Rights Commission's April 2002 resolution calling on the Secretary General to report on the enforcement of international human rights for people with disabilities by UN agencies.

DETAILED RECOMMENDATIONS

A. To international relief and assistance agencies:

- **Adopt voluntary reporting requirements** to ensure that staff who observe human rights abuses against patients report it within their own organization and to appropriate public authorities. Protocols should be established to ensure that action is taken to investigate allegations and prevent further abuses when they are reported.
- **Incorporate human rights oversight, monitoring, and enforcement programs into the design of both institutional and community-based programs.** International organizations must take proactive steps to be prepared to operate within a context in which domestic laws do not provide adequate human rights protections for people with mental disabilities Funds should be set aside to train both local and international staff in basic measures to protect and prevent human rights abuses. The involvement of people with mental disabilities experienced with human rights advocacy would aid in the design and implementation of effective rights enforcement programs.

B. To the Dutch Government and other international funders:

- **Shift funds from refurbishing Shtime to community alternatives** – International funders should insist that UNMIK and the Kosovar Ministries of Health and Welfare shift existing assistance funding away from fixing up institutions. While some funding is needed to end conditions that are imminently dangerous in institutions, most international funds should be used to create community housing

and supportive services to promote the community integration of people with mental disabilities.

Funds should also be set aside to ensure the creation of human rights oversight andenforcement systems.

- **Support advocacy by Kosovar activists with mental disabilities and their allies** –All foreign assistance programs should comply with the UN Standard Rules on Equalization of Opportunities, which require stakeholder participation in program planning and implementation. In a society in which independent advocacy by people with mental disabilities does not yet exist, there should be a priority on the training of activists and the support of new advocacy organizations led by people with mental disabilities. Support for organizations made up of family members of people with disabilities is also necessary. Investment in these non-governmental organizations (NGO's) will provide deeply committed and low-cost partners who will greatly aid in the development of effective, culturally appropriate, and sustainable programs.

C. To the United States Government:

- **Earmark USAID funds for the human rights of people with mental disabilities** –Section 504 of the Federal Rehabilitation Act requires that all US government programs be fully accessible to people with mental and physical disabilities. The US Agency for International Development (USAID) currently has a non-binding "Policy Guidance on Disability and Development" that says all international assistance programs should be open to people with disabilities. The existence of the abuses documented in this report demonstrates that current human rights and civil society programs have not reached people with mental disabilities. While the USAID has invested extensive funds in human rights, civil society, and rule of law, these programs are inaccessible to most people with mental disabilities. These programs will remain inaccessible until outreach programs are targeted to ensure the inclusion of this population and to accommodate their needs. Thus, the US Congress should require USAID to set aside funds for training and support of disability advocacy organizations.

  US Department of State should report on abuses against people

with disabilities in **Kosovo** – The US Department of State should include an overview of the human rights abuses now taking place against people with mental disabilities in its Annual Reports on Country Practices that document human rights abuses in every country.

D. To UNMIK and the Government of Kosovo:

- **Protect the safety of people detained in institutions** - UNMIK and the new Government of Kosovo should take immediate action to protect the safety of people detained at Shtime, the Elderly Home, and the psychiatric wards of general hospitals in Kosovo. A response to the problems of physical abuse and sexual violence in institutions cannot wait until new international funds are raised or until new community-based alternatives to institutions are created. Authorities at Shtime must identify abusers and keep patients with a record of abuse away from others who are vulnerable. Authorities should recognize that women are particularly vulnerable to abuse in institutions, but the existence of abuse should not be used as an excuse to lock up or isolate women. Institutions must guarantee safe living areas for all institutionalized persons consistent with the right to live in the least restrictive environment.
- **Establish independent investigation, oversight, and enforcement mechanisms to protect rights** - UNMIK should immediately establish mechanisms to investigate allegations of abuse in institutions and in community-based programs serving people with mental disabilities. These mechanisms must recognize that individuals re porting abuses by staff or other patients may be at risk of reprisals by these individuals.

  Therefore, policies and procedures must be established that protect individuals reporting abuse from being subject to further abuse during the investigation and afterwards. UNMIK should establish an oversight body that is independent of mental health and social welfare authorities. Criminal justice authorities should investigate allegations of abuse identified by this oversight body or from other sources.

  The oversight body should be empowered to investigate abuses and conduct unannounced visits with full access to wards and

patient records. Non-governmental advocacy groups – particularly with representation by women's rights organizations – should be included in this oversight body. People with mental disabilities and other former patients, particularly women, should be trained as investigators; these individuals have unique abilities to understand and gain the trust of individuals subject to abuse.

- **Improve use of existing staff and hire staff as necessary** - At Shtime and in the psychiatric wards of general hospitals additional staff is needed to ensure adequate care and safety. At both institutions, we observed staff sitting in groups and not actively engaged in patient care. Training and oversight is needed to ensure that current staff is actively engaged in assisting patients. Staff not complying with job requirements should be removed. If necessary, UNMIK must be willing to raise salaries to hire qualified professionals. Specialists in the care and assistance of people with intellectual disabilities are essential.
- **Create "trauma-informed" services** - Given Kosovo's history of violence, combined with a lack of protection against physical and sexual abuses within institutions, service providers should assume that a large percentage of people in institutions have been subject to trauma. The deprivation of control over basic decisions of living, lack of privacy, contact with former abusers, or even association with the location in which previous abuse has occurred, can cause psychologically damaging "retraumatization". Retraumatization is the stimulation of traumatic feelings associated with prior violence or other extremely stressful events. This experience can cause great suffering and can compound pre-existing post-traumatic stress, dissociation, and other psychological or somatic conditions. All inpatient and community services should be designed to protect against practices that may cause retraumatization. Both Kosovar and international staff should be sensitized to these dangers and trained to respect the choices of people in their care. Linkages should be established between public mental health services and trauma programs in the community so that people detained in institutions can receive care and assistance from community-based counseling and trauma programs. Community based trauma programs should create necessary accommodations to assist people

with psychiatric or intellectual disabilities in the community instead of referring them to institutions.

- **Create a comprehensive system of community services and support systems** – *The Ministries of Health and Social Welfare* should collaborate on the creation of plans to establish and finance a community-based service and support system for all people with disabilities. The community system must include support for people with intellectual disabilities as well as people with psychiatric disabilities. The system should plan for the community integration of people now detained in institutions, and it should meet the needs of people with mental disabilities now living on their own or in families.

  Community service programs should include supported housing and supported employment. The community system should provide alternatives for women and men who have no family or who cannot live with their families because of a past experience of abuse or for other reasons. It is particularly important to create independent living situations or single-sex living situations for women who have been subject to sexual abuse. Community placements should also ensure that women can remain with their children.

  Independent monitoring programs must be established to ensure quality of care and rights enforcement in community programs.

- **Set a timetable for the closure of Shtime** – Shtime is inappropriate, unhealthy, and dangerous for all its residents. The same funds now sought from the Dutch government to rehabilitate the institution should be used instead to create communitybased housing for Shtime's population. People now residing at Shtime should be guaranteed safe, supported community services before the facility is closed. A timetable should be established for the transfer of Shtime's entire population to community-based services. A number of individuals in Kosovo will need inpatient care. Once safety precautions have been established in psychiatric wards of general hospitals, these facilities should be used to provide short-term acute care. Long-term care for people with psychiatric or intellectual disabilities should take place in facilities that are as small and homelike as possible. Such care should be in the least restrictive setting suitable to the individuals' health needs and the safety of others.

- **Build on existing "natural supports" in the community, including peer support and non-governmental organizations** - Given the shortage of trained professionals in Kosovo, and the lack of sustainable funds for important programs, the community system should rely heavily on existing support systems in Kosovar society. This includes training and assistance for peer-support programs to involve consumers in the delivery of services. Families should also receive support to assist relatives with mental disabilities.
- **Create a system of family support and foster care for children with disabilities, and continue funding existing programs** – UNMIK and UNICEF should continue funding for two group homes administered by Doctors of the World to ensure that these children are not returned to Shtime. The current program should be made independent of Shtime as soon as possible. UNMIK and the Ministries of Health and Welfare should begin planning immediately for the creation of a family support program to prevent further abandonment of children with disabilities. UNMIK and the government of Kosovo should also begin planning for the creation of a supported foster care system that will include children with disabilities.
- **Support participation by people with mental disabilities and families** - The UN General Assembly's resolution, "Standard Rules on the Equalization of People with Disabilities," (Standard Rules) recognizes that people with mental disabilities have a right to participate in human rights advocacy, policy-making and program implementation regarding matters that affect their lives. In order for meaningful participation to be possible, authorities must invest in training and support for individuals with mental disabilities and organizations made up of people with mental disabilities. Groups made up of people with different disabilities (physical, mental and sensory disabilities), such as Handikos, can serve as valuable partners. Support for advocacy by people with mental disabilities is also essential.

  While not a substitute for the direct involvement of people with disabilities, authorities should also support advocacy by families of people with disabilities.

Internationally funded civil society, rule of law, and human rights programs should ensure the inclusion of people with disabilities. Full inclusion and access to such programs for people with mental disabilities will require the creation of targeted outreach programs designed to accommodate the special needs of individuals with mental disabilities.

- **Adopt comprehensive anti-discrimination legislation** that protects the rights of people with mental and physical disabilities. As the UN Committee on Economic, Social and Cultural Rights' General Comment 5 states, "such legislation should not only provide persons with disabilities with judicial remedies as far as possible and appropriate but also provide for social-policy programmes which enable persons with disabilities to live an integrated self-determined and independent life."45
- **Do not let stigma based on disability or ethnicity stand in the way of community integration** – Various UN agencies have pointed to stigma against people with mental disabilities as an excuse for not including this population in community programs. UN Agencies have also stated that people who are ethnically Serbian cannot be integrated into Kosovar society. The Doctors of the World program that has integrated ethnically Serbian children from Shtime into community life in a Serbian enclave demonstrates that stigma based on disability and ethnicity can be overcome.

  The anti-discrimination law of Kosovo should prohibit the exclusion of people with disabilities from community programs based on stigma, disability, or ethnic origin. Special accommodations will need to be created to overcome these barriers – as they are in any society in the world.
- **Establish legal protections against arbitrary detention and coercive treatment** – OSCE has drafted legislation that would protect against arbitrary civil commitment. It is essential that this legislation provide the procedural protections required under international human rights law, including a right to review by an independent judicial authority, a right to representation by counsel, and a right to appeal to a higher court.

Under international law, detention in a psychiatric facility does not entail the forfeiture of all other rights. Thus, the right to make choices about treatment should be recognized even for people who have been involuntarily detained. Legislation should provide an independent right to refuse treatment.

- **Protections against improper guardianship should be established** – Protections against the deprivation of liberty or coercive treatment can be circumvented unless there is also an effective law to protect against the improper use of guardianship. Under international law, people with mental disabilities have the same rights as other citizens. Thus, guardianship should be limited only to those activities for which an individual is found to be mentally incompetent. Given the lack of attorneys in Kosovo, civil commitment and guardianship legislation should permit representation by specially trained and licensed lay advocates. Funds should be set aside to provide training for such counsel. UNMIK authorities should not recognize Yugoslav-era legislation providing Centers for Social work with guardianship authority without the provision of full protections required by international human rights law.

7.12d

CHILDREN IN RUSSIA'S INSTITUTIONS: HUMAN RIGHTS AND OPPORTUNITIES FOR REFORM

FINDINGS AND RECOMMENDATIONS OF A UNICEF SPONSORED FACT-FINDING MISSION TO THE RUSSIAN FEDERATION

Following is excerpted from the above report written by Mental Disability Rights International (MDRI). MDRI is an advocacy organization dedicated to the international recognition and enforcement of the rights of people with mental disabilities. Please visit their website at www.mdri.org to read the full report. MIUSA wishes to thank Eric Rosenthal of MDRI for permission to reprint this excerpt.

The Russian Federation has inherited from the Soviet Union an extensive institutional system of services and education for children that unnecessarily and improperly segregates them from society. The vast majority of children we observed within Russia's institutions and special schools could live, grow, develop, receive an education, and maintain family ties in a more integrated community environment. This is true for children with disabilities and children without disabilities who are orphaned or who come from troubled families. The health, education, and social services necessary to permit children to remain in the community with their own family or with substitute families are lacking. The MDRI team interviewed numerous parents of children with disabilities who are desperately trying to keep their children at home but find it difficult to do so in the absence of adequate government support. The great majority of children in Russia's institutions are "social orphans," many of whom have been placed in institutions by parents as a result of the lack of economic resources and other needed social support. Both real and social orphans could live with their own family or a substitute family if adequate educational services and support were available.

Russia's recent economic hardship has contributed greatly to problems facing children with disabilities and their families. With fewer resources available to them in the community, more and more parents are forced

to place children in institutions. Institutional budgets, already stretched thin, are forced to cover the costs of serving an increased number of children. Children in institutions and in the community are increasingly at risk of impoverishment and neglect.

The near exclusive reliance on institutional care for children who require support contributes to the disabilities of children. Research in child development and the experience of other countries around the world has demonstrated that children experience developmental delays and potentially irreversible psychological damage by growing up in a congregate environment. This is particularly true in the earliest stages of child development (birth to age four), in which the child learns to make psychological attachment to parents (or substitute parents). Even in a well staffed institution, a child rarely gets the amount of attention he or she would receive from his or her own parents. Consequently, institutionalization precludes the kind of individual attachments that every child needs. In Russia, the MDRI team observed many caring staff doing everything they could to spread their attention to meet the needs of all the children under their care. Resources are inadequate to meet the needs of all children. The situation is particularly serious for children with disabilities who need the most care. Overworked staff are not able to meet their needs. Many children are left to spend long hours, days, or years in a crib without the attention or stimulation needed to grow and develop. The damage caused in their early years will likely stay with them forever. These children are effectively denied the opportunity to lead the full life of which they are capable.

Older children also suffer from unnecessary and improper institutionalization. Many older children are placed in institutions "temporarily" for a host of stated reasons - to give them an evaluation diagnosis, to provide "corrective services," or to give parents the time to get over a difficult period. Children labeled as "disabled" are placed in segregated classrooms in institutions or in the community, where they receive an inadequate or second-class education. Lacking contact with the mainstream, children fail to develop the social skills necessary to thrive in the community. Frequently, children temporarily placed in an institution lose contact with family or friends in the community. The loss of these social ties makes return to the community more and more difficult over time. Once family

ties are severed, a child may lose hope of ever returning to the community. Children with mental disabilities are often consigned to a lifetime in an institution.

MDRI's major recommendation is that the Russian Federation should commit itself to a policy of community integration. To implement this new policy, appropriate authorities must create a network of community-based services and support systems to permit children to live, grow, and receive an education in the community. This system will end the unnecessary break-up of families and will help prevent mental disabilities that are caused by children's institutionalization. Educational systems must also be reformed to permit integration of children with mental disabilities within mainstream schools and classes. Ultimately, every child should grow up with a family and no child should ever have to be placed in an institution.

The International Convention on the Rights of the Child (CRC) embodies the principle that all children - regardless of disability - have value as human beings. The CRC establishes that the opportunity to grow up with a family in the community is a fundamental right of all children. The CRC specifies that health, education and social services be provided - to the extent of available resources - to ensure enforcement of these rights. The CRC requires laws to be reformed to protect all children against discrimination in society. These laws should also assure children access to needed social services and education in the community. Human rights oversight mechanisms (including ombudsmen) should be established to protect children against neglect and abuse and to ensure the enforcement of basic human rights for children remaining in institutional care. Oversight mechanisms must also be established to ensure enforcement of the rights of children receiving community-based services.

The Russian Federation must commit itself to a new policy of promoting the maximum possible community integration and family support for all children, particularly children with disabilities. As the United Nations has called for in the "Standard Rules on Equalization of Opportunities for Persons with Disabilities," national planning is needed to ensure enforcement of human rights and full opportunity to participate in public life in the community. Planning on the regional and local levels is needed to develop programs to bring about long-term reform. People with disabilities and

their families should be invited to work with government authorities at all levels to develop effective reform plans and programs.

While the Russian Federation is going through a difficult time of transition at present with hardships shared by much of the population, the humanitarian concern of children in institutions are urgent. A delay in the development of community-based alternatives creates increased human and financial costs. As institutional placements rise and more families break-up, children face rising levels of mental disability. Public exposés of abuses in institutions will increasingly pressure government authorities and international donors to invest in improving institutions. These new investments may increase the incentives for financially-strapped parents to place children in institutions. While emergency efforts may be needed to ensure sufficient food, heath, clothing, sanitation, and medical care in institutions, the bulk of assistance should go to children and families in the community. The Russian Federation should avoid the path taken by countries such as Romania, where international exposure of abuses in orphanages was followed by new investments in institutions - and an almost fifty percent rise in the total population of institutionalized children. The challenge to community integration will be even greater and more difficult if Russia follows this path. Russian authorities should respond to the current crisis by creating community services to meet the needs of children in their own home and community. As soon as possible, the entry door to institutions should be closed - and all new admissions should be terminated.

International assistance at this time is critical. Programs targeted to support families with children at-risk of institutionalization can prevent unnecessary break-up of families. These programs should be linked to advocacy training programs to empower family members to take part in reform efforts at the national level and through their local and regional authorities throughout Russia. International funding can lead the way to reform by supporting model programs that demonstrate the effectiveness of community integration. Russian models for community integration for children in out-of-home care do exist. These programs should be expanded to serve children with mental disabilities, and these models should be replicated throughout the Russian Federation.

INTERNATIONAL COOPERATION

International cooperation and support is urgently needed to respond to the humanitarian concerns of the 400,000 to 600,000 children in Russia's institutions - and a larger number of children now living with their families who are at-risk of being placed in institutions because their parents lack the resources and support necessary to keep them at home. As economic hardships increase pressure on the families of children with disabilities, there is a great risk that many new children will be placed in institutions. Emergency foreign assistance programs can prevent the break-up of the family by targeting assistance to the families of children most at-risk of institutionalization.

Improperly directed foreign assistance may unintentionally strengthen the current outmoded and segregated system of services and may delay the process of reform. Investments in orphanages - as well as programs that support living conditions in institutions without supporting families in the community - may create increased incentives for financially strapped parents to place children in institutions. Thus, new investments in orphanages may increase the total population in orphanages, contributing to disability among children and increasing the total cost of reform.

A well planned and focused response to the current crisis facing Russia's children can have a major, long-term impact if funds are used to promote structural reforms in the service system for children. International donors are strongly encouraged to concentrate their efforts to support advocacy for service system reform to bring about community integration of children, particularly children with disabilities. Programs should assist Russian national, regional, and local authorities to implement the strategic recommendations described in Chapter III of this report. International programs should also support non-governmental advocacy for rights enforcement and service system reform. Advocacy training, combined with professional development and exchange programs, will have an impact on the rights of children well after the immediate crisis. International support for a media and public education campaign can promote Russian support for community integration, raise the public profile of Russian reformers, and ensure a national impact for new investments in reform.

A. Recommendations to international donors

The following principles should guide the development of programs to assist children in Russia's institutions. While each of the proposed program areas is valuable alone, these projects are mutually reinforcing. Each type of project proposed will have a greater chance of success if it is linked with a larger, more ambitious campaign for reform. MDRI strongly encourages international donors to cooperate among themselves - and with Russian counterparts - to develop a reform package that ensures funding for each of the following components:

1. Model programs linked with advocacy for systemic reform

The international community should promote rights enforcement of children by assisting Russia in making the transition from an institution-based to a community-based service and education system. Investments in education and social programs for children should encourage the adoption of internationally recognized "best practices." Investments in programs that bring about incremental improvements in the current system will eventually have to be replaced, raising the total cost and slowing down the process of reform.

2. Rule of law and human rights enforcement

Russia should receive assistance in reforming its laws to protect the rights of children in institutions. In addition to protecting rights within institutions, law reform should be used to promote community integration and to protect against discrimination in the community. Law reform projects should be linked with programs to create human rights enforcement mechanisms. As with other model programs, internationally recognized best practices should be used. Special training should be provided to ensure the involvement of lay advocates in human rights enforcement programs. Training for lawyers, judges, and other human rights enforcement personnel will be needed.

3. Rights-based advocacy and citizen participation

Advocacy by people with disabilities, families of children with disabilities, and progressive service system professionals, have been critical to reform efforts around the world. In Russia, there are a number of impressive activists dedicated to the rights of people with mental disabilities. Advocacy organizations exist, but they function at a basic level

and are in great need of development. In the Russian Federation, as in many other countries of the world, these organizations have not received the kind of international support or recognition that has been made available to other human rights organizations. Due to the discrimination they face throughout society, and the lack of government support for their financial needs, people with mental disabilities and families often live at the margins of society in great economic hardship.

4. Advocacy training

Advocacy training for people with disabilities, family members, and progressive service professionals can greatly assist disability rights organizations and can make a major difference in the ability of activists to participate in policy-making and new program implementation. Activists are often unfamiliar with models of community integration that have proven effective in other countries. Advocacy groups can benefit greatly by studying the experience of activists in other countries. Government officials and participants in new human rights oversight and enforcement mechanisms can also benefit from advocacy training programs. For people involved in a specialized area of policy development or program implementation, it is extremely important to be exposed to the broad goal of community integration as well as the operation of service systems and human rights enforcement programs. Government officials involved in program development and planning can benefit greatly from meeting with counterparts involved in similar work in other countries.

5. Professional development

Funds for the development of model programs should be linked with professional development and training. Short-term practical training should be emphasized at the outset. In the long-run, it will also be necessary to develop university programs to train professionals and educators in the full range of services required for community integration.

6. Emergency assistance to families and children most at-risk

This report identifies a number of practices that create direct health risks for children in institutions and in the community. International programs can make a particularly important contribution to preventing the health and development risks associated with family-breakup and institutional placement. Funding for these programs should be directed

to community-based structures at the local level. Family advocacy organizations can be a particularly valuable partner in these projects. Family members are uniquely positioned to identify the needs of children and other family members, and they can help identify children most at risk. Programs to assist these children and their families will help family organizations strengthen mutual support networks.

7. Ensure participation of people with disabilities and family organizations in all programs

People with disabilities and family members should be actively involved in public policy advocacy, program development and implementation, and human rights enforcement efforts. In societies that place a great value on professional training and experience, the introduction of non-professional participants may meet opposition or resistance. Once people with disabilities and family members are introduced into jobs and perform effectively, resistance to their participation will diminish greatly or disappear. International funders can play a key role in ensuring that people with disabilities and family members are included in all programs affecting their rights. People with disabilities and their families should make up at least half of all participants in all advocacy programs, human rights enforcement projects, and public policy advisory boards.

8. Public education

A public education campaign through the mass media is needed to change attitudes about people with disabilities and to raise public support for reform. The great majority of the Russian public has not been exposed to the community integration of people with disabilities. Most people do not know that a person with a severe disability can lead safe, productive, and meaningful life in the community. Popular support for reform will be difficult until the public knows about the potential for reform.

APPENDICES

8

8.1

INFORMATION ON SPECIFIC DISABILITIES

One of the challenges that the disability community has had to face is that there is no single definitive definition of disability. There is a great range of definitions currently in use, depending on the situation and environment, be they medical, social, or legislative.

AMERICANS WITH DISABILITIES (ADA) DEFINITION OF DISABILITY

The ADA has a three-part definition of "disability." This definition, based on the definition established under the Federal Rehabilitation Act (1973), reflects the specific types of discrimination experienced by people with disabilities. Accordingly, it is not the same as the definition of disability in other laws, such as state workers' compensation laws or other federal or state laws that provide benefits for people with disabilities and disabled veterans.

Under the ADA, an individual with a disability is a person who:

- has a physical or mental impairment that substantially limits one or more major life activities;
- has a record of such an impairment; or
- is regarded as having such an impairment.

Please note: The ADA has been amended several times since its passage in 1990 and is undergoing continuous interpretation in the court systems.

Contact your regional DBTAC at 1-800-949-4232 V/TTY for the most up-to-date information.

WORLD HEALTH ORGANIZATION DEFINITION

The World Health Organization (WHO) began a process in the mid 1990's of examining their classification of Impairment, Disability and Handicap (ICIDH). The result is the International Classification of Functioning (ICF), which strongly reflects the social (human rights) model of disability in contrast to the medical model previously used.

The International Classification of Functioning (ICF) defines disability as the outcome of the interaction between a person with an impairment and the environment and attitudinal barriers s/he may face.

Disabled Peoples' International was represented in the process of examining the classification and uses this definition as well.

DISABILITY DESCRIPTIONS

Amputated or Short Limbs

People with missing limbs are often referred to as amputees. A large number of amputations are the result of automobile, machinery or explosive accidents, such as landmines. Certain diseases, such as diabetes, may also necessitate amputations. Some people are born with limbs that are short or formed differently than usual.

Arthritis

In arthritis, joints become inflamed and may become enlarged and painful to move, causing a loss of range of motion. Rheumatoid arthritis is a common type of arthritis which causes disability. Rheumatoid arthritis is systemic, meaning that it affects all of the body systems, causing pain and fatigue. People with arthritis often use medication for pain and inflammation. Other important ways of dealing with arthritis include getting enough rest and exercise and protecting joints by using crutches or electric wheelchairs.

Blindness/Visual Impairment

People who are visually impaired have a wide range of abilities. There are many types and degrees of visual impairments. Someone who is describe as legally blind may be able to read large print and walk without mobility aids in many or all situations. Some individuals are able to perceive light and darkness and perhaps even some color, while others who are legally blind may not necessarily have any of these attributes.

It is impossible to generalize visual impairments into one problem with one solution. People with congenital visual impairments (impairments present from birth) may have learned skills in reading Braille and using tactile orientation aids. People who have lost their sight later in life may not use Braille and may have visual memories of color and scale that others do not.

The most important thing to remember is to ask the person who is blind/visually impaired how he or she would like to be assisted. Remember that the individual may choose not to be assisted at all.

Cerebral Palsy

Cerebral palsy (often referred to as CP) is a neurological condition resulting from damage to the brain before, during or just after birth. Control of the muscles is affected, ranging greatly in type and degree of impairment. Depending on which part of the brain has been affected, one of the following may occur: increased or decreased muscle tone, spasms, involuntary movement, unique gait and mobility, impairment of sight and hearing or speech. The three main types are spastic—stiff and difficult movement; athetoid—involuntary and uncontrolled movement; and ataxic—unique sense of balance and depth perception. One person may experience a mixture of these types of cerebral palsy.

Cognitive Disabilities

In people described as cognitively disabled, learning ability develops at a slower-than-average pace. Reasoning and judgment capabilities may also develop at a delayed rate. For most people with cognitive disabilities, the ability to learn is not absent—they simply learn at a slower speed and with less ease. Some social skills may be impaired as well.

The range of capabilities in people with cognitive disabilities is probably greater than in any other disability group. The general public has great apprehension and misconceptions about people with cognitive disabilities.

When provided with appropriate support and adaptations, many people with cognitive disabilities are able to perform a wide range of tasks and activities with nondisabled people. Others may require more structure and assistance.

Emotional Disabilities

There are many situations or behaviors that may lead to labeling an individual as emotionally impaired. Other terms used include psychiatric illness/disability and mental illness. See the description of psychiatric disabilities.

Epilepsy

Epilepsy is a term used to cover more than 20 different kinds of seizure disorders. Seizures may include convulsions, short periods of unconsciousness, distortion of the senses or loss of control over movement. Basically, seizures are classified by variations in severity, duration, frequency and warning of impending attacks. Three of the most common types are grand mal, petite mal and psychomotor seizures.

An individual's seizure threshold can be influenced by many things, such as emotional upsets, bodily discomfort, stress, hunger, environment, certain activities, tiredness or a change in medications. Some people who have epilepsy use medication to control their seizures, in combination with lifestyle accommodations like good nutrition and rest.

Head Injuries

A head or brain injury is caused by trauma to the brain in the form of an accident, assault, infection or an incident resulting in deprivation of oxygen to the brain. A head injury may cause only temporary, mild effects, or may lead to permanent disability. Depending on the area and amount of damage, a head injury may affect physical abilities, cognitive abilities, speech, emotions or behavior. A person who has experienced a disabling head injury may display a wide range of effects, including paralysis, seizures, sensory difficulties, mood swings, depression or difficulty with remem-

bering, learning or concentrating. Many people who become disabled as a result of head injury are able to return to active lives after recovery and rehabilitation. Helpful strategies for working with someone with a head injury include establishing routines, writing down important information and breaking complex tasks into simple steps.

Hearing Impairments

Hearing impairments affect people of all ages and may occur at any age. The degree of loss ranges from mild to very significant. Each individual's adjustment to hearing loss is different, depending upon the degree and type of loss, the age of onset and individual coping skills. Some people with hearing impairments can be assisted by hearing aids, while other types of hearing impairments cannot be corrected.

People with mild hearing loss are able to function with little adaptation in group and individual conversations. People with more significant hearing impairments usually have difficulty understanding speech from a distance of more than a few feet and may not be able to follow group conversations with or without the aid of an amplifier. People with profound hearing impairments cannot understand spoken language by ear alone, even with amplification of sounds, and must use other methods for communication.

The two main approaches to sign language for Deaf or hard of hearing individuals in the United States are American Sign Language (ASL) and Manual or Signed English. American Sign Language (ASL) uses English words but has its own grammar, vocabulary and syntax. Manual or Signed English uses signs, but is based on English word order and grammar. Other methods of communication used by people who are Deaf or hard of hearing include fingerspelling and speech or lip reading. People who communicate with fingerspelling use signs representing each letter of the alphabet to spell out words and sentences. Those who use speech or lip reading are able to understand conversations by interpreting lip movement, facial expression and other visual cues.

It is important to note that not all deaf people choose to use sign language. Some prefer to be exclusively oral, reading lips and voicing. Many deaf people use some combination of communication methods depending on the environment.

Learning Disabilities

"Learning disability" is an umbrella term used to discuss a wide range of information processing disorders that affect academic or experiential learning skills. Though by definition people with learning disabilities are of above-average intelligence, they may have trouble with reading, math, writing, orientation or other skills.

There are many different types of learning disabilities and it is very important to find out as much as possible about the strengths and weaknesses of each individual.

People with learning disabilities, with appropriate support, do attend college, enter every profession and lead active lives. Most learn ways to compensate for learning deficits by using accommodations such as calculators and tape recorders. Most people with learning disabilities can function effectively by avoiding problem areas or finding other ways to compensate for their learning disabilities.

Mobility Impairments

Wheelchairs and electric scooters help increase mobility for many people with physical disabilities. People who use wheelchairs or scooters for mobility have many environmental concerns. Requirements include ramped entrances, elevators rather than stairs, adequate parking in convenient areas, level sidewalks with firm surfaces and wide aisles in stores, classrooms and other public places. Access to toilet facilities, drinking water, telephones, doors, tables and shelves are just some of the considerations to take into account when accommodating people who use wheelchairs.

Many people with upper- and lower-limb impairments or reduced stamina use electrically powered wheelchairs for mobility. Uneven surfaces, such as cobblestones, can cause a moving power chair to jolt, become erratic or malfunction. Uneven surfaces can also aggravate pain in some individuals.

Multiple Sclerosis

Multiple sclerosis (often referred to as MS) is a chronic condition of the central nervous system characterized by a wide range of symptoms. MS is progressive and aggravated by stress and high temperatures, and an individual's condition may vary from time to time. Symptoms may

include partial to complete paralysis involving one or more limbs, visual or speech disturbances and, occasionally, memory changes or confusion.

Symptoms vary greatly from person to person and from time to time in the same person. In general, however, the typical pattern of multiple sclerosis is marked by periods of active disease called exacerbations and symptom-free periods called remissions. Others may experience a chronic progressive form of the disease. People who have MS may be especially concerned with stress, fatigue, nutrition, and temperature levels, as these may affect their physical condition.

Muscular Dystrophy

Muscular dystrophy (MD) is a disability affecting the muscles which manifests itself in many different ways. MD causes gradual weakening of voluntary muscles. Muscular dystrophy itself is not fatal. However, with some types of muscular dystrophy, eventually muscles may cease to be able to perform their functions in respiration and circulation. Some types of MD are not progressive.

Poliomyelitis

Poliomyelitis or polio is a disability caused by a virus that affects motor cells in the spinal cord. This virus destroys the nerve impulses in certain muscles. Residual effects of polio vary depending on the level of nerve damage. Some people experience only mild residual effects of the disease while others may have mobility impairments. Weakness in upper and lower limbs or other body systems may be a part of post-polio syndrome as well. Individuals with post-polio syndrome often monitor exercise and activity levels, and use energy conservation methods to prevent pain and fatigue.

Speech Impairment

Speech impairments are caused by many different types of diseases and disabilities. Some types of speech difficulties are present from childhood, while others may occur as the result of an accident or other trauma. The severity of speech impairments varies widely among those affected.

Spina Bifida

Spina bifida is a congenital malformation of the spinal column in which

some portion of the vertebra fails to form over the spinal cord, leaving it exposed. This can be corrected with surgery to some extent. Varying degrees of neurological impairment are associated with spina bifida. The effects of this disorder may include reduced leg strength as well as bowel and bladder control issues. People who have spina bifida may walk with crutches or braces, or may use wheelchairs.

Spinal Cord Injury

When the spinal cord is damaged or severed, sensory and motor nerves are not able to send impulses below the level of the injury. Some individuals with spinal cord injuries may have reduced bowel or bladder control. Others may need to take extra care in protecting their skin. Paralysis may also affect responses to external stimuli like touch, temperature and pain. People with spinal cord injuries (and other types of paralysis) need to pay special attention to padding, posture and activities to avoid pressure sores.

People with spinal cord injuries are referred to either as quadriplegic if all limbs are fully or partially paralyzed, or paraplegic if two limbs are affected.

Stroke

A stroke involves the destruction of brain tissue resulting from the rupture or blockage of a cerebral blood vessel or vascular insufficiency. Hemiplegia (paralysis on one side of the body) and speech impairment are common effects. Other people who have had strokes may also have mobility impairments. While the majority of people experiencing strokes are age 50 and over, younger people are also affected.

HIDDEN DISABILITIES

Diabetes

People with diabetes are not able to effectively process glucose (sugar) from food into energy for daily activities. The most common types of diabetes are Type I or insulin-dependent and Type II or non-insulin-dependent diabetes. Type I diabetes usually appears in people under age 30, and requires regular doses of insulin through injections or an insulin pump, regular exercise and daily self-monitoring of blood glucose. Type

II diabetes develops most often in adults and is managed through diet, exercise and monitoring of glucose levels. People with Type II diabetes may or may not use oral diabetes medication or insulin injections.

People who have well-controlled diabetes usually live active lives with few complications. People who are managing diabetes will need to take into account factors which influence glucose levels and insulin sensitivity, including type and quantity of food, physical activity, stress, emotions, sleep schedules, temperatures and illness. On occasion, serious situations may arise which require immediate and sometimes emergency treatment. These include hypoglycemia (blood sugar that is too low) and insulin shock, which are treated by rapidly administering fast-acting forms of glucose. Ketoacidosis, a serious condition that happens when blood sugar levels get too high, may also occur. Ketoacidosis requires medical care, and is treated by giving fluids and insulin.

Symptoms of undiagnosed or untreated diabetes include excessive thirst, frequent urination, weight loss, unusual hunger, fatigue, and blurred vision. People who live with uncontrolled diabetes may develop long-term complications, including cardiac, circulatory, nervous system and renal problems or vision impairments.

Environmental Sensitivity

Environmental sensitivity is a medical condition in which chemicals, dyes, perfumes and other pollutants have a severe and pronounced effect on an individual's immune system.

Sensitivities vary greatly from person to person. Reactions range from skin rashes and more severe allergic reactions to respiratory problem such as asthma. There is still much to be learned about environmental sensitivity in the medical community.

PSYCHIATRIC DISABILITIES

Some people who have been labeled with psychiatric disabilities consider the label itself a disability.

* The following information has been adapted from Job Accommodation Network, National Alliance for the Mentally Ill and Center for Psychiatric Rehabilitation, Boston University.

•*Anxiety disorders*
Anxiety disorders are characterized by severe fear or anxiety associated with particular objects and situations. Anxiety disorders include panic disorder, post-traumatic stress disorder (PTSD), obsessive-compulsive disorder (OCD), generalized anxiety disorder, and phobias (social phobia, agoraphobia, and specific phobias).

•*Panic disorder*
The sudden onset of paralyzing terror or impending doom with symptoms that closely resemble a heart attack.

•*Post-traumatic stress disorder*
A psychological syndrome characterized by specific symptoms that result from exposure to terrifying, life-threatening trauma such as an act of violence, war, or a natural disaster.

•*Obsessive-compulsive disorder*
Persistent distressing thoughts (obsessions) that a person attempts to alleviate by performing repetitive, intentional acts (compulsions) such as hand washing.

•*Phobias*
Excessive fear of particular objects (simple phobias), situations that expose a person to the possible judgment of others (social phobias), or situations where escape might be difficult (agoraphobia).

•*BiPolar disorder*
Bipolar disorder (manic depression) is a brain disorder involving episodes of mania and depression. It causes extreme shifts in mood, energy, and functioning.

•*Depression*
Depressive disorders affect a person's mood, concentration, sleep, activity, appetite, social behavior, and feelings. Depressive disorders

come in different forms, the most common being major depression (unipolar depression).

•*Major depression*
An extreme or prolonged episode of sadness in which a person loses interest or pleasure in previously enjoyed activities.

•*Dysthymia*
Continuous low-grade symptoms of major depression and anxiety.

•*Seasonal affective disorder (SAD)*
A form of major depression that occurs in the fall or winter and may be related to shortened periods of daylight.

•*Schizophrenia*
Schizophrenia impairs a person's ability to think clearly, manage his or her emotions, make decisions, and related to others. People with schizophrenia suffer terrifying symptoms that often leave them fearful and withdrawn.

8.2

TIPS FOR APPROPRIATE LANGUAGE

Guidelines for terms referring to people with disabilities

AVOID	APPROPRIATE
Abnormal, subnormal. Negative terms that imply failure to reach perfection.	Specify the disability.
Afflicted with. Most people with a disability don't see themselves as afflicted.	Say the "person has (the disability)."
Birth defect, also congenital defect, deformity.	Say the "person with a disability since birth," or "person with a congenital disability."
Blind (the), Visually impaired (the).	Say "person who is blind," or "person with a vision impairment."
Confined to a wheelchair, wheelchair-bound. A wheelchair provides mobility not restriction.	Say "uses a wheelchair."
Cripple, crippled. These terms convey a negative image of a twisted, ugly body. Avoid.	Say "has a physical or mobility disability."

AVOID	APPROPRIATE
Deaf (the). People who are deaf are those who identify as a part of the deaf community or who use sign language.	"The Deaf community" is only appropriate when referring to the community. When speaking about an individual say "person who is Deaf."
Deaf and dumb. Inability to hear and speak. Does not imply any intellectual disability. Avoid.	Say "hearing impaired." Lack of speech usually results from impaired hearing.
Defective, deformed. Degrading terms. Avoid.	Specify the disability.
Disabled (the).	Say "people with a disability."
Dwarf. Negative connotation.	Say "short statured person."
Epileptic.	Say "person with epilepsy."
Fit, attack, spell.	Say "seizure."
Handicapped (the).	Say "person with a disability" unless referring to an environmental or attitudinal barrier, in such cases "person who is handicapped by a disability" is appropriate.
Insane, also lunatic, maniac, mental patient, mentally diseased, neurotic, psycho, psychotic, schizophrenic, unsound mind, etc. Derogatory terms. Avoid.	Say "person labeled with a psychiatric disability" or specify the condition.

AVOID	APPROPRIATE
Invalid. The literal sense of the word is "not valid." Avoid.	Say "person with a disability."
Mentally retarded, also defective, feeble minded, imbecile, moron, retarded. Offensives, inaccurate terms. Avoid.	Say "person with a mental or developmental disability."
Mongol. Outdated and derogatory.	Say "has Down Syndrome."
Patient. Only use in context of doctor/patient relationship or in hospital.	Say "person with a disability."
Spastic. Usually refers to a person with cerebral palsy or who has uncontrollable spasms. Derogatory, often term of abuse. Should never be used as a noun.	Say "person with a disability."
Special. Over and often inappropriately used term, for example, "a special person," "a special story," " a special achievement."	Describe the person/event/achievement as you would normally.
Suffers from, sufferer, stricken with. Not all people with disabilities actually suffer. These terms should not be used indiscriminately.	Say "person with a disability."
Vegetative. Offensive and degrading.	Say "in a coma," "comatose," or "unconscious."

AVOID	APPROPRIATE
Victim. People with a disability are not necessarily victims and prefer not to be perceived as such.	Say "has a disability."

Adapted from:

Disability Program
Department of Families, Youth and Community Care

For further information contact:

Telephone: 3224 8045
Freecall: 1800 177 120 (outside Brisbane)
TTY: 3224 8021
Website: www.families.qld.gov.au

GPO Box 806,
Brisbane Qld 4001

Acnowledgements: Disability Council of NSW, Joan Hume, Cathy Wilcox

8.3

RESOURCES AVAILABLE

Disability and Business Technical Assistance Centers (DBTACs)
Tel: 1 (800) 949-4232 (V/TTY)
Web: www.adata.org/dbtac.html

The National Institute on Disability and Rehabilitation Research (NIDRR) has established ten regional centers to provide information, training, and technical assistance to employers, people with disabilities, and other entities with responsibilities under the ADA. The centers act as a "one-stop" central, comprehensive resource on ADA issues in employment, public services, public accommodations, and communications. Each center works closely with local business, disability, governmental, rehabilitation, and other professional networks to provide ADA information and assistance. Programs vary in each region, but all centers provide the following:
technical assistance, education and training, materials dissemination, information and referral, public awareness, and local capacity building.

Disability Rights Education and Defense Fund (DREDF)
Contact: Susan Henderson
2212 Sixth Street
Berkeley, CA 94710 USA
Tel: (510) 644-2555 or (800) 348-4232
TTY: (510)- 644-2555
E-mail: dredf@dredf.org
Web: http://dredf.org

The Disability Rights Education and Defense Fund (DREDF) was established on October 1, 1979 in Berkeley, California. A nonprofit national law and policy center run primarily by people with disabilities and parents of children with disabilities, DREDF is dedicated to protecting and advancing the civil and human rights of people with disabilities through law and policy development, litigation, advocacy, technical assistance, and the education and training of attorneys, advocates, persons with disabilities and parents of children with disabilities. DREDF serves as one of the disability community's primary national legal defense organizations.
With offices in Berkeley and Washington, DREDF has approximately 20 staff members, the majority of whom are people with disabilities or parents of children with disabilities.

DREDF has been a national leader in developing federal disability civil rights laws and policies, most notably the landmark 1990 Americans with Disabilities Act, and enforcing these policies through litigation in the United States. DREDF has also forged alliances with disability organizations around the world and has consulted on disability policy and programs in 17 countries, including Costa Rica, Bosnia, Vietnam, New Zealand, Ecuador, South Africa, and Japan. The DREDF website houses a listing of international disability laws worldwide and DREDF is developing an Internet-based International Clearinghouse on Disability Law and Policy. In 2002, DREDF published *Disability Law and Policy: International and National Perspectives*, the first comprehensive analysis of global disability rights.

UN Special Rapporteur on Disabilities
Bengt Lindqvist
Spektern, S-103 33
Stockholm, Sweden
Tel: (46) 8 405 2421, or (46) 8 405 1768
E-mail: un-spec.rapp@telia.com
Web: www.disability-rapporteur.org/index.htm

The United Nations Standard Rules on the Equalization of Opportunities for Persons with Disabilities were adopted by the UN General Assembly in 1993. In the last chapter of the Rules - Monitoring Mechanism – it is

indicated that a monitoring mechanism should be established. "A Special Rapporteur with relevant and extensive experience in disability issues and international organizations shall be appointed."

The purpose of the monitoring is to further the implementation by member states of the Standard Rules. The Special Rapporteur goes on missions to individual countries and participates in various forms of seminars, workshops and conferences, promoting the implementation of the rules. The Special Rapporteur shall seek to establish a direct dialogue not only with states but also with local non-governmental organizations.

8.4

DISABLED PEOPLES ORGANIZATIONS AROUND THE WORLD

By strengthening our networks and broadening our partnerships, our work becomes more inclusive. The following country-by-country list of disabled peoples organizations (DPOs) in over 160 countries form part of the Mobility International USA (MIUSA) network of resources. These organizations can also be accessed through the MIUSA website through the online searchable database. Networking with these DPOs may assist your organization as an important strategy towards inclusive development. If you would like more assistance please contact us at: development@miusa.org or visit our website at www.miusa.org.

Albania
Albanian Disability Rights Foundation
Albanian Humanity Association of Disabled Workers
Albanian National Association of the Deaf
Albanian Paraplegic Association
Association of Independent Civil Invalids
Humanitarian Association of Disabled Workers

Algeria
Fédération Algérienne pour le Mouvement de Promotion des Handicapés
Organisation Nat. des Sourds-Muets d'Algérie Centre Familial de Ben-Aknoun
Panafricaine des Personnes Handicapees

Angola
Associacao Nacional de Deficientes Angolanos
Antigua and Barbuda
Antigua & Barbuda Association of Persons with Disabilities

Argentina
Biblioteca Argentina para Ciegos (Argentine Library for the Blind)
Confederación Argentina de Sordomudos
Ente Nacional Coordinador de Instituciones de Discapacitados
Federación Argentina de Instituciones de Ciegos yAmbliopes
(Argentine Federation of Blind Institutions)

Armenia
Armenian Deaf Association
Armenian Union for the Disabled

Australia
ADDults with ADHD (NSW) Inc.
Australian Association of the Deaf, Inc.
Australian Council for the Rehabilitation of the Disabled
Australian Learning Disability Association
Australian Quadriplegic Association
Blind Citizens Australia
Disability Australia Ltd.
Disability Services Commission - Australia
Mental Health Association NSW Inc.
Multiple Sclerosis Australia
National Council on Intellectual Disability
National Institute of Deaf Studies
Royal Victorian Institute for the Blind
SANE Australia
Victorian Deaf Society
Women with Disabilities Australia
World Federation of Occupational Therapists

Austria
Allgemeine Unfallversicherungsanstalt
Berufliches Bildungs und Rehabilitationszentrum Linz

Bizeps
Osterreichische Arbeitsgemeinschaft fur Rehabilitation
Österreichischer GerhörlosenBund

Azerbaijan
Association of Disabled People of the Azerbaijan Republic
Azerbaijan Deaf Society
Azerbaijan Republic Society For International Cooperation of Disabled People
Azerbaijani Society of Disabled Women

Bahamas
Disabled Persons Organization of Bahamas

Bahrain
Friendship Society for the Blind
Ministry of Labour and Social Affairs

Bangladesh
Bangladesh Dristihin Foundation
Bangladesh National Federation of the Deaf
Bangladesh Protibandhi Kallyan Somity
Bangladesh Protibondhi Foundation (Foundation for the Developmentally Disabled)
Blind Education and Rehabilitation Development Organization

Barbados
Barbados Council for the Disabled
Barbados National Organization of the Disabled

Belarus
Belarusian Charitable Fund For the Children of Chernobyl
Belarussian Society of the Deaf
Belorussian Society of the Handicapped
Beylorussian Society for Disabled People

Belgium
Agence Wallonne pour l'Integration des Personnes

Handicapees (A.W.I.P.H.)
Disability Care Province of Antwerpen
European Association of Service Providers for Persons with Disabilities
European Disability Forum
European Forum of Sign Language Interpreters
FEVLADO - Federatie van Vlaamse DovenOrganisaties v.z.w.
Independent Living Vlanderen
Mobility International Vlaanderen (Flanders)

Belize
Belize Council for the Visually Impaired
Belize National Association of the Deaf
Belizean Assembly of and for Persons with Disability

Benin
Association Nationale des Sourds du Benin
Federation des Associations des Personnes Handicapees du Benin
Organisation des Femmes Handicapees du Benin

Bolivia
Confederación Boliviana de Personas con Discapacidad
Federación Boliviana de Sordós
Bosnia and Herzegovina
Association of the Hearing Impaired of Bosnia/Herzegovina
Center for Integration of People with Disabilities/Centar za Integraciju sa Onesposoblijenjem
Information Center for Disabled People "LOTOS" Tuzla

Botswana
Botswana Society of People with Disabilities

Brazil
Associacao Brasileira Beneficiente de Reabilitacao
Associacao de Assistencia a Crianca Defeituosa
Associacao Fluminense de Reabilitacao
Associacao Para Valorizacao e Promocao de Excepcionais
Associacao Paranaense de Reabiltacao
Centro de Vida Independente - Araci Nallin

Centro de Vida Independente - Maringa
Centro de Vida Independente do Rio de Janerio
Federaçâo Nacional das APAE
Federacao Nacional des Sociedades Pestalozzi
Federacion Nacional de Educacion e Intergracao dos Surdos
IID Regional America Latina
Instituto Brasileiro de Defesa dos Dereitos da Pessoa Portadora de Deficiencia
Niteroi Disabled Association
Organizacion Nacional de Deficientes Fisicos
Projeto Fênix
Uniao Brasileira de Cegos

Bulgaria
Association of Students with Disabilities
Ministry of Health National Center of Physical Therapy and Rehabilitation
Union of Disabled People in Bulgaria
Union of the Deaf in Bulgaria

Burkina Faso
Association Nationale des Deficients Auditifs du Burkina
Association pour la Rehabilitation des Handicapes du Burkina-Faso

Burundi
Union des Personnes Handicapees du Burundi

Cambodia
Cambodian Disabled People's Organization
National Center of Disabled Persons
Women with Disabilities in Development of the Disabilities Action Council

Cameroon
Association des Handicapes Moteurs et Amputes du Cameroon
Cameroon National Association of the Deaf
Union Nationale des Associations des Personnes Handicapees du Cameroun

Canada
Accessible Transportation Directorate
Active Living Alliance for Canadians with a Disability
Atlantic Centre of Research, Access and Support for Disabled Students
Canadian Abilities Foundation
Canadian Association for Independent Living Resource Centers
Canadian Association of the Deaf
Canadian Centre on Disability Studies
Canadian Hearing Society
Canadian Mental Health Association
Canadian National Institute for the Blind
Council of Canadians with Disabilities
Deaf Children's Society of B.C.
Disability Information Services of Canada
Disabled Peoples' International
Disabled Women's Network Canada
Global Applied Disability Research and Information Network on Employment and Training
Human Resources Development Canada
International Wheelchair Basketball Federation
Learning Disability Association of Canada
Les Groups Rigionaux de Defense des Droits En Sante Mentale
Motor Adaptation Foundation
National Educational Association of Disabled Students
Society for Disability Arts and Culture
Society for Muscular Dystrophy Information International

Cape Verde
Associacao de Apoio Aos Deficientes

Chad
Association d'entr'aide des Handicapes Physiques au Chad

Chile
Asociación de Sordomudos de Chile
Asociación Nacional de Personas Discapacitadas
Sociedad Pro-Ayuda del Niño Lisiado

China
China Association of the Deaf
China Disabled Persons' Federation
China Fund for the Handicapped
China Rehabilitation Research Center
Chinese Academy of Science, China Association for the Blind
Zhejiang Provincial Federation for the Handicapped

Colombia
Federación Nacional de Sordos de Colombia

Congo
Communauté Chrétienne des Sourds du Congo
Federation Zairoise des Personnes Handicapees
Union Nationale des Handicapes du Congo

Costa Rica
Asociación Nacional de Sordos de Costa Rica
Asociación Costarricense de Padres de Niños Excepcionales
Asociación Nacional de Mujeres Ciegas
Consejo Nacional de Rehabilitación y Educación Especial
Patronato Nacional de Ciegos (National Committee for the Blind)
Prosperar

Cote D'Ivoire
Association Nacionale des Sourds de Côte d'Ivoire
Association Nationale des Handicapes Physiques de Cote d'Ivoire

Croatia
Association of Organizations of Disabled People of Croatia
Croatian Union of Physically Disabled Persons' Associations/Hrvatski Savez
Udruga Tjelesnih Invalida

Cuba
Asociación Cubana de Limitados Fisicos-Motores
Asociación Nacional de Ciegos y Débiles Visuales
Asociación Nacional de Sordos de Cuba
Fraternidad de Ciegos Independientes de Cuba

Cyprus
Cyprus Federation of Organisations of the Disabled
Pancyprian Organisation of the Deaf

Czech Republic
Association of Disabled Persons in Czech Republic
Czech Blind Union
DPI - Czech Republic

Denmark
Danish Center for Congenitally DeafBlind People
Danish Deaf Association (Danske Doves Landsforbund)
Danish Multiple Sclerosis Society (Scleroseforeningen)
Danish Women with Disabilities
Information Center for Acquired Deafblindness
International Federation for Hard-of-Hearing Young People
Rehabilitation International Denmark
World Network of Users and Survivors of Psychiatry

Dominica
Dominica Association of Disabled People

Dominican Republic
Asociación Dominicana de Rehabilitación, Inc.
Asociación Pro-Educación de los Sordomudos, Inc.

Ecuador
Centro de Capacitación, Asesoria, Documentación e Investigación Social
Federación Nacional de Ecuatorianos conDiscapacidad Física
Federación Nacional de Sordos del Ecuador
Fundación General Ecuatoriana
National Federation for the Blind of Ecuador (Federación National de Ciegos del Ecuador)

Egypt
Egyptian Federation of Organizations for People with Special Needs
Future Society for the Disabled

El Salvador
Asociación Cooperativa del Grupo Independiente Pro-Rehabilitación Integral
Asociación Cooperativa del Grupo Independiente
Associación Cooperativa del Grupo Independiente Por Rehabilitación

England
Action on Disability and Development
Association for Spina Bifida and Hydrocephalus
Association of Camphill Communities
British Council of Disabled People
British Deaf Association
British Dyslexia Association
British Institute of Learning Disabilities
Carelink Unit for Disabled Passengers
Centre for Deaf Studies
Depression Alliance
DIAL UK
Disability Awareness in Action Network
Disabled Drivers' Association
European Alliance of Muscular Dystrophy Associations
European League of Stuttering Associations
Foundation for People with Learning Disabilities
Holiday Care
International Cerebral Palsy Society
Leonard Cheshire International
Manic Depression Fellowship
Mental Health Foundation
Mind
Mobility Information Service
Mobility International Teeside
Motivation
Multiple Sclerosis International Federation
National Centre for Independent Living
National Childbirth Trust
ParentAbility
People with Disability Nepal

PHAB Ltd
RADAR
Rethink
Royal National Institute for Deaf People
Royal National Institute for the Blind
SCOPE
Sense International
Shaw Trust
Skill: The National Bureau for Students with Disabilities
TRIPSCOPE
WinVisible - Women with Visible and Invisible Disabilities
World Dyslexia Network Foundation

Equatorial Guinea
American Council of the Blind

Estonia
Eesti Invacihingute Liit
Estonian Association of the Deaf
Estonian Board of Disabled People
Independent Living Estonia

Ethiopia
Ethiopian National Association of the Blind
Ethiopian National Association of the Deaf

Fiji
Fiji Disabled Peoples' Association

Finland
Abilis
DPI Finland, National Association of the Disabled
European Network of Women with Disabilities
Finnish Association of People with Mobility Disabilities
Finnish Association of the Deaf
Finnish Federation of Visually Impaired
Rehabilitation International Finnish Committee
Service Foundation for the Deaf
World Federation of the Deaf

France
Aide aux Personnes A Handicap Moteur
Association des Paralyses de France
Centre de Readaptation Professionnelle et Fonctionnelle de Nanteau-sur-Lunain
Fédération des Aveugles et Handicapées Visuels de France
Fédération National des Sourds de France
Groupement Francais des Personnes Handicapées
Handicap International
Inclusion International
International Federation of Hard of Hearing
Réponses Initiatives Femmes Handicapées
UNESCO (United Nations Educational, Scientific, and Cultural Organization)
Union Nationale des Associations de Parents et Amis de Personnes Handicapées Mentales

Gabon
Association Nationale des Personnes Handicapees du Gabon

Gambia
Gambia Association of the Deaf and Hard of Hearing
Gambia Federation of the Disabled

Georgia
Georgian Disabled Women's International Association
Georgian League of Disabled Persons (a.k.a. League of Invalids)
Order of the Saint Queen Tamar of Veterans and Disabled of Georgia

Germany
Advice Center for University Applicants and Students with Disabilities
Bundersarbeltsgemeinschaft Hilfe für Behinderte e.V
Bundesarbeitsgemeinschaft fur Rehabilitation (Federal Rehabilitation Council)
Christoffel Blindenmission International
Deutsche Vereinigung fur die Rehabilitation Behinderter E.V. (German Society for Rehabilitation of the Deutscher Gerhörlosen-bund)
DPI Germany
International Federation of Workers with Physical Disability

ISL e.V. - Disabled Peoples' International - Germany
MOVADO
Weibernetz e.V. Bundesnetzwerk von FrauenLesben und Madchen mit Beintrachlingun

Ghana
Brotherhood Link Ghana
Ghana Federation of the Disabled
Ghana National Association of the Deaf
Ghana Society of the Physically Disabled

Greece
Disability NOW
Hellenic Society for Disabled Children
Panhellenic Association of the Blind
Paraplegics Association of Greece
Rehabilitation Center for Disabled Children

Grenada
Grenada National Council of the Disabled

Guatemala
Asociación de Sordos de Guatemala
Asociación Guatemalteca de Rehabilitatión de Lisiados
Consejo Nacional para la Atención de la Persona con Discapacidad Enfermas y con Discapacidad
Transiciones: Una Organización de Personas Discapacitadas

Guinea
Club Unesco, N'Zerekore
West African Federation of Disabled Persons

Guyana
Guyana Coalition of Citizens with Disability

Haiti
Association Haitienne pour la Rehabilitation des Handicapes

Honduras
Fraternidad Cristiana de Enfermos y Limitados Fisicos
Hong Kong
Hong Kong Association of the Deaf
Hong Kong Society for the Deaf
Joint Council for the Physically and Mentally Disabled

Hungary
De juRe Alapitvany (Disability Rights Advocates Hungary)
Hungarian Federation of the Blind and Partially Sighted
Hungarian National Association of the Deaf
National Federation of Disabled Persons' Associations

Iceland
Félag Heyrnarlausra / Icelandic Deaf Organization
Organization of Handicapped in Iceland
Öryrkjabandalag Íslands (Organization of Disabled in Iceland)

India
All India Federation of the Deaf
All India Sports Council of the Deaf
Amar Jyoti Charitable Trust
Association of People with Disability
Center for Advocacy in Mental Health
Children Welfare Trust
Community Aid and Sponsorship Programme
Diabetic Association of India
Disability India Network
Disabled Peoples' International - India
Kutch Youth Disabled Association
MANTHAN
Mobility India
National Centre for Promotion of Employment for Disabled People
National Federation of Orthopedically Handicapped
Rehabilitation - India
Rehabilitation Coordination-India
Spastics Society of Tamilnadu
UNNATI
Volunteer Health Association of India

Indonesia
Indonesian Disabled People Association
Indonesian Society for the Care of Disabled Children
Indonesian Welfare Association of the Deaf
Persatuan Penyandang Cacat Indonesia (Indonesia Disabled Peoples' Association)

Iran
Iranian National Center for the Deaf
Welfare Organization

Iraq
Al Qadisia Warrior Welfare Council

Ireland
Association for Higher Education Access and Disability
Brainwave - Irish Epilepsy Association
Center for Independent Living Dublin
Comhairle
COPE Foundation
Disability Federation of Ireland
Disabled Drivers Association of Ireland
Galway County Association for Mentally Handicapped Children
Irish Deaf Society
Irish Guide Dogs for the Blind
Irish Kidney Association
Irish Wheelchair Association
Mental Health Association of Ireland
Muscular Dystrophy Ireland
National Council for the Blind of Ireland
National Rehabilitation Board
Rehab Group

Israel
Association of the Deaf in Israel
Israel Center for Technology and Accessibility
Israel Rehabilitation Society

Italy
Associazione Italiana Assistenza agli Spastici
Associazione Italiana Diabetici (Italian Diabetes Association)
Associazione Italiana Persone Down (Italian Association of People with Down Syndrome)
Biblioteca Italiana per i Ciechi (Italian Library for the Blind)
Center Disabili Information
Consulta Nazionale per la Salute Mentale (National Council on Mental Health)
Cooperative Integrate Onlus
Disabled Peoples' International - Italy
Ente Nazionale Sordomuti
Federazione delle Associazioni Italiane dei Para-tetraplegici (Federation of Italian Associations of Paraplegia)
Mason Perkins Deafness Fund
Scuola Nazionale Cani Guida per Ciechi (National School of Guide Dogs for the Blind)
Stamperia Braille
Unione Italiana Ciechi (Italian Union of the Blind)
Unione Nazionale delle Associazioni per la Salute Mentale (Italian Association for Mental Health)

Jamaica
Combined Disabilities Association

Japan
Center for Supporting the Lives of Handicapped People
Footloose
Humana Care Association
Japan Association for Employment of the Disabled
Japan Council on Disability
Japan Council on Independent Living Centers
Japan Federation of the Blind
Japan National Assembly of Disabled Peoples' International
Japan National Group of Mentally Disabled People
Japanese Federation of the Deaf
Japanese Red Cross Language Service Volunteers Executive Committee

Accessible Japan
Japanese Society for Rehabilitation of the Disabled
Kyoto Light House
Nation-wide Support Center for Students with Disabilities
Zenkaren

Kenya
Association for the Physically Disabled of Kenya
Ecumenical Disability Advocates Network of the World Council of Churches
Kenya Disabled Development Society
Kenya Institute of Special Education
Kenya National Association of the Deaf
Kenya Programmes of Disabled Persons
National Rehabilitation Committee
United Disabled Persons of Kenya
Korea, Republic of (South)
Bitjang Research Institute on the Rights of Women with Disabilities
Disabled Peoples' International - Korea
Hanbeot
Korea Association of the Deaf
Korean Differently Abled Women's United
Korean Society for Rehabilitation of Persons with Disabilities
Volunteering Service Group for the Handicapped

Kosovo
Little People of Kosovo

Kuwait
Kuwait Association of the Blind
Kuwait Club for the Deaf
Kuwait Society for the Handicapped

Kyrgyzstan
Association Dostuk
Charitable Fund "ARUNA"
Independent Assoc. Women with Disabilities of Kyrgyz Republic
Society of the Invalids of Lenin Area Biskek City

Latvia
Disabled Peoples' Association of Latvia
Latvian Association of the Deaf
Latvian Disabled Children's and Youth Sports Federation
Special School Riga

Lebanon
Association de l'Oeuvre des Sourds-muets au Liban
Lebanese Council of Disabled People
National Association for the Rights of Disabled People
National Rehabilitation and Development Center

Lesotho
Lesotho National Federation of Organizations of the Disabled

Liberia
National Federation of the Handicapped
Libyan Jamahiriya (Libya)
General Federation of the Deaf Societies in the GSPLAJ

Lithuania
Lithuanian Association of the Blind and Visually Handicapped
Lithuanian Deaf Association
M95 - The Occupational and Business Support Foundation

Luxemburg
Centre de Readaptation
Fondation Association des Parents d'Enfants Mentalement Handicapes
Info-Handicap

Macau
Macau Deaf Association

Macedonia
Association of Deaf and Hard-of-Hearing of Macedonia

Madagascar
Association for the Deaf and Friends in Madagasikara
Union Nationale des Associations D'Handicapes de Madagascar

Malawi
Disabled Women in Development (DIWODE)
Federation of Disability Organizations in Malawi
Malawi Council for the Handicapped

Malaysia
Malaysia Federation of the Deaf
Malaysian Confederation of the Disabled
Malaysian Council for Rehabilitation
Malaysian Leprosy Relief Association
Malaysian Spinal Injuries Association

Maldives
Maldivian Association of the Handicapped

Mali
Federation Malienne des Associations de Handicapes
Panafrican Federation of the Disabled Persons

Malta
Katina
National Association of the Young Deaf
Physically Handicapped Rehabilitation Fund

Mauritania
Action for Social Development in Mauritania
Union Nationale des Handicapes Physiques et Mentaux

Mauritius
Federation of Disabled Persons' Organizations Mauritius
National Council for Rehabilitation of Disabled Persons

Mexico
Asociación Mexicana de Sordos

Asociación Tijuana en Apoyo al Sordo
Centro De Vida Independiente Para Mujeres Con Discapacidad A.C.
Confederación Mexicana de Limitados Fisicos y Representantes de Deficientes Mentales, A.C.
Fundación Mexicana de Integración Social (Mexican Foundation of Social Integration)
Project PROJIMO
Unión Mexicana de Organizaciones e Instituciones de y para Ciegos
Universidad Nacional Autónoma de México (UNAM) - Servicios para Personas con Discapacidades
Vision Sin Limites

Moldova, Republic of
Disabled Society of Moldova
Society of the Deaf of Republic Moldova

Mongolia
Mongolian Association of the Blind and Deaf
Mongolian Federation of Disabled Persons

Morocco
L' Association Marocaine des Sourds
L'Association Marocaine des d'ficients Moteurs

Mozambique
Forum of Associations of Disabled People in Mozambique
N. Ireland
Aware Defeat Depression
CAUSE
Disability Action
PHAB Northern Ireland

Namibia
Namibian National Association of the Deaf
National Federation of People with Disabilities in Namibia

Nepal
Association for the Welfare of the Mentally Retarded

Kathmandu Association of the Deaf
National Federation of the Disabled Nepal
Nepal Association for Welfare of the Blind
Nepal Diabetes Association
Nepal Disabled Association
Nepal Disabled Women Society
Nepal National Federation of the Deaf and Hard of Hearing
Sahara Griha

Netherlands
Dovenschap
Dutch Council of the Chronically Ill and the Disabled
International Bureau for Epilepsy
Nederlandse Cystic Fibrosis Stichting
Netherlands Institute for Care and Welfare
SPD

New Zealand
Amputees Federation of New Zealand
Association of Blind Citizens of New Zealand
Deaf Association of New Zealand
Diabetes New Zealand
Disabled Persons Assembly New Zealand Inc.
Enable New Zealand
IHC New Zealand Inc
Mental Health Foundation of New Zealand
MS Society of New Zealand
Royal New Zealand Foundation for the Blind
Vision Pacific Trust
Workbridge Inc.

Nicaragua
Asociación de Mujeres Discapacitadas de León (Association of Women with Disabilities)
Asociación Nacional de Sordos de Nicaragua
Asociación Nicaraguense de Apoyo al DisCapacitado
Centro de Promoción de la Rehabilitación Integral
Los Pipitos: Association of Parents of Families with Children with Disabilities

National Network of Disabled Women
Organización de Revolucionarios Discapacitados, Ernesto Che Guevara

Niger
Association des Sourds du Niger
Federation Nigerienne des Personnes Handicapes

Nigeria
Nigeria National Association of the Deaf

Norway
Funksjonshemmedes Fellesorganisasjon (Norwegian Federation of Organisations of Disabled People)
Norges Blindeforbund (Norwegian Association of the Blind and Partially Sighted)
Norwegian Association of the Disabled
ULOBA

Oman
Oman Association of the Disabled

Pakistan
Association of Physically Disabled People
Disabled Peoples' International - Pakistan
Pakistan Association of the Deaf
Pakistan Foundation Fighting Blindness
Pakistan Society for the Rehabilitation of the Disabled

Palestine
Jerusalem Princess Basma Center for Disabled Children

Panama
Asociación Nacional de Personas con República de Impedidas
Foundation for Equality of Opportunities/Fundación para la Igualdad de Oportunidades
Instituto Panameno de Habilitación Especial

Papua New Guinea
Simbu Disabled Association
Paraguay
ARIFA
Centro Sordomudos del Paraguay

Peru
Asociación de Sordos del Perú
Confederación Nacional de Discapacitados de Peru
Sociedad Peruana de Polio

Philippines
Federation of Organizations of Persons With Disabilities in the Philippines
General Assembly of the Blind - Philippines
National Council for the Welfare of Disabled Persons
Samaka Club Student's Association, Inc.
Tahanang Walang Hagdanan, Inc.

Poland
Association of Helping Hand for the Hearing Impaired
Catholic Association of the Disabled
Disabled People's International - Poland
Polish Association of Disabled People
Polish Society for Rehabilitation of the Disabled
Polski Zwazek Gluchych

Portugal
Associacao Portuguesa de Deficientes
Associacao Portuguesa de Surdos
Cooperativa Nacional de Apoio a Deficientes
Liga Portuguesa dos Deficientes Motores
Secretariado Nacional de Reabilitacao

Romania
Asociatia Nationala a Surzilor Din Romania
Association of Neuromotor Handicapped People of Romania
Association of Support for the Physically Disabled Children
Association of The Physically Handicapped From Lugoj

National Organization of Disabled People in Romania (ONPHR)
Romania Connect Bucharest
Society For The Physically Disabled Bacau
Society Of People with Locomotion Handicap From Romania

Russia
All Russian Society of the Blind
All Russian Society of the Disabled
All-Russian Society of the Deaf
ARIADNA
Caritas Primorye
Down's Syndrome Association
Novosibirsk Center for Independent Living
Novosibirsk Regional Special Library for the Blind and Visually Impaired
Perspektiva: Regional Society of Disabled People
Program for Students with Disabilities
Raduga (Rainbow)
Ravenstvo: Municipal Rehabilitation Center for the Disabled, Samara

Rwanda
Associacion des Sourds du Rwanda
Federation Rwandaise des Associations et Centres pour Personnes Handicapées
Saint Kitts Nevis
St. Kitts Association of Disabled Persons
Saint Lucia
National Council of the Disabled
Saudi Arabia
Islamic World's Council of Disability and Rehabilitation
Joint Centre for Research in Prosthetics and Orthotics and Rehabilitation Programmes
Medical and Rehabilitation Consultancy House

Scotland
Advice Service Capability Scotland
Diabetes UK
Drumchapel Disabled Action Group
Epilepsy Scotland

PHAB Scotland
Scottish Association for Mental Health
Scottish Council on Deafness

Senegal
Association Nationale des Handicapes Moteurs du Senegal
Association Nationale des Sourds du Sénégal
Serbia and Montenegro
Association of Disabled Students
Center for Independent Living of People
Iz Kruga "Out of Circle"

Seychelles
Rehabilitation Centre - Victoria Seychelles
Seychelles Disabled Peoples' Organization

Sierra Leone
Sierra Leone Association of the Deaf

Singapore
Disabled Peoples' Association Singapore
National Council of Social Service
Singapore Association for the Deaf

Slovakia
Alliance of Organizations of Disabled People Slovakia
Slovak Union of Physically Disabled People
Slovak Union of the Deaf and Hard of Hearing
Slovensky Zvaz Telesne Postihnutych (Slovak Union of the Handicapped)

Slovenia
Institute for Rehabilitation
Solomon Islands
Disabled Persons Rehabilitation Association, Solomon Islands

Somalia
Association of the Physically Disabled of Somalia

South Africa
Deaf Federation of South Africa
Disabled People South Africa
National Council for the Physically Disabled in South Africa
South Africa Diabetes Association
South African National Council for the Blind

Spain
Asociación Española de Lucha Contra la Poliomielitis
Confederación Coordinadora Estatal de Minusvalidos Fisicos de España
Confederación Española de Agrupaciones De Familiares Y Enfermos Mentales
Confederación Nacional de Sordos de España
Cruz Roja Española
FEAPS
Federación de Asociaciones de Minusválidos de Madrid
Federación ECOM
Fundación ONCE
Fundación ONCE Perro Guía
Instituto de Migraciones y Servicios Sociales
Instituto Universitario de Integración en la Comunidad (Institute on Community Integration)
La ONCE
Real Patronato sobre Discapacidad
Solidarios para el Desarollo
World Blind Union

Sri Lanka
Association of Women with Disabilities
Central Federation of the Deaf
Foundation for Independence of Women with Disabilities
Sri Lanka Confederation of Organizations of the Handicapped People
Sri Lanka Federation of Special Needs Persons
St. Vincent and the Grenadines
National Association of Disabled Persons

Sudan
Sudanese National Society for the Deaf

Swaziland
Federation of the Disabled in Swaziland
Federation Organization of the Disabled in Swaziland
Swaziland National Association of the Deaf

Sweden
European Federation of Kidney Patients
Forum Women and Disability in Sweden
Institute on Independent Living
Samhall Group
Svenska Handikapporganisationers Internationella (Swedish Org. of Disabled International Aid Federation)
Sveriges Dövas Riksförbund
Swedish Association of Neurologically Disabled
Swedish Committee for Rehabilitation International

Switzerland
ASKIO
Association Suisse des Paralyses
CIL Zurich
Disabled People Switzerland
Fédération Suisse des Sourds
Fondation suisse en faveur de l'enfant infirme moteur cérébral
INSIEME
International Labour Organization Disability Programme
Mobility International Switzerland
Pro Infirmis
WHO Disability and Rehabilitation Progamme

Syrian Arab Republic
Syrian Federation of Deaf and Mute Welfare Societies

Taiwan
Chinese National Association of the Deaf, R.O.C

Tanzania
Tanzania Association of the Deaf

Tanzania Association of the Disabled Women Development Program
Zanzibar Association of the Disabled

Thailand
Association of Blind Women in Thailand
Council of Disabled People of Thailand
Goodwill Industries of Thailand

Togo
Federation Togolaise es Associations des Personnes
Handicapees
Trinidad and Tobago
Disabled Women's Network of Trinidad and Tobago
Trinidad & Tobago Chapter of DPI Chest & Heart Foundation

Tunisia
Union Nationale des Aveugles de Tunisie

Turkey
Turkish Association of Neuromuscular Disorders (TurkiyeKas
Hastaliklari Dernegi)

Uganda
Action on Disability and Development
Disabled Women Network and Resource Organization in Uganda
National Disablement Advisory Council
National Union of Disabled Persons of Uganda
People with Disabilities Uganda
Uganda Disabled Women Association

Ukraine
Achilles Track Club Kharkiv
Lybomyra - Women's Information and Rehabilitation Center
Medical and Social Rehabilitation Center
Ukrainian Diabetes Association
United Arab Emirates

Al-Fajer Information and Services Organization

United States of America
Access Exchange International
ADAPT
Advocating Change Together, Inc.
Alexander Graham Bell Association for the Deaf and Hard of Hearing
American Amputee Foundation, Inc.
American Association of People with Disabilities
American Chronic Pain Association
American Council on Rural Special Education
American Diabetes Association
American Foundation for the Blind
American Indian Disability Technical Assistance Center
American Printing House for the Blind, Inc.
America's Athletes With Disabilities, Inc.
Arc
Arts for All, Inc.
Asperger Syndrome Coalition of the U.S.
Association for Education & Rehabilitation of the Blind & Visually Impaired
Association on Higher Education and Disability
Brain Injury Association
Camp Courageous of Iowa
Carroll Center for the Blind
Center for an Accessible Society
Center for Assistive Technology
Center for International Rehabilitation
Center for Research on Women with Disabilities of Physical Medicine & Rehabilitation Department
Center on Human Policy
Children and Adults with Attention-Deficit/Hyperactivity Disorder
Christian Record Services, Inc.
CODA
Council for Exceptional Children
Disability Rights Education and Defense Fund
Disabled Persons Unit/Division for Social Policy and Development
Disabled Sports USA
Division of Rehabilitation-Education Services

DO-IT
Dwarf Athletic Association of America
Easter Seals National Headquarters
Educational Resources Information Center Clearinghouse on Disabilities and Gifted Education
Epilepsy Foundation
Federation of Families for Children's Mental Health
Foundation for Science and Disability
Friends of Leonard Cheshire
Gazette International Networking Institute
Goodwill Industries International USA
Health Resource Center for Women with Disabilities
HEATH Resource Center: National Clearinghouse on Postsecondary Education for Individuals with Disabilities
Helen Keller Worldwide
Human Ecology Action League
Independent Living Research Utilization Program
Inter-American Institute on Disability
International Association of Special Education
International Committee of Silent Sports
International Dyslexia Association
International Educators for Persons with Disabilities
International Polio Network
Jewish Guild for the Blind
Landmine Survivors Network
Learning Disabilities Association
Learning Disabilities Network
Lighthouse International
Mental Disability Rights International
Mental Health Workers Without Borders
Mobility International USA
Muscular Dystrophy Associations of America, Inc
National Amputation Foundation
National Asian Deaf Congress
National Association of Protection and Advocacy Inc.
National Association of the Deaf
National Ataxia Foundation
National Business and Disability Council

National Center for Learning Disabilities, Inc
National Center for Youth with Disabilities
National Center on Accessibility
National Center on Deafness
National Center on Disability and Journalism
National Center on Secondary Education and Transition
National Clearinghouse for Professions in Special Education
National Coalition for PKU & Allied Disorders
National Council on Disability
National Council on Independent Living
National Deaf Education Network and Clearinghouse Publication and Information Dissemination
National Disabled Students Union
National Empowerment Center
National Federation of the Blind
National Information Center for Children and Youth with Disabilities
National Information Clearinghouse on Children who are Deaf-Blind
National Kidney Foundation
National Library Service for the Blind and Physically Handicapped
National Multiple Sclerosis Society
National Multiple Sclerosis Society (Gateway Area Chapter)
National Organization for Rare Disorders
National Organization on Disability
National Rehabilitation Information Center
National Scoliosis Foundation
National Spinal Cord Injury Association
National Sports Center for the Disabled
National Theatre of the Deaf
Office of Disability Employment Policy
Paralyzed Veterans of America
Parent Advocacy Coalition for Educational Rights (PACER) Center, Inc.
Parent Educating Parents and Professionals, Inc.
Quota International
Recording for the Blind and Dyslexic
Regional Resource Center on Deafness
Registry of Interpreters for the Deaf, Inc.
Rehabilitation International
Self Help for Hard of Hearing People, Inc.

Sensory Access Foundation
Society for Accessible Travel and Hospitality
Society for Disability Studies
Society of World Deaf Magicians
Special Olympics, Inc.
Spina Bifida Association of America
Support Coalition International
Through The Looking Glass
TRIO Clearinghouse
TRIPOD
United Cerebral Palsy Association
United Nations Disability Program- Disabled Person's Unit
United Parents Syndicate on Disabilities
United States Association for Blind Athletics
United States Cerebral Palsy Athletic Association
United States International Council on Disabilities
USA Deaf Sports Federation
Vietnam Assistance for the Handicapped
Vinland Center
VSA Arts
Wheelchair Sports, USA
Whirlwind Wheelchair International
Whirlwind Women - Whirlwind Wheelchair International
WinVisible USA - Women with Visible and Invisible Disabilities
Women with Disabilities Resource Center
World Association for Psychosocial Rehabilitation
World Inclusion Network
World Institute on Disability
World Recreation Association of the Deaf

Uruguay
Plenario Nacional de Organizaciones de Impedidos
Union Latinoamericana de Ciegos (Latin American Union of the Blind)

Uzbekistan
Assistance Center for Disabled People
Center of spirituality and Enlightenment of women and children with disabilities of Tashkent city

Kibrai district disabled women's society, Opa-Singillar
KRIDI Club (Club for Integration and Rehabilitation of Children with Special Needs)

Venezuela
Federación Venezolana de Sordos
Paso a Paso

Vietnam
Association for the Support of the Handicapped and Orphans of Vietnam
Association of Disabled Youth
Bright Future for People with Disabilities Group
Club of Young Disabled Vocational
Culture and Sports Club for People with Disabilities of Hanoi
Disability Forum Vietnam
Hanoi Rehabilitation and Vocational Training Center for the Blind
Hanoi Self-help Club for People with Disabilities
Hue Medical School Office of Genetic Counseling and Disabled Children
Office of Disability Technical Assistance
Vietnam Blind Association
Vietnam Rehabilitation Association

Wales
Disability Wales
Wales Council for the Disabled

Zambia
Deaf Women's Network Zambia
Zambia Council for the Handicapped
Zambia Federation of Organizations of the Disabled
Zambia National Association of the Deaf
Zambia National Association of Women with Disabilities

Zimbabwe
Development Initiatives and Services
Disabled Women Support Organisation
Jairos Jiri Association for the Rehabilitation of the Disabled and Blind

8.5

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Web: http//www.disabilityworld.org/index.htm

Disability World is a web-zine dedicated to advancing an exchange of information and research about the international independent living movement of people with disabilities.

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The National Center on Disability and Journalism (NCDJ) is an independent journalism organization with a mission to educate journalists and educators about disability reporting issues in order produce more accurate, fair and diverse news reporting.

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8.6

US AID DISABILITY POLICY

Bureau for Policy and Program Coordination
U.S. Agency for International Development
Washington, D.C.
September, 1997

INTRODUCTION

This policy paper articulates the U.S. Agency for International Development's (USAID) commitment to pursue advocacy for, outreach to, and inclusion of people with physical and cognitive disabilities, to the maximum extent feasible, in the design and implementation of USAID programming, and provides guidance for making that commitment operational. It is the product of a comprehensive consultative process between USAID and its partners, and responds to issues identified in that process. Note that this policy applies to the use of Agency program funds only and complements USAID's personnel and staffing disability policies. The paper provides the basis from which a policy directive will be developed.

This policy paper does not represent a new initiative. Instead it describes the importance of considering concerns of the disabled within ongoing and future programs. Implementation of the policy will be within existing staff and financial resource levels as determined by each operating unit, and no additional financial reporting will be necessary.

The paper outlines the fundamental principles on which the USAID disability policy is based, including: (1) need for a comprehensive and consistent approach to considering people with disabilities, being sure to include women and children, within USAID and in USAID assisted activities; (2) outreach to and early consultation with persons with disabilities and the community of organizations concerned about them as part of

ongoing participatory processes; (3) intent to work as development partners with US and foreign PVOs and NGOs committed to persons with disabilities and to facilitate relationships among these entities; and (4) encouragement of U.S. interagency collaboration and networking among donors and other diverse entities concerned about persons with disabilities with a view to increasing impact and sustaining these efforts.

I. USAID DISABILITY POLICY

The U.S. Agency for International Development (USAID) is committed to the inclusion of people who have physical and cognitive disabilities and those who advocate and offer services on behalf of people with disabilities. This commitment extends from the design and implementation of USAID programming to advocacy for and outreach to people with disabilities. USAID's policy on disability is as follows: To avoid discrimination against people with disabilities in programs which USAID funds and to stimulate an engagement of host country counterparts, governments, implementing organizations and other donors in promoting a climate of nondiscrimination against and equal opportunity for people with disabilities. The USAID policy on disability is to promote the inclusion of people with disabilities both within USAID programs and in host countries where USAID has programs.

For purposes of this policy, a disability is defined as a physical or cognitive impairment that affects a major life function, consistent with the definition of the Rehabilitation Act.

USAID commitment to disability issues is not new. A 1996 report ("Activities Addressing the Needs of Person with Disabilities," USAID document PN-ABY-746) described the many and varied Agency-sponsored activities in provisioning of prosthetics, treatment and prevention of blindness and special education, providing medical training of individuals who assist persons with disabilities, building advocacy and management capabilities of local organizations that represent the disabled, and the like. This policy is designed to build upon current activities and to enhance the effectiveness of the Agency's commitment.

The policy applies to Agency program funds only, and complements existing USAID disability policies which relate to staffing and personnel procedures. One of the best means of raising awareness in programs is to actively pursue those personnel procedures so that Agency staffing patterns reflect the intention of Agency programs.
The Americans with Disabilities Act of 1990 (ADA) is generally not applicable to USAID's overseas programs. While the ADA applies to U.S. citizens (including USAID employees) overseas, it does not apply to non-U.S. citizens, who are the primary beneficiaries of USAID programs. The USAID disability policy is thus in part an effort to extend the spirit of the ADA in areas beyond the jurisdiction of U.S. law.

II. POLICY OBJECTIVES

The objectives of the USAID policy on disability are: (a) to enhance the attainment of United States foreign assistance program goals by promoting the participation and equalization of opportunities of individuals with disabilities in USAID policy, country and sector strategies, activity designs and implementation; (b) to increase awareness of issues of people with disabilities both within USAID programs and in host countries; (c) to engage other U.S. government agencies, host country counterparts, governments, implementing organizations and other donors in fostering a climate of nondiscrimination against people with disabilities; and (d) to support international advocacy for people with disabilities.

III. POLICY FRAMEWORK

A substantial segment (often ten per cent or more) of any population has impairments. Those individuals are often limited in participating in society by obstacles in the physical or social environment. It is widely recognized that the response to this problem must be a balanced combination of prevention, rehabilitation and measures for the equalization of opportunities. Individuals with disabilities and their caregivers often are taken out of the workforce. The reasons are many: discrimination, lack of educational, vocational rehabilitation or training opportunities,

etc. These factors place further economic burden on poor countries where USAID has sustainable development programs. People with disabilities have the same needs as others for nutrition, family planning, health care, training and employment. Many mainstream programs, with minor modification at the design stage, help address these needs. For example, education programs can be developed which promote inclusion of children with physical or cognitive disabilities to the maximum extent feasible. Economic growth activities, such as small business loans lending, can be developed to assure that people with disabilities have equal access to credit. Infrastructure projects can be designed, with acceptable marginal cost, to assure barrier-free access.

In providing humanitarian assistance in post-conflict situations and disaster assistance, early strategically aimed programs both help address the immediate needs of people with disabilities and also provide a foundation on which these individuals more effectively make a positive contribution to the economic development of their country. The disabling injuries caused by landmines provide yet another compelling reason for such programs.

USAID promotes advocacy as an integral part of its democracy and governance objective. As a world leader in the civil rights movement for people with disabilities, the U.S. has seen a strengthening of many local organizations which have formed to support independent living and other disability initiatives as a critical need. In many countries, individuals with disabilities have been 'warehoused' in abysmal conditions with total disrespect for their rights. Those rights must be respected. As young democracies decide where they will concentrate scarce resources, people with disabilities and those interested in the issues of people with disabilities must be among the voices that are heard.

Recently, in certain developing countries, indigenous non-governmental organizations (NGOs) interested in the concerns of people with disabilities have emerged. USAID's general policy with regard to partnership with private voluntary organizations (PVOs) encourages the use of U.S. PVOs to help strengthen indigenous NGOs ("USAID-U.S. PVO Partnership," April 12, 1995; Handbook 1, Policy Papers); inclusion of NGOs interested in issues of persons with disabilities should be considered for this kind of support.

USAID also recognizes the appropriate role of host country governments in creating the enabling environment for disability advocacy and services. Host governments not only create the regulatory environment, but they also assure quality standards and, for donor programs, provide the basis for sustaining these efforts.[1]

IV. OPERATIONAL PROCEDURES

A. Consultation

Each USAID Bureau, Mission and Center of the Global Bureau must determine the best ways to consult with the disabled and with those who advocate on behalf of, or provide services for individuals with disabilities. Each USAID Bureau, Mission and Center of the Global Bureau must also determine best ways for consulting with appropriate host government officials to assure that issues are reviewed with respect to the enabling environment, regulatory concerns, quality assurance standards and maintenance of donor-financed disability activities. USAID will also look to organizations and individuals with in-depth local experience to assist in designing and implementing participatory mechanisms to ensure that USAID strategic objectives and activities incorporate, to the extent feasible, the priorities and values of people with disabilities and groups pursuing these issues and interests in the host country.

B. Areas to be considered in the consultative process

The concerns of people with physical and cognitive disabilities should be considered in the variety of USAID programs for the poorest elements of society including but not limited to programs for children and women, especially early childhood interventions, child survival programs and curriculum development for special education within basic education programs; mass communication and printed materials; development of basic infrastructure (e.g., roads, water and sanitation, public transportation, telecommunications); development of small scale industries or workshops; introduction of new machinery; development of products the use of which requires specific skills; urban or rural community development; development of health care facilities or systems; development of formal and non-formal education, training, career development and job placement services; family planning and health education programs;

design and construction activities; and activities related to democracy and good governance, human rights initiatives, and income generation. Where appropriate, USAID may also encourage relevant policy dialogue with host governments.

C. Supporting U.S. PVO and indigenous NGO relationship

Indigenous NGOs, as part of the host society, can serve as a voice for the interests and perspectives of the community of individuals with disabilities or groups interested in their issues. USAID will look to an increasing role for indigenous NGOs to carry out service delivery and to advocate on behalf of the interests of people with disabilities. USAID will actively encourage the formation of effective partnership relations between U.S. PVOs and indigenous NGOs interested in issues of concern to people with disabilities.

D. Trainig and enhanced awareness

USAID employees and contractors will be trained in issues of relevance to people with disabilities so that, as appropriate, USAID programs reflect those issues. Grantees and contractors will be encouraged to provide relevant training to their staff.

8.7

INTERACTION PVO STANDARDS APPROVED DISABILITY AMENDMENTS WITH REVISIONS

The Disability Amendments to the InterAction PVO Standards were Adopted by InterAction in 2000.

SECTION 2.0 GOVERNANCE

2.6.3 Each agency will develop a written policy that affirms its commitment to the inclusion of people with disabilities in organizational structures and in staff and board composition. The policy should be fully integrated into an organization's plans and operations, in a manner consistent with its mission and the constituency it serves.

SECTION 6.0 MANAGEMENT PRACTICE AND HUMAN RESOURCES

6.4.3 Promoting People With Disabilities.

6.4.3.1 Agencies will strive to increase the numbers of people with disabilities, where there is under-representation, in senior decision-making positions at headquarters, in the field and on Boards of Directors.

6.4.3.2 In order to embrace diversity in its organizational culture, agencies will integrate disability into the diversity sensitization program within an organization's human resource development program for staff at all levels. This will improve organizational effectiveness, promote non-discriminatory working relationships and create a respect for diversity in work and management styles.

SECTION 7.0 PROGRAM

7.4. Promoting People With Disabilities.

7.4.1 Consistent with its mission and the constituency it serves, members will establish a mechanism which operates with a mandate from the CEO to promote and monitor the inclusion of people with disabilities in programs.

7.4.2 Disability inclusion strategies will be integrated into each stage of the program process, from review of project proposals to implementation and evaluation to ensure that projects foster participation and benefits for all affected groups, including disabled men, women and children. Members will collaborate with local NGO partner organizations in the field on these efforts.

7.4.3 Member programs and activities should be held in accessible locations to the maximum extent feasible. Organizations will provide training and conference materials in alternate formats as applicable (Braille, sign language interpreters, etc.). Member agencies should plan financially to reasonably accommodate people with disabilities in member programs and activities.

SECTION 7.6 MATERIAL ASSISTANCE

7.6.2 Materials provided shall be appropriate, based on an assessment of local needs, and sensitive to the local culture and situation. Any donations of goods and services will be accessible to disabled men, women and children.

SECTION 7.9 CHILD SPONSORSHIP

7.9.15 Members engaged in child sponsorship should develop policies that support the inclusion of children with disabilities and their families in child sponsorship programs and child-focused community development projects.

8.8

THE CONVENTION ON THE RIGHTS OF THE CHILD, IN BRIEF

Adopted by the U.N. General Assembley in 1989.
Please contact the United Nations for the complete text.

ARTICLE 1

Definition of a Child

A child is recognized as a person under 18, unless national laws recognize the age of majority earlier.

ARTICLE 2

Non-Discrimination

All rights apply to all children without exception. It is the State's obligation to protect children from any form of discrimination and to take positive action to promote their rights.

ARTICLE 3

Best interests of the child

All actions concerning the child shall take full account of his or her best interests. The State shall provide the child with adequate care when parents, or others charged with that responsibility, fail to do so.

ARTICLE 4

Implementation of rights

The State must do all it can to implement the rights contained in the Convention.

ARTICLE 5

Parental guidance and the child's evolving capacities

The State must respect the rights and responsibilities of parents and the extended family to provide guidance for which is appropriate to his or her evolving capacities.

ARTICLE 6

Survival and development

Every child has the inherent right to life, and the State has an obligation to ensure the child's survival and development.

ARTICLE 7

Name and nationality

The child has the right to a name at birth. The child also has the right to acquire a nationality and, as far as possible, to know his or her parents and be cared for by them.

ARTICLE 8

Preservation of identity

The State has an obligation to protect, and if necessary, re-establish basic aspects of the child's identity. This includes name, nationality and family ties.

ARTICLE 9 SEPARATION FROM PARENTS

The child has a right to live with his or her parents unless this is deemed to be incompatible with the child's best interests. The child also has the right to maintain contact with both parents if separated from one or both.

ARTICLE 10

Family reunification

Children and their parents have the right to leave any country and to enter their own for purposes of reunion or the maintenance of the child-parent relationship.

ARTICLE 11

Illicit transfer and non-return

The State has an obligation to prevent and remedy the kidnapping or retention of children abroad by a parent or third party.

ARTICLE 12

The child's opinion

The child has the right to express his or her opinion freely and to have that opinion taken into account in any matter or procedure affecting the child.

ARTICLE 13

Freedom of expression

The child has the right to express his or her views, obtain information, make ideas or information known, regardless of frontiers.

ARTICLE 14

Freedom of thought, conscience and religion

The State shall respect the child's right to freedom of thought, conscience and religion, subject to appropriate parental guidance.

ARTICLE 15

Freedom of association

Children have a right to meet with others, and to join or form associations.

ARTICLE 16

Protection of privacy

Children have the right to protection from interference with privacy, family, home and correspondence, and from libel or slander.

ARTICLE 17

Access to appropriate information

The State shall ensure the accessibility to children of information and material from a diversity of sources, and it shall encourage the mass media to disseminate information which is of social and cultural benefit to the child, and take steps to protect him or her from harmful materials.

ARTICLE 18

Parental responsibilities

Parents have joint primary responsibility for raising the child, and the State shall support them in this. The State shall provide appropriate assistance to parents in child-raising.

ARTICLE 19

Protection from abuse and neglect

The State shall protect the child from all forms of maltreatment by parents or others responsible for the care of the child and establish appropriate programmes for the prevention of abuse and the treatment of victims.

ARTICLE 20

Protection of a child without family

The State is obliged to provide special protection for a child deprived of the family environment and to ensure that appropriate alternative family care or institutional placement is available in such cases. Efforts to meet this obligation shall pay due regard to the child's cultural background.

ARTICLE 21

Adoption

In countries where adoption is recognized and/or allowed, it shall only be carried out in the best interests of the child, and only with the authorization of competent authorities, and safeguards for the child.

ARTICLE 22

Refugee children

Special protection shall be granted to a refugee child or to a child seeking refugee status. It is the State's obligation to co-operate with competent organizations, which provide such protection and assistance.

ARTICLE 23

Disabled children

A disabled child has the right to special care, education and training to help him or her enjoy a full and decent life in dignity and achieve the greatest degree of self-reliance and social integration possible.

ARTICLE 24

Health and health services

The child has a right to the highest standard of health and medical care attainable. States shall place special emphasis on the provision of primary and preventive health care, public health education and the reduction of infant mortality. They shall encourage international co-operation in this regard and strive to see that no child is deprived of access to effective health services.

ARTICLE 25

Periodic review of placement

A child who is placed by the State for reasons of care, protection or treatment is entitled to have that placement evaluated regularly.

ARTICLE 26

Social security

The child has the right to benefit from social security including social insurance.

ARTICLE 27

Standard of living

Every child has the right to a standard of living adequate for the child's physical, mental, spiritual, moral and social development. Parents have the primary responsibility to ensure that the child has adequate standard of living. The State's duty is to ensure that this responsibility can be fulfilled, and is. State responsibility can include material assistance to parents and their children.

ARTICLE 28

Education

The child has a right to education, and the State's duty is to ensure that primary education is free and compulsory, to encourage different forms of secondary education accessible to every child and to make higher education available to all on the basis of capacity. School discipline shall be consistent with the child's right and dignity. The State shall engage in international co-operation to implement this right.

ARTICLE 29

Aims of education

Education shall aim at developing the child's personality, talents and mental and physical abilities to the fullest extent. Education shall prepare the child for an active adult life in a free society and foster respect for the child's parents, his or her own cultural identity, language and values, and for the cultural background and values of others.

ARTICLE 30

Children of minorities or indigenous populations

Children of minority communities and indigenous populations have the right to enjoy their own culture and to practice their own religion and language.

ARTICLE 31

Leisure, recreation and cultural activities

The child has the right to leisure, play and participation in cultural and artistic activities.

ARTICLE 32

Child labour

The child has the right to be protected from work that threatens his or her health, education or development. The State shall set minimum ages for employment and regulate working conditions.

ARTICLE 33

Drug abuse

Children have the right to protection from the use of narcotic and psychotropic drugs, and from being involved in their production or distribution.

ARTICLE 34

Sexual exploitation

The State shall protect children from sexual exploitation and abuse, including prostitution and involvement in pornography.

ARTICLE 35

Sale, trafficking and abduction

It is the State's obligation to make every effort to prevent the sale, trafficking and abduction of children.

ARTICLE 36

Other forms of exploitation

The child has the right to protection from all forms of exploitation to any aspects of the child's welfare not covered in articles 32, 33, 34 and 35.

ARTICLE 37

Torture and deprivation of liberty

No child shall be subjected to torture, cruel treatment or punishment, unlawful arrest or deprivation of liberty. Both capital punishment and life imprisonment without the possibility of release are prohibited for offences committed by persons below 18 years. Any child deprived of liberty shall be separated from adults unless it is considered in the child's best interests not to do so. A child who is detained shall have legal and other assistance as well as contact with the family.

ARTICLE 38

Armed conflicts

States Parties shall take all feasible measures to ensure that children below 15 years of age have no direct part in hostilities. No child below 15 shall be recruited into the armed forces. States shall also ensure the protection and care of children who are affected by armed conflict as described in relevant international law.

ARTICLE 39

Rehabilitative care

The State has an obligation to ensure that child victims of armed conflicts, torture, neglect, maltreatment or exploitation receives appropriate treatment for their recovery and social reintegration.

ARTICLE 40

Administration of juvenile justice

A child in conflict with the law has the right to treatment, which promotes the child's sense of dignity and worth, takes the child's age into account and aims at his or her re-integration into society. The child is entitled to basic guarantees as well as legal or other assistance for his or her defense. Judicial proceedings and institutional placements shall be avoided wherever possible.

ARTICLE 41

Respect for existing standards

Wherever standards set in applicable national and international law relevant to the rights of the child are higher than those in this Convention, the higher standard shall always apply.

- in order to "foster the effective implementation of the Convention and to encourage international co-operation", the specialized agencies of the UN (such as ILO, WHO and UNESCO) and UNICEF would be able to attend the meetings of the Committee. Together with any other body recognized as "competent including NGOs in consultative status with the UN and UN organs such as UNHCR, they can submit pertinent information to the Committee and be asked to advise on the optimal implementation of the Convention.
- a reservation incompatible with the object and purpose of the present Convention shall not be permitted.

ARTICLE 42-54

Implementation and entry into force

The provisions of articles 42-54 notably foresee;

- the State's obligation to make the rights contained in this Convention widely known to both adults and children.
- the setting up of a Committee on the Rights of the child composed of ten experts, which will consider reports that States

Parties to the Convention are to submit two years after ratification and every five years thereafter. The Convention enters into force - and the Committee would therefore be set up - once 20 countries have ratified it.

- States Parties are to make their reports widely available to the general public.
- the Committee may propose that special studies be undertaken on specific issues relating to the rights of the child, and may make

its evaluations known to each State Party concerned as well as to the UN General Assembly.

This summary of the Convention on the Rights of the Child is reprinted with permission from "Disabled Children's Rights – a practical guide", Save the Children 2001

8.9

THE SALAMANCA STATEMENT AND FRAMEWORK FOR ACTION ON SPECIAL NEEDS EDUCATION

Agreed to at the World Conference on Special Needs Education: Access and Quality, organized by the Government of Spain in cooperation with UNESCO in 1994.

Reaffirming *the right to education of every individual, as enshrined in the 1948 Universal Declaration of Human Rights, and renewing the pledge made by the world community at the 1990 World Conference on Education for All to ensure that right for all regardless of individual differences,*

Recalling *the several United Nations declarations culminating in the 1993 United Nations Standard Rules on the Equalization of Opportunities for Persons with Disabilities, which urges States to ensure that the education of persons with disabilities is an integral part of the education system,*

Noting *with satisfaction the increased involvement of governments, advocacy groups, community and parent groups, and in particular organizations of persons with disabilities, in seeking to improve access to education for the majority of those with special needs still unreached; and recognizing as evidence of this involvement the active participation of highlevel representatives of numerous governments, specialized agencies and intergovernmental organizations in this World Conference,*

1.

We, the delegates of the World Conference on Special Needs Education representing ninety-two governments and twenty-five international organizations, assembled here in Salamanca, Spain, from 7-10 June 1994, hereby reaffirm our commitment to Education for All, recognizing the necessity and urgency of providing education for children, youth and

adults with special educational needs within the regular education system, and further hereby endorse the Framework for Action on Special Needs Education, that governments and organizations may be guided by the spirit of its provisions and recommendations.

2.
WE BELIEVE AND PROCLAIM THAT:

- Every child has a fundamental right to education, and must be given the opportunity to achieve and maintain an acceptable level of learning
- Every child has unique characteristics, interests, abilities and learning needs
- Education systems should be designed and educational programmes implemented to take into account the wide diversity of these characteristics and needs
- Those with special educational needs must have access to regular schools which should accommodate them within a childcentred pedagogy capable of meeting these needs
- Regular schools with this inclusive orientation are the most effective means of combating discriminatory attitudes, creating welcoming communities, building an inclusive society and achieving education for all; moreover, they provide an effective education to the majority of children and improve the efficiency and ultimately the cost-effectiveness of the entire education system.

3.
WE CALL UPON ALL GOVERNMENTS AND URGE THEM TO:

- Give the highest policy and budgetary priority to improve their education systems to enable them to include all children regardless of individual differences or difficulties
- Adopt as a matter of law or policy the principle of inclusive education, enrolling all children in regular schools, unless there are compelling reasons for doing otherwise

- Develop demonstration projects and encourage exchanges with countries having experience with inclusive schools
- Establish decentralized and participatory mechanisms for planning, monitoring and evaluating educational provision for children and adults with special education needs
- Encourage and facilitate the participation of parents, communities and organization of persons with disabilities in the planning and decisionmaking processes concerning provision for special educational needs
- Invest greater effort in early identification and intervention strategies, as well as in vocational aspects of inclusive education
- Ensure that, in the context of a systemic change, teacher education programmes, both preservice and inservice, address the provision of special needs education in inclusive schools.

4.
WE ALSO CALL UPON THE INTERNATIONAL COMMUNITY; IN PARTICULAR WE CALL UPON:

- Governments with international cooperation programmes and international funding agencies, especially the sponsors of the World Conference on Education for All, the United Nations Educational, Scientific and Cultural Organization (UNESCO), the United Nations Children's Fund (UNICEF), United Nations Development Programme (UNDP), and the World Bank:

- to endorse the approach of inclusive schooling and to support the development of special needs education as an integral part of all education programmes;
- the United Nations and its specialized agencies, in particular the International Labour Office (ILO), the World Health Organization (WHO), UNESCO and UNICEF:
- to strengthen their inputs for technical cooperation, as well as to reinforce their cooperation and networking for more efficient support to the expanded and integrated provision of special needs education;

- Non-governmental organizations involved in country programming and service delivery:

- to strengthen their collaboration with the official national bodies and to intensify their growing involvement in planning, implementation and evaluation of inclusive provision for special educational needs;

- UNESCO, as the United Nations agency for education:

- to ensure that special needs education forms part of every discussion dealing with education for all in various forums,
- to mobilize the support of organizations of the teaching profession in matters related to enhancing teacher education as regards provision for special educational needs,
- to stimulate the academic community to strengthen research and networking and to establish regional centres of information and documentation; also, to serve as a clearinghouse for such activities and for disseminating the specific results and progress achieved at country level in pursuance of this Statement,
- to mobilize funds through the creation within its next Medium-Term Plan (1996-2002) of an expanded programme for inclusive schools and community support programmes, which would enable the launching of pilot projects that showcase new approaches for dissemination, and to develop indicators concerning the need for and provision of special needs education.

5.

Finally, we express our warm appreciation to the Government of Spain and to UNESCO for the organization of the Conference, and we urge them to make every effort to bring this Statement and the accompanying Framework for Action to the attention of the world community, especially at such important forums as the World Summit for Social Development (Copenhagen, 1995) and the World Conference on Women (Beijing, 1995). *Adopted by acclamation, in the city of Salamanca, Spain, on this 10th of June, 1994.*

8.10

SUMMARY OF THE UNITED NATIONS STANDARD RULES ON THE EQUALIZATION OF OPPORTUNITIES FOR PERSONS WITH DISABILITIES

Adopted by the General Assembly of the United Nations in December 1993. Please contact the United Nations for the complete text.

1. PRECONDITIONS FOR EQUAL PARTICIPATION

_ Rule 1. Awareness-raising

'States should take action to raise awareness in society about persons with disabilities, their lights, their needs, their potential and their contribution'

_ Rule 2. Medical care

'States should ensure the provision of effective medical care to persons with disabilities'

_ Rule 3. Rehabilitation

'States should ensure the provision of rehabilitation services to persons with disabilities in order for them to reach and sustain their optimum level of independence and functioning'

_ Rule 4. Support services

'States should ensure the development and supply of support services, including assistive devices for persons with disabilities, to assist them to increase their level of independence in their daily living and to exercise their rights'

2. TARGET AREAS FOR EQUAL PARTICIPATION

_ Rule 5. Accessibility

'States should recognize the overall importance of accessibility in the process of the equalization of opportunities in all spheres of society. For persons with disabilities of any kind, States should (a) introduce

programmes of action to make the physical environment accessible; and (b) undertake measures to provide access to information and communication'

_ Rule 6. Education

'States should recognize the principle of equal primary, secondary and tertiary educational opportunities for children, youth and adults with disabilities, in integrated settings. They should ensure that the education of persons with disabilities is an integral part of the educational system'

_ Rule 7. Employment

'States should recognize the principle that persons with disabilities must be empowered to exercise their human rights, particularly in the field of employment. In both rural and urban areas they must have equal opportunities for productive and gainful employment in the labour market'

_ Rule 8. Income maintenance and social security

'States are responsible for the provision of social security and income maintenance for persons with disabilities'

_ Rule 9. Family life and personal integrity

'States should promote the full participation of persons with disabilities in family life. They should promote their right to personal integrity, and ensure that laws do not discriminate against persons with disabilities with respect to sexual relationships, marriage and parenthood'

_ Rule 10. Culture

'States will ensure that persons with disabilities are integrated into and can participate in cultural activities on an equal basis'

_ Rule 11. Recreation and sports

'States will take measures to ensure that persons with disabilities have equal opportunities for recreation and sports'

_ Rule 12. Religion

'States will encourage measures for equal participation by persons with disabilities in the religious life of their communities'

3. IMPLEMENTATION MEASURES

_ Rule 13. Information and research

'States assume the ultimate responsibility for the collection and dissemination of information on the living conditions of persons with disabilities and promote comprehensive research on all aspects, including obstacles which affect the lives of persons with disabilities.

_ Rule 14. Policy-making and planning

'States will ensure that disability aspects are included in all relevant policy-making and national planning'

_ Rule 15. Legislation

'States have a responsibility to create the legal bases for measures to achieve the objectives of full participation and equality for persons with disabilities'

_ Rule 16. Economic policies

'States have the financial responsibility for national programmes and measures to create equal opportunities for persons with disabilities'

_ Rule 17. Co-ordination of work

'States are responsible for the establishment and strengthening of national coordinating committees, or similar bodies, to serve as a national focal point on disability matters'

_ Rule 18. Organizations of persons with disabilities

'States should recognize the right of organizations of persons with disabilities to represent persons with disabilities at national, regional and local levels. States should also recognize the advisory role of organizations of persons with disabilities in decision-making on disability matters'

_ Rule 19. Personnel training

'States are responsible for ensuring the adequate training of personnel, at all levels, involved in the planning and provision of programmes and services concerning persons with disabilities'

_ Rule 20. National monitoring and evaluation of disability programmes in the implementation of the

Standard Rules

'States are responsible for the continuous monitoring and evaluation of the implementation of national programmes and services concerning the equalization of opportunities for persons with disabilities.

_ Rule 21. Technical and economic co-operation

'States, both industrialized and developing, have the responsibility to co-operate in and undertake measures for the improvement of the living conditions of persons with disabilities in developing countries'

_ Rule 22. International co-operation

'States will participate actively in international co-operation concerning policies for the equalization of opportunities for persons with disabilities

This summary of the "United Nations Standard Rules on the equalization of opportunities for persons with disabilities" is reprinted with permission from "Disability, poverty and development", DFID, 2000

FORMS

9

9.1

BUILDING AN INCLUSIVE DEVELOPMENT COMMUNITY:

A Manual on Including People with Disabilities in International Development Programs

Please help us to ensure that our next edition of Building an Inclusive Development Community continues to be informative and useful for your work by taking a moment to answer these two short questions.
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