

# **HEAR OUR VOICES:** A GLOBAL REPORT

**People with an Intellectual Disability  
and their Families Speak Out  
on Poverty and Exclusion**



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The Atlas Alliance (Norway) is pleased to have had the opportunity to support this important initiative. By drawing global attention to the exclusion and marginalization of people with intellectual disabilities and their families worldwide, Inclusion International has given voice to those who would otherwise be unheard.



## Foreword

Inclusion International has fought for more than 40 years to ensure that people with an intellectual disability and their families can be recognized as full citizens, enjoy the rights enjoyed by others, and feel valued as contributors to their communities. In 1971, at our urging, the United Nations adopted the Declaration on the Rights of Mentally Retarded Persons (we would never use that term now!). Our members have gained new human rights provisions in national laws, and we have secured additional international provisions – in the United Standard Rules, in the United Nations Convention on the Rights of the Child. There is promise in the new United Nations Convention on the Rights of Persons with Disabilities, which is on its way to adoption by the United Nations General Assembly as this report is being finalized. But the reality facing our members is that despite the increase in the number of human rights provisions, the lives of people with an intellectual disability around the world are characterized by exclusion.

At the same time, over the past decade there has been global effort to reduce poverty, especially of those most affected by it. Beginning with the World Social Summit in 1995, and most recently popularized by stars like Bono and Madonna, there have been various initiatives to mobilize change. The framework for these efforts has been the development of the Millennium Development Goals, a series of 8 time-limited and specific targets. Yet again, despite these global efforts, people with an intellectual disability and their families continue to be economically disadvantaged. Even in areas where poverty as a whole has been reduced, the situation of people with an intellectual disability and their families remains unchanged, and often, they remain the poorest of the poor.

Why have people's lives not improved with the adoption of new human rights provisions? Why are people who have an intellectual disability and their families not benefiting from poverty reduction strategies?

We went to our members to try to answer these questions. This report contains their answer. It is the story of poverty and exclusion told by individuals and families in more than 80 countries. It is a story of poverty and exclusion. But it is also a story of hope. Because in the stories told by

our members there were also clues about how to overcome poverty and exclusion. We cannot wallow in our dissatisfaction with what exists today. We need to use our energy to translate what we have learned to create more inclusive communities. We need to find new partners to work with us. We owe it to all those who have shared their stories to unite our voices and to build a better world for all.

***Diane Richler***

President

Inclusion International

## Acknowledgements

This report brings together the voices of our movement. It reflects the work and contribution of people all over the world who struggle daily to improve the lives of people with intellectual disabilities and their families. From the beginning, this initiative was not designed as an academic research study to be carried out by consultants. Rather, we designed a participatory process that would engage our members around the world and allow them to describe in their own words their experiences as individuals and families.

The starting point for this study was the recognition that our members – individuals who have an intellectual disability, their families, and supporters – have a wealth of knowledge about how having an intellectual disability leads to poverty and exclusion. But because these individuals are too often invisible, their stories are not influencing decisions that affect their lives. We wanted to bring about change on a global scale – by convincing governments, multi-lateral institutions, and communities of the current injustice of exclusion. Where before our members' voices were not being heard because they were isolated, we wanted to bring them together into a loud chorus. We wanted to link those local voices to bring about global change.

This report is the culmination of three years of work by hundreds of families, people with intellectual disabilities and family based organizations in over 80 countries. We wish to thank and acknowledge all those individuals and organizations that participated in this process, many of whom volunteered their time and effort.

First, we express our sincere appreciation to The Norwegian Association for Persons with Developmental Disabilities, NFU, and the Atlas Alliance of Norway for their partnership and financial support. Without your contribution, this project would simply not have been possible.

Thanks also to the Office For Disability Issues, Government of Canada for their contribution to the development of this report.

We appreciate the support of the UN Voluntary Fund whose assistance enabled participation of self advocates in the regional forums.

Special thanks to each of our regional associations for leading and coordinating the regional processes. Specifically, thanks to: Roberto Leal Ocampo and his team at Inclusión Interamericana for coordinating the research and organizing the Regional Forum in Managua; Rosalie Bassolé, Secretary General, Kadiatou Sanogho, President of Inclusion Africa and the Indian Ocean and Yves Giraud and the organizing committee Inclusion Africa and Indian Ocean for their effort and diligence in planning, organizing and facilitating the research process and Pan-African Regional Forum in Ouagadougou, Burkina Faso; Françoise Jan, Past-President of Inclusion Europe, Geert Freyhoff, Director, and Diana Voicu at Inclusion Europe for conducting the research; and Emanuela Leampar, Inclusion Romania and Laila Onu from Pentru Voi Foundation for organizing and hosting the Regional Forum in Bucharest; Moussa Charfeddine, Vice-President of Inclusion International, Roland Tamraz (Lebanon) and Mariette Ziade (Lebanon) in the Middle East North Africa region for their coordination of the research and TUTAIM (the National member organization in Tunisia) for hosting the Regional Forum in Tunisia; and Osamu Nagase for assisting with the preparation and organization of the Asia Pacific consultation in Bangkok. Inclusion International suffered a great loss last year with the death of Mrs. Sanogho and it is with sadness that we remember her contributions and insights.

Special thanks to J.P Gadkari and Vijay Kant (Parivaar, India) for developing a paper and hosting a national conference in India; also thanks to Jan Vorstman for his support to our member organizations in India and the Philippines.

Our biggest thanks go to those who participated directly in the research. Research teams in each region designed a process to engage people with disabilities, families, civil society organizations and governments in the collection of information and stories. These teams and the people who visited families, conducted focus groups, developed country reports, shared stories, filled in surveys and participated in Regional Forums are the reason for the wealth of information and the richness of the evidence provided in this report. In many cases, families reported that no one had ever before shown an interest in their family member with a disability.

This report would not be complete without the incredible pictures that help convey our message. For that we thank photographer Carlos Reyes-Manzo.

We want to recognize David Towell for his unwavering support and his critical eye and Michael Bach and his staff at the Canadian Association for

Community Living for their support and contributions throughout the process.

This project would not have been possible without the dedication of Connie Laurin-Bowie. We thank her for her vision and direction in developing and executing this project and for helping us to continue to move forward with this work.

Finally, to the hundreds of individuals and families who are not listed by name but who shared their personal stories, experiences and hopes so generously with us in every part of the world, thank you. We hope this report does justice to what you know to be true and what you imagine is possible.

## Introduction

**T**here are 130 million people with intellectual disabilities and their families around the world and the vast majority live in poverty. Regardless of where they live – in the populous countries of the Asia Pacific Region, in North America, Central, East or West European countries, the Caribbean, Central and South America, Africa, or the Middle East – they tell a remarkably similar story. People are excluded from education, employment, health care and other services, and from belonging in their communities. Parents and siblings face barriers to employment, adequate income, community services and community acceptance. People find their rights are denied. They feel invisible in development and poverty reduction strategies.

Inclusion International launched this study so others could begin to hear the voices of this often forgotten group in the human family. For the first time at a global level, this study consolidates information on the status of people with intellectual disabilities and their families. Most importantly it shares their perspectives on poverty and exclusion and what can be done to confront them.

### **Beginnings**

No study starts in a vacuum. We began this global research project for a simple reason. Every day our two hundred member associations, and their thousands of local members hear from an individual or a family who is struggling to belong, get needed supports, find a place in school, get a job. We know about these experiences, we do everything we can as an international network to respond. But it's not enough. People with intellectual disabilities are missing out on opportunities, being denied their rights, dying unnecessarily; wonderful lives cut way too short. Families who love and cherish their family member with an intellectual disability time and again face rejection by others.

We know this, but as we've learned others don't. So we began this study to tell the stories and share the experiences of people with intellectual disabilities around the world. We have a profound belief that knowledge is

power. If we share the knowledge we have gained as a parent and family movement with others, they will be in a better position to use their own power to make a difference. Stories can move others. Voices calling for change can compel action. Knowledge shared generously helps others to learn. This was the hope that gave birth to this study and this Global Report.

This study is a journey with thousands of participants, via hundreds of interviews, country and community surveys, focus groups and conferences, and study Forums in every region of the world.

Every journey needs some guideposts. This introduction offers ours.

## **Defining Poverty and Exclusion**

The first guidepost is the overwhelming extent of poverty our international federation collectively witnesses every day. Whatever the country in which they reside, people with intellectual disabilities live in poverty. They are vastly over-represented among the world's poorest of the poor. Even in wealthy countries, people with an intellectual disability and their families are much more likely to be poor than the general population. These were some of the compelling realities that urged us to carry out the study.

We did not restrict our study to a one-dimensional 'basic income' view of poverty because we did not want to prescribe the terms of the stories and experiences we might hear and learn from. Rather we took an expansive view of its meaning. At Regional Forums that gathered together research and participants in this study, we drew on a number of perspectives to explore the meaning that could be given to people's experience.

We are grateful to Inclusion Europe who contributed to this study a very helpful literature review on the concepts of poverty and exclusion.<sup>1</sup> Their report emphasizes that poverty is indeed a multi-dimensional concept and includes unacceptable social and economic deprivation, and lack of empowerment and security. As Amartya Sen suggests poverty should also be understood in relation to human development and the 'capabilities' necessary for maximizing potential in the life of each and every individual, family and community.<sup>2</sup> The OECD (Organization for Economic Cooperation and Development) uses this approach to define five dimensions of deprivation in relation to economic, human (health, education, clean water, etc.), socio-cultural (valued participation in community life), political and protective capabilities for a good and productive life.<sup>3</sup>

If poverty is defined by deprivation, why are people with intellectual disabilities and their families so deprived? Universally, those who participated in this study gave a similar answer: because we are excluded – from social, economic, and political systems that give opportunity, resources, recognition and rights.

This was another guidepost in our journey – poverty, disability and exclusion seem fundamentally linked. We need to understand how this comes to be, and how we might unravel their bonds so that people with intellectual disabilities come to belong, are included and take their rightful place in their families, communities, and society.

## **Defining Ourselves – People with Intellectual Disabilities and their Families**

Our member associations are often asked by others to define who we are and who we advocate for. Defining oneself can be tricky business. Too often people with intellectual disabilities are defined and labeled by others in ways that devalue and objectify. Who is the 'we' this study is about? Our answer is a third guidepost for our study.

We are people who have been identified as having an intellectual disability, and their families. We are mothers and fathers, sisters and brothers, aunts and uncles, cousins, nieces, nephews, grandchildren, grandmothers and grandfathers. We are children of parents who have an intellectual disability. We are friends and advocates who make a commitment to help advance full inclusion, citizenship and human rights.

People with intellectual disabilities are neighbours and community members, schoolmates, co-workers and fellow citizens. As self-advocates and families, we call on others to recognize that we all learn in different ways and make our own unique contributions to families and communities. We no longer want people to refer to the 'mentally retarded,' a term that has been used to devalue, segregate and discriminate against people.

We challenge all those who would define intellectual disability as simply slower or deficient ways of remembering, thinking and communicating. Our message is clear. Respect and understand differences. Value all people for their contributions. Treat all people with equality regardless of their disability, religious, gender, ethno-racial-cultural, sexual orientation, and other differences.

This does not mean that people do not want to develop. On the contrary, we all want support to develop to our maximum potential and to pursue our

own unique life path. We all want to thrive with other members in our families, communities, schools, and places of work. People with intellectual disabilities just want the same.

So we use the term intellectual disability in this report to refer to that group of infants, children, youth, adults and seniors who are first and foremost members of families and communities; people who sometimes need particular support and care because of their unique learning, communication and other needs and contributions.

While there is no absolute count of people with intellectual disabilities around the world, we use in this report the average of the estimates that researchers and demographers in the field tend to use – 2.0% of the global population or about 130 million people.

## **Millennium Development Goals – Vantage Point for the Study**

Calls to combat global poverty are resounding, even if they have not yet been met with effective response. National governments, donor countries, international financial institutions, United Nations agencies, NGOs, citizens from around the world join their voices to the call. The most comprehensive commitment to end global poverty is the United Nations Millennium Development Goals (MDGs) adopted in 2000 at the UN Millennium Summit by Heads of State from across the globe.

The MDGs are a set of eight measurable goals and targets for combating poverty and many of its dimensions. They are to be achieved by 2015. The goals are as follows:

- Eradicate poverty and hunger (halving between 1990 and 2015 the proportion of people whose income is less than \$1 a day)
- Achieve universal primary education
- Promote gender equality and empower women
- Reduce child mortality
- Improve maternal health
- Combat HIV/AIDS, malaria and other diseases
- Ensure environmental sustainability (assuring principles of sustainable development, access to safe drinking water and basic sanitation and improving the lives of slum dwellers)

- Develop a global partnership for development.

We applauded efforts of governments to establish the MDGs and work towards them. However, at first we could not find our place in the goals or targets to be achieved. So we defined our own targets. We began with the MDGs and asked ourselves: What would it mean if these were to be achieved for people with intellectual disabilities and their families? The table on page 10 provides our answer.<sup>4</sup>

Inclusion International's MDG framework is the fourth guidepost for our journey. The MDGs, as seen from our perspective, define the vantage point for the study. With this tool we set out with our regional and national member associations in a research dialogue with people with intellectual disabilities and their families about their daily lives in an attempt to comprehend the realities of 130 million people. We then used our MDG framework to analyze what self-advocates and families told us. This report tells their stories and what we found.

## **Organization of the Report**

This Global Report is organized into four main sections.

The first section outlines the approach to the Global Study. Undertaking an initiative of this magnitude was challenging and inspiring. This section of the report reviews objectives, ways we gathered information, the research challenges and the regional structure of the study.

We report our findings in the second section, against each of the MDG targets we defined. This section draws on both personal accounts and secondary research sources. It makes clear the depth and extent of poverty and exclusion of people with intellectual disabilities and their families – the many causes, and the devastating consequences.

In the third section we draw together the many recommendations and directions for change that study participants suggested. Looking across the recommendations from all of the regions, building blocks for a global agenda to combat poverty and exclusion begin to emerge. This section also outlines suggested roles for civil society organizations, governments and donor and international agencies in beginning to advance this agenda.

The report concludes by calling on these actors to move forward this immense agenda and stresses the urgency to do so.

## **Inclusion International's Millennium Development Goals: Vision and Targets for 2015**

***Eradicate Extreme Poverty For People with Disabilities and their Families:*** By 2015, people with intellectual disabilities and their families will live free of poverty and discrimination.

***Achieve Inclusive Education:*** By 2015, all children with intellectual disabilities will receive good quality, inclusive education with appropriate supports to ensure that each child reaches their highest potential.

***Promote Gender Equality for Women with Disabilities:*** By 2015, social, economic and political discrimination against women and girls who have a disability and their mothers will be eradicated.

***Reduce the Mortality of Children with Disabilities:*** By 2015, the mortality rate of children who are born with a disability or become disabled in the early years will be reduced by two-thirds.

***Achieve the Rights of Children and Families:*** By 2015, the rights of children with disabilities, as outlined in the UN Convention on the Rights of the Child, will be respected; mothers will receive adequate pre- and post-natal health care to ensure the well being and healthy development of all children; families will get the help they need for the care and support of their member with a disability.

***Combat HIV/AIDS:*** By 2015, the spread of HIV/AIDS in the community of people who have a disability will begin to be reversed and children with disabilities who have been orphaned will be supported and cared for in the community.

***Ensure Environmental Sustainability:*** By 2020, achieve significant improvement in the lives of people who have an intellectual disability and their families who live in extreme poverty.

***Develop a Global Partnership for Development and Inclusion:*** By 2015, global efforts to promote good governance and global partnerships will contribute to the human rights of people with intellectual disabilities, including citizenship and economic rights.

# Approach to the Global Study

## Introduction

This global study on poverty and exclusion was, by definition, an enormous undertaking. How can one grapple with the task of a global inquiry into the status of over 130 million people worldwide, and their families? How does one account for the diversity of social, economic, political and geographic realities? We confronted this challenge by drawing on the immense capacity of our international federation, our regional members, and our network of 200 national parent and family associations to reach people with intellectual disabilities and their families across the globe. We decided at the outset that it was essential that we draw primarily on their voices and knowledge. They are the experts in poverty and exclusion, they know it 'from the ground up,' and have a wealth of knowledge and ideas for change. The best way to engage and listen to those voices was through the local-to-global networks created over the past 40 years by Inclusion International and its member national and regional associations.

The organizing principle for the research was a series of regional studies undertaken through the auspices of our regional members in each of five global regions – the Americas, Africa and the Indian Ocean, Europe, Middle East and North Africa, and Asia Pacific.

This section of the report outlines the process for gathering and analyzing information, the challenges in doing so, and provides a regional perspective on the research process.

### ***Towards a Global Report***

**August 2004:** The First Inter-American Forum on Poverty and Disability (Managua, Nicaragua) - Latin America and Caribbean Regional Report

**September 2004:** Pan Africa Regional Forum on Poverty and Disability Ouagadougou (Burkina Faso) - Pan Africa Report

**October 2005:** European Forum on Poverty, Disability and Social Exclusion (Bucharest, Romania), Regional Report and Regional Strategy

**December 2005:** Middle East and North Africa (MENA) Forum on Poverty and Disability (Tunis, Tunisia) Regional Report and Regional Strategy

**October 2006:** Asia Pacific Regional Consultation, Thailand (Bangkok)

## **Gathering and Analyzing Information for the Global Report**

Each region designed their own research study within a set of common objectives:

- to draw global attention to the conditions of poverty;
- to understand the causes of poverty; and,
- to develop strategies to address not only poverty but its root causes.

Information was gathered for regional studies in a number of ways:

- country-level studies that involved interviews with people with intellectual disabilities and their families; surveys; and, focus groups of individuals and families;
- review of secondary research sources; and,
- Regional Forums which provided valuable opportunities to bring these perspectives, voices and experiences together, and chart directions for change.

Information was analyzed using Inclusion International's MDGs to identify the nature and extent of poverty and exclusion. Regional research reports identify what individuals and families told us about the extent to which the eight MDGs are realized in their own lives (e.g. about poverty, education, gender equality, etc.), and also what was learned from other sources. Through focus groups and the Regional Forums participants drew on this information in examining the underlying causes of poverty and exclusion. They also developed recommendations for change. Common across the analysis and recommendations generated through the regional studies was a recognition of the need to integrate disability into mainstream policy development if we are to confront the structural causes that bind disability to poverty and exclusion.

The results of this information gathering and regional analyses are contained in regional reports and consolidated in this Global Report. Regional reports were prepared in all regions except for Asia-Pacific, where a regional consultation brought together people from this vast and most populous region of the world to share their experiences and perspectives on poverty and exclusion. Our international federation has not yet been able to develop strong national and regional networks across most countries in Asia-Pacific, although there is strong leadership and growing capacity in some countries. Consequently we do not have a detailed report from this region.

The systemic link between poverty and disability can no longer be ignored. The findings of this report reflect the need for a shift in the focus of development assistance from the traditional means of addressing issues of disability as unique programming issues to begin to integrate disability issues into government, donor agency and NGO strategies across sectors at the national, regional and global level.

– From *Voices from the Americas: Status Report on Poverty and Disability in the Americas*

## Challenges in the Research

Many regions experienced similar difficulties and challenges in the research process – particularly in relation to identifying individuals and families to participate, coordinating research across such vast areas and numbers of communities, and accessing reliable data. International statistical data sources on people with intellectual disabilities are largely unavailable given the different definitions used, and lack of attention to this group in global monitoring reports in education, children, human development, or other areas. There are no consolidated information sources to provide a clear picture of their social, economic, and political status on a regional, much less global basis.

As well, in some regions it was the first time persons with intellectual disabilities and their families were being brought together to discuss shared issues. This created challenges in identifying participants and providing them with the comfort to speak up and have their voices heard.

In some communities, the research process itself raised suspicion. In Zambia for instance, like in many other countries studied, researcher facilitators had to go door-to-door in villages or ‘compounds’ to seek out families with a member with an intellectual disability. So used to hiding their family member from view, families were often reluctant to come forward and there were limited means for communicating about the study. Facilitators reported a number of challenges in this process, including suspicion by residents that they were ‘satanists,’ or refusal to participate because research in the past had not produced tangible results, or simply because people could not be found at home.

Finally, while our international federation has developed extensive networks over the past four decades, there is still clearly much to be done. Many countries do not have strong civil society associations, and the capacities for networking within and across regions to share information and develop common analyses are extremely limited.

This study makes clear the importance of developing more consolidated global information sources, and of strengthening our own capacities to link local knowledge and experience to national, regional, and international analyses.

The facilitators were breaking new ground so a number of problems arose:

- Progress was slow because the disabled persons were being searched for. Facilitators went door-to-door asking for directions.
- Makululu has a lot of illiterate people who are very superstitious. In most cases, the facilitators were suspected to be Satanists enlisting future victims or intending victims. So on many occasions, the facilitators were rejected or threatened with violence if they visited again. The facilitators were informed that some people had been stoned when conducting similar activities.
- Some did not want to respond because they claimed that many people had conducted similar activities before without any tangible results. They felt they were being used and cheated.
- Facilitators failed to capture some disabled persons because they were not found at their respective homes most of the time they were visited.

— From the Zambia Country Report, Status of Poverty and Disability in Africa: Summary Report

## **Overview of Regional Studies**

Each regional study presents a unique picture of the lives of people with intellectual disabilities and their families in that particular part of the world. We outline below the approach taken for each study.

### ***The Americas***

To grapple with the size and diversity of the Americas, Inclusión Interamericana (IIA) used three main research approaches.

First, they organized a participatory research process with parent organizations in 13 countries in Latin America and the Caribbean. Participating countries included: Argentina, Bolivia, Brazil, Caribbean, Chile, Colombia, Ecuador, Guatemala, Honduras, Mexico, Nicaragua, Peru and El Salvador. The purpose was to engage people with disabilities, families, civil society organizations and governments in collecting three types of information:

- data and existing research related to poverty and disability;
- stories and experiences of individuals and families about the relationship between poverty and disability; and,
- the policy context (legislation, programmes relevant to poverty and/or disability).

*“Unless disabled people are brought into the development mainstream, it will be impossible to cut poverty in half.”*

*– James D. Wolfensohn,  
Former President, World Bank*

Second, national members in some countries also prepared country-level reports including Mexico and Canada.

Third, to consolidate the findings from across these country-level studies, and to draw on information from across the region, Inclusión Interamericana hosted a Regional Forum (Inter-American Forum on Poverty and Disability in the Americas: Towards Inclusion, August 2004) that brought together representatives from 24 countries in the Americas. Forum participants organized their analysis of findings from country reports into key themes related to civil society capacity building to promote change: empowerment, lobbying, advocacy, networks, knowledge, information, and leadership. The 13-country participatory research study and the findings from the Regional Forum on Poverty and Disability were published as *“Voices from the Americas: Status Report on Poverty and Disability in the Americas.”*

Overall, participants found this research process resulted in:

- a body of information on poverty and disability, and country reports that can be used in mobilizing change;
- a sense of shared identity across the region about the sources of poverty and exclusion and what needs to be done to address them;
- a sense of empowerment by civil society groups that they can make a difference in confronting the issues;
- partnerships and alliances with other organizations that are not part of Inclusión Interamericana; and,
- the first ever dialogue on poverty and disability in the region with regional-level institutions.

## ***Africa***

In the Africa and the Indian Ocean region, research was undertaken with three main strategies:

- initial country studies in Burkina Faso, Mali and South Africa which provided some basic information about the population of people with disabilities;
- country-level studies in four countries – Zambia, Malawi, Tanzania and Zimbabwe;and,
- consultations at a 2004 Regional Forum in Ouagadougou, Burkina Faso.

The research in the region benefited from the earlier development of the African Network for Developmental Disability (ANDD), an umbrella organization of ten parent organizations in the Southern and Eastern part of Africa.<sup>1</sup> This network was established through partnership with Inclusion International and the Norwegian Association for Persons with Developmental Disabilities (NFU). NFU hosted a Regional Forum in 2001 to help establish this network and ANDD then supported country-level studies in the four countries to contribute to an Africa Regional Report and this Global Study. Parent organizations led the research in each country using focus groups and questionnaires – in provinces and districts in their respective countries. Through this process, hundreds of families and individuals with disabilities participated in exploring the issue of poverty and disability in South and Eastern Africa.

At the Regional Forum, delegates were divided into working groups to review information presented in panel discussions and share personal knowledge and experiences. Strengths, weaknesses, opportunities and threats to achieving the full rights and inclusion for people with disabilities and their families were identified. Their discussions covered a wide range of topics including:

- discrimination, misconceptions and social exclusion
- family empowerment, networking, and financial constraints
- empowerment – ‘making our own choices’
- capacity building – especially in rural areas
- education
- legislation and development
- national and international mobilization

- deinstitutionalization
- employment
- accessibility
- HIV/AIDS and sexual abuse

The Africa Report draws on ANDD's four-country study and the information gathered at the Ouagadougou Regional Forum to provide a rich picture and valuable information about poverty and disability in Africa.

## ***Europe***

For the European regional study, four main approaches were used to gathering and analyzing information:

- a survey of member associations of Inclusion Europe – to gather information about living and working conditions of people with intellectual disabilities in Europe, as well as of legislation, policies and initiatives aimed at addressing poverty;
- a review of existing literature on poverty and intellectual disability;
- Focus groups of people with intellectual disabilities and their families in Romania to identify particular issues in this country; and,
- a Regional Forum in Bucharest, Romania in October 2005.

Inclusion Europe received 24 responses to its survey of member associations representing 21 European countries. Of these, 22 were from member associations of Inclusion Europe. Inclusion Romania conducted five focus groups in Romania from June to August 2005 in Baia Mare, Timisoara, Deva, Constanta and Bucharest.

The country-level survey was comprehensive and collected information on the population of people with intellectual disabilities; sources of disability-related income; national expenditure on supports to people with intellectual disabilities; rates of education and employment participation; family caregiving and household income; access to health care, housing, community activities; and, civil society engagement in policy making.

Together with statistical and other research sources, the European report shows that despite differences in economic wealth of a country people across different countries face a common experience of social and economic exclusion. Having undertaken an extensive study and search for information sources, the report concludes that one of the main reasons for

failure to improve the status of people with intellectual disabilities is the lack of information. It makes a number of recommendations for more comprehensive information gathering and reporting by national, regional, and international bodies. At the same time, the report is clear that information on its own is not enough. Without engaging real people in local places in the process of developing policy “little will be achieved.”

More research and data in the area of poverty and intellectual disability in Europe is needed to better understand the issue of multiple disadvantage and to develop policy recommendation. However, without efforts to link the voices of real people to the process of policy development little will be achieved. Even among other excluded groups in society and people with other forms of disability, the perspectives and experiences of people with disabilities themselves and their families are poorly understood and rarely heard.

— From *Poverty and Intellectual Disability in Europe*

### ***The Middle East and North Africa***

In the Middle East and North Africa (MENA) region, Inclusion International and its Committee of the MENA region have worked collaboratively to develop a report on poverty. Two major sources for the report include:

- eighteen country papers drawing on national statistics, literature reviews, and interviews with almost 200 families throughout the region; and,
- consultations at a Regional Forum on poverty and disability held in Tunis in December 2005, where the country papers were presented. The Regional Forum was organized by Inclusion International with member associations from the Middle East and North Africa Region, in cooperation with the Arab States League, the Arab network of NGOs for Development, the Arab Organization for Persons with Disabilities, and the Tunisian Federation of Aid for People with Intellectual Disabilities.

The country research papers drew on a number of sources including:

- national statistics about poverty and disability – which use differing definitions of intellectual disability from country to country;
- survey of studies and reports published about poverty and disability;
- proposed solutions from other reports about how poor people and families face difficulties related to disability and how they deal with it;

- analysis of legislation and policy related to disability; and,
- interviews and focus groups with families.

For the purposes of organizing the regional study, and of developing a sub-regional network for the MENA region for ongoing collaboration, six sub-regions were 'tentatively' identified:

- Saudi Arabia, Libya, and Iraq
- UAE, Kuwait, Bahrain, Qatar
- Oman
- Syria, Lebanon, Jordan
- Palestine, Morocco, Yemen, Sudan
- Egypt, Tunisia, Algeria, Iran

It was agreed that while some countries, such as, Iran were not formally considered a part of the MENA region, they have similar characteristics, opportunities, and challenges to its Middle Eastern neighbors. In the interests of being as inclusive as possible and to build the strongest possible network for disability advocacy in the region, representatives from this country were also included and contributed to the Regional Forum.

Participants at the Regional Forum in Tunis included representatives from over 25 countries in the region. Facilitators from the various sub regions engaged families in focus group studies and collected the voices of people with disabilities living in poverty in the region. Twelve groups presented reports on the status of poverty and disability in their area, including Iraq, Iran, Sudan, Bahrain, Morocco, Palestine, Syria, Jordan, Lebanon, United Arab Emirates, and Libya.

### ***Asia Pacific***

The initiative did not originally include a budget to undertake a regional study in the Asia Pacific Region but in order to develop a global report it was clear that at least a consultation with members in the region was needed. In Asia Pacific, Inclusion International worked with a small group of member organizations and partners such as Handicap International and the Asia Pacific Disability Forum to scan existing research in the area of poverty and disability and to consult our members in the region on the particular issues affecting people with intellectual disabilities and their families.

One member organization, The National Federation of Parents' Association for Persons with Mental Retardation, Autism, Cerebral Palsy and Multiple Disabilities (Parivaar) in India, developed a paper on poverty and disability and hosted a national conference on the topic in Bangalore, in February 2006. This paper and other studies conducted by United Nations Economic and Social Commission on Asia Pacific (UNESCAP) on poverty alleviation for people with disabilities (China, Vietnam, Nepal, others) in 2004, as well as several surveys on disability conducted in different pacific countries by IHC New Zealand provide a picture of some of the challenges and issues facing people with disabilities in the region.

In order to review these issues and develop recommendations a workshop was hosted in conjunction with a meeting organized by UNESCAP and the Asia Pacific Disability Forum. Thirty-five participants representing family based organizations, disability organizations and others like Handicap International came together to review what we know about the life conditions of people with intellectual disabilities and their families in the region and to exchange ideas about strategies for addressing exclusion. Jointly, the representatives brought information and experiences from 8 countries in the region.

## **Summary**

Collectively, the Global Report is the result of research and consultations with participants in more than 80 countries and represents the local voices of people with intellectual disabilities, their families and associations. The five regional studies tapped the local knowledge of individuals and families in communities across the globe, often under very difficult circumstances. Together these studies provide a remarkable global picture of the daily lives, the disadvantage and the shared ideas for change that people from all regions are calling for.

We begin their findings in the next section of this report – which looks at how the status of people with intellectual disabilities and their families 'measures up' against the targets set in 2000 by countries around the world when they signed the 'Millennium Development Goals.'

# Our Report on the Millennium Development Goals (MDGs)

## Introduction

Our study asked people with intellectual disabilities and families in each region to share their experiences of poverty and exclusion in relation to the United Nations MDGs. They did so through surveys, focus groups and dialogues at Regional Forums. We also drew on data from published reports to help contextualize individual and family perspectives. The results reflect the real voices of people who have experienced exclusion and isolation from their communities, and show the scale of the issues they reported. By drawing on their knowledge this study provides clear evidence in each of the MDG areas that people with intellectual disabilities and their families are among the most disadvantaged, isolated and excluded.

The following sections report on each of Inclusion International's MDGs. They report what people with intellectual disabilities and families told us about the gap facing them in achieving the goal in their own lives and communities.

## Inclusion International's MDG #1

### **Eradicating Extreme Poverty of People with Disabilities and their Families**

By 2015, people with intellectual disabilities will live free of poverty and discrimination

Our research confirms that people with intellectual disabilities and their families are disproportionately represented among the poor, regardless of the country they live in. Individuals with intellectual disabilities are largely unemployed and living far below the poverty line.

Families of children with disabilities find themselves with household incomes below the national average, and parents have to forego paid employment, work less hours or give up on job advancement in order to provide needed care for their child.

Un-reimbursed costs of disability contribute to poverty, debt and a downward spiral of exclusion from the labour market and community for both individuals and families. Many have precarious livelihoods. The numbers are staggering:

***Twenty-six million people with intellectual disabilities are living on less than \$1 a day***

- The World Bank estimates there are approximately 1.3 billion people worldwide who are the 'poorest of the poor' living on less than \$1 a day. While it is estimated that 10% of the global population or 650 million people have disabilities, they make up 20% of the world's 'poorest of the poor'.<sup>1</sup> This means that people with disabilities are over-represented among the poorest of the poor by 100%.
- We use the guideline that people with intellectual disabilities make up 2% of the world population, and assume that like other people with disabilities, 20% of people with intellectual disabilities are among the poorest of the poor. This means that 26 million people with intellectual disabilities and their families are among those living on less than \$1 a day.

**CASE STUDY**

***Poverty and intellectual Disability in Slovenia***

The most typical example of poverty in Slovenia is a person with an intellectual disability living at home alone with his/her old mother. If the mother is a peasant (such cases are numerous), her pension is very low, sometimes lower than social allowances. The only income that this person with a disability has is his/her disability allowance, which makes the family income very low...

Members of our [associations] are mostly parents from lower social classes with usually low incomes. As our members, they are at least given the possibility to obtain various compensations (bonuses, trips, etc.)... The gap between the poor and the rich becomes bigger and bigger.

Source: SOZITJE Association, Slovenia, 2005

***For others, individual and household incomes fall well below the poverty line***

- In Brazil, disabled workers earn 45% less than non-disabled workers.<sup>2</sup>
- UNICEF reported in 2005<sup>3</sup> that:
  - In Moldova, one third of households that have a child with disabilities fall into the lowest-income quintile.
  - In Romania, households that have children with disabilities have 65 per cent of the per capita income as those without.
  - In Hungary, household income where a child with a disability lives is 79% of average household income.
  - In Estonia, households with disabled members aged 0 to 24 years of age have incomes that are 84% of those households with no disabled members.
- The Middle East and North Africa (MENA) report indicates that in countries included in that study, the general poverty rate ranges from about 27% of the population in higher income countries to between 35% and 48% in less developed states, and increases to as high as 60% in Palestine. Like in other regions, people with disabilities and their families are highly over-represented among those in poverty.

Agnes Anyendwa is a widow and a mother of twelve children... She used to sustain her family by selling foodstuffs at the market. She used to spend the whole day working at her stand before she had an eleventh child called Agnes Nyangu. Agnes has a developmental disability. Since then the mother has no time to be at the market for the whole day, so she spends much of her time at home with her disabled child. Life since then has never been the same.

Source: *Status of Poverty and Disability in Africa*

***Over 70% of adults are unemployed or out of the labour force, in some countries almost 100%***

In El Salvador, approximately 98% of people with disabilities are unemployed.<sup>4</sup>

- In Canada, over 70% of working age adults with intellectual disabilities are either unemployed or not in the labour force, leaving the majority without adequate income.<sup>5</sup>

- The Europe study reports that 78% of people with severe disabilities age 16-64 are outside the labour force, compared to 27% without disabilities.
- In country surveys conducted for the Europe study very low employment rates of people with intellectual disabilities were reported for some countries: 3% for Bulgaria; 2% for Cyprus; .5% for Denmark; 2% for Greece; 7% for Hungary, 8.6% for Portugal, and 1.2% for Romania. Employment rates are not likely comparable across countries in Europe and North America given different survey methods and definitions. However, regardless of the country, the rates are extremely low.

P.R. is a girl with intellectual disability. She is 10 years old. Since she was diagnosed, she underwent several treatments in different towns. These are very expensive for her family. When she was 4 years old, her father abandoned her. Now she lives with her mother, but the latter does not always have enough money to buy all the medicines her daughter needs. The little girl has no friends. She usually accompanies her mother to various places (parks, artistic performances, etc.).

Source: *Poverty and Intellectual Disability in Europe*

### ***Costs of disability borne by individuals and families***

- Un-reimbursed costs of care giving, health care, medications, and technical aids and devices contribute to individual and family poverty. In most majority countries of the south there are no reimbursement schemes, and in northern industrialized countries provisions are often meager, based on charity.
- In many accounts from the Americas study, the profiles of families show the impoverished conditions in which parents are trying to raise their children with intellectual disabilities.
- The largest un-reimbursed cost is that of care giving provided by family members, usually mothers. As the Mexico country study reports, families provide 80% of care for family members with intellectual disabilities, and as in other countries mothers provide the bulk of care.
- The consequence of the almost exclusive reliance on mothers for needed support is often ill health and lost opportunity to earn income, as well as increased family debt. Caregivers also lose any future pension benefits if they have to stay out of the paid labour market to provide care to their family member. As a case study in the European Report on families with disabled children in the UK shows, extra costs

of disability + inability to work (only 16% of mothers in this study were in full or part-time employment) = poverty + debt.

- For those living in many poor countries of the South, the Middle East and Asia Pacific, the cost of aids, devices, and needed health and social services is not the issue – these supports are not even available in their communities.
- The MENA study reports that families who live in villages, rural and remote areas face particular challenges in caring for a child with a disability. Poverty becomes ingrained in their lives through a combination of factors: lack of economic opportunity; women's entrenched inequality (confining their role to the home, unable to advocate in their communities); community rejection of those with disabilities; and lack of services, transportation, and access to information (e.g. publications and media about rights and opportunities).

## Inclusion International's MDG #2

### **Achieving Universal Primary Education for ALL Students**

By 2015, all children with intellectual disabilities will receive good quality, inclusive education with appropriate supports to ensure that each child reaches their highest potential.

Our studies confirm the findings of many others: that children with intellectual disabilities are largely excluded from regular education. They bear the cost throughout their lives. The actual number included in school in many developing countries is impossible to determine definitively because of lack of published information. We know from the research gathered and accounts provided in this study that it is very small compared to the general population.

*Basic education is, and always has been, the key to freedom from subjugation, fear and want. Education is an effective weapon to fight poverty.*

— UN Cyberschool

### **CASE STUDY**

Annad was born in the rural area of Suriname in a traditional Hindustani family, He can hear but cannot talk and he has a mental disability.

By the time he was about 5 years old, the family decided that they could not accept a child that cannot talk because “when you are not able to speak you are not a human being”.

They put him in a cage with a chain on his neck, feeding him the kind of food he could not chew.

That’s how he was found at the age of seven. Social workers tried to get him into a home for orphans but he was not an orphan.

Then they tried to get him into a foster home.

Then they tried to get him into a school, but even special schools did not accept him.

At last they found a family who wanted to have him for the weekends and holidays but because of the revolution this family had to leave the country.

Right now Anand is an adult living in an institution that does not want to be an institution. They want to have their pupils live in a family or on their own. But they have seen that it is very hard to get all of them out into society. So they created their own home for a group of 7 or 8 adults and bring society in by doing day care and vocational training for inhabitants of the district they are working in.

Source: Case Study, Suriname

### ***Less than 5% of children in majority countries of the South complete primary school***

- The World Bank Estimates that fewer than 5% of children with disabilities in majority countries do not complete primary education. It also suggests this “number may be growing due to global conditions of increasing poverty, armed conflict, child labor practices, violence and abuse, and HIV/AIDS.”<sup>6</sup>

- The Africa regional study confirms this assessment. It reports very low education attainment of students with disabilities in countries studied – for example, with only 6.9% reaching high school level of education; 8.6% achieving basic education level; and 60% achieving less than basic education.
- Parents in focus groups in Tanzania reported that their children with disabilities are often segregated and many times are not in school.
- The study from Europe reports that the majority of people with intellectual disabilities only attain primary education. As well, most countries surveyed in Europe found that individuals have difficulty accessing mainstream education.
- Reports suggest that the exclusion starts early in life – with parents in many countries unable to access early childhood education and care, infant stimulation programmes, etc. Fewer opportunities and expectations for further education result.

***Family poverty, lack of trained teachers and other barriers to inclusive education***

- Our studies found that family poverty combines with other factors to make it especially difficult for children and youth with intellectual disabilities to access inclusive education, or any education at all. Families in the Africa and Americas country and regional studies report that cost is a major barrier to poor families. They are unable to pay the costs of school fees, the cost of transportation, or parents have to choose which of their children will go to school. As we found in other aspects of their lives, children with intellectual disabilities are usually the last in line.
- Most countries studied in the South and many in the MENA region lack basic educational services especially for those living in rural areas – inaccessible buildings; over-crowded schools; lack of transportation to get to school; and lack of needed school-based supports (e.g. speech and occupational therapists and health services).
- Throughout country and regional reports, participants identified lack of trained teachers, continued specialized schools, and little or no leadership from educators and principals as key factors limiting access to inclusive education and opportunity for students with intellectual disabilities.
- Our regional studies point to laws and policies for more inclusive education in a number of countries in all regions. However, implementation is lacking. As a participant in the Regional Forum in

Ouagadougou, Burkina Faso said, “Our country (Lesotho) has inclusive education by law, but in reality there is a lack of facilities and trained teachers.”

- Negative community attitudes reinforce exclusion. One participant in the Africa study reported “Even if parents succeed in placing their disabled child in a mainstream school, the problems continue because other parents often take their children out of that school because of the stigma.”
- We learned through our regional studies from MENA, Africa and the Americas that children with intellectual disabilities are so devalued in many countries that they remain invisible from view. Hidden by their parents who fear rejection and harm will come to them, they don’t go to school at all.
- In this context, opportunities for children and youth to learn and develop are practically non-existent. With no community services or public transportation especially in rural areas, and often prohibitive school fees, the vast majority of children with intellectual disabilities are not in school. As the Africa study reports the few financial resources tend to be saved so the “good ones” in a family can go to school.

The Casitas Canton, jurisdiction of the Santo Tomas municipality, department of San Salvador, is located at 12 kilometres of San Salvador city, with approximately 3,000 inhabitants. Electric service exists in the majority of houses. Potable water service is not generalized. There is one school that takes care up until sixth grade, without health service... The families participating in the focal group (for this study) are low income and low schooling families with children with disabilities that are making enormous efforts to bring up their children.

Source: *Voices of the Americas Report*

### ***Mandated exclusion***

- In several countries, families reported that it was not just a lack of services or inaccessible schools, or the cost of school fees. There was a legal barrier to enrolling their children in school, since a social ministry rather than the Ministry of Education had responsibility for educating children with disabilities and their children had no right to go to the regular school.
- Others reported that the only option for education was a private school run by a non-government organization and outside of the formal system. It was reported that even these options were unavailable in rural areas. In the Africa Regional Forum, one of the reasons

participants advanced for promoting inclusive education was the recognition that it would be impossible to find enough resources to start new special classes for all the children with an intellectual disability now out of school.

### ***Long-term costs of exclusion***

- People with intellectual disabilities pay a high price for being excluded from education, inclusive education in particular. Research shows that children with even significant disabilities who are included in regular education are much more likely to finish school, go onto post-secondary education and training, get jobs, have decent incomes, and become active members in their communities.<sup>7</sup>
- Research for the Europe study reports a low percentage of people who have pursued secondary or upper secondary education. The report suggests that this “drastically reduces their chances to access the labour market.”
- Most regional reports also pointed to extremely low literacy rates for adults with intellectual and other disabilities as a result of lack of access to basic education. For example, the MENA study reports illiteracy rates in Libya of 55% among persons with disability, but even higher for people with intellectual disabilities – for example, 78% in Lebanon. Reports from the Americas – Canada, and from Latin American and the Caribbean – confirm this scale of the problem. The Africa report suggests the problem is even more challenging, because so many parents of people with intellectual disabilities have such low literacy levels: “High levels of illiteracy negatively affects parents/guardians of the persons with disabilities and their families in fighting poverty. This is as a result of not attaining a decent education level.”

*“Education is the key to the new global economy, from primary school on up to life-long learning. It is central to development, social progress and human freedom.”*

*– Kofi Annan, The Millennium Report<sup>1</sup>*

## Inclusion International's MDG #3

### **Promoting Gender Equality for Women with Disabilities and Mothers**

By 2015, social, economic and political discrimination against women and girls who have a disability and their mothers will be eradicated.

Self-advocates and family organizations identified many ways in which gender underwrites poverty and exclusion of girls and women with disabilities, as well as their mothers and grandmothers. Girls and women who have a disability are doubly disadvantaged in accessing education, health care and employment because of gender and disability discrimination, and they are more likely to be victims of violence. Mothers who have a child with a disability are also doubly disadvantaged. They bear the majority of care giving responsibilities, which limits opportunity for paid employment and often isolates them in their communities. Discrimination because they bore a child with a disability devalues and isolates mothers even more. As the Africa study reports, increasingly grandmothers are carrying the costs of care, as their grandchildren with disabilities lose parents to the HIV/AIDS pandemic.

Our study shows that gender matters. Across all of the factors that bear on poverty and exclusion of people with intellectual disabilities and their families, girls, women, mothers and grandmothers fare far worse than males. This does not excuse or mitigate the discrimination that boys, men and fathers experience. It simply shows that to combat the poverty and exclusion of people with intellectual disabilities and their families we must better understand the gendered ways that discrimination and disadvantage operate.

#### ***Education***

- Country studies and other research reviewed indicate that particularly in poor countries in Africa, Asia-Pacific, Latin America and parts of the Middle East and North Africa, girls are less likely to go to school than boys. In Malawi, for example, the country study indicated that 41% of disabled females never attended school compared to 29% of disabled males.

- Our studies report that one consequence of gendered exclusion from education is that women with disabilities have higher illiteracy rates than the general population, and women with intellectual disabilities have higher illiteracy rates than other women with disabilities

### ***Income and Employment***

- Gendered exclusion begins in childhood; its consequences continue into adulthood. While labour force participation rates for both men and women with intellectual disabilities are drastically low, men have higher participation rates than women in all regions, and all countries studied.
- In Morocco, for example, 18% of working age men are economically active, while the rate among women is only 4%. In Libya the gender difference in employment rates are 31% for men and 5% for women. For both women and men these employment rates indicate the vast majority is without adequate income to live, reinforcing dependence on their families throughout their adult life. Nonetheless, these figures show that women with disabilities are particularly disadvantaged (MENA Report).

A mother with five children was left by her husband with one child with a severe disability. The two of them live in a very small village. The mother is taking care of the child and therefore cannot work. They live from the benefits. The child gets no education as no education professional goes to his house. The child's clothes and diapers have to be changed many times a day, but the mother does not have enough money to buy all of them. She has to wash them all the time.  
Source: *Poverty and Intellectual Disability in Europe*

### ***Unpaid Care giving***

- By and large women carry the primary responsibility for caring for disabled family members. As the MENA study reports, "The common denominator among all families is the mother's shouldering the foremost and main responsibility of caring for the family member with disability. In case she is not there, the burden falls upon the older sister."
- We found the stigma and misconceptions associated with the birth of a child with a disability leads to family breakdown, particularly in countries in poor countries of the South. It is usually fathers who abandon, leaving mothers and sisters with the total responsibility for care.

When a child with a disability is born into a family, the mother is often blamed. Many men then leave their wives and children and marry other women. There are therefore a lot on single mothers with disabled children.

Source: *Status of Poverty and Disability in Africa*

### **Community Services**

- Access to community services also varies by gender, especially in countries where women's sphere is still primarily the family home. A number of country reports from the MENA region, for example, suggest that the chances of men gaining access to rehabilitation services are almost double those of women with disabilities.

### **Violent victimization**

- Women and girls with disabilities are at a higher risk of violence than other women, in particular of sexual abuse. Research has suggested that over 60% of girls and women with intellectual disabilities have been sexually abused at some point in their lives.<sup>8</sup>
- A common theme from participants at the Africa Regional Forum was that women and girls with disabilities are especially vulnerable to sexual abuse as they are often seen as not sexually active and therefore targets of attempted "virgin cleansing." It was also reported, as confirmed by published research, that women with intellectual disabilities are targets for rape because they are considered unable to testify against the rapist.
- Findings from the country studies for the Americas report also conclude that women with disabilities are more likely to be abused and mistreated than men, another reflection of the gender inequality that girls and women with disabilities face.

## Inclusion International's MDG #4

### **Reducing Child Mortality Rate Among Children with Disabilities**

By 2015, the mortality rate of children who are born with a disability or become disabled in the early years will be reduced by two-thirds.

Mortality rates for children with disabilities are estimated to be as high as 80% in countries where under-five mortality as a whole has decreased to below 20%.<sup>9</sup>

Our studies suggest that this 400% difference in mortality rates for children with disabilities cannot be explained by genetic or bio-medical factors alone. In reporting on this goal we look at other factors that make children and youth more vulnerable to disease and death.

#### **CASE STUDY**

Kalifa was four months when Eugenia noticed that her daughter was not well. The doctors knew right away that she had Cerebral Palsy but just as the unusual birth, could not explain what went wrong.

Eugenia's family is not supportive of her position or her daughters and is very unwilling to help. She cannot maintain a full time job because she has no one to care for Kalifa nor to take her to school or therapy. She lives in a one-room shack in a squatting village without running water, lights or proper toilet facilities. Not to mention, no security. She accepts whatever financial aid she can get and is very grateful for the fact that at least her daughter is alive. Kalifa may never walk nor talk and her chances for a semi-normal life are very slim.

Eugenia's life of poverty is a major factor in Kalifa's eventual fate. She cannot afford specialists or specialty treatments that are limited to the paying few. Her lack of a proper education lent a hand in her limited understanding of her daughter's condition and treatments that are necessary. Both her and Kalifa have a very hard road ahead. Kalifa is now four years old.

Source: Case Study, Trinidad and Tobago

***Lack of access to needed early intervention, rehabilitation, health care and other services***

- Our reports show that in poor countries families with children who have a disability generally do not gain equal access to vaccination and early intervention programs, making them more vulnerable to disease, later onset disabling conditions and underdevelopment. Research in the Asia Pacific region has shown that even in countries like India with huge investments in early childhood development programs, in the slums and poorer areas where children with disabilities are over-represented, this group remains largely invisible to program providers, and their health suffers as a result.<sup>10</sup>
- The Americas report suggests lack of access to needed rehabilitation services makes children more vulnerable than they would otherwise be in their communities, and less able to cope when “natural disasters or unfavorable events” hit.

Poor access to early childhood education (programmes for children under 5 years) is identified as an overarching issue for all children but particularly for children with disabilities and poor children because most of the existing programmes are privately run and inaccessible.

Source: *Voices from the Americas*

- The Africa report indicates that access to needed health care is a major problem in most countries. The primary factors restricting access is lack of services and high cost in impoverished communities. Health care facilities are often physically inaccessible. The report also indicates that health care professionals are unaware of the needs of individuals with disability and routinely deny them access to HIV testing, AIDS care, and place a lower priority on disabled individuals with AIDS when scarce AIDS drugs and services need to be rationed.
- In the Middle East and North Africa, countries surveyed for our research found that high health care costs outside major centres are a major factor preventing access. As well, medications are much less available. For those in more remote areas transportation is the main problem. If families do get to a hospital, access is often denied because of long waiting lists.
- In the Americas, families also reported that lack of transportation to health care centres and cost are the major factors preventing access to needed services and medications.

- Similar factors limiting access were found in the report on European countries, including negative attitudes by health care professionals, poorly trained health care workers and, to a less extent than developing countries, but still relevant, the cost of care. The cost of health care is a more acute problem for individuals and families in Central and Eastern Europe.

***Poverty and poor living conditions contribute to health risks for children***

- Families with children who have a disability in poor countries are more likely than others to live in housing conditions that make children vulnerable to disease. The MENA study reports that with over-representation among the poor, children with disabilities and their families are more likely to live in unsanitary housing conditions, with over-crowding, bad ventilation and lighting, and without access to potable water and proper sewage systems. The report notes that all of these factors contribute to deteriorating health and psychological conditions of the disabled as well as their non-disabled parents and other family members. The consequence is families with weakened capacities to nurture a child with a disability.
- The Africa study found that when families have little food and access to health care, children with disabilities are often the last in line. As we witness increasing rates of malnutrition in the developing world, the report suggests children with disabilities are usually the worst off, systemically the 'last in line.'

## Inclusion International's MDG #5

### **Achieving the Rights of Children with Disabilities and Families**

By 2015, the rights of children with disabilities, as outlined in the UN Convention on the Rights of the Child, will be respected; mothers will receive adequate pre-and post-natal health care to ensure the well-being and healthy development of all children; families will

## get the help they need for the care and support of their family member with a disability.

Using the World Health Organization's definition of people with a disability, some 200 million children and youth – 10% of the world's young people – are born with a disability or acquire a disability before age 19.

Disability not only affects children, youth and adults with disabilities. It affects their families as well. The World Bank estimates that when families are included in the global picture of disability at least 25% of the world population is directly affected<sup>11</sup> Thus, a discussion of the rights of children with disabilities must also take account of the place of families in securing those rights, and the rights of family members who are the front-line of support, advocacy and protection for so many children.

Previous sections of this report make clear that children and youth with intellectual disabilities are particularly vulnerable to poverty and exclusion. With their families they lack access to needed health care, rehabilitation, and other community services. And, they are vulnerable to sexual abuse and victimization.

This section looks at how poverty and exclusion come to violate basic rights of children and youth with intellectual disabilities. These rights are protected under the *UN Convention on the Rights of the Child* and include rights to survival and development; to protection; and to participation. We also look at how the capabilities of families are undermined in the process.

### ***Denial of rights to survival and development***

- The Africa study reports, much like other regional studies, that negative misconceptions of disability are pronounced in many countries and underlie the exclusion and rights violations people with intellectual disabilities face. The report tells of people with disabilities commonly being referred to as 'snakes,' and being the object of witchcraft to cure the evil spirits or 'bad luck' disability signals. Especially in rural areas the shame of disability results in parents "locking their children up" to keep them out of sight; often because they fear for their child's safety when they have no community support and they work away from home. The shame usually extends to the extended family, another reason to keep a child secluded.
- Stigma places children with intellectual disabilities at risk. It was reported that in some cultures, family beliefs and/or mythologies about disability result in infanticide. Short of this, stigma places children and youth at higher risk of disease because as we have seen they are

excluded from needed health, rehabilitation and other services simply because of their disability.

- Devaluing attitudes are deeply woven into long-standing traditions and cultures. According to the MENA Report an individual's disability is seen as a "decree of fate... accepted as a preordained, inescapable destiny... inevitable and there is no way to change it or alter anything about it." The Report suggests the marriage prospects of a non-disabled woman are more limited if she has sibling with a disability, an intellectual disability in particular. Prospective husbands fear the potential of disability being hereditary and the stigma that will result for him and his family.

*"The principle of 'all children, all rights'  
is still much too far from being a reality."*

— Secretary-General Kofi Annan  
in "The Progress of Nations 2000"

- As reported in the Zimbabwe country report: "Negative attitudes by members of the general public in the areas visited... [found] that people who live around the areas understudy discriminate the disabled persons and their families...reviews [showed] that health officials have negative attitudes toward children with disabilities making it difficulty to access the much needed drugs and [they] end up being stigmatized."
- Results from the Asia Pacific Regional Consultation suggest that disability remains largely hidden in many countries in the region, with people with intellectual disabilities often shunned and seen as having little or no value or potential, and not deserving of public investment.
- In most regions, including participants at the Africa Regional Forum, self-advocates and families pointed to institutionalization of people with intellectual disabilities as a denial of basic rights. Institutions find their roots in the same kinds of stigma and stereotyping that leave children, youth and adults with disabilities isolated in their communities. Country reports did not generally report the numbers of people still in institutions. The Canada country report indicated 10,000 to 12,000 people with intellectual disabilities are still institutionalized in that country. The Europe report finds that while persons with disabilities living in institutions are not generally affected by poverty-level income, they remain "victims of major social exclusion."
- When stigma and rejection are combined with the depths of poverty, education exclusion and lack of access to needed services we have reported, children and youth with intellectual disabilities are left vulnerable outsiders either in institutions or in their own communities –

hardly an environment for survival or development. In fact, they are left as victims for exploitation.

### ***Denial of rights to protection***

- To a much greater extent than most other children and youth, those with intellectual disabilities are without the basic protections that keep them safe from harm and exploitation. Participants in the Africa country studies and at the Regional Forum report that children and youth with intellectual disabilities are so stigmatized in their communities that girls in particular are targets for rape and victimization. Some participants recounted that because it is assumed girls and women with intellectual disabilities are not sexually active, they become particular targets for rape for the purposes of ‘virgin cleansing’ – the myth that sex with a virgin cures HIV/AIDS. As families reported in the Zimbabwe study, for example, there are huge challenges to face in confronting the sexual exploitation of children with disabilities – one of the most demoralizing being that some men believe raping a disabled girl child cures them of HIV/AIDS. Another is the fact that authorities fail to recognize or address the systemic abuse.
- All regions report that authorities are ineffective in protecting rights of children, youth and adults with intellectual disabilities, even though their rights are recognized. The Europe study reports that people with intellectual disabilities have difficulty in all European Union Member states, accession countries, and Council of Europe member states in accessing rights protection and the justice system. All countries in the Americas study reported that legislative frameworks in force recognized and guaranteed the rights of persons with disabilities. They also reported “lack of regulations in the majority of these laws and their lack of compliance on the part of the governments.”

### ***Denial of rights to participation and self-determination***

- Reports from all regions indicate that children, youth and adults with intellectual disabilities are generally not encouraged or supported to develop their own ideas, raise their voices for what they want, or make their own decisions. The Africa report found that “children with disabilities are undervalued and are not given the opportunity to speak for themselves, or express what they want to do. Decisions are made for them. At times people are making decisions that are not in the best interest of a person with a disability, or with that person’s input.”
- Rights to participation, to be involved in decision making with others, and to have your own rights to self-determination respected are fundamental rights in *the UN Convention on the Rights of the Child*. As we learned in the accounts from self-advocates, because children and

youth are not encouraged to exercise these rights, there are few expectations that people will make their own decisions as adults, or be included in decision making with others. And, in many countries these low expectations are reflected in law: legal representation, guardianship and other laws remove people's decision-making rights.

In a township in Gauteng, South Africa I have come across 3 teenage sisters (all have an intellectual disability) in a special school who have been repeatedly sexually abused by the neighbour who has HIV/AIDS. When the girls told their mother she beat up on them and said they had been lying. When this was reported to the police, they turned a blind eye. Upon my last visit to the school the one sister had already died (from HIV/AIDS related illnesses) and the principal informed me that the other two would not last very long. They looked sick and malnourished.

— Report from a participant at the Ouagadougou Regional Conference  
Source: *Status of Poverty and Disability in Africa*

- The Africa study reports that without schooling most youth do not develop the skills they need for employment and more independence, and parents and others continue to make decisions for them. Yet when people with intellectual disabilities were asked in the study about their needs they said much the same as any others in their communities: food, shelter, income, care from others, and “belonging to one’s community.” With low expectations from others, youth and adults do not get the skills training, or on-the-job opportunities.
- Participants in our studies pointed many times to the lack of self-advocacy and family advocacy as one of the missing pieces in protecting people’s rights and supporting them to make their own decisions. As the Europe study suggests: “The absence of advocacy structures to facilitate personal decision-making of adults with intellectual disabilities may result in extensive use of measures of partial of full legal incapacitation...”

### ***The place of families in protecting rights***

- Families of people with disabilities, especially parents, are sometimes seen by self-advocates to be part of the problem when it comes to protecting their rights, rather than the solution. It is true that people with intellectual disabilities have sometimes been harmed in their families, institutionalized against their will, and physically and sexually abused by family members. We heard reports of such abuse in our study, and heard reports of the hugely disproportionate numbers of

children with disabilities who come into contact with child welfare authorities (where they exist) because of such harm.

- We heard in focus groups in all regions, that families could encourage decision-making rights, or deny them. They are the front line for self-determination for children, youth and in most cases adults with intellectual disabilities, simply because they provide the majority of supports individuals need.

**Description notes on focus group participants in Colombia country study:**

Families that are in danger of abandoning their members who have a disability, or who are subjected to psycho-social risk factors and the violation of their rights; who belong to the lower level on the socio-economic classification; the majority, with no academic training and without a job, dedicated to the informal economy or begging. Located in the deprived outskirts sectors of the city of Medellin, in the department of Antioquia.

– Focus group, Colombia  
Source: *Voices from the Americas*

- We heard from families about the stresses that raising a child with an intellectual disability can bring, not because of the disability, but because of the desperate living conditions that families forced into poverty must bear; the unavailability of needed services for their children; the lack of transportation; the struggles that come with unemployment and living in remote areas; and the rejection they face from health care professionals, educators, and community members. These are not excuses. They don't justify families failing to protect child rights. But the accounts from this study help to understand what they struggle with.
- We also heard reports of families placing their children in institutional care, but most often because they had no choice.
- The MENA study emphasizes that families of people with disabilities are an essential asset in advancing inclusion in the region. They make it possible for people to be cared for and supported in the family home and in the community. However, the report also finds that because of the broader community context people end up being confined in their families. For the most part there remain entrenched negative attitudes and rejection of people with disabilities in immediate and extended families and the clan; and at school, recreation, health care centres, places of worship, public spaces, and other places in the community.

Consequently, disability is still largely a private issue and hidden from public view as much as possible.

- Resoundingly, we also heard that families are among the most committed of advocates to their family members with intellectual disabilities. They can be a bridge between a person with an intellectual disability and their rights; between a person and their community – friends, school, training work, community services if they can get them, and social participation. But as we were told many times over in this study, they can only play these roles effectively if they are supported by their communities, and if they have the information, basic resources, and civil society and advocacy support to do so.

### **Interview with a Mother**

Myriam is forty-four years old. She works as an office assistant; she lives alone after her divorce. She educates 4 children: two boys and two girls. Myriam lives with her family in a small

house near Charleroi. The eldest child assumes the father's role. The second child, Eric, is 18. He has a severe intellectual disability... His disability is characterized by a physical hyperactivity; he is constantly moving and therefore needs continuous support during the day and confinement at night. The two younger sisters often take care of their big bother on the weekends. They are very close to him and wouldn't allow their mother to permanently leave Eric in the institution.

Eric goes to his father every second Saturday from 10h to 18h. His mother prefers that he come back home, instead of going to the IMP (the Medical-Pedagogical Institute) in order to provide him a maximum of family life. It is very painful for her to have placed him in an institution in order to be able to work and secure the family needs. Even the word "placement" hurts her deeply. The institution has proved to be the only solution to allow for both work and private life. Eric stays there from Sunday evening to Friday evening. If he stayed with his family, he would need a support person from 7h to 17h; this system does not exist in the region and it would probably cost a fortune. In the institution, Eric is put to bed at 19h and is locked into his room until the next morning.

Source: *Poverty and Intellectual Disability in Europe*

### **Story of Ousmane and his family**

Ousmane is a 15-year-old boy who has an intellectual disability. He was born in the small village of Sourgoubila, 32 km outside of Ouagadougou, the capital of Burkina Faso. He has a polygamous family. His mother is the fourth wife of his father who has many other children. Until he was ten he was kept anonymous and hidden. In polygamous families there is a lot of competition between wives and half-siblings. As a result Ousmane's mother kept him hidden out of shame and feelings of inferiority for being the wife who had a child with a disability. Thus, he had been given no value or respect within his family.

In the last few years his mother allowed him to wander around the village, and brought him to the fields and taught him how to cultivate crops. Slowly the community began to interact with him, and as they did, the family began to become more accepting of him too. They involved him in family discussions and events, and started to realize what he is capable of.

Report from a participant at the Ouagadougou Regional Forum  
Source: *Status of Poverty and Disability in Africa*

## **Inclusion International's MDG #6**

### **Combating HIV/AIDS Among People with Disabilities**

By 2015, the spread of HIV/AIDS in the community of people who have a disability will begin to be reversed and children with disabilities who have been orphaned will be supported and cared for in the community.

The issue of HIV/AIDS came up many times in the Africa study. We do not have data on the extent of HIV/AIDS among people with intellectual disabilities and their families. However, the Africa study provided many accounts of the devastating impact on children, youth and adults with intellectual disabilities and their families. Yet until recently family-based organizations advocating for the rights of people with intellectual disabilities have not been actively involved in HIV/AIDS campaigns. HIV/AIDS workers have not considered the needs and issues affecting the community of

people with intellectual disabilities. And they are not counted in the statistics. The Africa study points to some of the causes and issues to address.

### **Sexual Abuse**

- The terrible accounts cited above show that one of the biggest challenges in combating HIV/AIDS among children, youth and adults with intellectual disabilities is the stigma and isolation that make them so vulnerable.

#### **Zambia Country Research Report: Grandmothers in the Linda Compound, Livingstone District, South Province**

The residents in Linda Compound have access to piped water which is supplied to the area by the councils. However, the commodity is erratically supplied to the area. The roads and the surroundings have no proper drainage system, during the rain season the area is usually flooded which in turn attracts a lot of diseases.

The Compound has the highest number of old people – 66 years and above. The majority of these residents are unemployed and mostly depend on handouts from the well wishes. From observations, the area had more old women keeping several dependants, mostly grandchildren (orphans) whose parents have since died due to HIV/AIDS and other diseases.

The residents hardly afford all daily meals needed for them to live healthier. The only groups in formal employment, we came across are; Teachers, Police officers, Nurses and shop keepers.

The main source of livelihood in this area is from Trading and farming. The major enterprises are:

- Growing maize on rented pieces of land in the outlying areas
- Growing vegetables (rape, cabbage, tomato, egg plants) on rented pieces of land
- Buying and selling farm produce
- Inter-border trading in small items like bread, sugar and clothes between Zambia and Zimbabwe
- Begging from well wishes usually at market places
- Sub renting their small houses for the starving families. That is done by making illegal extensions to the existing structures that are constructed using sub standard materials like cartoon boxes, plastics for roofing and muddy brinks.

Source: *Zambia Country Report, Status of Poverty and Disability in Africa*

### ***Lack of Education***

- Lack of education is a major risk factor involved in HIV contraction for people with disabilities. Because many children and youth are not in school, they are not receiving education about sexuality and safe sex. So when they become sexually active, they are less able to protect themselves. As well, it was reported that parents often assume their children with intellectual disabilities will not become sexually active, so they don't provide the education their sons and daughters need.

### ***Compounded Disadvantage***

- Individuals with intellectual disabilities are at higher risk for HIV infection because of lack of education about sexuality and HIV/AIDS prevention. They are also more likely to be sexually abused than most other groups. Our studies suggest that among people with disabilities some are more vulnerable than others – girls and women with disabilities, given the incidence of sexual abuse they suffer; disabled members of ethnic and minority communities (likely because they are isolated from mainstream HIV/AIDS education); and people with disabilities who live in institutions where higher than average rates of sexual abuse by residents and caregivers are reported.
- Individuals with a disability who become HIV positive are doubly stigmatized – by their disability and because they are a victim of HIV/AIDS.

### ***Vulnerable Families***

- Regardless of how they acquire HIV/AIDS, people with intellectual disabilities live in families and communities where others who support them are also at risk. We heard many accounts of people with intellectual disabilities who lost parents, and the support systems they provided, to HIV/AIDS. The lucky ones have grandmothers to support them, as precarious as their situation might be; it was reported to us that others are simply abandoned.

## Inclusion International's MDG #7

### **Ensuring Environmental Sustainability for People with Disabilities**

By 2020, achieve significant improvement in the lives of people who have an intellectual disability and their families who live in extreme poverty.

UN Millenium Development Goals target the living conditions of people who live in extreme poverty and specifically the 100 million people living in slums. The regional studies examined some of the issues affecting people with disabilities living in these conditions and some of the reasons why this group is over represented in shanty towns and other such communities. They also point to factors that underlie the social and economic instability in some countries and communities that are making it impossible to address the exclusion faced by people with intellectual disabilities and their families.

#### ***Precarious livelihoods***

- The, at least, 26 million people with intellectual disabilities who live on less than 1\$ a day live very precarious lives – many with no roof over their head, living in shanty towns, or remote villages, without adequate food, water, or basic sanitation.
- Their families are among the poorest in their countries, and rely on very low earnings in the formal, informal or self-employed sectors; or on begging and scavenging.
- When the costs we reported in MDG #1, of caring for a son or daughter with an intellectual disability are combined with living in extreme poverty, the math simply does not add up. In conditions of such deprivation individuals with intellectual disabilities and their families have little chance of developing the human, socio-cultural, economic, political and other capabilities that mark the path out of poverty.
- For example, the Americas report profiles families included in one focus group this way: one parent (mothers) homes with absent fathers, with an average size of four to eight members; without schooling, unemployed or dedicated to the informal economy, with dissatisfaction

of their basic necessities, [with children with disabilities] in high risk of being abandoned and with little protection.

- The Zambia country study reports that 85% of people with disabilities and their families rely primarily on agriculture – growing maize and vegetables and selling their produce at market. With the majority of families relying on agriculture, the economic consequences of drought are hitting this group in particular.
- The Africa regional report finds that the extreme poverty, stigma and exclusion that many people with intellectual disabilities and their families face marginalize them even more in communities already suffering from social alienation, poverty, unrest, environmental degradation and lost productive capacity.

### **CASE STUDY**

Eighteen year old Ringo lives in a fishing village with his seventy five year old grandmother. Ringo has severe physical disability and mild to moderate speech impairment. His speech is understood mostly by his grandmother. He is small in stature and seems to be under fed and poorly kept.

Along the shores of one of Jamaica's popular fishing village in St Catherine, Ringo's home can be found among many shacks. The people living within this community make themselves comfortable regardless of the state and conditions they are living in.

Ringo's grandmother's house is made from pieces of old zincs, pieces of board that are old and rotten. The roof leaks and there are holes and cracks through the walls. The dwelling consists of three rooms. The grandmother occupies one, an elderly gentleman lives in another and also a son of hers shares the other room with a common-law-wife and two children and a brother of his.

You are wondering now where Ringo stays. Well, Ringo is put away at the back of the building in a make shift-room...

When Ringo's grandmother was asked about sustainability and survival for herself and Ringo she said her children sometimes provided her with food and the necessary things she needs. She quickly added that Ringo is given a meal three times each day.

Ringo is left at the back all alone without friends, no love and comfort. His mother left him with his grandmother because of her other four children. She said Ringo's brothers and sister are afraid of him. They complain that he drools and wet the bed, among other things. When we asked Ringo's mother what she will do about Ringo if the grandmother should pass away (die), she calmly said, "When the time comes she will deal with that".

Source: Case Study, Jamaica

### ***Lack of basic services***

- The Africa, Americas, and Asia Pacific studies found that in many makeshift communities, slums and shantytowns there are disproportionate numbers of people with disabilities. People with disabilities and their families often live in these settlements without access to basic services, sanitation, and few income-generating opportunities. Living conditions can often cause or exacerbate disability-related conditions.
- The Africa country and regional studies report that many families do not have access to clean water – water is either not piped into their communities, or it is unreliable, or there is no potable water available. Many also report limited means to transport water.

### ***Natural disasters and environmental degradation***

- It was also reported both in the Africa and Americas studies that in situations of natural disaster people with disabilities are often left behind or abandoned by their community. As we have reported above, many are already isolated because of stigma and rejection by their communities. When disasters hit we were told that aid workers don't know where people are, and so they cannot be evacuated from their communities.
- Both studies report that environmental degradation is taking its health and economic toll on people with intellectual disabilities and their families, driving even more into precarious living conditions and deepening their poverty and deprivation.

### ***Life in conflict zones***

- Countries in many parts of the MENA Region are in situations of conflict and war. The Regional study reports conflicts are contributing to rising rates of poverty, disability, environmental instability, and a sharp rise in mental illness in many communities. Conditions of political unrest and conflict exacerbate exclusion of vulnerable groups and the political environment in some countries makes it difficult for civil society organizations to promote human rights.
- Huge displaced populations arising from conflicts and wars in the region pose unique challenges for integration of disabled members into the broader community, which the MENA report notes is a main source of needed social support and services. The stresses of daily life under conflict, forced movement from their communities because of war, and life in refugee camps confound and often make impossible

parents' capacity to secure basic necessities of life for their son or daughter with an intellectual disability.

### ***Social and economic instability***

- Country and regional studies in Africa and the Americas suggest that current trends in the broader political, economic, environmental and social context makes action on disability issues extremely difficult in some countries and communities, if not impossible. The Americas study, for example, suggests the dominant economic agenda in many countries is to reduce public expenditure, privatize public services, and expand foreign investment and thus capital mobility. The results, participants in the Regional Forum suggested, are weakened domestic economies; dependence of many countries on trading regimes beyond their control; economically polarized populations, all of which breed social conflict and political apathy. Participants suggested that in this context, governments can diminish their role and claim insufficient finances to address poverty and invest in needed health care, housing and support services.
- Participants at the Americas Regional Forum told us that countries in the region are witnessing what happens when these trends combine with cultural attitudes about disability and little recognition of rights in the new democracies in the region. A cycle of poverty and exclusion is being created for individuals with disabilities and their families that seems almost impossible to break.
- The Americas study suggests these trends are creating a breeding ground for corruption and growing criminal networks in some countries, further destabilizing their social and economic foundations. Participants suggested that in these contexts there are few, if any, prospects for countries to slow the tide of deteriorating living conditions for people with intellectual disabilities and their families.

## Inclusion International's MDG #8

### **Developing a Global Partnership for Development and Inclusion**

By 2015, global efforts to promote good governance and global partnerships will contribute to the human rights of people with intellectual disabilities, including citizenship and economic rights.

In promoting partnerships for global development, the UN and world leaders have recognized the need to base these partnerships on good governance structures, policies and practice. But what should count as 'good'?

Our findings on the MDGs should make clear that people with intellectual disabilities and their families are not benefiting from current governance structures, public policies or partnerships for development. Studies from all the regions show why.

#### ***Excluded from dialogue on public policy and poverty reduction strategies***

- All regional and country studies report that disability and family organizations are not effectively engaged as partners in policy development at national, regional or global levels. The Africa and Americas regional studies indicate that national government 'Poverty Reduction Strategies' do not effectively engage civil society organizations.
- As the Europe study notes there has been little or no attention to the role of families within policy development in countries in that region. Processes for developing National Action Plans for social inclusion – being coordinated with shared objectives across the European Union – are not generally visible or transparent, and there are few chances for civil society organizations to influence policy. The same exclusion holds true across all the regions.
- Participants at the Asia Pacific Regional Consultation also reported that people with intellectual disabilities and family organizations in their

region are not included in regional-level planning processes. And, the MENA study reports there is no representation of people with disabilities in national advisory committees or other consultative bodies to governments.

*The economic sphere cannot be separated from the more complex fabric of social and political life, and sent shooting off on its own trajectory. To survive and thrive, a global economy must have a more solid foundation in shared values and institutional practices—it must advance broader, and more inclusive, social purposes.*

— Millennium Report pg.10

### **Civil society capacity is lacking**

- Part of the reason for little or no presence in policy dialogue is that civil society capacity is lacking. Regional reports point to the existence of a growing number of disability and family civil society organizations, but these remain for the most part highly localized without the resources for broader mobilization across communities, and without national and international linkages. Consequently, the disability issues they are trying to profile are not getting the broader public or political coverage that would result in real investment in disability. At the same time, family representatives in the Regional Forums for this study stressed that they cannot begin tackling national and international policies all at once. They must first be able to connect locally with other families to build their collective capacities before they are able to make a difference on the global scale.
- As we have seen in our study, the families most affected by underdevelopment and entrenched poverty have very limited capacity to organize for change. Families already marginalized in their communities lack the political clout and experience to have an impact on policy decision making. The Africa report stresses this point: even if there were opportunity to participate in poverty reduction strategy consultations with governments, civil society organizations, especially family organizations, would not have the capacity to contribute effectively. The report suggests that in large part this is because there is no tradition of local civil society advocacy for people with disabilities. It is also because, as we see in the accounts from Africa, individuals and families are consumed in so many cases with basic survival.
- Participants at the Asia Pacific Regional Consultation report that national family-based organizations have little or no capacity to

participate in anti-poverty strategies and that no strong regional capacity exists to work on behalf of persons with an intellectual disability and their families.

- Extensive gender inequality compounds the problem of limited civil society capacity. The MENA report suggests that with women's status so confined to the private home, they are unable to advocate effectively for their son or daughter with a disability. This also limits their capacity to form civil society organizations with other women in similar situations.
- The MENA study also suggests that professionals largely control family-based organizations and their agenda continues to focus on delivery of much needed services and not on human rights. Thus, the capacity of these organizations to support advocacy, disability and gender equality, and policy change is largely underdeveloped.
- Limited self-advocacy capacity is another barrier to having our voices heard. Self-advocates who participated in the Regional Forums said they lack information about their government's development strategies and poverty reduction initiatives, and feel their organizations are not supported to get involved.

### ***Development assistance tends to ignore disability***

- Participants in regional studies in the Americas and Africa suggested that donor aid programmes give little, if any, focus to the needs of people with intellectual disabilities and their families. Sometimes aid dollars do go to NGOs to deliver services for people with disabilities and their families. However, there is a concern that such NGOs become less effective advocates for change as they become more reliant on government aid dollars.
- Participants also told us that if special programmes for people with disabilities are funded they are usually too small scale to make a difference. Moreover, they do not tackle the larger social and economic issues driving people into poverty and keeping them excluded. Study participants suggested that aid agencies and international institutions need to invest in labour market policies, health care systems, education policies and infrastructure, gender equality, the HIV/AIDS pandemic, and environmental sustainability. But they need to do so in ways that take account of the extensive needs of people with intellectual disabilities and their families.

### ***Invisibility in social and economic policy and plans***

- Good governance and partnerships to address the poverty and exclusion of people with intellectual disabilities and their families would require a clarity about what is to be done in government policies and plans to make a difference. Yet all of our regional studies report that people with intellectual disabilities and their families are by and large invisible in public policy and poverty reduction initiatives of governments, donor agencies and international institutions.
- Both the Africa and Americas studies found the underlying cause of individuals' and families' poverty and exclusion to be both government policies and international regimes that have contributed so much to underdevelopment in their regions. As the Africa report concludes: "Real change for people with developmental disabilities and their families depends on their needs being considered and included in macro-economic decisions and mainstream policy making."
- The Europe study found little attention to intellectual disability within the European Union's social inclusion agenda. As well, the report on East European and Eurasian countries shows that the transition to market economies in Eastern European countries has not accounted for people with intellectual disabilities and their families. Dysfunctional labour markets mean people with disabilities are unlikely to get jobs. There is need for pension reform for income security in old age. Social assistance programmes to assure adequate income are not in place. The post-conflict environment has not adequately addressed disability issues. And despite efforts to advance deinstitutionalization in the region, social exclusion persists. The report suggests that persistent barriers to participation of people with intellectual disabilities are not being figured in to the broader macroeconomic policies in the region.

Since persons with disabilities and their families are among the poorest of the poor, it is essential that the population is addressed and incorporated as a vulnerable group of interest, not only in the policies on disability, but in all the policies that are directed to reducing poverty and its impact on people and families, as a strategy to promote equity, participation and inclusion.

– Colombia Country Report  
Source: *Voices of the Americas*

### ***Ineffective implementation and coordination of public policies***

- Both national governments and regional-level institutions are beginning to develop and adopt comprehensive legislative frameworks and plans

to address issues of people with disabilities, but in most countries they do so primarily within a welfare and charity model. The MENA Report indicates that only in six countries in the Region are there explicit rights-based approaches to disability-related law and policy. For the most part, there is little coordination across governments and other sectors; inadequate investment for implementation; few, if any, monitoring and enforcement mechanisms; and often confusion about who is responsible for what in implementation. These findings are also reflected in other country and regional reports.

## Summary of Findings

It is undeniable. People with intellectual disabilities, their families, and their organizations face an enormous gap in achieving the Millennium Development Goals. They paint a stark picture of exclusion:

**Extreme Poverty** – A staggering 26 million people with intellectual disabilities live on less than \$1 a day. Even people with intellectual disabilities living in northern industrialized countries are hugely over-represented among the poorest in their countries. Families are similarly affected – with one or more parents not able to access paid work, or driven out of the labour market because they have no support to care for their family member with a disability. This makes their economic and social situation that much worse, contributing to a cycle of poverty and exclusion.

**Exclusion from Education** – Less than 5% of children with disabilities complete primary education. Large-scale exclusion from regular education – pre-school, primary and secondary schooling – leaves people without the knowledge and skills for employment, without basic literacy skills, without the support networks that come with inclusion, without recognition from others about the contribution they can make. The impact of exclusion from school extends to family members who care for children who are not in school and are therefore unable to participate in the labour market. The long-term consequences in terms of gender inequality, poor health, isolation and abuse, family poverty and poor living environments are irrefutable.

**Gender Inequality** – Gender inequality compounds the disadvantage and discrimination that comes with disability. Those children with disabilities who are lucky enough to get to school are more likely to be boys than girls. Along with cultural forces that tend to advantage males, gendered differences in education participation of children with disabilities multiply the inequalities later in life. Men with disabilities are far more likely than women, many more times likely in some countries, to be in paid employment.

The gender/disability nexus not only affects people with disabilities, but touches their families as well. Mothers who have a child with a disability generally bear the great majority of care giving responsibilities, and thus are not able to engage in other activities including employment and cultural activities. Myths and stereotypes about disability also disadvantage mothers – ‘blamed’ in some cultures for bearing a child with a disability – often devaluing and isolating them even more.

***Child Mortality*** – Despite growing investments in early intervention and child development programmes in all regions of the world, our study found that children with disabilities are regularly excluded from these opportunities; those who in fact have the most to gain. Access to vaccination and early intervention programmes is very poor. Cultural devaluing of people with disabilities is so intense in some communities that infanticide of newborns with disabilities is the result. Health and other challenges associated with childhood disability are exacerbated as families are driven into poverty. In families’ attempts to feed and care for all family members, children with disabilities are often the last in line. Add to this, disproportionately high rates of homelessness, poor sanitation, lack of education and health care for mothers and children with disabilities and the result, as despairing as it is, seems inevitable: a 400% higher level of mortality among infants with disabilities in some countries.

***Child and Family Rights Denied*** – Our study found far-reaching violation of the basic rights of children with disabilities and their families in countries across the globe. Their exclusion from early intervention programmes, from education, from supportive community services, and from employment opportunities for parents is nothing less than that. Many of the country and regional reports for this study point to impressive national and international laws and policies to protect and advance rights. Yet on the ground, in people’s lives and communities, when they are isolated in institutions, these rights are not being realized. The horrific accounts, like those of systematic rape of girls with intellectual disabilities cannot go unaddressed. Those participating in the study urged enforcement of existing rights as an essential step in alleviating the basic violations of human life we have witnessed.

When we add it up, the evidence is clear: basic development and survival, protection and participation rights under the UN Convention on the Rights of the Child are denied to children and youth with intellectual disabilities.

***Devastating Impact of HIV/AIDS*** – Family-based organizations advocating for the rights of people with intellectual disabilities have not been actively involved in HIV/AIDS campaigns and HIV/AIDS workers have not considered their needs and issues. Yet people with intellectual disabilities

are just as affected if not more than other members of their communities, given the high rates of sexual abuse they experience, and the lack of access to information on reproductive health. As families struggle to cope with the impact of a parent's or sibling's HIV/AIDS, there are even fewer resources and support for a family member with an intellectual disability. In the hardest hit regions of Africa if parents die of the disease a child with a disability is often abandoned.

***Environmental Instability*** – People with intellectual disabilities and their families are disproportionately a homeless population, living on the street or in inadequate housing and in parts of Africa, Asia, and the Americas in slums and shanty towns often without even the most basic needs met. In these situations, their housing and community environments contribute to ill-health, lack of education and opportunity, and deepen poverty. In many countries in Africa and Latin America, large numbers of people with intellectual disabilities live in households that rely entirely on agriculture for income and employment, or live in remote areas and are particularly vulnerable to drought and natural disasters. Environmental degradation impacts directly and disproportionately on people with intellectual disabilities and their families. In areas of conflict, where social and community environments are particularly precarious, the impact on households with a disabled family member is that much more acute. With intellectual disability so structurally related to poverty, inadequate housing, fragile livelihoods and environmental instability – equal life chances are impossible.

***Global InAction*** – Through this study individuals, families, and researchers reflected on effectiveness of government policies, poverty reduction initiatives and development assistance in addressing the deep gap in achieving MDGs for people with intellectual disabilities. We found that issues faced by people with disabilities are largely invisible to policy makers, decision makers and world leaders, even though they may be committed to combating poverty and exclusion. Civil society organizations are fledgeling and do not have the resources and leadership capacity to be heard by governments and donor agencies. The result is global inaction on disability, poverty and exclusion. Even a cursory look at development agencies and investment strategies shows two trends. They either ignore the plight of people with disabilities and their families altogether, or target disability programs in ways that largely keep them out of mainstream social and economic development.

The MDGs proved a powerful tool in this study for shedding light on the realities of people with intellectual disabilities and their families. The findings

point to a glaring divide between a world the MDGs aspire to, and the realities for the tens of millions of people with intellectual disabilities and their families who are left behind.

# Towards a Global Agenda to Combat Poverty and Exclusion

## Introduction

Despite the widespread exclusion and poverty they face daily, people with intellectual disabilities and their families were eager and willing to share their stories and add their voices to this Global Study. Through forums and consultations across the globe, individuals and families expressed their hopes and offered ideas to end the vicious cycle that keeps them poor and excluded.

At Regional Forums in Ouagadougou, Burkina Faso; in Managua, Nicaragua; in Tunis, Tunisia; in Bucharest, Romania; and in Bangkok, Thailand, people with intellectual disabilities and their families reviewed the country studies and information they had gathered through the research. They presented their findings to each other in a number of ways. Some read their research papers – analyzing country survey findings and pointing to regional implications. Others presented PowerPoint projections on the demographics of poverty, employment, or institutionalization. Policy experts invited to the Forums shared policy proposals to address issues. Participants showed documentary videos and photographs that provide graphic accounts of people’s exclusion. Often self-advocate and parent presenters didn’t report the statistics on poverty, but rather told its narrative in their daily lives.

The research presentations were compelling, heart-breaking and inspiring. In focus group discussions that followed, participants sifted through the findings, reflected on what they heard, talked about what they felt, analyzed and debated what it all meant. As participants began to explore the threads across country reports and personal accounts, larger regional trends began to emerge. Participants then examined opportunities for change, and challenges that would need to be confronted at all levels – local to global. With this view in mind, they defined the steps they believe must be taken to begin closing the gap in achieving the Millennium Development Goals.

In this section we draw together the recommendations from across the regions to chart a global agenda for change. First, we report what each regional study recommends must be done to confront poverty and exclusion. As one reads these prescriptions for change, the foundations they seek to lay down become clear. Together these reports show us the building blocks for a Global Agenda to Combat Poverty and Exclusion. And, they provide the directions to put them in place.

## Africa

In developing recommendations for this region, participants took into account the economic underdevelopment, extreme poverty, weak civil society capacity and the governance challenges across much of the region. These factors directly affect the situation of people with intellectual disabilities and their families, and the organizations that advocate on their behalf.

To combat poverty and exclusion in Africa people with intellectual disabilities and their families, in country reports and at the Regional Forum, recommend:

➤ ***Challenge Discrimination, Misconceptions and Social Exclusion***

- Raise awareness of families and communities with information, arts (such as dance, music and theatre, spaces for exchange of ideas)
- Work with children and youth on self-esteem, fears, self-actualization
- Link with schools and universities for awareness-raising
- Work with religious leaders and groups (because they have a lot of influence on the people)

➤ ***Empower People and Families to Address Poverty***

- Provide vocational training for disabled people
- Increase access to quality employment
- Provide access to income generating activities – micro finance, low interest loans from lending institutions, income generating groups to solicit credit
- Provide housing access – low income-income housing for parents with children with disabilities; reserved housing and access to credit for people with disabilities to purchase

- Ensure governments provide financial aid to families
- ***Empower people for “Making our own Choices”***
  - Train disabled people to make their own choices
  - Train families and parents about people’s rights
  - Challenge perceptions by using examples of good practice while being sensitive to cultural practices
  - Include disabled people actively in decision-making processes
- ***Achieve Gender Equality***
  - Ensure gender equality in families, school, community, and employment
  - Promote fathers becoming more involved in caring for their children with disabilities
- ***Make Inclusive Education Mandatory***
  - Make inclusive education mandatory
  - Assure free education, enroll children at school near their home, and ban special classes
  - Invest in teacher training
- ***Assure Accessible Communities and Services***
  - Make all schools and universities accessible
  - Link families to service providers and better coordinate with communities and governments
  - Ensure National Development Plans invest in accessibility
- ***Deinstitutionalize People***
  - Break through the barriers of exclusion caused by institutions
  - Ensure people with disabilities are no longer put in institutions
- ***Stop HIV/AIDS and Sexual Offenders***
  - Empower and educate girls and boys
  - Ensure strong laws and prosecution of sexual offenders
  - Provide information and support to parents (the taboo needs to be broken)

➤ ***Build capacity of disabled people and family organizations (especially in rural areas)***

- Establish disabled persons' organizations at national, regional, district, ward and village levels for networking and empowerment – to build awareness, mobilize communities, and have their voices heard (grass roots approach)
- Promote family empowerment – create family networks, link families to service providers, provide parent-to-parent training, establish sister-city programmes, use the web
- Promote leadership development to address issues such as access to schools, infrastructure and health services
- Establish sub-regional committees across Africa to support efforts

➤ ***Mobilize National and International Networks***

- Build partnerships with international organizations working in local areas
- Use South to South collaboration to share experiences and information
- Link African NGOs with Northern NGOs that have already “won” the battle
- Make sure partnerships involve individuals and families

➤ ***Push for Inclusive Policies and Legislation***

- Connect people and families to influence government
- Sensitize political structures and policy makers
- Establish budgets for disability-related services at national, province, district, and constituency levels and integrate disability issues into all aspects of government and services and the district level
- Influence existing programs – building a strong voice for inclusion

## The Americas

The *Voices from the Americas* Report focuses on Central and South America and the Caribbean and identifies economic, political and structural drivers of poverty and exclusion of people with intellectual disabilities. We also received country reports from Mexico and Canada in North America. Participants suggest that effectively engaging civil societies in the emerging democracies of the region, and strengthening social solidarity, is essential to

effective strategies for the region. With this understanding, participants in this region recommend:

➤ ***Increase social solidarity***

- Expand solidarity efforts for promoting inclusion and rights for people with disabilities and their families
- Establish alliances with different social sectors aiming to eliminate existing social and economic barriers
- Increase awareness about disability through widespread community information programmes
- Generate effective connections between international organizations, NGOs, governments, universities, and association of parents and people with disabilities.

➤ ***Strengthen civil society capacity and collective movements***

- Strengthen capacity to influence policy, demand compliance of policy and law with human rights, and develop more inclusive policies
- Fortify disability organizations and increase their capacity to influence broader civil society organizations
- Involve civil society organizations in the struggle against poverty, without losing the human rights perspective

➤ ***Mainstream disability in poverty reduction strategies***

- Promote direct participation of people with disabilities, their families and specialized civil society organizations in defining structured policies for poverty reduction
- Ensure policies are based on community experiences
- Increase visibility of the issues of poverty for people with disabilities
- Trigger social debate about poverty issues pertaining to people with disabilities
- Insist that the problem of poverty and disability is addressed in both the public and private sector

➤ ***Ensure education policy and practice addresses the needs of all learners***

➤ ***Integrate gender equality for women with disabilities in mainstream social and economic policies***

- ***Assure access to health and health care:***
  - Track health indicators for children with disabilities
  - Ensure access to vaccine programmes
  - Develop awareness of health care professionals, families and community workers
  - Implement processes of community-based rehabilitation
- ***In action plans on child rights address needs of children with disabilities***
- ***Ensure HIV/AIDS education and drug programmes target vulnerable populations including people with disabilities***
- ***Mainstream disability in homelessness strategies***
  - Include targeted programmes to address the needs of people who have a disability and their families
  - Take account of the barriers they face to economic, social, and political participation
- ***Address inequalities among countries and promote economic and social participation of all groups***
  - In multilateral investment strategies
  - In free trade policies

## Middle East and North Africa

The MENA report suggests two main factors need to be taken into account in developing strategies to address the poverty and exclusion of people with intellectual disabilities and their families. First, unrest and situations of conflict impact every aspect of society. Second, religious and cultural differences characterize the way in which people organize themselves and the way that disability is perceived by society. In considering and analyzing findings from the 22 country reports in the region, participants recommend:

- ***Assure access to free education for all, and ensure inclusion for children and youth with disabilities***
- ***Integrate and assure participation of people with disabilities in education and training – in schools, institutes, universities, and workplace training***

- ***Integrate people with disabilities within all workplaces and vocational and occupational positions***
- ***Address gender inequality in access to services, education, health and employment***
- ***Assure adequate income for individuals and families – through allowances, income protection, and insurance***
- ***Assure people with disabilities can access community rehabilitation, health care and other services***
- ***Assure people with disabilities and their families can access information about community services, education, and forms of assistance, etc. (e.g. through information “hot lines”)***
- ***Target public awareness programs to people with disabilities, families and decision makers at all levels:***
  - Focus on the rights of persons with disabilities and their successful experiences
  - Use various approaches - media, educational curricula, and published information
- ***Strengthen legislative, policy, and enforcement measures in education and employment to:***
  - advance and protect rights
  - address gender inequality
  - combat discrimination and exclusion
- ***Establish and strengthen coordinated National Plans to advance integration of people with disabilities, and ensure implementation of plans***
- ***Establish measures to coordinate and implement laws and policies:***
  - Engage all governmental and non-governmental parties concerned
  - Focus on coordination particularly between the Ministries of Social Affairs, Health and Education as well as agencies in charge of building codes and architectural specifications.

## Europe

The study from this region explored and contrasted the relative poverty faced by people with intellectual disabilities and their families across the very diverse countries in Western, Central and Eastern Europe. The findings show that despite differences in economic wealth among countries in the region, individuals and their families face a common experience of social and economic exclusion. In reviewing reports from across 21 countries in the region, participants recommend a shared 10-point agenda for change:

➤ ***Improve Access to education and lifelong learning***

- Ensure access to pre-school and school for everyone
- Promote access to adult education and lifelong
- Ensure teacher training for inclusive education at all levels
- Address lack of education through information exchange, monitoring policies, National Action Plans, and dedicated financing
- Ensure on the Rights of Persons with Disabilities recognizes right to inclusive education and lifelong learning
- Ensure children with disabilities are taken into account in international investments and programmes

➤ ***Fight against discrimination of persons with disabilities in employment***

- Promote hiring by local authorities
- Ensure adequate and effective non-discrimination laws
- Take active measures to finance reasonable accommodation
- Promote awareness
- Increase access to vocational training
- Exchange information on good policy and practice
- Gather information on lost economic capacity
- Ensure UN Convention recognizes right to non-discrimination in employment; ensure international agencies adopt inclusive strategies in poverty reduction efforts; and include people with disabilities and their families in strategies to meet Millennium Development Goals

➤ ***Create equal access to mainstream health care.***

- Ensure access to health care without discrimination

- Ensure training and raise awareness of local health professionals
  - Gather more information on health care access issues
  - Ensure UN Convention on the Rights of Persons with Disabilities recognizes right to highest attainable standard of health without discrimination
- ***Caring at home: Focus on families of persons with intellectual disabilities***
- Encourage local community voluntary support and respite services
  - Ensure families receive adequate financial support
  - Make leisure facilities accessible to people with disabilities
  - Recognize the value of non-remunerated caring work
  - Ensure UN Convention on the Rights of Persons with Disabilities recognizes the role that families play in supporting inclusion and participation of people with disabilities
- ***Ensure legal capacity and access to rights and justice for everyone***
- In all areas of government responsibility, ensure access to government services, provide accessible information, and develop and implement quality standards
  - Ensure adequate legislation in areas of legal capacity and guardianship that meet international recommendations
  - Integrate issues of legal capacity in strategies to address poverty and social exclusion
  - Ensure UN Convention on the Rights of Persons with Disabilities recognizes that all people with disabilities have the right to make decisions on their own behalf and that where support is required to exercise that capacity, the State provide appropriate supports
- ***Address the link between poverty, exclusion, and institutionalization***
- Commit to put deinstitutionalization policies into practice
  - Ensure governments commit to quality community-based services, with compulsory monitoring and evaluation
  - Ensure a rights-based approach to policies and planning
  - Change policies to ensure full participation of people with intellectual disabilities in society

- Provide needed support to families and communities and provide access to affordable accommodation
  - Address the problem of institutionalization in broader policies on poverty and social exclusion
  - Ensure UN Convention on the Rights of Persons with Disabilities guarantees the right to live in the community with supports
- ***Compensate for extra costs of disability***
- Encourage voluntary community support, and local leisure centres to lower admission
  - Design benefit schemes to compensate adequately for the extra costs of disability
  - Provide personal budgets or direct payment schemes to allow people to purchase the support they need
  - Ensure equal living conditions for all people in all Member States, and harmonize compensation systems across States
  - Ensure UN Convention on the Rights of Persons with Disabilities recognizes the right to an adequate standard of living
  - Develop strategies to address extreme poverty
- ***Develop specific measures for persons with intellectual disabilities in Central and Eastern Europe***
- Ensure financing instruments allocate funding to meet needs of persons with intellectual disabilities
  - Include issues people are facing in broader strategies to address poverty and social exclusion
- ***Create a better database for monitoring of social inclusion policies***
- In national census, distinguish disability and types of disability from long-standing health problems
  - Account for disability in indicators to evaluate social inclusion policies
  - Collect statistical information at the EU level about inclusion of persons with intellectual disabilities and other disability groups
  - Ensure UN Convention on the Rights of Persons with Disabilities requires governments to collect information needed for policy development to give effect to the Convention

- Include data on children and adults who have an intellectual disability in international reporting by UN Agencies
- Conduct additional regional research on poverty and disability
- ***Mainstream intellectual disability in national, European, and world policies***
  - Mainstream disability issues in planning, implementation, monitoring, evaluation, and revision of policies and actions at all levels – locally, nationally, regionally and internationally
  - Ensure legislation has appropriate implementation structures
  - Ensure information gathering and knowledge sharing about needs for supports and services
  - Establish good and continuous cooperation of authorities as all levels with organizations of people with disabilities
  - Strengthen family and informal support structures
  - Mobilize all actors for poverty reduction

## Asia Pacific

This region is home to over 50% of the world's population on 20% of its land area. Asia Pacific embraces diverse populations, millennia old civilizations, religions and traditions in the midst of the world's fastest growing economies. It includes countries like India and China with the largest populations of any other countries in the world, with distinct political systems, and rapidly developing economies; alongside already industrialized countries with comparatively small populations like New Zealand and Australia. There is widespread poverty in many areas of the region.

In this context, and with limited disability and family civil society organizations in the region, it was impossible in the time frame and with resources available to undertake country or region-wide studies for the purposes of this Global Report. However, a Consultation was undertaken with representatives from countries throughout the region. Results point primarily to the need to develop civil society capacity to raise awareness, encourage knowledge sharing and advocate for policy development. These are essential first steps in addressing poverty and exclusion. Participants in the consultations in this region recommend:

- ***Establish a comprehensive social security system to give the poorest of the poor a right to live and enjoy citizenship***

- ***Establish poverty alleviation programs inclusive of people with disabilities and their families***
- ***Assure access to inclusive education and employment***
- ***Build awareness and capacity among disabled persons organizations***
- ***Establish mechanisms to effectively implement policy***
- ***Ensure implementation of directions being developed through the Biwako Millennium Framework for Action Towards an Inclusive, Barrier-Free and Rights-Based Society for Persons with Disabilities in the Asia and the Pacific, including:***
  - Strengthening self-help organizations of persons with disabilities
  - Achieving gender equality for women with disabilities
  - Access to early intervention and education
  - Access to training and employment, including self-employment
  - Access to the built environment and public transport
  - Access to information and communication
  - Poverty alleviation
  - Promotion of rights-based approaches to disability
  - Sub-regional, regional, and international cooperation

## **Shared Foundations for Change – Building Blocks for a Global Agenda**

People with intellectual disabilities and their families have written a comprehensive agenda to combat their poverty and exclusion in every region of the world. In these recommendations, there is a consistent message to communities and broader civil society, to teachers, employers, administrators, health care and other professionals, to governments and international agencies: help lay down the foundations for a good life for all of us.

We want to believe that one of the main reasons these foundations are not yet in place for so many people and their families, is that others don't yet know how to lay them. From our own experience we know that it is

possible, even if at the beginning it looks challenging and unworkably complex.

Foundations begin with building blocks. In reviewing the comprehensive Regional Agendas participants in this study created five main building blocks with which to build the foundations of a good life for all. These are the starting points for a Global Agenda to Combat Poverty and Exclusion of People with Intellectual Disabilities and their Families:

- All people must be able to exercise **rights to self-determination and full citizenship** so they can choose their own path in life, and have their voice heard and respected by others.
- From birth and throughout their lives, **all people must live in the community** where they experience belonging, participation and membership.
- Children, youth, and adults must have **access to inclusive education and lifelong learning, health care and social supports** to get a good start and live a good life.
- Proactive strategies must be in place to assure people have **access to adequate income and employment** so that individuals, families, communities, and countries can develop and thrive.
- **Families must be fully supported** to provide each of their family members with opportunities, support, and high expectations for a good life.

The directions for putting these building blocks into place in different regions of the world are spelled out in the Regional Agendas above. They show that there are key roles to be played in putting the building blocks into place; in making sure the foundations that get built will be strong enough to combat poverty and exclusion, and enable a good life for all people with intellectual disabilities.

First, civil society organizations of people with intellectual disabilities and their families must be created, strengthened and supported – at all levels from local communities to global networks. Strategies must empower people to share their stories and knowledge, build networks, and raise their voices for change. Solidarity across civil society is critical, so that shared movements and common agendas are created.

Second, governments play a critical role. Their laws and policies must explicitly assure rights protections for people with intellectual disabilities and their families. These must provide the basis for policies and programs that are resourced, implemented, coordinated across levels and departments of

government, monitored, and evaluated. Most urgently, the issues of people with intellectual and other disabilities must be fully integrated into national, regional, and international social and economic policies and governance structures. From the outset, policy making must engage civil society organizations of people with intellectual disabilities and their families.

Third, donor agencies and international institutions must dramatically expand their policy focus and investment strategies on people with disabilities and their families. The depth of poverty and exclusion is growing. Social and economic means and capacities are diminishing for far too many people and their families. The cycle of poverty and exclusion is becoming a downward spiral. It must be stopped.

People must be given the basic building blocks and a foundation for a good life. With that they will learn, thrive, contribute, and make a difference in their communities. There are a number of recommendations in the Regional Agendas for multilateral and donor investment strategies to restructure and redirect international financing, policies and practices. There is also an urgent call to take the necessary steps in concert with people with intellectual disabilities, their families, and their local-to-global networks. They bring knowledge, expertise, resources and the capacity to make investments work on the ground, in communities, where it matters in people's lives.

## Conclusion

**T**wenty-six million people with intellectual disabilities are living on less than \$1 dollar a day. Relative poverty rates in countries around the world place the vast majority of people with intellectual disabilities at the margins of community life; many have fallen through its web altogether. Exclusion is pervasive in people's lives.

We began this Global Study to better understand the conditions that have led to these outcomes, and to better grasp what might be done. Across the globe people with intellectual disabilities and their families have gathered together over the past three years to shed light on their lives. To tell it how it is. To share knowledge. To foster hope together that their contributions and ideas will make a difference.

We have laid out a Global Agenda to Combat Poverty and Exclusion. We have written the Agenda to take account of diverse realities in countries around the world. We have a roadmap for change in every region of the world.

And we have a simple message. Hear our voices. It could make all the difference.

## Endnotes

### Introduction

- 1 Inclusion Europe (2005) Poverty and Intellectual Disability in Europe. Brussels: Author.
- 2 Sen, Amartya (1999) Development As Freedom. Oxford: Oxford University Press.
- 3 Organization for Economic Cooperation and Development (2005) DAC Guidelines on Poverty Reduction. <http://www.oecd.org/dataoecd/18/19/1849018.pdf>
- 4 Inclusion International reframed Goal 5 slightly for the purposes of its own MDG Framework – maintaining the intent but making the focus a bit broader to ‘Achieve the Rights of Children and Families.’

### Approach to the Global Study

- 1 Participating associations included Lesotho Society for Mental Handicapped Persons, LSMHP (Lesotho), APDSwa (Swaziland), Zanzibar Association of People with Development Disabilities, ZPPDD (Zanzibar), Tanzania Association for Mentally Handicapped Persons, TAMH (Tanzania), Disabled Children’s Action Group, DICAG (South Africa), Zimbabwe Parents of Handicapped Children Association, ZPHCA (Zimbabwe), Namibia Parents Association, NPA (Namibia), Zambia Association for Children and Adults with Learning Disabilities, ZACALD (Zambia), ACRIDEME, (Mozambique), Parents of Disabled Children Association of Malawi, PODCAM (Malawi).

### Our Report on the Millennium Development Goals (MDGs)

- 1 Elwan, A.(1999) Poverty and Disability: A Review of the Literature, Social Protection Discussion Paper No. 9932, The World Bank.
- 2 <http://www.ilo.ru/news/200305/docs/DiscriminationFactSheetsAmerica.pdf>
- 3 UNICEF (2005) Children and Disability in Transition in CEE/CIS and Baltic States. Innocenti Insight, 2.
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- 5 Crawford, C. (2005) ‘People with Intellectual Disabilities, Labour Force Participation and Social Assistance: Estimates and Future Directions.’ Toronto: The Roeher Institute.
- 6 World Bank (August 2003) Education for All: Including Children with Disabilities. Education Notes. [http://siteresources.worldbank.org/DISABILITY/Resources/Education/Education-Notes/Education\\_Notes\\_En.Aug.doc](http://siteresources.worldbank.org/DISABILITY/Resources/Education/Education-Notes/Education_Notes_En.Aug.doc)
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- 9 International Disability Foundation (1999) World Disability Report. London: The Winchester Group.
- 10 Alur, M. (2003) Invisible Children: A Study of Policy Exclusion. Delhi: Viva
- 11 World Bank (August 2003) Education for All: Including Children with Disabilities. Education Notes.

## List of Countries Participating in the Global Study

Algeria	Guatemala	Oman
Albania	Greece	Palestine
Argentina	Honduras	Panama
Austria	Hungary	Peru
Azerbaijan	Ireland	Philippines
Bahrain	India	Poland
Belarus	Iran	Romania
Belize	Iraq	Russia
Belgium	Jamaica	Senegal
Burkina Faso	Japan	Serbia and Montenegro
Bolivia	Jordan	Slovenia
Bosnia	Kuwait	Solomon Islands
Bulgaria	Latvia	South Africa
Brazil	Lebanon	Sudan
Canada	Lesotho	Suriname
Chile	Libya	Sweden
Columbia	Macedonia	Syria
Costa Rica	Malawi	Tanzania
Czech Republic	Mauritius	The Netherlands
Denmark	Mali	Trinidad and Tobago
Ecuador	Mexico	Uganda
Estonia	Moldova	United Arab Emirates
Ethiopia	Morocco	United Kingdom
Egypt	Mozambique	United States of America
El Salvador	Namibia	Thailand
France	Nepal	Tunisia
Georgia	New Zealand	Yemen
Germany	Nicaragua	Zambia
Ghana	Norway	Zimbabwe