

# Inclusive Communities = Stronger Communities



GLOBAL REPORT ON  
ARTICLE 19: THE RIGHT  
TO LIVE AND BE INCLUDED  
IN THE COMMUNITY

October 2012



choice  
support  
inclusion

Inclusion  
international



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GLOBAL REPORT ON ARTICLE 19: THE RIGHT TO  
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# Table of Contents

<i>List of Tables and Figures</i> .....	v
<i>List of Acronyms</i> .....	vi
<i>Acknowledgments</i> .....	viii
<i>Foreword</i> .....	xi
<b>INTRODUCTION</b> .....	1
<b>PART I: The Global Context</b> .....	13
Chapter 1: About the Global Study.....	14
Chapter 2: People with Intellectual Disabilities, Families and Community; Understanding the Roles and Relationships .....	23
Chapter 3: Regional Perspectives .....	34
<b>PART II: Our Vision of Inclusion</b> .....	43
Chapter 4: People with Intellectual Disabilities and Families Define What Living Independently and Being Included in the Community Means .....	44
<b>PART III: Where Are We on the Road to Inclusion?</b> .....	53
Chapter 5: Article 19 of the Convention on the Rights of Persons with Disabilities: Choice, Support, Inclusion .....	55
Choice .....	57
Supports .....	67
Supports to the Individual .....	68
Supports to Families .....	80
Inclusion .....	89
Chapter 6: Future Directions in Advancing a Framework for Inclusion in the Community .....	99
Chapter 7: Institutionalization: Ending the Cycle of Exclusion .....	109

<b>PART IV: Achieving Inclusion</b> .....	123
Chapter 8: The Role of Family Based Organizations in Making Change and Promoting Inclusion .....	124
<b>CONCLUSION</b> .....	131
<i>Appendices</i>	
Appendix 1: List of Countries and Participants in the Global Study .....	140
<i>Endnotes</i> .....	147
<i>Bibliography</i> .....	148

# List of Tables and Figures

## Tables

Table 1	Sources of Information .....	18
Table 2	It's Not Independent Living.....	32
Table 3	Euphemisms Used for Institutions.....	84
Table 4	The Right to Decide. Issues and Future Direction .....	101
Table 5	Where and With Whom. Issues and Future Direction .....	102
Table 6	To Individuals in High Income Countries. Issues and Future Directions.....	104
Table 7	To Individuals in Low Income Countries. Issues and Future Directions .....	105
Table 8	To Families. Issues and Future Directions .....	106
Table 9	Obstacles for Inclusion. Issues and Future Direction .....	108
Table 10	Second Order Deinstitutionalization .....	115
Table 11	Stronger Communities for All .....	128
Table 12	Using the Results of Inclusion International's Research on the Right to Live and Be Included in the Community. Steps to Inclusion .....	137

## Figures

Figure 1	Schematic view of Article 19.....	56
Figure 2	Where do people with intellectual disabilities live. Country profiles survey....	67
Figure 3	Community based programmes and services for people with intellectual disabilities. Country profiles survey .....	71
Figure 4	Forms of support given to families. Country profiles survey.....	79
Figure 5	Employment for adults with disability. Country profiles survey .....	91
Figure 6	Policies or legislation to promote employment on people with disabilities. Country profiles survey .....	91
Figure 7	Education for children with disability. Early Childhood education. Country profiles survey .....	92
Figure 8	Education for children with disability. Primary and secondary. Country profiles survey .....	92
Figure 9	Inclusive Education. Country profiles survey .....	93
Figure 10	Educational programmes for adults with disabilities. Country profiles survey .....	93
Figure 11	Characteristics of the health services for people with disability. Country profiles survey .....	94

## List of Acronyms

ADHD	Attention Deficit and Hyperactive Disorder
AKIM	National Association for the Habilitation of children and adults with intellectual disabilities Israel
API	Association for Promoting Inclusion
ASNIC	Asociación Nicaragüense
ASDOWN	Asociación Síndrome de Down de Colombia
CACL	Canadian Association for Community Living
CBR	The Community Based Rehabilitation
CIS	Commonwealth of Independent States
CRPD	UN Convention on the Rights of Persons with Disabilities
DECLOC	The Deinstitutionalization and Community Living – Outcomes and Costs
DPOs	Disabled People’s Organizations
EEC	Especial Education Classes
IDA	International Disability Alliance
II	Inclusion International
INGOs	International Non-Governmental Organizations
MDAC	Mental Disability Advocacy Centre
MDRI	Mental Disability Rights International
MENA	Middle East and North Africa
MENCAP	Inclusion International member in the UK
MHI	Mental Health Initiative
NGO	Non-Governmental Organizations
OSF	Open Society Foundation
PWID	Person with Intellectual Disabilities
RTE	Right to Education
UK	United Kingdom
UN	United Nations
UNICEF	United Nations Children’s Fund
UNESCO	United Nations Educational, Scientific and Cultural Organization
UNRWA	United Nations Relief and Works Agency for Palestine Refugees in the Near East
USA	United States of America
WHO	World Health Organization
ZAPDD	Zanzibar Association for People with Developmental Disabilities

## **The UN Convention for people with a Disability**

### **Article 19 – Living independently and being included in the community**

States Parties to the present Convention recognize the equal right of all persons with disabilities to live in the community, with choices equal to others, and shall take effective and appropriate measures to facilitate full enjoyment by persons with disabilities of this right and their full inclusion and participation in the community, including by ensuring that:

- a) Persons with disabilities have the opportunity to choose their place of residence and where and with whom they live on an equal basis with others and are not obliged to live in a particular living arrangement;
- b) Persons with disabilities have access to a range of in-home, residential and other community support services, including personal assistance necessary to support living and inclusion in the community, and to prevent isolation or segregation from the community;
- c) Community services and facilities for the general population are available on an equal basis to persons with disabilities and are responsive to their needs.

To learn more on the Convention visit

**<http://www.un.org/disabilities/>**



## Acknowledgments

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To all of our member organizations and the many individuals with intellectual disabilities and family members, we thank you for your courage and willingness to share your hopes, dreams and fears. We hope this report does justice to your vision for the future, your experiences of life in the community and all of your efforts to make our communities stronger for all.

Lastly, thank-you to those people whose voices are missing from this report. While people with intellectual disabilities remain incarcerated in institutions or hidden in their homes they remain invisible and voiceless. We hope this report helps give them a voice and helps to make that voice heard.

## Foreword

**TWO YEARS AGO** we embarked on a campaign to promote the right of people who have an intellectual disabilities to live and be included in the community. We have reached out to self-advocates and families around the world. We listened to their stories and heard about their challenges. For people with intellectual disabilities being included in the community is fundamentally about relationships, to families, friends and community. Families play a critical role in supporting people to be included and in building inclusive communities but just as people with intellectual disabilities feel excluded, families themselves feel isolated and overwhelmed.

The isolation and exclusion described in the report faced by people with intellectual disabilities and their families is not new but we are facing new challenges to inclusion in the community. The current climate has led to increasing pressure on adults with intellectual disabilities who are already more likely to live in poverty and be unemployed, more pressure on families who are caring for and advocating for their family members without support in the community and more pressure on communities that are divided and experiencing political and economic crisis.

More than 60 years after many of Inclusion International's national family organizations were founded to advocate for inclusion in the community, we face a critical turning point driven by social and economic pressures and outdated models of support. While the global financial crisis and the corresponding austerity measures have put enormous pressure on communities and on families, we are witnessing communities becoming increasingly



divided along ethnic, income, religious and other lines. Reduced investment in social infrastructure and social capital that holds communities together and is essential for social and economic inclusion is impacting directly on individuals and families who are already marginalized.

At the same time, the services and support models that governments and communities use to support people with intellectual disabilities are remnants of institutional, protectionist delivery systems and continue to segregate and isolate people.

In the face of these new challenges we have a choice to make. We can continue to try to do more with less and continue to focus our efforts on investment in service delivery; or we can fundamentally reorganize and renew our strategies to focus on high value supports and services that help fulfill the promises of the CRPD and especially of Article 19.

Self-advocates and families, by contributing to this report have provided a clear vision of what living and being included in the community should mean: Choice, Support and Inclusion. They have also provided a roadmap for building stronger more inclusive communities. The challenge for our international movement is to provide the leadership along this new road.

***Klaus Lachwitz***

President

# Introduction





# Introduction

**EVERYONE WANTS TO BELONG.** We value being a part of families, neighbourhoods, a group of peers at school, a group of colleagues at work, clubs and sports teams, and having friends and neighbours who care and look out for us. Unfortunately all too often people with an intellectual disabilities are left out – hidden, excluded or kept separated from the rest of their communities. That’s why Inclusion International fought for the right to be included in the community, to be recognised as a basic human right for people with disabilities. Community is fundamental to our sense of who we are. Communities are stronger when we are all included and when everyone can participate, contribute and be valued.

Article 19 of the Convention on the Rights of Persons with Disabilities (CRPD) articulates the right to Live Independently and Be Included in the Community. It obliges governments and societies to:

- Enable people to make choices about how and where they live;
- Provide support so that people who have a disability can live in the community; and
- Ensure that mainstream services and systems are available and accessible to people with disabilities on an equal basis with others.

Inclusion International (II) is the international organization that represents people with intellectual disabilities and their families. Our members are national family based organizations in 115 countries that work to promote the inclusion of people with intellectual disabilities in their communities. Inclusion International adopted its name in 1994 as a commitment to and a reminder of our vision: a world where people with intellectual disabilities and their families can equally participate and be valued in all



aspects of community life. With its member societies, Inclusion International acts as an agent for change on the basis of four main principles affecting the lives of people with an intellectual disabilities and their families:

- Inclusion in all aspects of everyday society
- Full citizenship which respects individual human rights responsibilities
- Self-determination in order to have control over the decisions affecting one's life
- Family support through adequate services and support networks to families with a member with a disability



As a result of our involvement in the CRPD negotiations, these principles are reflected throughout the Convention.

**For us, Article 19 is more than just the articulation of a human right. It provides us with a framework to understand what the right means, how policies to support that right should be developed and implemented and how to monitor progress.** Our members report that despite good examples and practices, there is no country in the world where the goals of

living and being included in the community have been fully achieved for people with intellectual disabilities.

In the absence of services and natural supports in the community and the failure of communities to build inclusive systems, the vast majority of people with intellectual disabilities around the world depend on their families for lifelong support and care. Relationships then become central to our vision of living “independently” and being included in the community; both the relationship between individuals and their families and the relationship of individuals and families to their communities.

Despite the promise of the Convention and Article 19 the reality for the vast majority of people with intellectual disabilities is that they are almost always denied the right to make decisions about where and with whom they want to live. They have little or no access to services and supports (other than those provided by their families) and they are excluded from participating and contributing in their communities because community supports are not welcoming or accommodating and/or because they lack the supports necessary to use these services (e.g. accessible transportation, personal supports, financial capacity).

While many issues emerge from the collection of experiences and knowledge of people with intellectual disabilities and their families in this report, the central messages from self-advocates and families are:

- **Choice** – People with intellectual disabilities require and have the right to choice and control about where they live and with whom; they have the right to support in their decision making and they have the right to choose from the same range of options that others in their community have.
- **Support** – To live and be included in the community individuals need disability related services and supports on a day to day basis. Some of those services are currently state sponsored but in the vast majority of cases they come from families. Families need support from governments and communities to play their role in promoting the inclusion of their family member into the community.
- **Inclusion** – Unless communities are organized to be inclusive of people with disabilities through education, employment, social, cultural and political processes, investments in services alone will not enable the realization of the right to live and be included in the community.

## A History of Exclusion

Throughout history people with disabilities have been excluded, persecuted, feared and discriminated against because of their disability. *“In ancient Sparta, children with physical differences were thought to represent the displeasure of the gods and many were left on hillside cliffs to die or were thrown off mountains. In ancient Rome, they were drowned in the Tiber.”*<sup>1</sup>

In the mid-nineteenth century industrialized countries began to build institutions, asylums and other large residential facilities to house, “treat” and “protect” people with intellectual and psychosocial disabilities. Later the eugenics movement which originated in England and spread to Europe, North America and other parts of the world, influenced societies’ perceptions of people with disabilities as defective and promoted the idea that the quality of the human race would be improved by preventing people with disabilities from existing. The result was the labeling and segregating of people with disabilities from society.

From the 1920s until the 1980s in economically developed countries institutions were the predominant form of public support for people with an intellectual disabilities. The story of, and the role played by, institutions in the lives of people with intellectual disabilities and their families varies greatly across countries and cultures. While the majority of people with intellectual disabilities have always lived with family, in many countries throughout the world institutions are/were used as a primary residential response to situations where individuals could no longer reside with family. Indeed in many countries, particularly in North America, Europe, and the former Soviet Union, institutional placement became the accepted response and indicated course of action upon the birth of a child with an intellectual disabilities.

Stories related by families throughout these countries tell of parents being advised by professionals to place their child with an intellectual disabilities in an institution, forget about them, and get on with their lives; that such a course of action was in the best interests of all concerned. Coupled with a general lack of support for families raising a child with a disability in many countries, the result was a high rate of institutionalization and, in many places, horrid, sub-human conditions in those institutions. Those horrid, sub-human conditions continue in far too many places.

The role of institutions began to be critically questioned when the collective societal view of intellectual disabilities began to change. This change was fueled in part by the principle of Normalization, a concept which began in Scandinavia and spread throughout the world. The principle of Normalization is that people with an intellectual disabilities should have a life that follows the patterns, routines and customs of other people (Wolfensberger 1972). This new approach increased demand by parents and self-advocates for a societal response that would enable people with intellectual disabilities to live in community, closer to family, and the rejection of the notion that people with intellectual disabilities needed to be separated, isolated or congregated for their own good.



In particular, in North America and Europe, increased questioning of the value of institutions led to many exposés, investigations and litigation that revealed the alarming extent of abuse and mistreatment that was routinely occurring in these institutions and this in turn further accelerated calls for institutional closures (i.e. deinstitutionalization). In the fifty or so years since many countries have undertaken deinstitutionalization efforts the research and evidence continues to confirm that large

institutions are not in the best interests of people with intellectual disabilities, that a variety of other smaller, more appropriate, more individualized options can be developed and sustained, that with appropriate supports persons with intellectual disabilities can live with family (until, in some cultures, they choose to leave) and that all persons with intellectual disabilities, regardless of extent or level of support need, can successfully live in community.

In countries where large scale institutions were not built, historically, people with intellectual disabilities have suffered prejudice and discrimination in their communities

and they have been denied their basic human rights. A legacy of medicalization of disability has meant that disability continues in many parts of the world to be considered as a health issue to be prevented, cured or treated. This has often meant few hours of actual treatment or rehabilitation but a reliance on medical professionals rather than educators or employers and little or no support for the family.



Even as the global disability movement has adopted and advocated for a human rights approach to disability, this history of

exclusion and isolation continues to play a powerful role in the way that people with disabilities and their families are treated by society and their communities and even in the way that policies and resources are used to provide services.

## **Purpose of the Report**

Inclusion International and its member organizations fought hard to ensure that the right to live and be included in the community was part of the UN Convention on the Rights of Persons with Disabilities (CRPD). The

challenges we face in turning this right into a reality around the world are multiple and complex.

The CRPD came into force in 2006 and has been ratified by more than 120 countries. Yet few governments fully understand the implications of implementing the Convention and specifically Article 19. In order to address the historic and systematic exclusion of people with disabilities, our communities, governments and societies will need to embrace a new paradigm (reflected in the CRPD). Shifting from seeing disability as a programme or issue area in which people with disabilities are the recipients or subjects of policy to a transformative process which helps to build stronger communities in which everyone participates and contributes. It means looking not only at the person with a disability but also at their families and support circles and the communities that they live in. Understand how to strengthen the social fabric of our societies.

Significant research and work has been done about deinstitutionalization and in understanding services and supports which people need to live successfully in the community. What is missing is the voice of people with intellectual disabilities and their families who have lived the experience of exclusion and isolation, who understand the causes and impact of that exclusion and who have a vision for what living and being included in the community should look like. We wanted to know:

- What the current situation of people with intellectual disabilities and their families is in relation to their inclusion in the community;
- What we have learned about why people are excluded and isolated;
- What progress has been made;
- What the new and emerging challenges are which threaten inclusion;

- What we and our allies should do to achieve the changes required to make Article 19 a reality across the world.

## Overview of the Report

The report will present the perspective of people with intellectual disabilities and their families on living and being included in the community. We want to share our experiences of inclusion in the community, of exclusion and isolation from the community and the impact that these experiences have had on the lives of people with intellectual disabilities and their families.

Part I of the report sets a global context for the study; explains the unique perspective of people with intellectual disabilities and their relationship to family and explores regional differences and commonalities in how we perceive living and being included in the community. In Chapter 1 we describe how we did the study, and the ways participants in over 95 countries contributed their stories, information and knowledge through focus groups, video and written submissions, surveys, regional forums and pilot initiatives. Understanding the relationship between a person with an intellectual disabilities, their family, community and society is critical to advancing human rights and building stronger communities. Chapter 2 describes the inter-dependence between people with intellectual disabilities, their families and communities which is the basis upon which we advance inclusion. In Chapter 3 we provide a context for the regional commonalities and distinct issues affecting people with intellectual disabilities and their families and the right to live and be included in the community.

In Part II we present the vision of inclusion in the community which people with intellectual disabilities and their families strive for and desire. Chapter 4 pulls together

a shared vision created by the voices of people with intellectual disabilities and their families from around the world.

In Part III we present the findings of our study using the framework of Article 19 as a basis for examining Choice, Support and Inclusion: we draw from those findings some future directions for the achievement of the right to live and be included in the community; and we explore the particular experience of institutions and the closure process. Chapter 5 details what we heard from people with intellectual disabilities and their families about being able to choose where and with whom they live; about the services and supports they receive and more often about what they do not receive; and about how communities and the systems within communities (education, health, employment etc) are organized. In Chapter 6 we explore the implications of our findings for governments and communities and we identify future directions for that work. Chapter 7 addresses the legacy of institutions and the learning we have done in the closure process.



Part IV of the report points towards directions for the future. Chapter 8 reflects on the role of families and family based organizations as agents for change in their communities. Finally in the Conclusion we summarize the findings of the report and provide a list of strategies for governments, communities and families to follow in their efforts to advance the right to live and be included in the community.





# **PART I: The Global Context**





## Chapter 1: About the Global Study

**INCLUSION INTERNATIONAL, THROUGH** participatory action, research efforts and the development of global studies, has demonstrated our capacity not only to monitor and report on key issues facing people with intellectual disabilities and families but to contribute to policy and practice by drawing from the knowledge and experience of people in communities around the world. Our goal is to link local voices to global change. Over the last decade we have developed and enhanced a participatory action research methodology that relies on

the expertise and experience of people with intellectual disabilities and their families. Each of our reports reflects the culmination of a process to hear and represent the collective voices of people with intellectual disabilities and their families.

In 2006, we issued our first Global Report on Poverty and Disability<sup>1</sup>. The report highlighted the relationship between poverty and disability and reflected the reality that in all countries, regardless of a country's socio-economic status, people with disabilities and their families are disproportionately poor. The message in the report from people with intellectual disabilities and families was "we are invisible because we are poor." The report pointed to the need for the UN Millennium Development Goals to include people with disabilities.

In 2009, in celebration of the 15 year anniversary of the Salamanca Statement and Framework on Special Needs Education, we released a Global Report on Inclusive Education<sup>2</sup>. The report confirmed that around the world children with intellectual disabilities are more often excluded from school than are other children with disabilities and in many countries are excluded from the education system entirely. The report presented a platform for the inclusion of children with disabilities in global strategies to achieve Education for All.

Two years ago, at our 2010 World Congress in Berlin, we launched a global campaign on Living Independently and Being Included in the Community; Article 19 of the CRPD. The purpose of the Article 19 Campaign was to explore what living and being included in the community means around the world and to better understand how this is being achieved. Our report draws from and builds on the significant research on institutionalization and on the



support needs of people with intellectual disabilities in the community including housing, employment and education.

The drafting process for the UN Convention on the Rights of Persons with Disabilities itself reflected a shift in thinking about the role of people with disabilities in shaping policy and practice that impacts their lives. It was the expertise of people with disabilities and families that was used to write the CRPD. As a result, the Convention firmly repositions people with disabilities and families from being the subjects of research and policy to being active participants in research and policy.

Living and being included in the community means different things in different places. There are vast – and often stark – differences in the socio-economic realities of countries; in the availability and provisioning of resources; in culture and tradition; and in the concept and understanding of “living independently” in the community. We knew there would be no one answer or one picture of what living and being included in the community looked like or felt like. We turned to people with intellectual disabilities and families to share their expertise and knowledge about what is working and what isn’t, about their hopes and dreams and their challenges and fears. We looked to people with intellectual disabilities and their families because living and being included in community is not one picture; rather it is millions of individual pictures that are ultimately framed by people with intellectual disabilities and their families; not experts, governments or service providers.

We needed a methodology and process to capture the diversity of perspectives and the complexity of the issues. Building on our methodology from previous global reports we developed processes to gather stories in a variety of formats from people with intellectual disabilities and their families; to collect information about policy and data at a

country level from our member organizations; and to engage groups of people at regional, national and community levels in interactive discussions. From our experience with previous reports we learned how to take better advantage of the vast number of stories we received and how to better support our members to contribute meaningful information.

The process was designed to reach down through our regional bodies (Inclusion Africa, Inclusion Asia Pacific, Inclusion Europe, Inclusion Inter-Americana and Inclusion Middle East North Africa), member organizations and networks to engage directly with people with intellectual disabilities and families. In addition, we connected with academics, government officials, human rights NGOs, and funding organizations to get their perspectives and input.

Our research sought to answer three main questions:

1. What does living and being included in the community mean for people with intellectual disabilities and their families, and what is their vision of this?
2. What exists now, and how does it compare to this vision?
3. What needs to happen to achieve this vision?

Through various processes we received contributions from thousands of people in over 95 countries. We received detailed country profiles from 41 countries; individual stories from 36 countries; and input from focus groups in 23 countries and 5 regional forums.



**Table 1: Sources of Information**

Country Surveys	Stories	Focus Groups	Organizations Consulted
Africa 14 Americas 9 Europe 9 MENA 4 Asia Pacific 5	36 Countries (people with intellectual disabilities and families)	23 countries	MDAC MDRI MHI IDA OSF Handicap International
Regional Forums and strategy meetings		Countries	Consultations and Country-level initiatives
Americas Regional Forum: Colombia, November 2010		95 countries	Consultation on country experiences in closing large-scale institutions, Brussels June 2012
Africa Regional Forum: South Africa, March 2011			
European Regional Forum: Portugal, October 2011			
Asia Pacific Regional Forum: Nepal, October 2011			
MENA Regional Forum: Jordan, March 2012			
Americas Regional Strategy Meeting: Mexico, February 2012			
African Regional Strategy Meeting: Kenya, March 2012			
European Regional strategy Meeting: Brussels, June 2012			
		Pilot initiative with the Kenya Association for the Intellectually Handicapped: Developing community supports in Kenya.	
		Pilot initiative with AKIM: Transforming supports and services to be more inclusive and community oriented in Israel.	

## How the Information was Collected

We deliberately developed multiple strategies for contributing to the report as we knew that limitations in time and human and fiscal resources, numerous languages, and geographical hurdles were just a few of the challenges that would be faced in the efforts to gather information for this report. In some countries, focus groups and events were held. In others, focused efforts were tacked on to existing events to take advantage of a group of people already gathered. Regional coordinators in each region helped initiate data collection and contact with families and people with intellectual disabilities at a local level.

We invited our national member organizations, allies, families, people with intellectual disabilities and partners to contribute to the research through:

- **Focus Groups** – We asked organizations and individuals to host discussions with families and people with intellectual disabilities to share their perspectives on what their lives are like, where they are living and whether or not they want something different.
- **Country Survey** – Available online and in hard copy, the survey was designed to collect national-level demographic data (where possible and available) and to help provide a snap shot of key issues, challenges and successes in achieving inclusion in the community.
- **Pilot Initiatives** – We worked directly with some countries to address particular issues they identified as barriers to living and being included in the community. These initiatives include developing alternatives to institutional care for children with disabilities in Colombia, developing community supports in Kenya, and supporting our member in Israel, AKIM, to explore the transformation of



supports and services to be more inclusive and community oriented.

- **Sharing stories** – We asked people with intellectual disabilities and families to share their personal stories with us. Through the submission of stories, both written and oral, poems, pictures and videos, people showed us and told us about their lives.
- **Regional Forums** – II hosted five (5) Regional Capacity Building Forums – Americas, Bogotá, Colombia, November 2010; Africa, Johannesburg, South Africa, March 2011; Europe, Peniche, Portugal, October 2011; Asia Pacific, Kathmandu, Nepal, November 2011; MENA, Amman, Jordan, March 2011 – and three (3) strategic regional meetings – Mexico City, Mexico, February 2012; Nairobi, Kenya, March 2012; Brussels, Belgium, May 2012.

Specific tools and resources were developed to assist our members and partners to participate in the process. Presentations on both the Campaign and on Article 19 were made available online in English and translated into Arabic, Japanese, French and Spanish to be regionally and locally relevant<sup>3</sup>.

Regional capacity building forums, regional strategy meetings and focus groups provided an opportunity to hear from families and people with intellectual disabilities about issues that were specific to each region of the world. The process of having people meet and share their experiences provided both important input for the report and opportunities for people to develop strategies to build inclusive communities.

In Bolivia we heard, “ This initiative helps to illustrate many of the protests led by families and civil society organizations over the years, in order to acknowledge and gain the rights of people with intellectual disabilities, in this case, the right to live in community. When trying to contribute to the report we realize the limited written

information available on the subject, it is unusual for disability organizations to document and share their experiences and best practices with others. Sharing best practices would enhance the impact of our interventions. It would enable us to break boundaries and distances between continents, and have stronger impact by drawing on the experiences and strategies developed in diverse situations and contexts. It would be a collective construction of knowledge in which all contributions are valued and diffused. Congratulations to Inclusion International's initiative!"

The Campaign tools, resources and materials<sup>4</sup> were used in many ways by our members. For example New Zealand, Ireland, Kenya, Colombia and Nicaragua used the tools to generate a country profile and developed publications that frame all the work they did for this initiative.

In Colombia, Fundown Caribe in Barranquilla worked with young adults with intellectual disabilities to create personal stories that reflected their own lives using the personal story questions and the focus group strategy. They shared the stories and they are continuing their work with this group.



Data analysis enabled inter-country commonalities to be discovered and further investigated. For example Canada, the United States, Norway, the United Kingdom and New Zealand had similar experiences related to closing large-scale institutions. We conducted a specific consultation about this to determine what lessons can be learned from their experiences. These findings are documented in Chapter 7.

Our analysis also revealed that countries in Latin-America, Africa, Asia and the Middle East faced similar realities in relation to a lack of services and supports and the

complete reliance on families to provide support and care for their son or daughter with an intellectual disabilities throughout their life.

In countries where we were working with partners on pilot initiatives about living and being included in the community, we were able to support our member organization in the process of leading community change and to better understand the role of family organizations in transforming communities. In Colombia we are working with a government department to explore alternatives to the current institutional services for children at risk. In Israel, we are supporting the family led organization in its efforts to transform its services to promote life in the community.



Throughout the campaign, and as a result of our approach, we have been able to collect information at the grassroots, national, regional and international level from diverse stakeholders around the world. We recognize we need to work harder to hear and understand the voices of all people with intellectual disabilities.

Even with our participatory methodology, we feel it is important to acknowledge that this report does not fully reflect the perspective of all people with intellectual disabilities. While we have made an effort to include some of their experiences, the voices of people with significant support needs, those who have higher challenges in communicating and people who live in institutions remain under-represented.

Our research is the result of the collection of voices from around the world telling us about the reality of their lives. As you will see in this report, the richness of our data and knowledge is in the stories of families and self-advocates; in their successes and struggles to make living and being included in the community a reality.



## Chapter 2: People with Intellectual Disabilities, Families and Community, Understanding the Roles and Relationships

### People with intellectual disabilities

**DURING THE NEGOTIATIONS** of the UN Convention on the Rights of People with Disabilities (CRPD) several disabled people's organizations (DPOs) advocated for specific accommodations related to their needs. For many of these groups the provision of a specific device or service such as sign language interpretation, a wheelchair or a ramp

enables inclusion and participation. For people with intellectual disabilities, while some specific accommodations are necessary and may improve access to the community, there is no service or support that will enable full inclusion. It is not sufficient to provide a child with an intellectual disabilities with physical access to a classroom nor is it sufficient to give them a teacher's assistant. Real inclusion requires a reorganization of the classroom, curriculum and teaching strategies. Similarly, real inclusion in the community requires the transformation of communities; education systems, labour market, political systems, transportation systems, etc.



For people with sensory or physical disabilities there has been a strong push for “Independence”. The Independent Living movement has emphasized the individual's right to live independently and to determine for themselves the life they want to live. Article 19 refers to the right to live “independently” and be included in the community. However the word independent is often misused to mean alone or without support and for people with intellectual disabilities and their families it can create a barrier to inclusion. If a person cannot live “independently” then they are considered not capable of living

and participating in the community. In order to live “independently” people with intellectual disabilities need support and need to have relationships with their families and others who enable them to live and be included in the community.

Although Inclusion International's name, our mission statement, and the CRPD all mention inclusion, it is in many ways a concept that is not well understood. In our mission statement we make it clear that inclusion is different from supports and services. Supports and

services are given to the individual or to the family whereas inclusion relates to the environment; to the presence or absence of barriers and to the individual's sense of belonging. Supports and services are the tools to be used, not the outcomes to be achieved. Supports to an individual may make participation possible, but unless the environment is welcoming, that individual may not be or feel included.

## The Role and Responsibility of Families of Persons with Intellectual Disabilities

For the purposes of this report, "families" refers not only to parents and siblings but to the extended family and those with whom a person chooses to share his or her life. It does not refer to paid caregivers or service providers or people one may be living with but with whom one has not chosen to have a relationship (e.g.: roommates in a group home where a person is "placed").

Since the first global commitment to human rights in the Universal Declaration of Human Rights (1948), the family has been recognized as "the natural and fundamental group unit of society ... entitled to protection by society and the State." The Convention on the Rights of the Child recognized that "the family should be afforded the necessary protection and assistance so that it can fully assume its responsibilities within the community". The Convention on the Rights of Persons with Disabilities (CRPD) recognizes that families have a role to play in ensuring that persons with disabilities can exercise their rights and stipulates "persons with disabilities and their family members should receive the necessary protection and assistance to enable families to contribute towards the full and equal enjoyment of the rights of persons with disabilities."

### In Siaya, Fidel has big ideas for his future.

"I want to live in an apartment in Nairobi and work as a doctor in a hospital, or maybe as a footballer. I will have my own family, a fridge and a car."

In contrast, Fidel's mother had simpler ambitions for her son, saying:

"I want him to be able to take care of himself and to live in the community like any other person, without discrimination. I want my son to be included."



**Self-advocates said:****IN BARCELONA ...**

- We know what we want and how we want to live. We need the opportunity to express it and support to get there.
- Few of us will choose an institution as a place to live. Support needs cannot override our wishes and wants of one's own life.
- We have the ability to assume the responsibilities of independent living, with adequate supports.
- The environments where we live give little credit to our desires and ability to manage an independent life and is a major obstacle.

While the Universal Declaration of Human Rights recognizes the family as the “natural and fundamental group unit of society”, their role is even more critical in the lives of persons who have an intellectual disabilities. The very nature of intellectual disabilities, difficulty in learning, in remembering, in problem-solving and often in communicating, means that people who have an intellectual disabilities usually require some degree of lifelong support. As we heard from our members, most of this support comes from family members. A mother in Bolivia told us, “Most of my time is spent helping my daughter with everything she needs.” Or as one mother in Russia told us, “It’s a shame that a mother’s life stops after the birth of such child”. We think it should not be a shame or an undue burden.

While most children without disabilities gradually require less and less support from their families as they grow up, and people with physical or sensory disabilities also start to develop more and more independence and less reliance on family, research has shown that after age 10, children with intellectual disabilities start to require disproportionately more support because:

- The family member does not go to school or work and requires someone at home caring for him or her;
- The family member can’t be left alone when parents and others go to work or to social occasions;
- Parents need to devote time to finding supports and services, attending doctors’ appointments, etc.;
- The family member requires assistance with daily life activities – feeding, bathing, toileting, etc.;
- The family member needs help to find and keep a job.

The nature of intellectual disabilities means that a person with an intellectual disabilities will usually require some form of lifelong support, and the responsibility for providing that support usually falls to families. The CRPD calls on families to “contribute towards the full and equal

enjoyment of the rights of persons with disabilities". Given the situation of most individuals who have an intellectual disabilities and of their families, this is a daunting challenge. If communities are not welcoming, if services and supports are not available, parents often find that contributing to the exercise of the most basic human rights for their family member with a disability – such as going to school or playing in a public park – is a major challenge. A recurring theme from focus groups was "What will happen to my child after I am gone?" The country survey from Myanmar (Burma) wrote, "Families feel that a person with an intellectual disabilities is also one of their family members. However, they have been feeling that sometime it is a burden. They don't [know] where they will take them when they die." However, the stories we heard also demonstrated that the more individuals were included in their communities the less was the burden on families.

In every country, our members confirmed that family (however defined) was the foundation to an inclusive life in community. There was full agreement that for children the family structure was critical. Simply stated our members believe that children need a family in which to grow, learn, thrive and be nurtured. Where life within the nuclear or extended family is not possible, then another family is the preferred option – rather than options such as orphanages, group homes or institutions.

The role of family with respect to adults with intellectual disabilities is a little more complex. Our consultations and supporting data confirm that the majority of adults with intellectual disabilities live with family. What is less clear is the extent to which this life within family is within the cultural norms of the particular society, whether living with family is a choice made by the individual and/or their family, or if living with family is simply the result of there being no other more appropriate options.

**SPAIN** "My family did not want me to live in a home away from them, but we decided to try independent living. If all went well perfect, but if not, then nothing would happen, I could come back to their home. I know that always I have my family with me. The problem comes when you have no one and you are helpless"





The parents were concerned about how the self-advocates would care for themselves and avoid harassment from the community.

– *Lesotho*

The other complicating factor in commenting on the role of family is that invariably, both families and individuals, reported that inadequate supports were being provided to families to assist in their role as primary caregivers to their sons and daughters.

There are many situations where continued living at home is the preferred and typical choice, but this is possible only when adequate supports are provided. In many countries it is the general expectation that adult children will leave the family home upon reaching adulthood. This is not possible for people with disabilities if other options do not exist. In such situations, even in the presence of adequate home supports, choice is being denied.

Families throughout the world told us that they do not deny their responsibilities for their family members, whether as a child or adult. They told us clearly that they do not wish to shift this responsibility to society or government. What they want – what they need – is support in fulfilling that responsibility. They need support that will provide for the health and well being of their family member and also their family.

The lack of a welcoming community or of supports and services does not limit the responsibility for families to “contribute towards the full and equal enjoyment of the rights of persons with disabilities”. The growth of the self-advocacy movement of persons who have an intellectual disabilities has demonstrated that many people who have an intellectual disabilities are very skilled at expressing their wishes and being much more independent than their families had ever believed. The focus groups of families and of people who have an intellectual disabilities showed the two sides of the coin of the right to autonomy and the need for support.

When people are included in their communities and when supports are provided in very natural ways those supports



often are invisible, but they are very necessary for the inclusion to be real. A survey response from India said, *“One of the positive features of Indian society is that Persons with disabilities generally live with their families in majority of cases. However there are times when natural parents are no more and when no support available by the extended family, they face a severe problem. This problem is very acute among nuclear families and in urban areas.”*

At the same time many of the concerns of parents are very real. For example, there is the potential for their sons and daughters to be exploited and abused, and sometimes the wishes of the person who has a disability may be unrealistic because of financial or other constraints; therefore parents may justifiably want to ensure that there are safeguards to protect their sons and daughters. The obligation on families to be responsible for their family member who has an intellectual disabilities needs to be carefully balanced against the right of the individual to make his or her own decisions.

However, there are challenges that persons with intellectual disabilities face with their families. The most common is overprotection. A focus group in Nicaragua reported that overprotection by families limits the participation and free expression of people with intellectual disabilities and also leads to their feelings of insecurity. A group of self-advocates in Europe explained it this way, *“We need your support but we are the ones to makes the choice!”* Self-advocates in Hong Kong had a message for their families:

*“We need your support.*

*We need your respect.*

*We need your understanding.*

*We need you to have confidence in us.*

*We need you to learn to change with us.*

*We need you to welcome us to be part of the family.*

**ISRAEL** *“My family lives on a Kibbutz (“Beit Alfa”). Three years ago I moved to Kibbutz Hefziba where I live with my friends who have down syndrome. I wanted to live here in this neighbourhood. I chose to live with my friends. I am independent in my choices in life. I sleep alone in the room where I have my own shower. I am independent at work. I work in the “Izrael” Kibbutz at the dining room. I love living here in the Hefziba Kibbutz”*

*— Irit Regev*



*We need our brothers and sisters to work together to support our dreams and aspirations.*

*We hope we can learn from each other.”*

Another issue is that families sometimes fail to recognize the rights of a person with an intellectual disabilities as separate from the rights of his or her family. This may result in parents’ decisions to sterilize their daughters to eliminate any chance of pregnancy or to ease care for personal hygiene. In extreme cases this has led to surgery and hormone treatments to prevent children from growing and maturing physically to make care by parents easier.

Further, the right of children to grow up as part of a family is often ignored because of disability-specific systems. In countries with institutions, families are given the option to place their child in a residential facility instead of pursuing options for alternate family care such as fostering and adoption.

### Parents and siblings said ...

**KENYA** "My concern is about the future and the kind of poverty that we are living in. We are aging and it's a very bad scenario."

**UGANDA** "Who's training our child who has a disability – father not willing; mother no skill; community no time; government no resources."

**COLOMBIA** "With regard to the autonomy to move from place to place me as the father of Laura would NOT allow it, I will never let her go out by herself and not because she cannot be trusted, but because I do not trust the environment in which we live" – *Father in a focus group*

**BENIN** "Application of this article will be difficult in our context, the ideal desire is that somebody lives all the time with the person with an intellectual disabilities, because they can't stay alone they need support So living independently is not possible, do we have to say our wishes or to make realistic suggestions?"

"We are so sorry because she can[not] tell us what [is] wrong. We are tired, we cry also and we have to go to work at 8. Every night we are anxious, are we going to sleep or not? We suffer a lot but she is included at home, in the family. We love her so much, and give her affection, we think that she needs specialist therapist and institution, but we don't have it in Benin. We are not happy at all, we are afraid for the future because intellectual disabled people are marginalized."

**COLOMBIA** "Sadly I have to say with the death of my mother and Margarita moving with me, we have been able to open many doors," says Beatriz. She strongly believes her sister has to be more independent. Not all her other sisters believe the same but Beatriz has shown that by her sister attending an inclusive arts school, where they give painting classes for adult women, has been a very successful experience for her and for the women who study there.

**JAPAN** "For it is essential to have the support of family they represent our main source of help. Many of us share our parents concern for the future without them, but rarely talk about it together. Anticipating a life project itself is reassuring to our families and encourages the opportunity for them to see their children / as to their vital needs and desires met when they are alive."

**ZANZIBAR** "Too much freedom exposes our children to grave danger, they are prone to assault by bad people, sexually abused, over-dependent on parents, excluded, don't feel good about themselves, people look down upon them, they are called names."

**Table 2. It's Not Independent Living**

## IT'S NOT INDEPENDENT LIVING

### Article 19 and The Declaration of Interdependence

*Steven M. Eidelman – June 1, 2012*

*H. Rodney Sharp, Professor of Human Services Policy and Leadership*

The heading of Article 19 of the UN CRPD “Living independently and being included in the community” is disconcerting to many families, and I think it is a misnomer.

Article 19 says “States Parties to this Convention recognize the equal right of all persons with disabilities to live in the community, with choices equal to others, and shall take effective and appropriate measures to facilitate full enjoyment by persons with disabilities of this right and their full inclusion and participation in the community, including by ensuring that:

- (a) Persons with disabilities have the opportunity to choose their place of residence and where and with whom they live on an equal basis with others and are not obliged to live in a particular living arrangement;
- (b) Persons with disabilities have access to a range of in-home, residential and other community support services, including personal assistance necessary to support living and inclusion in the community, and to prevent isolation or segregation from the community;
- (c) Community services and facilities for the general population are available on an equal basis to persons with disabilities and are responsive to their needs.”

Article 19’s language is strong and clear, although it does not specifically call for closing institutions. However, its provisions cannot be implemented in the context of residential institutions. Article 19 (a), (b) and (c) are simply incompatible with institutionalization.

Article 19 is also interdependent with other parts of the CRPD, with everything from transportation, to respect for the person, to mobility, to education and so on. As with all people, the concept of interdependence is an important principle inherent to the CRPD. For example, Articles 3 and 26 of the CRPD support the concept of interdependence as well.

The whole idea of “independence” is culturally specific. In some societies we value the idea of an individual living alone (“making it on their own”). However, in many parts of the world, for all people in a culture, the extended family is seen as a support network and link to the community. The extended family may include people not related by blood or marriage, and as with all people, people with intellectual disabilities experience community in a variety of ways, interacting and forming relationships with many different people.

To effectively implement Article 19 we need to stop telling families that people with intellectual disabilities are going to live independently. To many families that sounds as if people will live alone and Article 19 does not call for people living alone nor does it call for people to live without needed supports. Article 19 does not define independence as people living alone but rather is about choices and control of one's life. Living alone is not the goal, though some people may prefer to live that way. However even people who want to live alone do not want to be lonely. Humans are dependent and interdependent on other humans. Interdependence is a good thing; it is desirable. Multiple studies show that people with disabilities are all too often lonely. Studies also show that when you live with a lot of people who are not your family you are more likely to be lonely than when you live with a few people. Study after study also show that we can help people with all levels of disability plan and take control of decisions large and small impacting their lives. We sometimes call this "person centered planning and supports." The goal of Article 19 and the CRPD is interdependence, self-governance and self-determination, not independence from other human beings. Article 19 is about people with intellectual disabilities being full citizens, people with meaningful and realistic choices and people with both rights and responsibilities in their community and in their nations. It is about the quality of life a person can enjoy when properly supported, not about how much support they need to live. For some people this interdependence means that they need support to exercise both their rights and responsibilities. Article 12 provides a framework for people who may need support with some or most decision making.

It is of course possible for people to be independent in performing tasks e.g. dressing oneself, feeding oneself, getting around the community without support from paid staff or other people. The concept of independence as it relates to disability comes from the tests and scales used to measure functioning; can a person dress independently, can a person make their meals without assistance, etc. Ability does not mean readiness for living in the community interdependently, however. We know how to support people to be interdependent and in control of the major aspects of their lives, regardless of their level of disability. However for most people with and without disabilities, an important goal in life is meaningful relationships, friendships and community connections. In other words – interdependence.

The interdependence of human beings builds social capital, and social capital strengthens people and communities. Being part of a naturally occurring network in a village, city or town, one to which people not directly connected to disability are part of, builds value for people with intellectual disabilities and for families. It connects people with and without paid relationships. Being part of a community, being networked with other people fulfills so much of what the CRPD is all about.

So let's stop saying people are going to live *independently*. It scares families. It scares me.



## Chapter 3: Regional Perspectives

### One World, Universal Principles, Diverse Realities

**AS A GLOBAL ORGANISATION,** Inclusion International has opportunities to bring its members, including people with intellectual disabilities and their families together, across the diversity of geography, language, culture and other differences. That is of course one function of this global report.

A striking aspect of these transnational encounters among people with intellectual disabilities is that typically, even if

they do not share a common language – or indeed in some cases have no spoken language – almost always there is a sense that people understand each other and empathize with each other’s situation. Certainly for those who as self-advocates already have some experience of speaking up for themselves, they are quite quick to share both some common features of the discrimination they face. A common theme is not having access to the same life opportunities as their brothers and sisters. They also discover they have common aspirations like wanting to be listened to by those around them, get the support they need to lead their own lives and join in with what their non-disabled peers take for granted.

When family members get together, especially parents of children with intellectual disabilities, they almost always have an immediate and intrinsic understanding of the stories told by other families. They share their experiences of giving birth to a child with a disability, the struggles to get an education for all their children, the need for their children with disabilities to have opportunities to contribute as young adults and the almost global concern about what will happen to their children when they are no longer around.

In these senses our movement is based in a very real shared experience of ‘being in this together’ despite other differences which may include personal affluence or access to publicly-funded services.

We published much of the material generated through our global studies on the internet. One such publication is the national report from our member in New Zealand (IHC) which gives a particularly clear account of what people with intellectual disabilities and other family members say about their lives and aspirations. Soon after posting this report, we had a message from a Colombian reader whose younger brother is currently attending a special school there to say both how similar what the New Zealanders are saying is to the views of her brother – and how great it was that she and he could take inspiration from the images of a better life shared by people on opposite sides of the Pacific Ocean!<sup>1</sup>



This of course is also the core sentiment which underpins the 1948 Universal Declaration of Human Rights and the latest (2006) United Nations Convention on the Rights of Persons with Disabilities. The human rights on which the Convention are based are universal: we are one humanity. Our challenge as a global organization is to campaign for these universal principles while recognising and understanding the different realities experienced by our members in different places, and therefore the need to shape strategies for making progress which recognise different starting points, different opportunities and barriers, and different priorities on the long road to building just and inclusive communities across the world.

In this report we both concentrate on what is common e.g. the visions shared by people with intellectual disabilities and families summarized in Chapter 4 and also on how efforts to advance the three building blocks for achieving Article 19, (choice (greater self-determination), support and inclusion in the wider community) need to be sensitive to these diverse local and national realities as analyzed more fully in Chapter 5. In the report we try to combine these two objectives, drawing on the material we generated from across the world. In addition we have developed a shorter paper which offers more distinct regional perspectives written by people who have worked with us in each of the five regions which make up Inclusion International and who know the material from their region. Summarizing some themes from these five perspectives highlighted intra-regional commonalities and differences and regionally-specific issues.

Our efforts in Europe revealed that as a region the situation of people with intellectual disabilities and families in different countries were more alike than in other regions. Generally, participants indicated that while there has been varying degrees of success in securing community living options, in most countries residential facilities continue to exist and there is consensus that improvements are needed to better support people to live

and be included in their community. Self-advocates expressed that while they are consulted on decisions about where they want to live, the final decision is usually made by the family or a legal representative. In Slovenia we heard: “Yes, person is consulted, but parent/guardian makes the decision.” And, in Belgium a self-advocate remarked “... since there are long wait lists and no place available there is no real choice.” Throughout the region a consistent challenge identified is the impact of austerity economic measures on the provision of supports needed to have a life in the community.

In the Americas, we found significant intra-regional differences. The realities for people with intellectual disabilities and their families in many countries in Latin America were more similar to those in Africa, Asia and the Middle East than to North America. However, similarities across all countries in the region include that families provide the majority – if not all – of the care and support for their family member with a disability across their lifespan; and, that people with disabilities are most likely to live in poverty.



The extent to which individuals and families are supported varies greatly throughout the region. In North America and some countries in Latin America, supports and services – including disability-related supports, income supports, and health care – are more readily available. In other countries there is nothing available for individuals or for families. Similar variations are also noticeable in the area of education. It is important to note that while the countries currently providing supports and services are comparatively doing better than other countries in the region, we know that the supports and services being provided often fall short of meeting the actual needs of individuals and families and need to be enhanced and improved.

Despite years of successful deinstitutionalization efforts in North America, institutions remain far too common throughout the region.

For this study, our regional coordinator in Africa visited 11 countries to conduct focus groups and meetings and supported the collection of 14 country surveys from African countries. Meetings were conducted in local languages and the regional coordinator was able to provide an analysis of the discussions. As a result, our knowledge about the region – one where little to no state

support is available to individuals or families and large scale institutions are relatively uncommon – was vastly enriched and the African perspectives on living and being included in the community are better reflected in the report.



While the lack of institutions and provision of supports enabled a focus on more natural community-based supports, it also reflects a stark reality that there are no public resources being used to support people with intellectual disabilities and families. As reflected throughout this report, it is largely

families – many living in absolute poverty – who are providing all of the support and care for people with intellectual disabilities. In addition, if a child with an intellectual disabilities cannot go to school, then the mother cannot work outside the home resulting in a double disadvantage. Commenting on the efforts of families the coordinator said, “Many are stumbling in the dark trying to find the right path unassisted; the vast majority are trying to offer their child a decent life, sometimes at enormous personal cost – both emotional and financial.” Beyond meeting the day to day needs of their family member with a disability, families in Africa struggle with societal prejudices and myths that disability was a punishment from God.

Issues of diversity and unique religious and cultural issues were raised in the Middle East and North Africa (MENA) region and others. Our efforts in regions where the cultural norm for all people is to continue to live within the family unit as adults, revealed confusion about what is meant by living and being included in the community. We discovered it is often inaccurately understood to mean living alone. Respondents informed us that cultural and religious perspectives on living and being included in the community had to be reflected in our understanding of Article 19.

Through focus groups, surveys and stories we heard that stigma and shame remain a challenge. In the MENA region, our regional coordinators reported that: “...admitting to having a girl with intellectual disabilities, especially if she has more than one sibling who is also a girl, might mean that sister/s will not be married.” Nevertheless there are currently encouraging developments in the emergence of self-advocacy and the understanding among people with intellectual disabilities that they too have rights.

Intra-regional differences were noted in most of the regions but nowhere more so than in the Asia Pacific region. The region is vast in size and home to 60% of the world’s population. The differences between countries in the region – New Zealand to India to Vietnam – are substantial. While the study pointed to the many differences in the lives and experiences of people with intellectual disabilities and families from country to country, it also highlighted a substantive rise in the self-advocacy movement throughout the region. We received many stories from self-advocates in Japan, Hong Kong, Malaysia, Myanmar, and Cambodia. These stories provide exciting examples of self-advocacy that are documented throughout the report.

## Responding to Diversity

Inclusion International regions are mainly a response to global geography. It is a potential strength that each includes a diverse range of countries. Within countries too there can be considerable diversity in people's experience, e.g. shaped by inequalities in income and the different patterns of life in urban and rural settlements. Learning from comparing and contrasting these different perspectives we can identify some of the most important structural, cultural, economic and historical factors which are important in planning action to advance the principles of Article 19 at different levels of aggregation (local, national, regional, global). These are elaborated more fully in what follows, especially Chapter 7, but we summarize here four important themes for subsequent consideration.

### ► **Family structure, culture and personal autonomy**

Family is critical to the well-being of people with intellectual disabilities but family structures vary hugely, from the single parent or small nuclear family common in economically rich countries to the large extended families and indeed membership in local clans which are still common, for example in some rural parts of Africa. Alongside these structural factors there are also differences in family expectations e.g. whether and when (adult) children should leave home and the family members' responsibilities to each other. Another aspect of culture relates to the basis on which people with disability experience discrimination, e.g. from traditional views about disability being a punishment for wrong-doing or a condition which is infectious, to the medically-inspired attention to the person's "deficits" as the cause of their problems. As well in many parts of the world the concept that a person with an intellectual disability has rights and has the legal capacity to exercise those rights is not understood or accepted. In turn there are widely

different expectations in different cultures about the extent to which individuals are “free” to make their own choices or instead bound by what the community deems appropriate for their social status.

### ► The strength of civil society

Overlapping with these issues of family structure and culture is the nature of community and the forms of voluntary organisation which societies encourage. In some high income countries, traditional social capital (e.g. in extended family structures) is weak but there are many ways in which citizens can come together voluntarily for mutual aid and to advance their interests, as indeed we see in some of the family associations which constitute our movement. In other developed countries such as the former Soviet bloc, non-governmental organisations (NGOs) are both a recent and a relatively fragile network for supporting people with intellectual disabilities and their families. In other societies such as in Africa and Asia, there is very strong social capital but it is based on traditional clan and local authority structures. Choices and control for many people in those cultures are dictated by the clan or tribe.



### ► Economic development and social inequality

Beyond these social connections there are of course also massive global inequalities in the extent of economic development and the distribution of access to the world’s material resources. Within countries too there can be huge disparities in wealth (including between urban and rural areas) and therefore in the resources available for action, e.g. to fund support for people with disabilities and their families. Indeed the absolute poverty experienced by

so many families in most countries of the global “South” is a huge constraint on their scope for achieving better lives. Everyday reality is about survival and the ‘vision’ of people with disabilities is likely to be highly practical, concerned only with how to get by and make a contribution to their household.

► **State investment in equal citizenship and its history**

Finally, and overlapping strongly with economic and political development, there are huge variations in our reports from countries in the extent to which governments have accepted responsibility for ensuring equal citizenship for all the population, e.g. through investing in universal education, access to health services and social security benefits or by contrast the extent to which people, especially people with disability are dependent for support on family and charity. As we shall see however, there are also significant differences in how governments have invested in social welfare, especially in the extent to which historical and current investments either support the full inclusion of people with disabilities in their communities or promote (for example through institutionalization) their social exclusion.

We will keep referring to these four aspects of diversity as we report the findings from our study in the coming pages and show how they are relevant to weaving together the strategies required to achieve fuller implementation of Article 19 in different places.

# PART II: Our Vision of Inclusion







## Chapter 4: **People with intellectual disabilities and Families Define What Living Independently and Being Included in the Community Means**

**IN THE DEVELOPMENT OF THIS REPORT** we collected contributions from families and self-advocates in over 95 countries. Through focus groups, interviews, written and video stories as well as regional forums, we heard from them about what they believe being included in the community means.

In some regions of the world the question and the idea was difficult for both self-advocates and families to define. Self-advocates who live at home and receive little or no support often could not imagine alternatives and families feared for the safety of their family member in poor and violent communities. In many countries living away from one's family is not the norm. For those families imagining and developing supports and services to help the family is the challenge. For others the limited options available for housing, poor access to education, employment and transportation and the denial of the right to exercise choice made the question of what inclusion in the community might look like especially difficult. Yet despite the challenges of imagining real inclusion, self-advocates in every region expressed clearly what inclusion should look like from their perspective.

## Self-Advocates Have A Clear Vision

Self-advocates told us very clearly that living independently and being included in the community means being able to make decisions for themselves: choosing where and with whom they live, deciding when and what they eat and how they spend their days. They may need help and assistance with shopping, with finances and with day to day tasks. For some more significant supports such as assistance with communicating and eating are needed. They may want to have that assistance from their family but there are times that they need other people in their lives to help with these things. In the receipt of support and assistance they want choice and control in from who and how that support is provided. Most of all self-advocates described how inclusion meant having friends, going to school, having a job, participating and being accepted and respected in the community. One self-advocate commented that living in the community meant "realizing our dreams". Another said "you only know that you are

### In Swaziland they told us inclusion means:

- Freedom of speech and being free to live anywhere one wants
- Having employment like other people who do not have disability
- Being included in community activities
- Being helped to have fulfilled future
- Being respected and honoured
- Being heard and listened to
- Having self esteem

### From the stories in Barcelona

"Living alone means: more freedom, not rely on what anyone else says. What I like is that after work and get home I can relax and be calm. Visit family whenever I want. For me it means I can do whatever I want without been controlled. By having less control I have more freedom."

"Independent Living means having obligations. Before I came home and everything was done, now I have to do everything myself. If I do not do the things, no one will do them for me and if I do not do them well will be my responsibility. For example, with the money, now I know the value of things what they are worth, I know I have to make ends meet, I have to organize myself to pay all expenses. I know that not everyone has the opportunity to live alone and I am very lucky to be able to choose where to live. Living in an institution is not independent ever."

**Self-advocates in Spain told us:**

Community living is ...

- a personal challenge and an opportunity to grow and perform
- access to independent living and adult life
- about quality of life and personal satisfactions
- encouraging more social presence
- being treated with respect and dignity

We need ...

- the labour market to open for us as the gateway to live in the community. Disabled people live in very vulnerable economic situation that limit their ability to work.
- personal support services to ensure safety and wellbeing to those of us who live independently and our families.
- the development of public housing initiatives
- to broaden our very limited social environments. Our families, professionals and other people with disability remain our main and only connections

respected when you live in the community.” Self-advocates know what it means to be excluded and they also defined inclusion. In Kenya self-advocates said, “Inclusion is to do what other people do.” In Nicaragua self-advocates said, “(Community) is the grouping of people who live and communicate with each other, whether they have a disability or not.”

**A focus group in Hong Kong told us:**

Living in the Community meant ...

- To have the key
- To have total freedom
- Free to shop whatever I like
- Have choices in what I want to eat
- Free to choose how to spend my leisure
- Free to choose where to hang around
- To be with my parents
- Be able to do all the house work
- Free to date my girl friend
- Able to plan my schedule
- Free to meet friends
- Being an adult
- Being independent.
- Free to enjoy life
- Free to enjoy the cultural performance until the show ends.
- To have privacy
- Have more personal space
- Need support to guide me in daily living, to get a job or even my dating and marriage
- I need to pay rent and organize my activities
- I need to find social workers to guide me to all the housework and manage my finance
- Best to have a helper to do the housework
- Be with my family

## A Family Perspective: Imagining a Better Future

Families who participated in the focus groups and regional forums told us their stories of the struggle to support their family member. The idea of a better future and inclusion in the community inspired both hope and fear. When asked to describe what inclusion in the community might look like for their family member, families talked about having their sons and daughters respected, valued and supported. They talked about the family member going to school, being able to play with other children, participating in religious groups and having neighbors who accepted and supported their family member. Even as they imagined a better future, the hope was always tinged with fear – fear for the safety of their family member, fear for the future when they would no longer be there to provide care and support.

In Chile, we were told “This initiative seems excellent to me because it will help us understand [that] although sometimes we think we are far from the goal, [this is] not a tragedy, the tragedy is if we lose hope in change and when we get discouraged by what we lack to reach the goal. Those who say this is IMPOSSIBLE, stray from the path of which people, as you and I, have undertaken, the path of change!”

In our regional forums families defined community as a place where you belong; a place where family, friends and neighbors enjoy life together; where people support one another. Living and being included in the community means having friends and living a typical life. Participants also recognized the challenges and fears about living in the community. Often communities are not very welcoming or accepting. A participant expressed



**In Ghana they said ...**

“It takes the whole community to make Article 19 happen.”

**BOLIVIA, COCHABAMBA**

We need “To learn to respect the rights of our children and acknowledge that they are actually self-advocates and trust them”

“We don’t want our son/daughter at home, depending on us for life”

“Sometimes is easier to do things for them, than to teach them.” “...never is too late to promote the independence of our children, teaching them, trust them and let them lead a life in the community freely.”

“We are struggling with faith and hope for our children with disabilities so they have more opportunities in our society”

**BENIN, AFRICA**

That it is quasi impossible to dream that children with intellectual disable can be independent fully because of their small IQ. He wanted to understand the meaning of article 19 in this case. He said after the focus group “Maybe the key to make them independent is to include them to all work and activities as possible.”

**JAPAN**

Seven years ago many of the residents of Hyakuninchou-3-choume opposed having a living accommodation for people with intellectual disabilities in their neighbourhood. It was because the residents were uninformed and biased about intellectual disabilities. Also, some had a strong feeling that such an accommodation would devalue their real state value. Big signboards opposing the group home were put up in the neighborhood. But today the residents of Group Home Pocket are very much included in the community and living an independent life with the support they need.

“community has no respect for people with disabilities”. Families expressed anxiety about their sons and daughters with an intellectual disabilities living in community and concerns about safety and protection. Living in the community can be difficult and isolating if there aren’t supports in place and if strategies to meaningfully include people are not adopted. Many countries provide no support to help people live apart from their families and they have to rely on their families for lifelong support. This also means that parents are never done parenting, even as they themselves become elderly.

**Inclusion Is Possible**

While the vision and goal of full inclusion in the community has yet to be fully realized in any country, we heard about good examples from around the world of people with intellectual disabilities living, working and participating in their communities. So, we know it is possible. We heard about people being given the opportunity to decide where they wanted to live, having control over their day to day lives, being given support for the things they needed help with and being accepted by people in their communities – or on a journey where more and more of these things are gradually being accomplished through personal effort, increasing opportunities and support from a circle of friends. These success stories are about people with different kinds of needs and they are from very different economic, social and political contexts showing that inclusion is not just possible for those most able who live in wealthier parts of the world but rather it is possible regardless of the level of disability and it is not only about services.

**SPAIN** Montse tells us "I would like to marry and have my own apartment" I would like to marry my boyfriend and have my own apartment. In this moment I participate in a project of the Foundation to share an apartment with some mates. I use my mobile as an alarm clock, I get dressed and have breakfast while watching the news, and at 8.20 I take a train to Plaza Catalunya and then the tube to Muntaner. From the tube station I walk to the chemist's.

I work in the store, labelling products, placing orders or attending the home delivery service. I work four hours a day from 9.15 to 13.15.

On Mondays, Wednesdays and Fridays I go to the Down Syndrome Foundation in Conte Borrell Street. There we attend workshops on computing, oral expression and ballroom dancing, we write a magazine and we chat about our worries.

I've been going out with my boyfriend for one year and a half. His name is Carles and he's 26. He works in a supermarket.

I go to the disco, to the cinema, to have lunch or dinner with friends and some instructors that come with us... Weekly, in the meetings of the foundation, we decide where to go at the weekend and how much we will spend.

**NEW ZEALAND** Matthew David Corner I live in Wellington New Zealand in a three bedroom home with my flat mate who owns the house, my neighborhood is friendly and it is easy to find my way around it. I have a village within walking distance, I go to holidays together with my family and have a good time, we live in different cities. I have a volunteer buddy that I chat with and have coffee with.

I work 4 days a week and I am employed by the IHC to support and encourage other people to learn about self advocacy I have been doing it for over 15 years.

I am involved with different organisations and am on different boards and I am a member of People first. I have never lived in an institution and have always lived with my family while I was growing up because of my back ground and education in special classes I have a lived experience of disability and have wanted to be treated the same as other people regardless of my disability. I have visible and invisible supports from people using different communication tools for example face book Skype email

If it wasn't for the support and guidance and people believing in me I wouldn't and couldn't achieve what have in life so far.



**ISRAEL** *Gili achieved targets which only few people reach. He lives a full and fulfilling life: for the last 20 years he performs in the AKIM "other theater", performing throughout Israel. He is the proud winner of gold and silver medals at the "Specials Olympics International" and national games in aquatic sports – swimming. In 1994 he parachuted – tandem style.*

*Gili is often invited to speak before a forum of people –describing his life and the meaning of down syndrome recently, He was part of a small committee that examined the modification of the term "mental retardation". The committee consisted of the director of the ministry of welfare, the legal advisor of the ministry, two representatives of the ministry and representatives of AKIM Israel. Gili expressed the common feeling of dissatisfaction from the term and the conclusion of the committee was to officially change the term to "intellectual disabilities". Gili has been employed for the last 13 years at the Cellcom telecommunications company – and performs a regular job well appreciated.*

In Romania, we heard from three young self-advocates who successfully moved from an institutional environment to small apartments in Timisoara. In the institution they lived in a large group, had little to do and, experienced punishment. The three women now have paid employment, get support from NGO Pentru Voi, and are living in their community. One of the women realized her dream of owning a dog.

A young man in Japan told us the following:

"I live by myself. I decided live by myself after I consulted with my mother, sister, brother and the staff of my institution. I like where I live. In my free time, I enjoy watching baseball games and my favorite girl announcers and AKB48 (J-pop girls group) on TV. I also go shopping and read some books. To live by myself, some neighbors help me. And sometimes I talk to them. I use home care workers to live in the community independently. Also neighbors help me when I am in trouble."



**COLOMBIA** Juana is 32 years old, lives in Bogotá Colombia with her family.

She works as an ambassador for Special Olympics, volunteers in Best Buddies and works one day a week as an assistant teacher in an NGO that works with children with Down Syndrome, serving as a role model and as an inspiration to new families.

She plays the flute and is taking English lessons. She swims with Special Olympics so trains twice a week with the city league and with the swimming team on her club.

She goes out with Kristian her boyfriend for the last 7 years, enjoys been a connector for friends and others that have an intellectual disabilities. She perceives herself as a leader.

She likes watching funny videos and comedy, playing Nintendo, Wii and WIIFIT plus, watch videos on YouTube, connect with friends by email, skype and facebook.

Her brothers and sisters are able to move around the city as they wish and she is not, she thinks that the fears of people around her about what can happen to her is an obstacle for her independence.

She feels people see her and think she is not able. That hurts; they do not let me tell them what I think.

She would like to become a preschool teacher, be a leader with her friends, travel by herself without having to be recommended and continue to be a volunteer.

Live with my parents them in their world and myself in mine. I want to make decisions, be more independent in my outings with my friends and move around the city alone. I would like to go out with my boyfriend any day we want, she says.



**JAPAN** Moe Uchlyama lives with her family, she is an artist, she works, enjoys swimming and horses, she turn 20 majority age in Japan and she says I hope to create many good art works because people around me are happy when they see my work.

I am helping my mother in cooking, cleaning, and laundry. I like cooking. My work includes key chains, post cards. They are sold at shops. When I am ready, I hope I can live in a group housing scheme under instructor's supervision like other member of the Studio

Now, I am happy working in the Studio and living at home. I worry about my grandparents because they become weak and old. But I can help them. Now I am an adult, I should be kind to all people.

Last month, when I celebrated Coming-of-Age, I wore formal KIMONO. All my family, my neighbors, and friends joined to celebrate. I was very happy.





# PART III: Where Are We on the Road to Inclusion?





## Chapter 5:

# Article 19 of the Convention on the Rights of People with Disability: Choice, Support, Inclusion

**IT IS NOT A COINCIDENCE** that the description by families and people with intellectual disabilities that we heard in Chapter 4 of what it means to be included in the community is reflected in Article 19 of the Convention on the Rights of Persons with Disabilities. Article 19, as with the CRPD as a whole, was structured to represent the understanding of people with intellectual disabilities and their families, not only of the right to live and be included

in the community but also the elements of what is necessary to achieve inclusion. We learned from families and persons with intellectual disabilities that physical presence in the community is necessary, but not a sufficient condition for being included.

Article 19 provides a framework for thinking about the necessary elements for achieving full inclusion. In addition to the main commitment that, *“States Parties to the present Convention recognize the equal right of all persons with disabilities to live in the community, with choices equal to others, and shall take effective and appropriate measures to facilitate full enjoyment by persons with disabilities of this right and their full inclusion and participation in the community...”*; the article specifically identifies three inter-related measures to achieve this right: Choice, support and inclusion.

19 (a) clearly requires that people have **choice** in where they live and with whom. *“Persons with disabilities have the opportunity to choose their place of residence and where and with whom they live on an equal basis with others and are not obliged to live in a particular living arrangement;”*

19 (b) refers to the kinds of **supports** including services that a person may require to live and be included in the community, *“Persons with disabilities have access to a range of in-home, residential and other community support services, including personal assistance necessary to support living and inclusion in the community, and to prevent isolation or segregation from the community;”*

19 (c) describes the need for **inclusion** in community, *“Community services and facilities for the general population are available on an equal basis to persons with disabilities and are responsive to their needs.”*

In listening to the key messages from families and self-advocates about their vision of inclusion as well as the

**ARGENTINA** *Juan Cobeñas – I have some disabilities that can be summarized as multiple disabilities. When I was a kid, they considered I was uneducable. They excluded me from special school because I did not speak, I did not make understandable gestures, or used my hands, and neither did I look well. They left me out of any kind of social participation. The outcome of being left out of school when you should have to be starting your school life is that you remain isolated. The excluded person suffers from a cultural handicap, therefore becoming different from the rest. That was how I felt, although I could not put it in words at that time, when I found myself in a group of “normal” babies in a nursery school, the only place that would accept me, at eight years old.*

realities which they currently face in achieving the right to be included in the community, it is evident that the three elements of choice, support and inclusion each impact the other. The messages delivered by self-advocates and families about the right to live and be included in the community fall into these three categories.

**Figure 1: Schematic view of Article 19**



## Choice

19 (a) “Persons with disabilities have the opportunity to choose their place of residence and where and with whom they live on an equal basis with others and are not obliged to live in a particular living arrangement;”

The first section of Article 19 about choice has two important aspects; the right to exercise one’s choice on an equal basis with others and having the same options available to choose from as others in the community. Through our consultations and surveys we heard that for the vast majority of people with intellectual disabilities the decision about where and with whom they live is made by family members, guardians or service providers. People with intellectual disabilities are limited in the options available to them because communities continue to create alternative and segregated residential options which are different from those available to others in the community.



## The Right to Make Decisions

From focus group discussions, surveys and stories from self-advocates, we heard about how people’s rights to make decisions for themselves are restricted. People with intellectual disabilities are consistently denied the right to express their preferences, to make decisions and to have their voices heard. Formally, through guardianship orders, or informally through an accepted practice that a third party makes all the decisions for a person with an intellectual disabilities, people with intellectual disabilities are not having their voices heard. As a result they are not having a say in the big decisions (e.g. where to live, who they want to live with) or the day-to-day decisions (e.g. when to eat, when to go out, what to do when they go out) that impact their life. For self-advocates in all regions of the world, a key issue in achieving the right to live and be included in the community was having control in their lives.

**ZANZIBAR** *I get financial support from my family and whenever I am going out, I am asked to return home early. If I don’t listen, I get beaten up so I rectify myself. I like to have more freedom, work and a wife. I would also like to train to be a doctor. I would also like to travel to other areas, such as the rural areas and attend all sports functions.”*

In the UK, a self-advocate talked about what she liked best about living in the community: *“I get to live my life the way I want to, make my own choices, have dinner when I want to have dinner, go out and come in whenever I want! I love it!”*

Having the right to make decisions in our lives is fundamental to our right to live and be included in the community. Some people may make these decisions without any formal support. Some may need support to understand what their choices are and what the outcomes of their decisions will be. Others may need support to articulate their decisions and to make their voices understood by others. Regardless of the supports required for someone to make decisions in their lives, it is still up to them to decide.

**NEW ZEALAND** *My name is Moana Parker and I am nearly 50 years old. I live Wellington, New Zealand. I am Maori and my ancestors come from the Wanganui area. When we were all small we were split up by the social workers and went to live with different people. I went to stay with my Aunty and Uncle but my brothers and sister went to live in foster homes with people they did not know. When I was 10 I went to live at a place called Salisbury Home for Girls- It was in the South Island a long way from my family. All the girls at Salisbury needed to live there because they could not live with their own families.*

*I lived there for 6 years. I hated the food at Salisbury because it was different from what I was used to. I had to stay at the table for hours until someone said I could leave the table. I slept in a big room with about thirty other girls. We went to school there too and I liked doing my maths- that was my favourite thing. We were not allowed to go home in the holidays. Some of the staff were not good to us and they smacked us with a ruler and that hurt. They used to tell us off. If we didn't do what they said they would sometimes lock us up in a "jail". It was horrible the girls did not like it. I was really happy to leave Salisbury when I was 16 years old. But I didn't know where to go or have anyone to pick me up at the airport. A Maori Police lady came and got me and took me to my aunty and uncle's place. She told me not to put my feet up on the car seat.*

*After a while I went to live in an IHC home near them in Gloucester St. Then I moved to Miramar. I have lived in fifty different places in a lot of different ways. I have flatted with one other person and lived in a house with four others and in the last 10 years I have lived with a family who I board with. I like living with a family especially when we laugh and have fun. I don't like living on my own. When I was 19 I started working at IHC. I answered the phones, did the mail, filing and all sorts of jobs. I worked at IHC for 22 years. I left that job two years ago because I wanted a change. I have not been able to find a job since then even though someone was meant to be helping me to do that.*

The right to make decisions (Article 12 of the CRPD) is intertwined with the right to live in the community (Article 19 of the CRPD) and these two rights must be read together. Article 12 of the CRPD secures that all people with disabilities have the full and equal right to make decisions in their lives. It further recognizes that using support to make those decisions does not diminish the individual's right to make their own decisions.

### **CRPD Article 12**

#### **Equal recognition before the law**

1. States Parties reaffirm that persons with disabilities have the right to recognition everywhere as persons before the law.
2. States Parties shall recognize that persons with disabilities enjoy legal capacity on an equal basis with others in all aspects of life.
3. States Parties shall take appropriate measures to provide access by persons with disabilities to the support they may require in exercising their legal capacity.
4. States Parties shall ensure that all measures that relate to the exercise of legal capacity provide for appropriate and effective safeguards to prevent abuse in accordance with international human rights law. Such safeguards shall ensure that measures relating to the exercise of legal capacity respect the rights, will and preferences of the person, are free of conflict of interest and undue influence, are proportional and tailored to the person's circumstances, apply for the shortest time possible and are subject to regular review by a competent, independent and impartial authority or judicial body. The safeguards shall be proportional to the degree to which such measures affect the person's rights and interests.
5. Subject to the provisions of this article, States Parties shall take all appropriate and effective measures to ensure the equal right of persons with disabilities to own or inherit property, to control their own financial affairs and to have equal access to bank loans, mortgages and other forms of financial credit, and shall ensure that persons with disabilities are not arbitrarily deprived of their property.



## Key Issues in Decision Making:

### ► **Formal Guardianship and Substitute Decision Making**

While guardianship and substitute decision making were not the principle subject of our consultation with members, our research showed that guardianship and other forms of substitute decision-making deny people with intellectual disabilities a voice and control in their own lives. It is clear that this lack of control has resulted in people with intellectual disabilities not being able to choose where and with whom they live. We heard that it is often families or third parties that make this decision. As a result, people with intellectual disabilities are being institutionalized against their will and living in places not of their choosing. Law reform is needed but law reform alone cannot achieve the level of change required. Investments in families is needed to support them to understand the rights of their child with an intellectual disabilities and how to empower that child as s/he grows and develops, to make their own decisions. Investments are needed in community supports and systems that recognize and enable supported decision making.

### ► **Culture of Substitute Decision Making**

Even where formal guardianship does not exist we heard that in practice families and communities often do not even consult the person when making decisions for them. Throughout our lives our experience with and ability to make decisions grows and develops. Certain cultures recognize decision-making in terms of individual autonomy, while others emphasize group and mutual responsibilities. Too often people with intellectual disabilities are presumed by others to not able to make their own decisions. A participant in one of the focus groups in Africa told us: *“Starting from the home, intellectually*

*disabled children are not benefiting. People have not accepted the idea that these people can be educated and that they can live independent life."*

Ensuring that people with intellectual disabilities have the right to make their own decisions requires changing the practices that deny people with intellectual disabilities a voice in their daily lives. It's about transforming communities and societal relationships so that people with intellectual disabilities have their decisions heard and respected by others. It's about building the capacity of communities to understand how supports can be provided so that all persons with disabilities, regardless of perceived level of support need, are able to make their own decisions.

### ► **Lack of Models and Infrastructure for Supported Decision Making**

In some of the focus group discussions it became clear that while families understood that their family member could and should be enabled to express themselves and make decisions in their lives, they (the families) lacked the tools and support from the community to put supported decision making into place.

From the focus group facilitator in Kenya we heard, *"The parents were concerned about how the self-advocates would care for themselves and avoid harassment from the community."* One parent commented: *"Their ideas are good but there is no way they can achieve them."* Youthful vision and ambition remains a distant dream to many and sometimes fails to be endorsed by parents worn down by community disapproval, negative attitudes and a lack of opportunities and resources. The stories and experiences of families and people with intellectual disabilities demonstrate that this has a lot to do with a lack of understanding about supported decision-



### The Swensons' story

*Charlie Swenson does not communicate in traditional ways and has significant support needs. His family and support team, based on their deep knowledge of who he is, what he likes and does not like, work together to articulate Charlie's decisions. His mother, Sue knows the dangers of guardianship—of having one voice speak for Charlie—and believes in the need for a collective approach to ensure that although Charlie doesn't communicate his decisions the way others do, his decisions are still his. This was evident in the way the Charlie's family and support team helped him find his own place in the community.*

*Charlie informed the family he was ready to move out on his own. Charlie, who uses a wheelchair to move around, had taken to wheeling himself to the front door and knocking on the back of it. People who do not know Charlie might not have understood what he was communicating—or that he was communicating at all. But the Swenson's knew, and so began a long journey to find appropriate housing in the community for Charlie. A possible roommate was quickly found. On paper it was a great match. The families knew each other, shared similar values and a commitment to inclusion, the young adults knew each other and got along well. But there was a hitch. Charlie liked Opera and he liked it loud. His potential housemate didn't and preferred a quiet living environment. Under guardianship, or if less care and consideration was given to Charlie's will, it would have been easy to have the two become housemates. However, through supported decision-making and a dedicated family, the Swenson's knew this would not be the decision Charlie would make for himself. So they went on a new search until they finally found a house that Charlie can call home.*

making and the lack of legal mechanisms to enable supported decision-making. The history of families making these decisions is an uneasy one. We know the vast majority of families are driven by love and their desire to “protect” their sons and daughters. Yet, under the name of protection, individuals are being denied their rights. Families are often led to believe that “protection” is best secured through substitute decision-making arrangements. In many countries there is little experience or understanding that people with intellectual disabilities can make their own decisions. Particularly, for people with significant challenges in communicating in traditionally understood ways, it is difficult for others to see how a person can make their own decisions. As we witness the rise in self-advocacy movements around the world we are seeing people with intellectual disabilities challenge stereotypes and traditional assumptions. They are pushing for change and leading the way forward. They are challenging “protectionism” and tell us they want to make mistakes and learn from them like people without disabilities. They are demonstrating that with support they can make their own decisions.

Despite the fact that Article 12 obliges governments to develop supported decision making models, formal recognition of supported decision making exists in only a very few countries and is not always well understood by families, professionals or communities. Supported decision-making is an approach to decision making that can be used when an individual needs help to make decisions in their lives. Supported decision making recognizes that everyone makes

decisions with the help of the people who they are closest to and who they trust, like family, friends and colleagues. For people who require support to make decisions, supported-decision making is a process that grows and changes as the person does.

Supported decision-making can take many forms and encompasses a range of supports. It could include minimum levels of support such as assistance in understanding a decision. This could require the provision of plain language and/or support to understand a decision or more intensive levels of support like a support circle or network that articulates an individual's decision through knowledge about the individual's will or preference. Even for those who can articulate with words their vision for living and being included in the community or other decisions in traditional ways, the right to support in decision making is critical to inclusion. Supported decision-making is a way for ensuring that all people – regardless of how others perceive their capacity to make decisions – are able to have control in their own life.



### ► Denial of the Right to Enter into Contracts

Not only do people with intellectual disabilities need to be able to decide where and with whom they live, living in the community requires being able to enter contracts. We heard from families and self-advocates about people being denied the right to enter rental agreements, utilities contracts, employment contracts, marriage, etc. whether because of a guardianship order or because of the perception by third parties of their “incapacity”. Third parties including medical professionals, service providers, financial institutions, lawyers, etc, who have liability



concerns about consent and informed decision making can refuse to provide treatment or service to the individual. With no decision-making alternative, families are required to seek guardianship to secure treatment and/or services.

## **Where and With Whom**

Around the world, people with intellectual disabilities have been clear that they want to live and be included in their community in the same ways people without disabilities are. We know that the vast majority of adults with intellectual disabilities live at home with their families and receive little or no support from governments. Residential institutions continue to exist in a number of countries and segregated settings which are highly regulated by service providers and separate different living arrangements continue to be developed and presented as “community living” options in many countries. We heard from self-advocates and families about some of the reasons why the residential options have been limited, segregated and isolating.

## **Key Issues About Having Options for Where and With Whom We Live**

### **► Families are the Only Source of Support**

For the majority of people who have an intellectual disabilities the only support which they receive in their day to day lives is from their families. This means living at home with their families is the only place they can get the support that they need. Many governments, even those that have ratified the CRPD, have failed to provide individualized flexible supports and services (these supports and services are further discussed in the next section of this chapter).

### ► **State Sponsored Residential Options are Segregated and “Institutional”**

When families break down or are unable to care for a person with an intellectual disabilities, state sponsored supports and services are tied to residential facilities that are institutional in structure, and segregated or isolating in the way they are delivered. Where people with intellectual disabilities are admitted to institutions our members report that usually there is not even a process for consulting the person. The breakdown of families is often the result of the failure of governments and communities to adequately support families and individuals to the point of crisis. A mother in Canada expressed her frustration with the lack of supports provided to enable families to allow their sons and daughters with intellectual disabilities to grow-up at home, “Faced with inadequate services and supports, parents are essentially being told that unless we can find a way to do it all ourselves, our choices are to turn our kids over to the Children’s Aid or to the criminal justice system. Really? Is that the best we can do?”

### ► **Daily Living Supports Attached to Real Estate**

Where some efforts have been made to develop supports and services which are physically in the community, many continue to be separate and isolating either because services are attached to specific homes, apartments or facilities or because instead of allowing people to use the housing options which are available to others in the community, governments and community agencies continue to create separate “disability-specific” options specifically for people with disabilities. In the Netherlands, the eligibility criteria for support needs were identified as a significant barrier to access residential options. Under the General Act on Extraordinary Healthcare Costs, “one group is not entitled for residential care and receives support based on individual needs. One group is considered to be in high need for support

**KENYA** *“I am not worried because I know her cousin will treat her well and knows how to communicate with Damaris. She is still nearby and we talk on the phone every day so I would know if anything was wrong. As well as learning hairdressing at her cousin’s home salon Damaris is helping to take care of the two children and learning about family life and looking after a home Ndumberi in Kiambu county.”*

*“Not everyone accepts people with disabilities in the communities where we live. Some people who do not know people with intellectual disabilities treat them as dirty people and not all teachers accept them in classrooms. We want our children to be included in the community.”*

*In addition many of the female self-advocates commented that they worry about cases of rape and are scared to go out. They also reported being pressured into sexual activity by their peers. Such sexual violence and exploitation is indicative of a lack of respect within the community.*

and is then eligible for residential care. People with disabilities cannot choose themselves to belong to either of these groups. The choice is up to the independent Agency CIZ who decides on care eligibility in all cases.”<sup>1</sup>

### ► Limited Vision of Options

Too often people’s vision and choices become limited by what is available and by attitudes and beliefs. A number of the stories we received from self-advocates talked about wanting to live in group homes because this was the only option that was offered to them in the community. In focus groups and more in-depth discussions, more often than not, it was revealed that group homes were the only option other than the family home. In Jordan and Nepal discussion participants were seeking group homes as it was the only model for supporting people to live in the community that they had ever heard about. In Mauritius we heard families and self-advocates say that living at home was their only option. They told us they have “no real choice and nothing else is available.”



Photo: Ulrich Eigner

### ► Safety and Violence

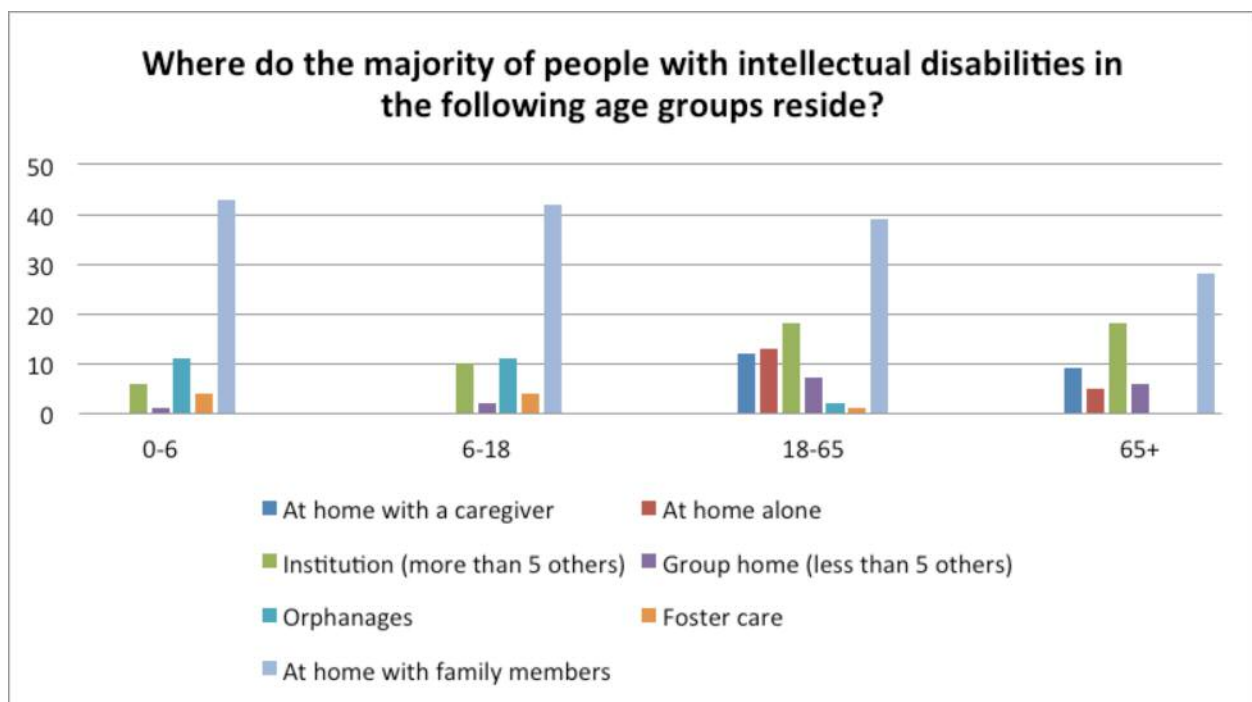
Sometimes our vision is limited by our fears and concerns about safety and life in the community. We heard from families and self-advocates that “community has no respect for people with disabilities” and that life in the community can be difficult and isolating without support. Families expressed concerns about safety and protection for their sons and daughters with intellectual disabilities. Some self-advocates expressed frustration that their parents won’t allow them to live apart from their families in the community while others expressed fear that if something happened to them they would have no one to help them.

## Supports

19(b) “Persons with disabilities have access to a range of in-home, residential and other community support services, including personal assistance necessary to support living and inclusion in the community, and to prevent isolation or segregation from the community;”

The vast majority of people with intellectual disabilities around the world live at home with their families and the vast majority of those people who live at home do not receive the supports they need to live “independently” in the community, nor do their families receive the support they need to enable their family member to be included. While there is little reliable national census data to show

**Figure 2: Where do people with intellectual disabilities live. Country profiles survey.**





where people with intellectual disabilities live, one hundred percent of our members who responded to the country survey indicated that the vast majority of people with intellectual disabilities in their countries live at home with their families.

While access to formal services for people with intellectual disabilities vary across regions and countries, the primary source of support that people with intellectual disabilities receive wherever they live in the world is from their families. Yet families consistently reported that they receive little or no assistance (financial support, services, information or planning support). This means we need to understand both the individual's need for services and supports at home in the community but also we need to understand the needs of the family in fulfilling their role as caregivers, advocates and as the economic and social link to the community.

## **Supports to the Individual**

For people with intellectual disabilities the kinds of supports and services which they need to function and participate in their communities vary greatly across cultures and regions and by the nature of support the individual wants and needs. For our purposes we refer to disability related services, financial assistance, information and planning provided or funded by governments as formal supports and unpaid assistance provided by families, neighbors, friends and others in the community as informal supports.

Supports may be focused on the person with an intellectual disabilities, or on the family or both. They can include assistive devices and physical aids but more often they are assistance with personal care, support in education or employment, support in decision making or support in housekeeping, preparing meals or managing finances. The type and availability of services and supports

for people with intellectual disabilities and their families vary greatly around the world and are largely dependent upon location. The services and supports that are readily available in urban areas are vastly different than those in rural areas, if they are available at all. In some countries services and supports are available for some or most people, though rarely did we hear families and self-advocates speak in glowing terms about the formal services and supports that are available to them. In Israel, a father of two sons with intellectual disabilities said “We fight for inclusion for our sons. Why should it be so hard? Why is the burden always on the parents?” This was a common theme in high income countries. In low income countries the population at large receives only limited access to school (for families who can pay for fees and uniforms) and some public health services. In these countries access to disability related supports and services is almost nonexistent. In large parts of the world specialized services (when they exist) – those tailored to the needs of people with intellectual disabilities and their families – have primarily been created through the hard work of families of people with an intellectual disabilities, sometimes with financial support from government but oftentimes with no such support at all.



We found no comprehensive and reliable source for data on what services and supports are available in each country, though there is one invaluable resource available. In 2007 the World Health Organization Published an Atlas on intellectual disabilities the introduction states,

*“At present, information on resources and services for persons with intellectual disabilities is scarce, fragmented, and relates mainly to high-income countries. To find data about availability of services, their nature, and access to them for a given country is hard, and such data does not exist at a global level. Large differences are seen between high-income countries and countries with low or middle*

*incomes with regard to the availability and the type of information about national services and resources. Considerable information exists for some high-income countries; detailed reports have been published, based on extensive information systems. By contrast, documentation is much more scarce and inaccurate in countries of low or middle income. Most of the time, such documentation is based on specific experiences of a given group of individuals, a type of diagnosis, or a territory. However, at all income levels, to find an overall figure that will describe the situation at the national level is difficult.”<sup>2</sup>*

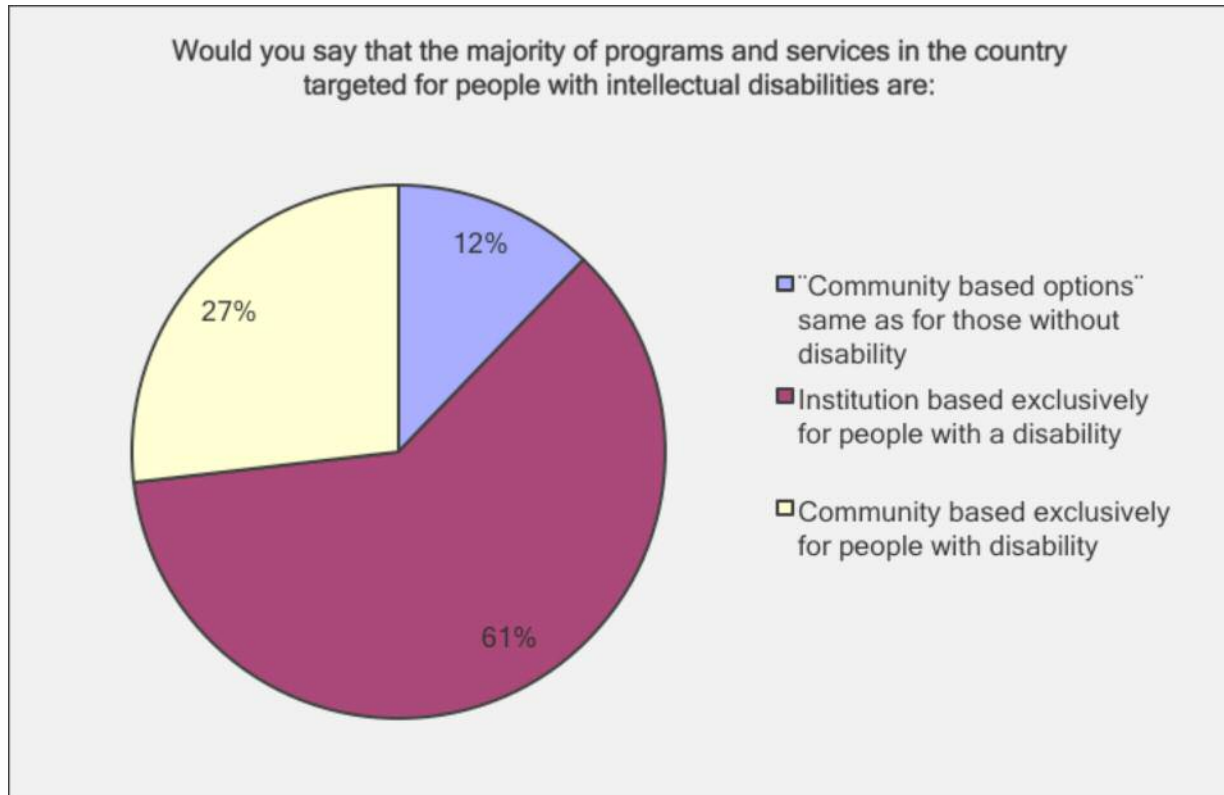
The *World Report on Disability* published in 2011 by the World Health Organization and the World Bank describes barriers to assistance and support for the population of people with disabilities and highlights some particular issues for people with intellectual disabilities.

*“Most assistance and support comes from family members or social networks. State supply of formal services is generally underdeveloped, not-for-profit organizations have limited coverage, and private markets rarely offer enough affordable support to meet the needs of people with disabilities.”<sup>3</sup>*

While these resources present policy and legislative level information, there is little information about services and supports for people with intellectual disabilities and families. The information that is available speaks to what is “on the books”, not the availability, quality or appropriateness of services and supports. The stories and experience of parents and people with intellectual disabilities which are presented here are an important and powerful source of knowledge and so crucial to improving their lives in the years to come.

Our survey respondents were clear that the services and supports that are available are segregated and institutional in nature:

**Figure 3: Community based programmes and services for people with intellectual disabilities. Country profiles survey**



## Supporting People in High Income Countries

In countries where government and community resources are being spent to support people who have an intellectual disabilities and their families we heard consistently about waiting lists for services, a continued emphasis on segregated programmes like group homes, sheltered workshops and isolation in the community. While many countries have moved away from former institutional settings, we heard from self-advocates and families that isolation and exclusion continue to be the norm. The services and supports that were set up in the community to move people out of institutions or to keep people from entering institutions, while they have improved people’s lives, have often failed to achieve real inclusion.

### In Israel ...

- The government encourages living independently in the community. Community living in Israel means apartments and hostels and 30% of people with intellectual disabilities live in out-of-home facilities.
- In Israel there are about 34,500 persons with intellectual disabilities, 24,000 out of which live with their families. Out of the 10,000 living in residential facilities, 7,500 live in institutions (over 60 persons per institution), 1,500 live in hostels (up to 24 persons per hostel) and 1,000 in apartments (up to 6 persons per apartment). Very few live on their own in a home with 1 or 2 others of their own choosing and very few couples live together in group homes or institutions.
- There are 9 government institutions. All the other residential facilities are operated either by NGOs or private companies and all are financed by the government

**PORTUGAL** Portugal considered "Group Homes" as community living since the homes are located inside common neighborhoods. However they described the group homes "more like institutions".

Some of the policy issues that we heard about included:

#### ► **Waiting lists**

A consistent issue reported by our member organizations was waiting lists for home care, for employment supports, respite and residential services. In the USA our member organization The Arc of the United States reported that, "One-third (32%) of parents/caregivers report that they are on waiting lists for government funded services, with an average wait of more than five years. They are waiting for personal assistance, respite, housing, therapy, employment supports, transportation and more. A conservative estimate is that there are more than 1 million people with people with intellectual disabilities waiting for services that may never come." (Finds, 2010)

#### ► **Eligibility for disability supports tied to income**

Many jurisdictions access to disability related services depends on whether a person falls below the poverty line or is eligible for financial assistance from government. This results in several problems for people with intellectual disabilities: Firstly, unless the family has low income the family member is not eligible to receive supports which they need (rent subsidies, disability allowance, medical coverage); if they leave the family home, the disability and income supports provided are not sufficient to cover their needs. Secondly, if a person with an intellectual disabilities gets a job and begins to move towards independence in the community, their income will often render them ineligible for assistance making it impossible for them to stay in the workforce. Policies that link eligibility for disability supports to income needs effectively trap people and prevent them from participating in the community and the labour market.

### ► Disability supports and services tied to housing

When a person with an intellectual disabilities decides that he/she would like to move out of their family home or when their family is no longer there to care for them, the residential options available to them are significantly limited by the fact that the supports and services which they need are only available in certain settings such as care homes (group homes, seniors homes etc.). Having access to services and supports which could be used in the residential setting of their choice would significantly change the way in which people are included in the community.



### ► Access to inclusive services

Families reported that even when they have the financial resources (personal or funded by government) to purchase services, the range of appropriate and reliable services available is extremely limited. From a public policy perspective this may be a result of the fact that government funding is heavily weighted towards the supply-side and the service agencies have not been forced to be accountable to what people with intellectual disabilities and their families are demanding. For example, government funding to sheltered workshops, group homes and day programmes means that people with intellectual disabilities who would chose to work in the open labour market or to live on their own or volunteer in the community often cannot access the supports they require to do so.

We learned that in many cases the lack of access to inclusive services stems from a misunderstanding of what “community based” should mean. Governments and those who deliver services believe that the location of services in the community in itself means inclusive services as is the example from a provincial government in Canada;

**CANADA** “Across the province of Ontario, there are 23,000 people with a developmental disability languishing on waitlists for services – 12,000 of those individuals are waiting for residential supports. 44-year-old Hamilton resident, Akhil Agarwal, is one of them. His 70-year-old father, Naresh Agarwal, is worried that families like theirs have to go into crisis to get the supports and services they need.”<sup>4</sup>

*The Developmental Services Act made some attempts to respond to the social model of disability. For example, the Act provided for public funding of community-based services and supports for people with intellectual disabilities. Such services include group homes, individual living arrangements in which people with disabilities received support services, **sheltered workshops, day programmes and life skills training programmes.***<sup>5</sup>

### ► **Government cut backs and austerity measures**

In countries impacted by the global financial crisis we heard that government cutbacks are making people with intellectual disabilities more vulnerable, that services are being cut and that eligibility for income support is being further restricted. Globally,

governments and service providers are experiencing significant economic pressure... pressure to do more with less and to reduce overall expenditures. In such a context services and supports to people with intellectual disabilities and families often become the targets of “cost-saving” measures. We have heard stories from individuals and families whose lives have been negatively impacted by such measures. We witness countries that choose to invest in “fixing-up” institutions rather than investing in community based supports and a process of deinstitutionalization with a rationale that such will reduce costs. We also heard that

families once again are picking up the additional responsibilities when services are not accessible.

*“Following cuts to services in England, our national member’s survey reveals that one in four people with an intellectual disabilities now spends less than one hour outside of their home everyday.”*

*– UK Country profile for the initiative  
MENCAP’s online survey*



Photo: Ulrich Eigner

## ► Institutions

The continued existence of institutions in high income countries reflects in part the failure of service systems to deliver adequate, flexible and self-directed supports to people with intellectual disabilities. We heard from our member organizations in countries where residential institutions continue to exist that they continue to consume a disproportionate percentage of resources while serving a comparatively small percentage of people needing supports. They continue to exist due to pressure from staff, sometimes from families and from local legislators who are focused more on jobs than on the best way to support people with an intellectual disabilities.

## Supporting People in Low Income Countries

In low income countries the infrastructure of services for the general population is limited and the services available to support people with disabilities and particularly people with intellectual disabilities are almost non-existent. Where disability related services do exist they are often provided by internationally funded NGOs and most often they are focused on services for people with physical and sensory disabilities. They are heavily centered on medical programmes and continue to be based on a medical model of disability.

We heard from national member organizations in Latin America, Africa, MENA, Asia and Eastern Europe about the particular issues that impact on living and being included in the community.

### Key Issues:

#### ► Poverty

One of the key factors which members reported that prevent people from being included in their

**SOUTH AFRICA** “We used to have our children with intellectual disabilities in the institutions before – We did not know what to do with regard to their care. But we were not happy with the care at the institutions we therefore took them out.” Some of the parents of children with disabilities are thinking of starting a day care centre to keep their children busy during the day and teach them different sports including dancing. But they are challenged by lack of resources and appropriate space to carry out the activities. They do not prefer institution life for their children. They said chances are that they could be ill-treated as abuse is rife in the institutions.



**KENYA** “The community doesn’t pay me any attention. Often when there is a big event like a wedding or funeral my family is not told about it even though we would like to be included. I think they don’t like me because I am often hungry and ask for food.”

communities was poverty. While we heard about the issues of poverty from families and self-advocates across all countries, poverty in low-income countries was especially definitive of the exclusion which individuals and families faced in their communities. For families who are poor the added cost of caring for a family member with a disability coupled with the need for someone (almost always the mother) to stay home and therefore not work results in extreme poverty.

Additionally, employment options for people with intellectual disabilities continue to be extremely limited and programmes that provide segregated day centres and sheltered workshops do not provide financial compensation. Where there are people with intellectual disabilities working it tends to mirror the activities of the family (for example cattle, agriculture etc.)

### ► Invisibility

Even in countries which have ratified the CRPD, it is clear from our members surveyed that governments and society in general do not include people with disabilities in their national plans for health, education, transportation or employment. Supports and services for people with disabilities where they exist tend to focus on aids and devices for physical and sensory disabilities. Over and over we heard that even within the disability movement people with intellectual disabilities were invisible in societal processes and in government policy and planning.

In Africa, over 15 million people are believed to have intellectual disabilities and the majority live in abject poverty, neglect and social isolation. Many more are victims of catastrophic human rights violations. The most marginalised underclass lives in the remotest, most isolated places in Africa, with hardly any safety nets. They are always at the bottom of the pile, even within the disability movement. The few national

**SWAZILAND** The latest Swaziland census of 2007 has statistics of people with all disabilities except that of people with intellectual disabilities. The disability grant of E250 (approximately USD 30) that people with disabilities who are registered receive every three months, is not given to those with intellectual disabilities.

action plans that target people with disabilities do not routinely recognize those with intellectual disabilities in education, health and poverty reduction.

### ► **Medical Model of Disability**

Many of the services offered for people with intellectual disabilities, where there are services, are medically oriented and based on the medical model of disability which focuses on rehabilitation and interventions focused on fixing or preventing disability. International development assistance and investments through International Non-Governmental Organizations (INGOs) continue to be weighted towards vaccinations and programmes for “training” people with disabilities e.g. The Community Based Rehabilitation (CBR) model is implemented and delivered by professionals and centres around adaptations for the individual rather than the community. While the World Health Organization (WHO) is making efforts to adapt the CBR model towards a human rights approach, in its current application in communities it fails to address systemic discrimination such as the exclusion of children with intellectual disabilities from regular education, or access to regular employment at later ages.

### ► **Investment in Segregated Programmes**

The lack of any kind of service or support to enable participation in meaningful activities such as education or employment results in efforts to establish and invest in segregated programmes. Governments, family organizations, disabled peoples organizations, INGOs and international development assistance programmes continue to invest in segregated and isolating programmes.

In Kenya, family support groups meet to learn about how to obtain the benefits government offers and to

**COLOMBIA** There remains a paradigm about disability based on a medical model and low value of people with intellectual disabilities in our country. Parents continue to receive supportive care focused on deficit and weaknesses generating attitudes of protection, fear and fear of letting their children attend inclusive settings. The alternative for adult life remains sheltered institutions or artistic and cultural centres. We hope that this report will give us ideas on how to transform existing institutions that simply provide care in segregated places so that we can advance new ideas of life in the community.

**NEPAL** “I was advised to take my son to physiotherapist. Regular physiotherapy was too expensive for my family. So I enrolled in a physiotherapy course through a distance learning programme. This allowed me to tend to my children, while gaining knowledge of physiotherapy. My experience, course work, and compassion for children with Down Syndrome led me to open a clinic in front of a renowned government hospital. The clinics proximity to the hospital allowed me to connect with other parents of children with Down Syndrome. In 2005, I registered and started Down’s Syndrome Association, Nepal – the first and only one of its kind in Nepal.

**NICARAGUA** Most sector organizations work with people with physical and sensory disability, although there are initiatives from small local organizations that develop specific activities with small groups of young people with intellectual disabilities. It is noteworthy that these actions, while remaining positive, have in most cases a special focus, as they become special centers only for people with intellectual disabilities that provide a free service for a period of 3-5 hours.

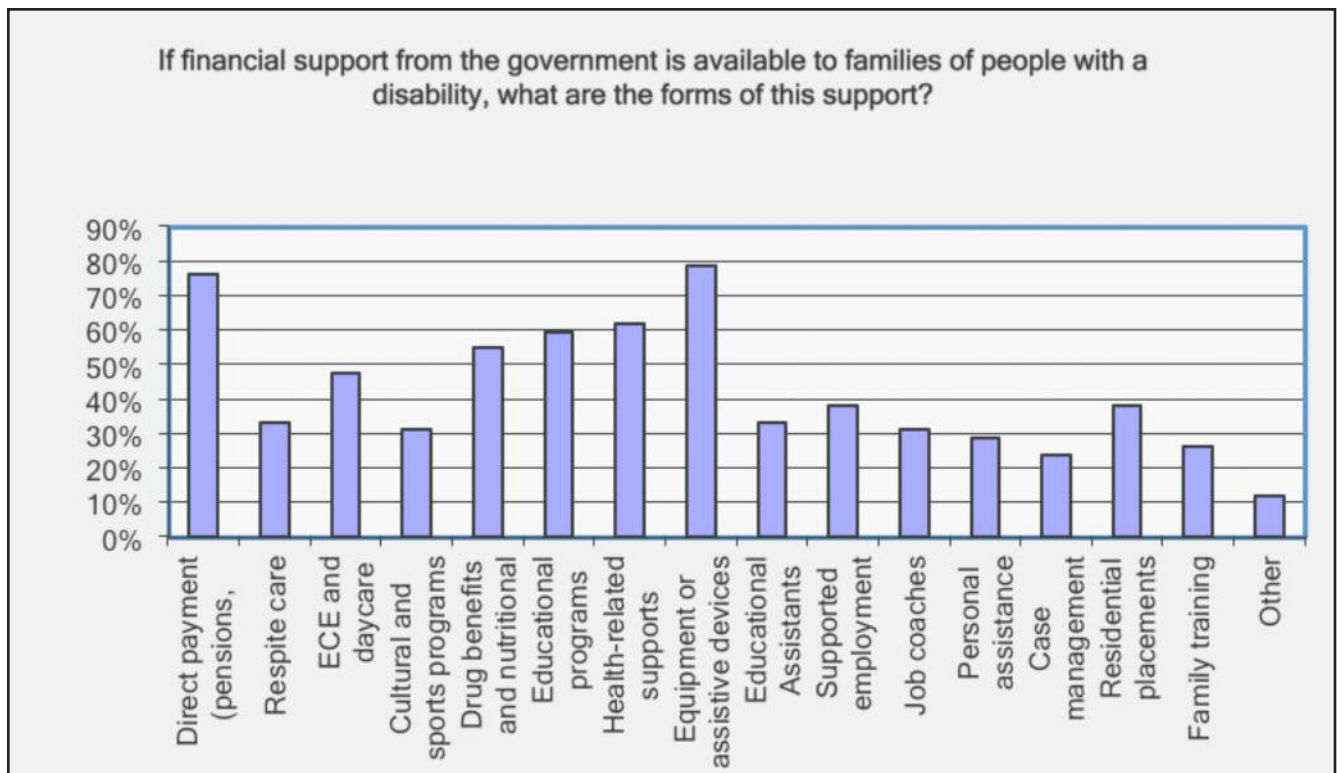
**BOLIVIA** Many parents are demanding the creation of institutions for placing their children with severe intellectual disabilities, because they have limited access to rehabilitation services and information that provide adequate support within the family and community. Rehabilitation institutions are located in intermediate cities, so there is a need to do boarding to children out of town, but their capacity was exceeded largely because of high demand.

work on projects to raise money to support their organization. With no residential institutions to speak of and with strong family networks, these families all wanted their sons and daughters to have something meaningful to do during the day other than to just be at home. The families that we spoke to could not conceive of adults who are not married living away from their families. This was an entirely foreign concept for them. For people with intellectual disabilities and families day supports serve two purposes; providing activities and socialization for the adult with intellectual disabilities and giving the family the ability to work and to take care of other people in the household. However, creating day programmes takes the emphasis away from working and contributing to society through labour or through entrepreneurship. As with institutions we have learned that day centres and sheltered workshops are best avoided. They may provide respite for families but actually interfere with including people in their communities. In economies where many people cannot find work, extraordinary efforts are needed to support people with intellectual disabilities in securing and maintaining productive work. While it is tempting to develop day centres, experience shows that people stay in them for a lifetime and they do not lead to inclusion in the community. In fact, quite to the contrary, they are isolating and stigmatizing.

From the MENA region we heard, "Since the political problems started in the region (and this goes back to right after the Second World War), we have witnessed more and more violations to the human rights understanding. In Palestine for instance, children were denied education and the only way they could access education was through United Nations Relief and Works Agency for Palestine Refugees in the Near East (UNRWA). The agency's main focus was not only education but health and social assistance as well.

Despite the good intentions of the agency, their approach played a major role in excluding children from regular education, emphasizing that children and young adults with disability in general, and intellectual disabilities particularly, are unable to learn alongside their peers and they needed to be isolated in special settings. This was a model that governments in the region especially those that had UNRWA, working in their countries due to high number of refugees, such as Jordan, Syria, Lebanon and Iraq adapted a charitable, segregated medical model and felt that who is better to follow but the United Nation and their way of dealing with persons with disability.”

**Figure 4: Forms of support given to families. Country profiles survey**



**UNITED STATES** *Shareen is the mother of a beautiful son, Stefon, 18, who has multiple disabilities, including Angelman syndrome (a genetic deficiency of the 15th chromosome), cerebral palsy, an intellectual disabilities, epilepsy, asthma, language impairment, and neuromuscular scoliosis. Stefon uses assistive devices for ambulation and requires support 100% of the time. For many years, Shareen was unable to work and unable to afford the type of services her son required. She and her son lived in distressed neighborhoods in public housing and relied on food stamps to survive.*



## Supports to Families

Our members report that families are the main source of support to people with intellectual disabilities wherever they live in the world. Families not only provide care, they support participation in the community (education, employment, recreation, building relationships and accessing services). Yet families report that they receive little or no support from governments or the community to fulfill this role.

Our focus groups of self-advocates consistently recognized the support provided by parents. A Spanish participant said, “I get a lot of support from my family. I know very well that without their help to pay my rent I never would have been able to leave home for a place of my own.”

Countries such as Japan and China have policies clearly stipulating that the responsibility for persons with intellectual disabilities rests with their families. Other countries may not have explicit policies, but families feel that responsibility. In a major survey done by The Arc of the United States in 2010 families reported the failure of communities to support them in their role.

*“While families continue to be the primary source of support and care for people with people with intellectual disabilities, the promise of community support to lighten the load is not being met. Parents, siblings and family members struggle mightily so that their family member with intellectual disabilities can continue to live at home, or independently, and have a typical life. The majority of families report that they provide personal care – such as bathing, feeding (61%), administer medications (69%), provide direct financial support (72%), maintain the home (74%), manage financial affairs (78%), arrange/monitor outside services (76%), make social arrangements (76%), cook, clean and do laundry (80%), provide transportation (84%) and emotional reassurance (86%) and more.*

- *58% of parents/caregivers report spending more than 40 hours per week providing support for their loved ones with intellectual disabilities, including 40% spending more than 80 hours a week.*
- *Nearly half (46%) of parents/caregivers report that they have more caregiving responsibilities than they can handle.*
- *The vast majority of caregivers report that they are suffering from physical fatigue (88%), emotional stress (81%) and emotional upset or guilt (81%) some or most of the time.*
- *1 out of 5 families (20%) report that someone in the family had to quit their job to stay home and support the needs of their family member” (Finds, 2010)*

The commitments to families in the Universal Declaration of Human Rights, the Convention on the Rights of the Child and the CRPD, should help to support people who have an intellectual disabilities to live and be included in the community. Unfortunately, our members have told us that both the State and society fall short in meeting these obligations. The capacity of families to provide this support depends on the way in which communities and governments provide assistance to them.

## Key Issues For Families:

### ► Need for Short Term Breaks

Families need relief from the sole responsibility for their sons and daughters 24 hours a day, 365 days a year. This is best accomplished by guaranteeing that children with intellectual disabilities have access to early education and education programmes as well as child care for non-school hours so parents can work. The inclusive pre-school programmes in Bogota, Colombia provide a good example as does the inclusive education system in New Brunswick,

**UNITED STATES** *Analee lives with her 21-year-old son Nicky, who has autism, in North Carolina. She quit her job three years ago to stay home with Nicky after he graduated from high school with no real idea of what would come next. Meanwhile, money is tight and Nicky’s dad has taken work in Florida to support the family. They would like to be together, but after checking into the possibility, they realize that the situation in Florida would be even worse than what they face in rural North Carolina. Recently Analee found a small group home about an hour’s drive away that she feels would be a good place for Nicky to make the transition from his family’s home to living semi-independently as an adult. That would also allow her to go back to work. She says, “it felt just right! I just couldn’t believe we had lucked out to find such a right fit for Nicky!” She has not been given a place there because of regulations and policies.*

### **Income benefit programmes**

“Applying a lens of social and economic inclusion to income security of people with disabilities means asking some difficult questions about the purpose and rationale of an income benefit programme: Is it welfare? Pension? Disability-related support? Income security? Replacement of employment income? Compensation for inaccessible labour markets? Under most benefit programmes that are currently available there is little clarity about these questions. The underlying rationale of an income programme affects every aspect of the way that it operates- from benefit rates and eligibility to rules that affect subsidized housing, student loans, employment supports, assets and even family and relationships. Policy analysis is needed that can assess income benefit programmes in terms of whether they enable a poverty exit strategy and access route to social and economic inclusion. Research has to take on some of these difficult questions and apply a lens of social and economic inclusion to income security in hopes of furthering discussion about how we can more effectively break the link between poverty and disability.”

— *Canadian Association for Community Living.*

Canada. The United Kingdom has invested heavily in providing parents with short breaks, which may be to catch up on sleep, to go out socially or to have short vacations. Non-government organizations such as Best Buddies and Special Olympics often provide the only opportunities for people with an intellectual disabilities to participate in an activity away from their family, which is a break for them and their families.

### ► **Poverty**

The high correlation between disability and poverty due to lost income and the cost of disability supports means that many families of persons with intellectual disabilities find themselves in desperate situations where they are grateful for any support that is given. (e.g. Residential institutions that might seem like bad options to families who have a range of choices may seem like a salvation for a family that can't afford to feed all its children and who sees the institution as at least providing a roof and three meals a day.) These families can't imagine a better alternative.

While many countries have some sort of cash transfer programme which provides some relief for the extra costs of having a family member with an intellectual disabilities, these rarely cover the actual extra costs and families reported that supports have been reduced due to the current economic situation. Some Western research shows that it costs 60% more to support a child with intellectual disabilities than a typically developing child.

### ► **Social Exclusion and Lack of Natural Supports**

Families often also suffer because of the stigma and prejudice against having a family member with a disability. The family member may be kept hidden so as not to jeopardize the marriage possibilities for other siblings. In addition, many of the mothers in

the focus groups for this report felt abandoned by the father. A mother from Namibia complained that a child with disability is “always the mother’s child”, not the father’s.

In high income countries the state also invests in the building of organizations of families of persons with disabilities so that they can play the role recognized in the CRPD of contributing to the full and equal enjoyment of the rights of their family member with a disability. Parent organizations in Africa have received such support from Norway, Sweden and Finland in particular.



Photo: Ulrich Eigner

*As the mother of a child with autism, I've seen my social circle shrink over the last ten years. I've fallen out of touch with friends and family while I devote all of my spare time to fighting for the services my son needs. It's no one's fault, really—it's just hard to go out for a coffee or invite someone over for dinner when you live with someone with autism, and that reality takes a slow but steady toll on social relationships. I've learned to live with it, and many people who were a huge part of my life in the past have now drifted away.<sup>6</sup>*

One of the implications of the CRPD for persons with an intellectual disabilities is the need to focus not only on supports and services for the individual who has a disability but to focus on the family as well. In most situations, families are the constant in a person's life and so the individual who has an intellectual disabilities may be helped the most when his or her family is supported so that they can continue to provide the love, care and attention that their family member needs and has a right to receive.

**MALAWI** *The school however, was not so easy. The Principal told me that all Sami needs is a kick in the butt and some good old discipline. I resigned from my full time job as an early childhood supervisor and took a part time job in order to help the KG teacher with Sami and the other children. I soon realized that having an ADHD child in the classroom is a nightmare to an inexperienced teacher. At night, I attended Special Needs in EEC classes in order to learn more on behavior modification. I would come back and translate them to my husband who was French educated.*



### Table 3: Euphemisms for Institutions

- ✓ Homes for Special Care
- ✓ Special Care Homes
- ✓ Personal Care Homes
- ✓ Farms/Ranches
- ✓ Gated Community
- ✓ Developmental Maximization Unit
- ✓ Community Living Centres
- ✓ State Schools
- ✓ Neuro-behavioural treatment Centres
- ✓ Long Term Care homes
- ✓ Centers of Excellence
- ✓ Cottages
- ✓ Living Centres

### ► Access to Information

Families talked about the need for information not only about disability related information but also about accessing services and supports in the community. They reported that the information they receive (often from doctors) was negative and outdated. In addition to care giving and day to day support, families play a critical role in securing access to education, employment, health care, recreation and community services. Without their efforts most people with intellectual disabilities would have no access to disability supports or to the community. Yet families report that they receive no assistance in accessing information in their communities except through family based organizations and other families who have a member with a disability.

### ► Institutionalization

Institutions remains a powerful and negative force for people with intellectual disabilities in both high income countries where they continue to exist and draw resources from the provision of services in the community and in low income countries (e.g. Eastern Europe) where the centralized state continues to invest in refurbishing and reinventing institutions. Despite many years of advocacy by self-advocates, families and other human rights activists, institutions continue to exist as a significant violation of the CRPD and other human rights conventions. In addition to the challenges of closing those institutions that remain there continues to be a real threat that they will continue to be built in different forms in the future. (See Table 3 on Different words for Institutions).

Despite advances made in our understanding of intellectual disabilities, successful deinstitutionalization efforts and our global efforts to ensure the right to live in communities for all people with intellectual

disabilities, arguments are still advanced to justify institutionalizing people.

Typically, these arguments include notions that institutions provide better care or ensure better health, that people are happier “with their own kind”, or that people with “severe” disabilities, complex health or behavioural issues cannot be supported in community. The reality however, is that research consistently demonstrates the benefits of community living and the harmful effects of institutionalization. Studies conducted over the past 50 years in North America, Europe and New Zealand have documented the following outcomes for people with disabilities in the community as compared to institution life:

- Maintained or improved health and health care
- Increased independence and adaptive skills
- Decreases/elimination of challenging behaviour
- Increased family involvement and support (families overwhelmingly support community living following institution closures, even if they had previously opposed it)
- The benefits and improvement in the quality of life for people leaving institutions continue to outweigh the costs
- Successful transitions to community by individuals with the most complex needs (people with severe disability, challenging behaviour, medical issues, or advanced age)



Photo: Ulrich Eigner

While we witness Norway, United Kingdom, New Zealand, Sweden, the United States, and Canada who

had previously relied on institutions as a residential option, closing or in the process of closing institutional facilities, there are other countries that are in the process of building (new) institutions and/or refurbishing existing facilities e.g. In Hungary, “Despite having a 30-year strategy to shut institutions and move people with disabilities into the community, the Hungarian government will build new 50-bed institutions – which it euphemistically calls “living centres” – instead of integrating and supporting people into the community.”<sup>7</sup>

Even in those countries that have a history of successful closures (i.e. Canada, the USA, the UK) we are seeing continued investment in institutional models of support.



There are also countries, particularly low income countries in Africa, in which the traditional concept of institutions does not exist. In these countries however, institutions do not exist not because other more appropriate options are provided, but rather because families were (and are still being) left to struggle on their own to raise and support their family member with little or no

outside support or assistance. Sometimes families who are desperate for any kind of support will suggest the creation of institutions because they cannot imagine any other options.

In Colombia families face a stark choice. They can give up custody of their son or daughter and in exchange a bed in a residential institution with three meals a day and some daytime activities will be provided. The one residential institution we visited in Bogota was stark, with little activity and no real personalization or sense of personal space or privacy. Should the family not want the institutional option, there are few services for children and virtually none for adults unless the family has the financial resources

to pay privately. The incentives are clearly in the wrong place and as with many places, it is a matter of decision making, a clear violation of the intent of Article 19, from a country that has ratified the Convention.

In Israel families and people with intellectual disabilities have an array of choices, running the spectrum from very segregated to inclusive, with (as of 2009) over 7,000 people with all kinds of disabilities living in large residential institutions. Where a person lives is a function of when they started to receive services more than a function of their wants and needs. Inclusion International's member organization AKIM, provides a range of places for people to live from apartments with six people in regular residential neighborhoods, to hostels with over twenty residents. Public policy in Israel currently supports six people living together, no fewer, and while many of the people become friends, would they have chosen to live together given the freedom to choose between more meaningful options?

In Central and Eastern Europe including countries of the Commonwealth of Independent States (CIS) there is reliance on large institutions for people with intellectual disabilities. The Deinstitutionalization and Community Living – Outcomes and Costs: Report (DECLOC) showed that over one million people with disabilities live in institutions.<sup>8</sup> The actual number may be higher because of the local control of institutions in many countries and “under the table” arrangements to admit people. Yet it does not have to be this way. In Croatia, The Association for Promoting Inclusion, API, is helping people who had spent their lives in residential institutions move into regular housing in the community. They are also helping other organizations start programmes to support people with intellectual disabilities and families in communities throughout the region. Soon,

they will open their first apartment for people with significant physical disabilities as well as intellectual disabilities, demonstrating for their government and for the region that all people can be included in their communities. They even made a movie showing how people who had been institutionalized, now living in the community, could enjoy a full life, including getting married!<sup>9</sup>

In Bahrain a young self-advocate said this in response to the question, how can life be better for people with intellectual disabilities? "There are some facilities for children with special needs and support for them, but eventually children grow up and there is nothing for adults." This is true in many places. Schooling is a common frame of reference for all families, and service for the population at large. There is not a framework for how best to support adults with intellectual disabilities living with their families anywhere we surveyed. Person and family centered planning and attention to the needs of the entire family as well as the family member with intellectual disabilities must be considered. Not one or the other, but both.

In New Zealand the last of their public institutions, the Kimberley Centre, was closed in 2006. The array of services and supports there shows that everyone, regardless of their level and type of disability, can be supported in community environments. Strong advocacy by families and people with intellectual disabilities themselves helped create the political will to close the institutions and to create a community system of services and supports. While much has been done, much remains. One father said, "While my daughter is living in the community, she is not yet a fully participating member of her community ... but we are making progress."

## Inclusion

19.(c) “Community services and facilities for the general population are available on an equal basis to persons with disabilities and are responsive to their needs.”

The concept that communities should be organized to ensure the inclusion of all its citizens is not a new idea, yet it is one that distinguishes the movement of people with intellectual disabilities and their families from other disability groups. For many people with physical or sensory disabilities, they may be able to receive a service or accommodation which would enable them to participate fully in the existing education system, access transportation or health care in much the same way that others in the community do. For people with intellectual disabilities there are no single or simple adaptations which enable them to participate on an equal basis with others. In order for real inclusion to be realized for people with intellectual disabilities, communities and mainstream systems (political, economic and social) must be designed to include all its citizens. While this paradigm shift is reflected in the CRPD, it is one that Inclusion International adopted in our work years before the Convention was negotiated.



The CRPD was crafted to make a paradigm shift in the way people think of disability. Part of that shift is the recognition that persons with disabilities are active members of society with something to contribute. In order for people who have a disability to participate and be included in society, several articles of the CRPD address participation and inclusion specifically:

- General principles (article 3)
- Right to education (article 24)

- Right to work and employment (article 27)
- Right to take part in the conduct of public affairs (article 29)
- Right to take part in cultural life (article 30)
- Right to live in the community (article 19)
- Right to habilitation and rehabilitation (article 26).

The general principle of non-discrimination in the CRPD includes both direct and indirect discrimination and

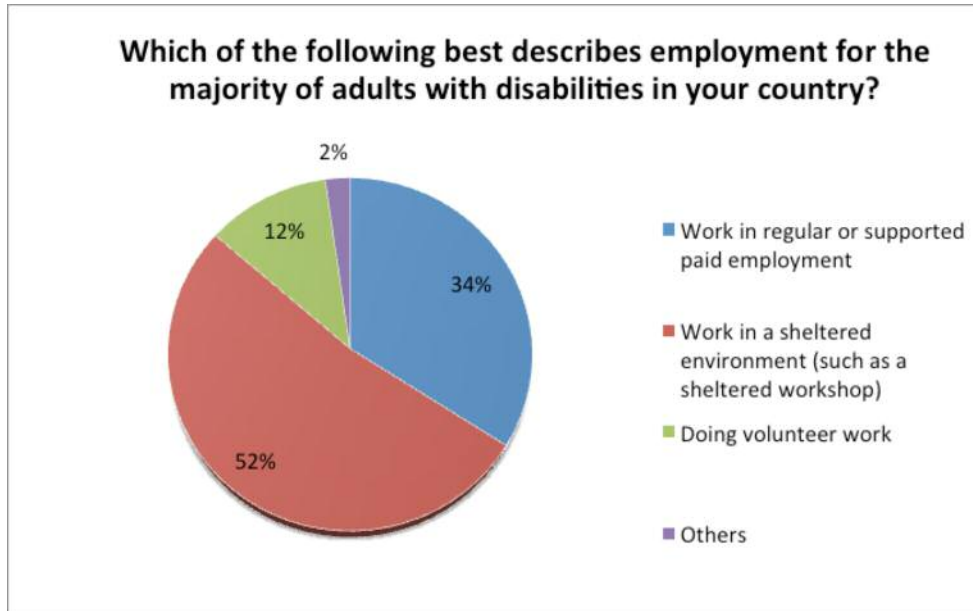
requires that there be *reasonable accommodation* made for persons with disabilities; that is that there is “necessary and appropriate modification and adjustments not imposing a disproportionate or undue burden where needed in a particular case to ensure to persons with disabilities the enjoyment or exercise on an equal basis with others of all human rights and fundamental freedoms”. This means that in order to ensure the full participation and inclusion of persons with disabilities to live in the community on an equal basis with others, people with intellectual disabilities may require some specific supports or reasonable

accommodation, but it also means that in order to ensure there is not direct or indirect discrimination *systems must change*.

We asked our members whether people with intellectual disabilities were able to access mainstream services and participate in community and citizenship related activities. While the results were uneven, the majority reported that people with intellectual disabilities continued to be denied meaningful education and employment opportunities. They fared somewhat better in accessing health services where they exist but overall they reported a continued failure of communities to build inclusive systems.

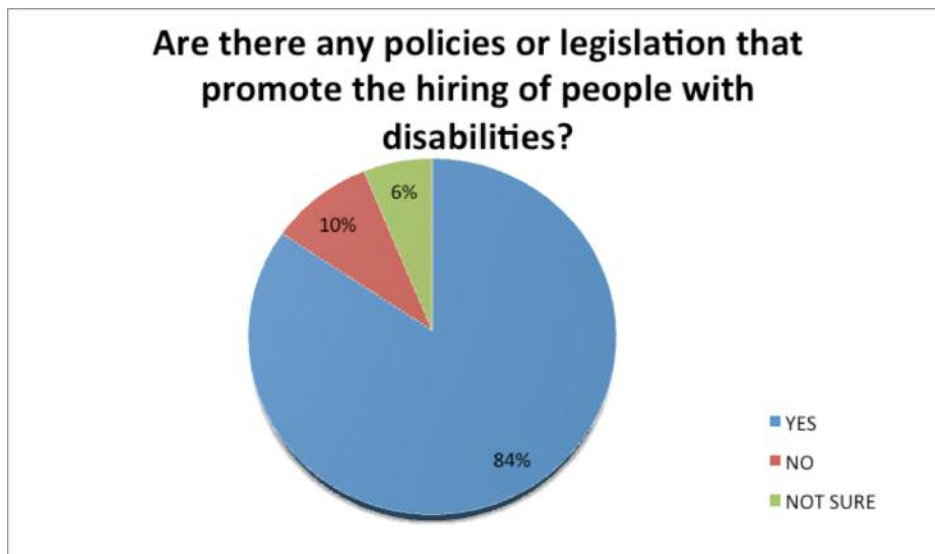


**Figure 5: Employment for adults with disability. Country Profiles survey**



Among those who are working, people with intellectual disabilities are most often employed in sheltered workshops or doing volunteer work.

**Figure 6: Policies or legislation to promote employment on people with disabilities. Country Profiles survey**

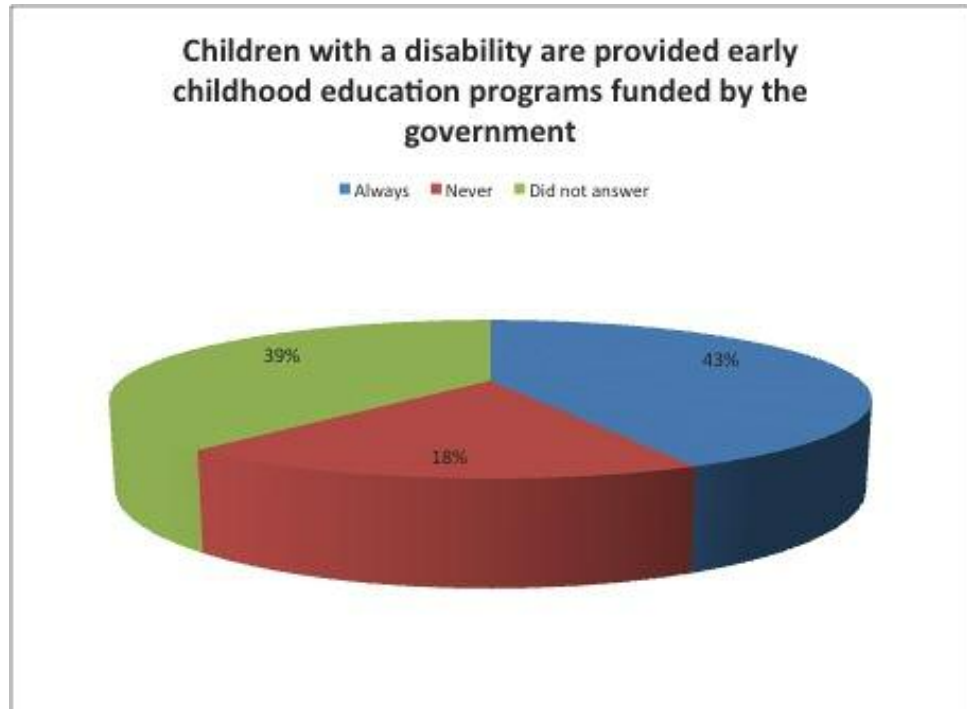


While many high and some low income countries reported that there is legislation or policy that promote the employment of people with disabilities, respondents commented that those policies have been ineffective and poorly implemented. Where there has been some employment progress it usually is for people with mild physical disabilities e.g. a person with low vision.

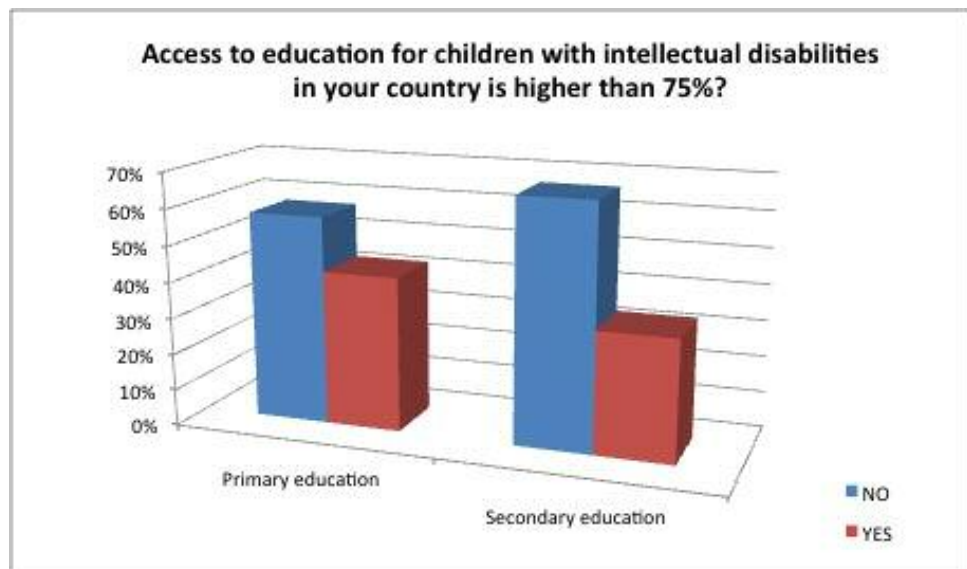


Survey respondents indicated that where children with intellectual disabilities are accessing education it is still usually in a segregated environments or programmes and that as children advance to the secondary level they are even more likely to be excluded from regular classrooms or any type of education.

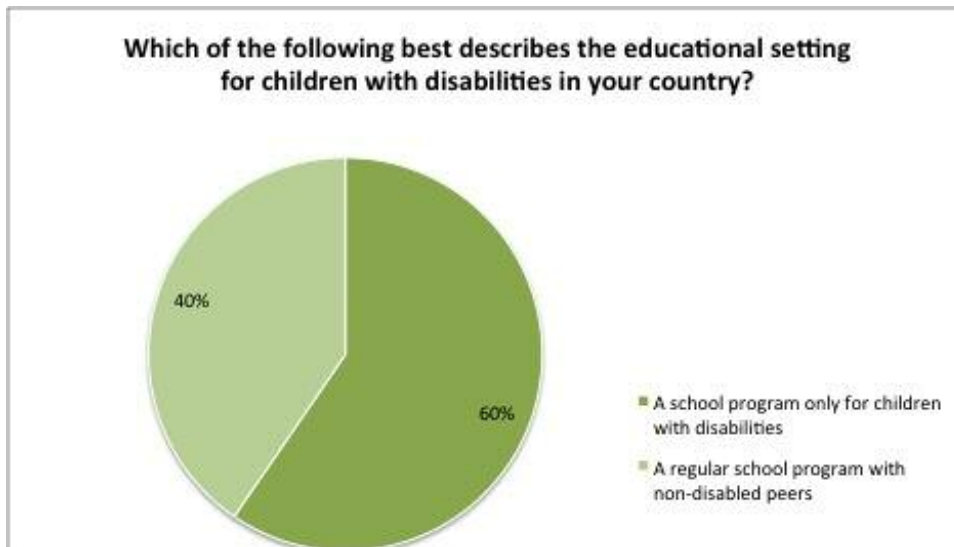
**Figure 7: Education for children with disability. Early Childhood education. Country Profiles survey**



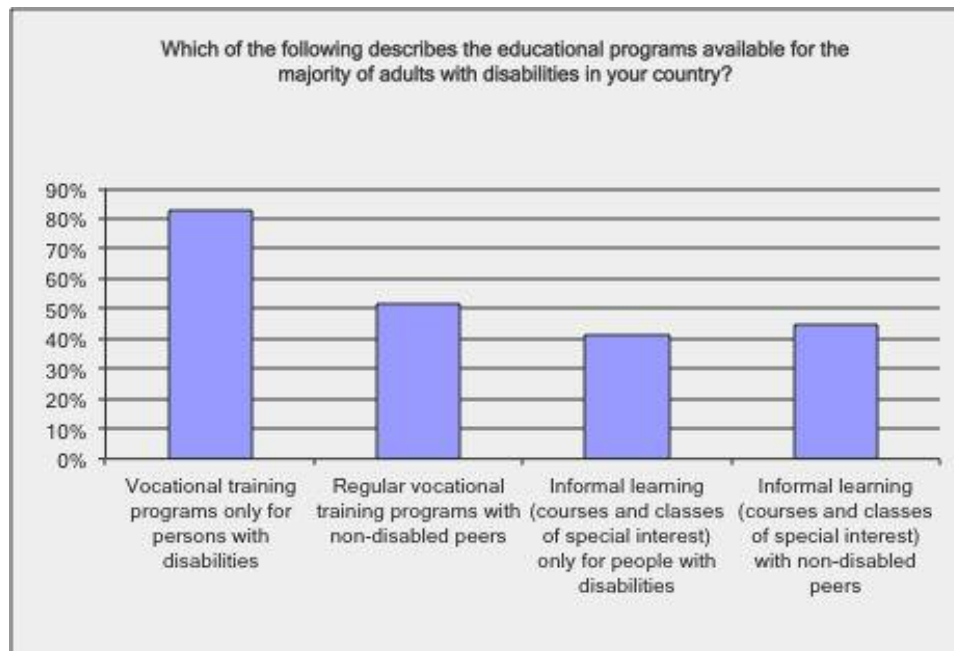
**Figure 8: Education for children with disability. Primary and secondary. Country Profiles survey**



**Figure 9: Inclusive Education. Country Profiles survey**



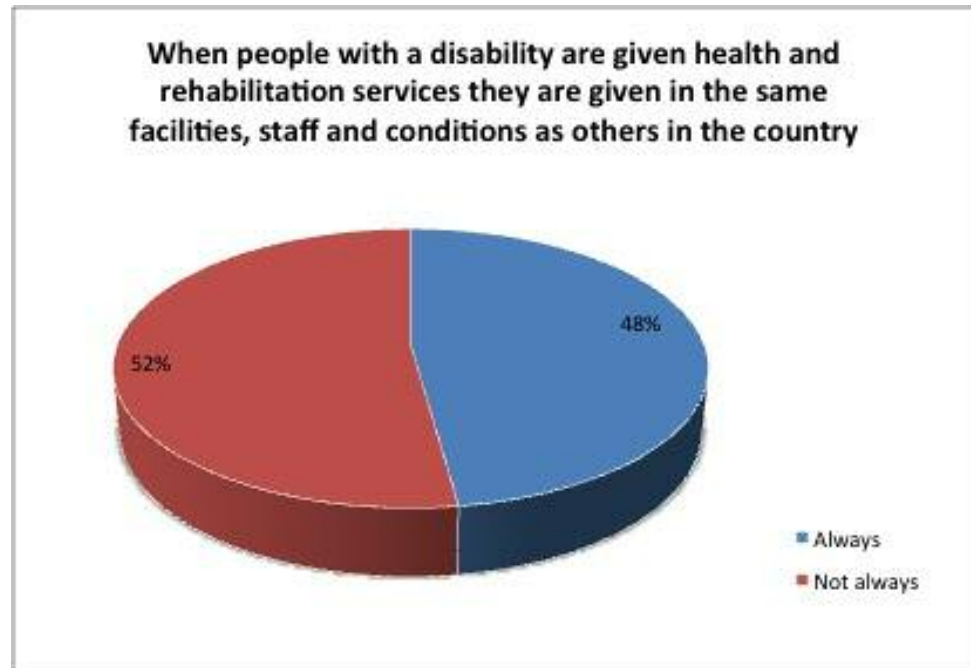
**Figure 10: Educational programmes for adults with disabilities Country Profiles survey**



For adults with intellectual disabilities little or no vocational training is available but for those that do access some programming it is most likely to be in programmes designed for people with disabilities and respondents indicated that many of these programmes are “life-skills” programmes which do not provide employment skills.

While people with intellectual disabilities seemed to fare better in accessing health care than education and employment, care tends to be delivered through disability specific programmes and services and is not delivered on an equal basis with others in the community. People with intellectual disabilities are more likely to live in poverty and people who are poor are much less likely to access health care in both high and low income countries.

**Figure 11: Characteristics of the health services for people with disability. Country Profiles survey**



Barriers to inclusion may be attitudinal or exist in policy or law. Several key issues were identified as critical factors in the exclusion faced by people with intellectual disabilities from their communities.

## Key Issues:

### ► Societal Attitudes

The overwhelming message from self-advocates and families was that communities and societal attitudes including religious beliefs were negative towards the inclusion of people with intellectual disabilities. Fear, prejudice and ignorance characterized the response from communities when people who had been excluded previously attempted to participate. A mother in Russia told us “I wanted to take my child to the children’s party devoted to the New Year celebration, but they didn’t let me. This is the attitude not only of our society but also of government and

every individual." A self-advocate said, "Some people just don't understand how passionately we want to be accepted as we are, to be understood and supported." In MENA when a family with a daughter with intellectual disabilities was approached about completing her education in an integrated educational setting her religious father interfered by responding. "God created them like that; he decided that they cannot be like others. Who are you to go against the will of God?" A mother added, "The biggest problem is not transport or education, it's that people don't know how to communicate with such children. If they don't overcome this fear and hostility, nothing will change. Some people even take their "normal" children away from our kids."

A group of self-advocates in Spain had the following discussion.

**M:** *There are discotheques where they won't allow people with Down Syndrome. I saw it on television.*

**C:** *I go to a discotheque but there is special session for people with disabilities.*

**A:** *I go to a discotheque for people without disabilities and I never had a problem.*

**MC:** *There are discotheques where they won't let anyone come in with sport shoes either.*

**AC:** *Not allowing sport shoes is one thing, but not being allowed in because of having Down Syndrome – that doesn't seem fair to me!*

A parent in Colombia recounted:

*"It was fine and successful when she was little and her Down Syndrome wasn't so evident. Then, in adolescence her isolation became more pronounced. Then no one invited her or included her in social events and everyday activities with friends. They left her out and she felt lonely."*

Other self-advocates in Latin America and Africa talked about being mocked for their looks, ignored by neighbors or called names. Bolivian families talked about discrimination on the bus, in the street, in public squares and in parks. A mother in Bahrain said *“I wish there would be someone to call my daughter and invite her for activities or to meet people.”*

Juan Carlos told us what it means for him to be part of a community.

*“I help my friends with math, playing the guitar, piano and flute. I like where I live. I feel part of the community and I belong to a political party and have an identity card so I can exercise my right to vote.”*

– Colombia

### ► Lack of Inclusive Education



Both Families and self-advocates talked about the importance of inclusive education as a key building block in achieving real inclusion in the community. We heard that when children with intellectual disabilities go to school with their non-disabled peers the natural supports which they receive in the classroom and from their community are fundamental to their inclusion in the community as they grow into adulthood.

Article 24 on education requires that States Parties ensure “an inclusive education system at all levels” and that “persons with disabilities are not excluded from the general education system on the basis of disability.” The United Nations Special Rapporteur on the Right to Education recommended that this means having one system responsible for the education of *all* students, rather than having a social ministry responsible for educating children with disabilities. It also means making certain practical accommodations.

*"I was told by teachers in the local secondary school that when a child on a wheelchair has to attend a class on a top floor, the whole class moves to the ground floor. There was a situation where the grade 12 could not be moved to the ground floor for other reasons, (so) the pupils had to carry their colleague on a wheelchair up and down every day".*

*– South Africa*

In Africa we heard: *"What do we want? The same things as people without disabilities. We want employment, our own house, to get married and have children. What can you do? Make sure we go to school. Help us build self-advocacy."*

Families in the focus groups in Colombia found many barriers to education for their children including the unwillingness to accept children, lack of knowledge in the schools and the lack of an accessible inclusive education system. The result was that these families had to leave their children in special institutions with low expectations and targeted to rehabilitation programmes. Families have been convinced that their children cannot develop skills and therefore must spend the rest of their lives with them. This leads to the big concern; what will happen to their children when they are not around?

A parent in Benin said that *"disabled people are marginalized by the government himself, there are schools for some disable but nothing for intellectual disabled children and without education no independence, no inclusion. We must work together to find the way to make them independent."*

The country report from India talked about the reality compared to the policy;

*Under the policy of Education for All, government has been trying to include all students with disability (6-14 yrs) in the mainstream education. They have*

**CANADA** In talking with a group of parents eager to learn about supported paid employment for their children an experienced advocate on job development for hard to place groups which include people with intellectual disabilities said “Everyone talks about life skill classes preparing people with intellectual disabilities to work but we know these are not the needed skills. People with intellectual disabilities need social competency skills, knowing how to move in the world, useful survival skills and interviewing skills. To keep a job they need motivation so we have to find jobs that are within their interests”.

**NICARAGUA** Exclusion in the labour market in Nicaragua is very high. Although the law provides for a 2% of people with disability for companies with 50 employees or more, this is not met, both by the state and private companies. There are very few initiatives for people with intellectual disabilities in ASNIC we believe we have a moral debt to the persons with intellectual disabilities and their families

**AUSTRALIA** The majority of people with intellectual disabilities are not in employment; of those who are most are in sheltered employment.

**MYANMAR (BURMA)**  
Jobless population is high.

*the assistance of resource teachers. These resource teachers are very few and not adequately trained. Regular education teachers are provided a short term orientation on disability which is wholly inadequate. The new act Right to Education (RTE) has mandated compulsory, free education for all children. The reality is too far from satisfactory.*

### ► Employment

For adults with intellectual disabilities one of the biggest barriers to living independently and being included in the community is exclusion from the labour market. Having an income in addition to the benefits of natural supports in the community when one is working is critical to real inclusion. Yet families and self-advocates reported that the kinds of support that people with intellectual disabilities need to find and keep a regular job are not available. While supports such as job coaches and supported employment agencies exist in high income countries access to them is extremely limited and their effectiveness is uneven at best. In low income countries the approach by family organizations, INGOs and governments has been to repeat the segregated approach of sheltered workshops and day programmes which we know to be ineffective in achieving inclusion in the community. Most often the programmes which people have access to during the day are segregated life-skills programmes which do not develop the necessary employment related skills and most people who enter the programmes continue to go there without ever being “ready” to move into real jobs.

Sometimes when there are no supports or services to guarantee inclusion, families take matters into their own hands as reported from Korea. *“My son wants to be a barista. I think he needs experience in a coffee shop. He wants to work in a Macdonald or so, but it is very difficult to get a job there. I am thinking of being an owner of a coffee shop so that he can work there!”*



## Chapter 6: Future Directions in Advancing a Framework for Inclusion in the Community

**ARTICLE 19 PROVIDES A FRAMEWORK** for understanding the barriers and opportunities for achieving the right to live independently and be included in the community. We heard from people with intellectual disabilities and their families about the issues that impact on the realization of this human right. In this section of the report we point to future directions which will enable the realization of Article 19.



## Choice

Choice, in the context of living and being included in the community, is about having housing options and support options that meet an individual's vision for living and being included in the community and being supported in making decisions about those options. Recognizing we all have realities that restrict and define our housing options such as our financial means, location, etc., we know that options cannot be open ended. Choices for everyone are shaped by socio-economic, cultural and geo-political

realities. However real choice is only possible when we have a voice and control in our own lives and when the options available to us are the same as options available to others in our community. It is about ensuring that adults with intellectual disabilities have the same options and choices as adults without intellectual disabilities to live and be included in their communities. For some people with intellectual disabilities this may mean living alone or with friends; for others this may mean living with family. What matters is that the choice is reflective of the individual's preference and not restricted by a lack of options and/or supports.



Families and self-advocates may need support to develop a vision of possible options and/or to think beyond what is currently available. Governments need to invest in ensuring that housing options and supports are available and delivered in ways that are responsive to and reflective of the vision that people with intellectual disabilities have about living and being included in the community

To be able to make a real choice about where and with whom one lives a person needs:

- To be **empowered and supported** to make decisions about their life and what they want
- A **positive vision** about where and how they would like to live and what they would like to do
- A **voice** that is heard, acknowledged and respected by others
- **Diverse options** that complement their vision
- **Supports** to make their decision a reality
- Innovative and creative **opportunities** to be included in community



**Table 4: The Right to Decide: Issues and Future Direction**

Issue	Future Direction
Guardianship and Substitute Decision Making	Investment in support networks, self-advocacy and supported decision-making mechanisms  Legislative reforms to eliminate guardianship
Culture of Substitute Decision Making	Development of self-advocacy networks and family based organizations to strengthen and enable people with intellectual disabilities to have their voices heard in their own lives and in the community
Lack of Models and Infrastructure for Supported Decision Making	Investment in pilot initiatives, model legislation and individualized supports to develop good practice in supported decision making
Denial of the Right to Enter Contracts	Review of law and policy at the national level to remove restrictions in employment law, family law and other relevant legislation  Establishment of mechanisms to enable recognition of supported-decision making in contracts

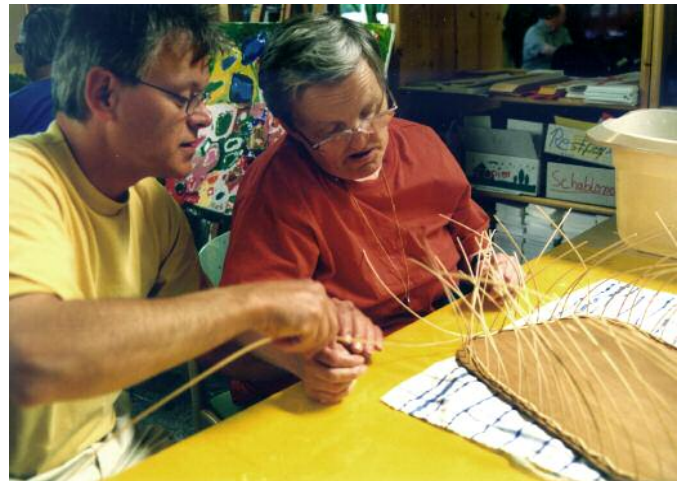
**Table 5: Where and With Whom: Issues and Future Direction**

Issue	Future Direction
Families are the only source of support	Investment in formal (state sponsored) and informal (friends, neighbors and community) supports for day to day living that are individualized and flexible
State sponsored residential options are segregated and institutional	Shift the focus of investments from group homes and “institutionally” operated housing to more individualized living arrangements which might include support to live at home with the family
Daily living supports are attached to real estate	Disentangle other supports from the provision of housing
Limited Vision of Options	Build and support family based organizations and self-advocacy groups to enable sharing of experience and examples across communities, countries and internationally
Safety and Violence	<p>Educate people with disabilities about their rights</p> <p>Ensure access to justice by people with disabilities (Article 13 of the CRPD)</p>

## Support

Services and supports for people with intellectual disabilities and their families will vary with a country's culture, history and tradition. There is no one “model” or way of doing things, however we do know from a half century of research and practice that institutional care is a model that does not and cannot work. The CRPD and especially Article 19, calls for people with intellectual disabilities and families to have the same access to services and the community as others in their society. It does not call for all services and supports to be of one type, or to all look alike. In the developed world challenges remain,

including second order deinstitutionalization (See Table 10 below). Another challenge is the separation from determining what a person wants and needs from the provision of those services and supports. In far too many places, eligibility and design of services and supports are made by the same entity providing them. This is clearly a conflict of interest. In other places people who have an intellectual disabilities risk losing their place to live if they don't "behave". This is entirely at the discretion of those in charge and with no recourse. In yet other places, people with intellectual disabilities remain segregated in large workshops or day programmes which are dependent upon the income from contracts for services with businesses or income from government for that person; thus the person who might want to do other things with their life is denied the choice and control to do so. For services and supports to be truly person centric, money from governments must be in tune with the wants and needs of the person. **The CRPD is about the rights of persons with disability, not the rights of organizations providing services and supports. There is a big difference.**



In countries without institutions, efforts should be made to help policymakers, advocates and national and local governments determine and implement the path to fulfillment of the promises of Article 19 without resorting to building institutions. The temptation of creating large places for people with intellectual disabilities to live is great and on the surface a ready solution to supporting people. However we know from countless studies, exposés, the experience of policymakers and experts and conversations with people who were previously institutionalized that regardless of the amount of money spent, that institutions by their very existence, separate and segregate people with intellectual disabilities from their community, and from their family. In addition, once an institution is built or remodeled it takes decades, not years to build community capacity and to get people out and eliminate the institution as an option.

In countries with large residential institutions the implication of Article 19 is that community capacity for all needs must be developed, and that people currently in institutions need to be supported to move to community-based settings, with those settings being consistent with what others in their society can access. Institutions, as long as they exist, consume important resources that could be better utilized in community based supports and are on their face, a violation of the intent of Article 19.

A challenge for those countries where institutions have been closed, as well as for countries developing systems of services and support for people with an intellectual disabilities, is developing alternatives. We have been calling this development “Second Order Deinstitutionalization.” Many of the services and supports developed over the past decades have been smaller images of what took place in the institutions. Family based organizations can be a driving force to help systems of services and supports improve to meet the needs of families and of people with an intellectual disabilities.

**Table 6: Supports to Individuals in High Income Countries: Issues and Future Direction**

Issue	Future Direction
Waiting Lists	Timely access to needed services and supports
Eligibility for disability supports tied to income	Eligibility tied to objectively assessed need
Access to inclusive services	Inclusion as the “default” option and gradual elimination of segregated options
Government cut backs and austerity measures	People with disabilities receiving guarantees of support
Institutions	Regular housing in the community and support for families

**Table 7: Supports to Individuals in Low Income Countries: Issues and Future Direction**

Issue	Future Direction
Poverty	<p>Economic opportunity and income support</p> <p>Inclusion of people with disabilities in national poverty reduction plans.</p> <p>Inclusion of people with disabilities in planning and investment in the UN Millennium Development Goals and future poverty reduction strategies</p> <p>Inclusion of people with disabilities and their families in International Development Assistance planning and financing</p>
Invisibility	<p>Participation and presence in the community</p> <p>Awareness raising strategies by governments and international NGOs</p>
Medical Model of Disability	<p>Strengthen the capacity of the disability movement, family organizations and self-advocacy groups to promote a human rights approach to disability issues</p>
Investment in Segregated Programmes	<p>Transformation of NGO strategies and programmes such as Community Based Rehabilitation and sheltered workshops into programmes that provide support to develop community capacity and support to enable participation</p>
Institutions and Risk of Institutionalization	<p>Adoption by international agencies and donor governments of a policy of no new capital investments in institutions</p> <p>Support to individuals, families and communities to eliminate the need for institutions</p>

**Table 8: Supports to Families: Issues and Future Direction**

Issue	Future Direction
Need for Short Breaks	Reasonable availability of supports and options for families to take short breaks either through informal supports or through state sponsored supports
Poverty	<p>Development of policies to off-set the additional costs related to disability</p> <p>Promotion of programmes for inclusion school and work that enable parents to be free to work during the day</p> <p>Economic opportunities such as microenterprise and entrepreneurial ventures as part of overall poverty reduction efforts</p>
Social Exclusion and Lack of Natural Supports	Strengthen the capacity of family based organizations, self-advocacy groups and community planning processes
Lack of access to Information	Information presented in multiple user friendly formats through schools, community centres, doctors' offices, parent resource centres, religious institutions, etc.

## Inclusion

The United Nations has stated that the CRPD demands a “no-gap” policy, stating that no entity can achieve the goal of equality for persons with disabilities on its own. Nowhere is the need for ensuring a “no-gap” policy more necessary than in the pursuit of the right to live and be included in the community. Awareness-raising (Article 8 of the CRPD) is required “throughout society including at the family level, regarding persons with disabilities and to foster respect for the rights and dignity of persons with

disabilities, to combat stereotypes, prejudices and harmful practices relating to persons with disabilities, and to promote awareness of the capabilities and contributions of persons with disabilities.”

The general principle of full and effective participation and inclusion in society means that major changes need to occur in society “to facilitate full enjoyment by persons with disabilities of the right to live in the community. This means making our communities fully accessible and welcoming of people who have intellectual disabilities and their families. When communities are fully accessible everyone benefits – not just people with disabilities and their families. This means that individuals and families may require direct supports, but also that there is a range of accessible housing options available and that people are guaranteed:

- Equal recognition before the law (Article 12)
- Access to justice (Article 13)
- Liberty and security of the person (Article 14)
- Freedom from torture or cruel, inhuman or degrading treatment or punishment (Article 15)
- Freedom from exploitation, violence and abuse (Article 16)
- Protecting the integrity of the person (Article 17)
- Liberty of movement and nationality (Article 18)
- Personal mobility (Article 20)
- Freedom of expression and opinion, and access to information (Article 21)
- Respect for privacy (Article 22)
- Respect for home and the family (Article 23)





- Education (Article 24)
- Health services (Article 25)
- Habilitation and rehabilitation (Article 26)
- Work and employment (Article 27)
- Adequate standard of living and social protection (Article 28)
- Participation in political and public life (Article 29)
- Participation in cultural life, recreation, leisure and sport (Article 30)

**Table 9: Obstacles for Inclusion: Issues and Future Direction**

Issue	Future Direction
Societal Attitudes	Efforts to change attitudes using a variety of approaches, including public awareness and inclusive policies and practices (inclusion in education, in recreation and cultural programmes, in political processes and in the labour market)
Lack of Inclusive Education	Inclusive education with training and support for teachers and school personnel
Employment	Employment in the general labour market for the prevailing wages through the development of microenterprises, supported employment, partnerships between community agencies and private sector businesses



## Chapter 7: Institutionalization: Ending the Cycle of Exclusion

**WHILE THE PRIMARY FOCUS** of this report is the majority of people with intellectual disabilities around the world who are living with their families but continue to live in isolation from their communities with little or no supports for themselves or their families and with poor access to education, employment and other community services, a massive human rights violation continues to exist in the form of institutionalization. Article 19 cannot be achieved without the eradication of existing institutions and the prevention of new ones.

“An institution is any place in which people who have been labeled as having an intellectual disability are isolated, segregated and/or congregated. An institution is any place in which people do not have, or are not allowed to exercise control over their lives and the day-to-day decisions. An institution is not defined merely by its size.”

– *The Canadian Association for Community Living – People First of Canada Task Force on the Right to Live in Community*

This section will present and discuss some of the major lessons learned as a result of past and ongoing institutional closures and some of the challenges that still remain as we move toward fuller compliance with Article 19 of the UN Convention.

Institutions are a direct contravention of the CRPD, Article 19 and the right of persons with disabilities to have the same opportunity to choose where they live, with whom they live, and not be forced to live in a particular living arrangement.

*“I want to go back to Fukushima!” “I cannot stand the life in this institution, since I cannot have my privacy.” “I want to go shopping and hold the event of self-advocacy activity as I want.” “I feel like I time travel to the old days when I was institutionalized.” “I want to have my own room as before.” “I want to work again in Fukushima as soon as possible.”*

– *Self Advocate, after the Tsunami in 2011 Japan*



Photo: Ulrich Eigner

We have learned that when asked, people with intellectual disabilities choose not to live in institutions. We know that institutions deny people basic rights of citizenship, personal control, personal privacy, decision-making and inclusion in community. Based on personal stories as told by people who have lived in these facilities, we know of the abuse, isolation and personal suffering that invariably occurs in these facilities. Not only do we continue to face the challenge of closing the institutions which exist, we also must address the legacy that institutional

care has left on our approach to supporting people in the community and we must guard against the threat of new investments in institutions and institutional approaches. To do this it is helpful to understand what we have learned about the closure process which has taken place in many countries.

### ➤ **Deinstitutionalization is more than closure**

Perhaps the first and most important lesson learned is that deinstitutionalization is not just about closing institutions – not just about the evacuation of people from one environment to another. We have learned that deinstitutionalization involves assisting people to leave institutions and take their rightful place in community and also that it involves the development and provision of appropriate and adequate community and family based supports and services for both those leaving the facility as well as for those persons who are currently living in community. We have learned from past efforts that deinstitutionalization must be as much about supporting people to continue to live in the community (e.g. prevention) as it is about closing facilities. To do otherwise simply means that over time persons leaving the facility will be replaced by others from the community who cannot access needed supports to continue to live in community.

### ➤ **Everyone can live and be included in the community**

Another major lesson learned is that all people living in institutions can live more successful and inclusive lives in community. We have learned that community living is for all people – not just those who have less significant challenges. Experience in countries such as the UK, Canada, USA, New Zealand, Norway and Sweden have demonstrated beyond doubt or debate that institutions do not need to exist (or continue to exist) to serve the needs of certain groups of people. Research from numerous institutional closures have unequivocally demonstrated that persons with “severe” disabilities, those with challenging behaviors, people who are “medically fragile”, and persons of advanced age (who have lived in the institution for many years) can all be successfully supported in community.

**AUSTRALIA** Not explicitly, but through funding people are hindered from living in the community.

**JAPAN** There have been initiatives in Japan, but at the same time we have the fact that the number of institutions is growing. From the research only 3.4% has been deinstitutionalized and two of the main new placements are their homes and group homes. We have to add another fact that almost the same number of people are newly institutionalized.

**LESOTHO** “We believe that people with disabilities should not be kept in institutions, since it’s like treating them like animals, where their minds are restricted. They have the right to be part of their families and siblings. Families and communities should learn how to take care of them”

We are now aware that the many of the limitations usually associated with disability are as much related to the surrounding environment and rules of society as they are to the individual. We know that people, regardless of type or extent of disability, do not need to live in institutions. Most importantly, we know that people flourish and thrive when they live in the community, with appropriate support.

We have learned that efforts to assist people to leave institutions must be guided by those values and principles that are known to achieve positive outcomes. A deinstitutionalization plan must ensure that people have:



Photo: Ulrich Eigner

- The right to choose where they will live, and with whom
- Services/programmes that are person centered, directed and controlled by the person and that are respectful of that person's right to make choices and take risks, within the context of their culture
- The right to individualized living arrangements and control over the needed resources
- The necessary disability related supports needed to fully participate in the community
- Support, as necessary, from friends/family/advocates to assist in decision making (supported decision making)
- Services that meet all of their needs and are of high quality, portable and accessible
- Help in developing natural supports including families, neighbors, friends

Drawing on the Canadian and USA experience, the Canadian Association for Community Living — People First of Canada Joint Task Force on the Right to Live in Community has identified 10 key recommendations as critical to creating real homes and planning the closure of an institution (The Right Way, 2010). To summarize, these are:

- **Involve champions for community living**
  - o The decision to close an institution requires vision, passion, leadership— and champions. While these champions can come from many sectors, traditionally family members and self-advocates take the lead role in demanding both institution closures and community supports.
- **Ensure that the needs and preferences of the person come first**
  - o Each individual must be empowered to choose where and with whom to live and the resulting living arrangement must truly be that person's home.
- **Respect the experiences and roles of families**
  - o The perspectives of families must always be taken into account when initiating planning for an individual to move to his or her own home in the community. Families will often be the best source of information about the person and often form the nucleus of the person's support network in the community.
- **Facilitate person centred plans and create a real home for each person**
  - o Engaging in respectful, person-centred planning will maximize the potential for achieving positive personal outcomes. The goal is to support the individual in ways that meet his or her needs and allow him or her to live in a real home, to participate meaningfully in community life, to make real choices and have his or her rights and wishes respected.
- **Create quality supports, services and safeguards**
  - o Resources previously allocated to the institutions are reallocated to communities to ensure adequate capacity to support everyone in the community. The need for increased capacity in communities is identified in a systematic and timely way, so that planning can occur and supports are in place when individuals make the move to their new homes.
- **Recruit and develop qualified support staff**
  - o The availability of skilled, knowledgeable employees to provide the individualized supports needed by individuals with intellectual disabilities in their homes and communities is vital to success. Many former institution staff can successfully transition to community-based environments and strategies for accommodating these staff need to be developed.
- **Establish community partnerships**
  - o The successful closure of an institution depends on sound collaborative working partnerships between individuals,

families, government and community organizations. Alliances should be nurtured with family support organizations, local advocacy groups, social justice advocates, service groups, unions, business leaders and other possible allies.

- **Establish a clear plan and time frame for closing the institution**
  - o Government and community leaders must share a clear, unequivocal, public commitment that the institution will be closed, that resources will be allocated to the community and that planning will ensure that each person residing in the institution will be supported to move to his or her own home in the community.
- **Communicate the announcement clearly and effectively**
  - o Careful consideration must be given to how the closure decision is announced and how messages will be conveyed. Undoubtedly there will be at least some opposition to the closure, from various sources, and government and community leaders must be prepared with clear information about what is planned and why.
- **Carefully coordinate/support each person's transition to the community**
  - o Many individuals make quick transitions to living in their new home with little to no negative impact. Others may require a more gradual change from the old environment to the new one. The people who know the person well will be in the best position to help plan the transition and any intermediate steps, if needed.

Also in the consultation our member in New Zealand said it was also important that:

- **Where individuals do not have families involved, independent advocates should be appointed**
- **People with disability who are moving from institutions and their families being able to visit good examples of community living so they can see how it works and undertake an evaluation**

While the real life stories of people who have left institutions, testimonials from families, and overwhelming research point to the world wide success of institutional closures, the process has not been without its share of mistakes. The way in which deinstitutionalization has taken place in many jurisdictions has left us with a legacy of institutional thinking which continues to characterize the way people receive supports and the way service systems are organized.

**Table 10: Second Order Deinstitutionalization**

## SECOND ORDER DEINSTITUTIONALIZATION

*Steven M. Eidelman*

*H. Rodney Sharp Professor of Human Services Policy and Leadership*

Over the past six decades it has been family run organizations that have led the way in the transformation of systems of support for people with intellectual disabilities, from large custodial institutions to a life in the community. In the 1960's and 1970's, the early days of the movement towards community based supports, families who were struggling without any services, providing care 24 hours a day, were frequently the first to open programmes in community settings for their sons and daughters. Most often it was a programme that provided something to do during the day, both for children who did not have the right to education and for adults. Later it was group homes. Those family run organizations applied what was known at the time, which mimicked the model of care that existed at that time – facility based services, but on a much smaller scale. As families and advocates worked to get people out of institutions, these models became the foundation for the service system.

These services changed how people in institutions lived and provided relief for families who were growing tired and wanted permanency for the future. While those changes were more than a change in real estate and geography and were a considerable improvement from the institution, they lacked an affirmative philosophy of person centeredness, self-determination, inclusion and full participation in the life and fabric of the community. While that was certainly not the intention, in all too many instances it has been the result.

Now, in light of the CRPD and the promises it puts forth about community living and supporting families, we must prepare for Second Order Deinstitutionalization: The Remodeling or Transformation of Existing Community Services, including traditional building-based day supports and many group homes.

What is Second Order Deinstitutionalization? It is the remodeling or transformation of existing community services. It is also difficult and important work. Many of the community programmes developed in the past as alternatives to institutions are now the very programmes which must change. Many of those programmes were developed by people who remain in leadership roles in family based organizations and are invested in the programmes they helped to create. We have learned that physical presence in the community does not necessarily assure integration and inclusion. While many community services remain traditional, based on what we knew how to do in years past, we also see examples of programmes that have learned how to include people with intellectual disabilities in both organizational decision making as well as having them self-direct and choose their own supports and services. We see programmes that support people living how they want, and with whom they want. We see programmes supporting people to volunteer in their communities, gain jobs in the main economy of their community and even in the creation of small businesses.

And all too often, programmes located nearby those fully including people with intellectual disabilities are segregating and isolating people with intellectual disabilities. There is expertise, globally, in how to



impact the transformation and remodeling of services. Individuals, families and family based organizations need partners and allies to cause these changes to happen. And we have to recognize the reality that remodeling existing services does not happen without transactional costs during the transformation process, and does not happen without opposition of multiple fronts and therefore can't happen without strong leadership.

Sometimes leaders of family-based organizations that run traditional congregate supports justify these by saying that the people who receive supports "like" these programmes; and don't object to the lack of choices and control in their lives. Sometimes people are in services that their families want or are have simply become accustomed to but the individual, him or herself, if presented with alternatives, would not choose. These arguments for traditional group homes, day programmes and sheltered workshops are much like the arguments families of people in institutions made, and make, e.g. "they are safer here, they like it, and we know this programme will be here as long as we need it."

There is security in buildings and in things that are known and familiar. For family based organizations changing supports and services often means asking families to imagine a different future and helping them do so. In the past we've asked families to trust the professionals, to work with them and their sons and daughters and, often, to agree to things they have never seen. But with person-centered planning, self-direction and choice, we can engage families in planning a new future by focusing on what their family member might want and building in the supports to minimize risk. In this process there are constant surprises about what is both better and possible. For all families, such change is hard. But if family run organizations do not take the lead, others will do so and family organizations risk abdicating their power and credibility by letting others act while they remain passive or even oppositional.

But, in the current global economic situation, resources, never plentiful in most places, are now in even shorter supply. There simply are not enough financial resources to maintain three levels of programmes:

- Large public/private institutions
- Medium sized facilities/Older community programmes
- Inclusive community supports and services

The leadership challenge for family based organizations, including self advocates, is to help shift services and supports from low value, segregated and isolating services to high value supports and services, those that help fulfill the promises of the CRPD, and especially of Article 19. There is risk in staying with what we know well – with service models from the past. If family based organizations do not lead by example, other service providers may take the lead, thereby weakening the voices of families. If family-based organizations do not take the lead in assuring fully included lives for people with disabilities, they may well lose some of their moral authority and the ability to impact change with other providers of services and with governments. People with intellectual disabilities and their families cannot afford for this to happen. Family organizations must create the vision and the passion for transformation, both for family based organizations themselves, and for service providers and governments. It is too important to leave to chance.

Both mistakes that we have learned from and in some instances mistakes that we continue to make. Some of the most important of these would include:

### ► Cost Savings

Many of the early efforts to close institutions were motivated, at least in part, by the lure of reduced costs of community supports as compared to institutional costs. This initial cost saving was due primarily to the disparity between institutional wages and community-based wages. In some countries this gap has been closed but it continues to be an issue in finding and keeping good support people in the community.

While reduced costs should never be the predominant consideration, the cost neutrality of the conversion from institutional model to a community-based model does pose increased challenges to securing needed government and community approval and endorsement. Furthermore in jurisdictions where only those people who live in institutions receive state sponsored support, the shift to community supports would require the opening up of resources to all people with intellectual disability.



Photo: Ulrich Eigner

Finally, while the average cost per individual living in an institution may be higher than for that person to live in the community with support, there are transactional costs associated with the closure process which require an initial investment. In the short term, using cost savings as a motivation for closing institutions is a mistake.

### ► Post Institutional Placements



Many early closure processes developed community based residential options (usually group homes) into which residents were “placed”. While certainly preferable to continued life in a large institutional setting, such a process did not make necessary accommodation for individual choice nor was attention given to ensuring the use of a person centred planning approach. Over time many of these “community options” became as restrictive and ‘institutionalized’ in nature as the institutions they were designed to replace. People want homes, not houses; people want meaningful lives, not entry into services.

### ► Specialized Services

In the transition to community many individuals were provided with supports and services as delivered by disability specific agencies. People lived in homes in which only people with disabilities lived, went to school or vocational/employment programmes that served only people with similar labels. Thus while having an increased presence in the community as a result of their move from the institution, many people were still isolated and congregated in services and programmes not typically used by other members of the community. In more recent times, greater success toward full inclusion and community participation has been achieved by linking resources to the person rather than to an agency, which enables the person greater choice and control over the supports they need and use in community.

### ► Easiest to Support

One of the basic mistakes made in institutional closures is that only those persons deemed “easiest to support / most able to live in community” were

**SWEDEN** Within many areas there are adequate laws and rulings – but they are not followed in practice. An example of this is a recent survey showed that only 6 of 271 government authorities had followed the regulations concerning accessibility for persons with disabilities. Additionally the report showed that the CRPD does not yet play an important role when studies and inquiries are carried that concern people with disabilities. And the CRPD is still not taken into consideration to any great extent in terms of court decisions or the practices of government authorities.

moved to community options while those with more significant challenges were often relocated to other institutional settings such as nursing homes, rehabilitation centres or other similar long term care facilities.

We know that deinstitutionalization is not a simple matter of closing a facility and moving residents to the community. To be successful and sustainable, the process must involve careful individual and systems level planning.

Additional community based supports must often be created and/or expanded to support those returning to community as well as those who are already in community (usually with families). Adequate and appropriate support must be provided to both individuals and families. Full consideration must be given to ensuring that individuals become full and participating members of their community and not have simply exchanged one institutional setting for another that is merely different in size and location. Self-advocates from across the world have told us that life in community – inclusion in community – is possible only if it comes with the ability to make choices, take risks and have control.

As countries complete their deinstitutionalization efforts, continue to close existing facilities and/or begin to consider the merits of initiating such a process, there are several emerging and ongoing challenges that must be addressed.

### ► Other Institutional Settings

Stories told to us by families and self-advocates, particularly in countries where traditional institutions specifically for people with intellectual disabilities have been closed reveal an increasing trend of using other institutional placements as an acceptable option. In countries such as Canada, the USA, Japan, New Zealand, Australia and the UK families and self

**AUSTRALIA** There are a variety of lessons learned – eg. people invariably live better lives, families often resist the move, government commitment is influenced primarily driven by the cost, it is harder to develop individual alternatives than group ones (e.g. group homes).

**INDIA** “Our students sometimes come from home with nothing: no school equipment or basic necessities. We are starting to keep chickens and grow vegetables so we can improve the children’s diet and help them stay healthy.”

One young boy at the school adds: “I like to board at the school because there I have a bed with a proper mattress. We play with children from the mainstream classes at break times.” His friend, a young girl, adds: “I would even prefer to stay at weekends too.” Their parents reported being pleased that their children were now in school, where they are learning more than they were at home, and they do not have to travel so far each day.

**AUSTRALIA** “Governments are not being held accountable for what they have agreed to under the CRDP. There are not “a lot of votes” in the provision of disability services, and little pressure from the public to deliver or improve disability services. Many people with disabilities and their families and carers do not have a strong voice to influence the delivery of services. There is an important place for campaigns and external advocates to hold governments accountable and to raise awareness of people's needs and rights.”

advocates are often given little or no choice in housing options, often being referred to seniors' residences, nursing homes, and/or other inappropriate long term care settings. Additionally, the size of these settings also continue to grow as governments cut back spending in the social sector.

### ► **Something is Better Than Nothing**

In many countries, particularly low income countries where community supports and services to families and individuals are minimal or nonexistent institutions are being considered as a legitimate response to the critical need for support services. Sometimes, due to cultural issues, but more often because no other services are available or being offered, families mistakenly see this offer of institutional care as a step forward.

### ► **Services as Outcomes**

Many deinstitutionalization processes still measure success in terms of the number of buildings closed, placements made, and residential options created. Doing so however confuses “tools” with outcomes. The closure of an institution is not the goal; it is merely the result of assisting people to take their rightful place in community. If in helping people leave an institution we do not ensure that they have meaningful lives in community, then the process is seriously flawed. Many countries continue to rely almost exclusively on traditional residential models such as group homes. Yet a move to a group home is a “success” only if it provides a vehicle through which the person can create for themselves a meaningful and participatory life in community. Experience has taught us that options such as group homes, while an expedient tool to assist in the deinstitutionalization process, do not necessarily enable meaningful lives in



community; indeed many times they are an obstacle to achieving that goal. Buildings do not provide meaningful lives – choice, access to appropriate supports, and relationships are the elements needed to establish and maintain inclusive lives in community.

Based on institutional closures in many countries across the world we now know that to ensure successful and positive outcomes, efforts toward deinstitutionalization must reflect the following elements:

- Individuals and families must be given status and support to exercise personal choice
- Supportive relationships for people must be built that give people value and respect
- Opportunities and support must be established for people to learn and work in the community
- Community services and structures must be available and accessible (that is they must be usable by all people, free of barriers, etc.)
- Flexible and responsive personal supports must be provided to meet disability related needs



We must learn from our mistakes, not repeat them. Deinstitutionalization must be about more than simply closing large institutions, about more than simply replacing large institutions with smaller ones, about more than creating networks of group homes, and ultimately about more than substituting isolation outside the community for isolation within the community. Deinstitutionalization must be about creating capacity within community to support people with intellectual disability and their families, to live as full and equal citizens, in ways that reflect and respect the prevailing culture and traditions. The outcome must be lives that are typical and ordinary, yet valued.



# PART IV: Achieving Inclusion







## Chapter 8: The Role of Family Based Organizations in Making Change and Promoting Inclusion

**DESPITE THE VAST DIFFERENCES** in their lives, people with intellectual disabilities and their families all around the world share a common experience. Through the process of sharing those experiences like the ones that resulted in this report, we are able to learn about systemic barriers and identify common challenges. We also learn about which strategies are successful in overcoming those barriers. In turn, this shared knowledge enables us to provide our members with another lens through which

they may do a critical analysis of the challenges in their countries. By **linking local voices to global change and global knowledge to local change** we create a cycle of learning and a vehicle for using knowledge sharing to affect change. For example, while national member organizations work to get children with intellectual disabilities in school, Inclusion International draws from their experience and knowledge to influence agencies like UNICEF and the World Bank to develop policies and investment strategies to promote inclusion.

For over 50 years Inclusion International has worked with its member organizations around the world to improve the lives of people with intellectual disabilities. Our members are national family based organizations that vary from large agencies that provide supports and services in the community to small grassroots organizations that have no staff, budget nor offices. All of these organizations were established by families who wanted to develop something better for their sons and daughters.

Historically, many parents in all parts of the world were told by doctors and other professionals that their sons and daughters could not function in society and that they should be put in institutions or kept at home, out of school, out of sight, out of the public eye. In some parts of the world families with children with disabilities were shunned by their communities. Family based organizations provided families with information and peer support and they began to develop programmes and services to meet the needs that were not being served.

As the organizations matured, they began to include the voices and perspectives of adults with intellectual disabilities. Self-advocacy, organized groups of people with intellectual disabilities, are well established in some parts. People with intellectual disabilities have organized



themselves to raise awareness, to make demands of governments and to claim their rightful place in communities. However, not everyone's voice is heard; those who remain in institutions, those in parts of the world where self-advocacy is not yet supported or understood and those who cannot communicate in ways that people outside of their closest supporters can understand are all still ignored or unheard. Today, family based organizations serve a global movement of people with intellectual disabilities and their families that has advocated for a vision of "a world where people with intellectual disabilities and their families can equally participate and be valued in all aspects of community life."<sup>1</sup>



During the negotiations of the UN CRPD Inclusion International was mandated by its members to ensure that the perspective and priorities of people with intellectual disabilities and their families was reflected in the Convention. The real impact that the voice of self-advocates and families had on the Convention was not the inclusion of a list of specific accommodations for people with intellectual disabilities but rather a shift in understanding that clearly calls on governments and societies to take responsibility for building inclusion. The

Convention is about more than ramps and laws, it is about building inclusive societies, schools, labour markets and communities. The shift towards inclusion which is reflected in the CRPD is the legacy of the inclusion movement.

The challenge we have now is to consider our role in making change happen at the local, national and international levels. The activities and mandates of family based organizations that are the members of Inclusion International reflect the demands and needs expressed by people with intellectual disabilities and their families. However, in attempting to address these immediate and

urgent needs, we are often limited to short term, stop gap measures which serve only a small number of those who require support and tend to be focused on protection. Families would like to be assured that their family member with an intellectual disabilities is safe, has opportunities to be included in the community as a contributing member and that he/she be valued for who they are. They would like their family member with a disability to have a life like their brothers and sisters but since they are the main support in their family member's life, their greatest fear is what will happen when they are not around. They know segregation has led to isolation and exclusion for the person with a disability and for them as families but they are tired and they are struggling to develop strategies for the future.

To be effective in meeting the challenges ahead we must identify new strategies, shifting from the role of filling gaps to one that focuses on affecting social change. As agents of change in our communities, we need to deploy our limited resources to strategies which will have a lasting and transformative impact on our communities by:

- Building partnerships with other community stakeholders (employers, cultural and religious groups, political parties, colleges and universities, media etc.)
- Working with governments to ensure mainstream systems are inclusive (Education, employment, housing, transportation, justice etc.)
- Strengthening the voice of self-advocates and families in their call for inclusion in the community

As we contribute to making our communities more inclusive for people with intellectual disabilities, we help make them more inclusive of all people who are at risk of being excluded, and thereby strengthen our communities. Shifting our priorities to focus on building stronger communities for all will mean shifting from filling gaps to building inclusive communities (Table 11) ;

**Table 11: Stronger Communities for All**

From Filling Gaps	To Building Inclusive Communities
Providing segregated employment, housing and education services for a few	<p>Providing supports to individuals to access regular employment, housing and education</p> <p>Working with community stakeholders to identify existing systems and supports</p>
Training self-advocates in “life skills”	Building and supporting self-advocacy groups
Training parents in “intellectual disability”	<p>Developing family resource and training programmes to enable families to access and use supports in the community</p> <p>Providing supports to families to assist in planning</p> <p>Assisting families to build and sustain natural supports in the community</p>
Rehabilitation: skills measured as outcomes	Community development: Inclusion in the community as outcomes
Supports defined and delivered by service providers (supply side)	Supports defined by needs and demands of individuals with intellectual disabilities (demand side)
Advocating for budget allocations for disability supports	Advocating for budget allocations for disability supports and inclusion in mainstream budgets
Low expectations and negative attitudes	<p>Raising Public Awareness of human rights and inclusion</p> <p>Sharing examples of people with intellectual disabilities living and being included in the community</p>

By shifting our strategies to focus more attention on communities and systems and less on the person's disability, we are helping to build communities that are more inclusive of all groups and therefore stronger. When teachers learn how to teach students with a range of learning styles, with different types of intelligence, how to adapt curriculum, they become better teachers of all students. Likewise, an education system that makes supports available to the teacher, that draws on all personnel to help problem solve, that is committed to making every student succeed rather than banishing the ones having trouble is a better system overall.

The presence of a worker with a disability in the workplace can help build morale and it means fewer people dependent on income support. Inclusion and inclusive strategies that develop relationships and strengthen the informal connections between people contribute to social capital for both families and individuals. The inclusion of people with intellectual disabilities in the community contributes to social cohesion; the acceptance of difference in the community.



While inclusion in the community is important to individuals and families, it is also essential to building stronger social and economically cohesive societies. Families and family organizations have often been the drivers of change in communities, as volunteers as advocates and as support systems but they need help to play those roles. We need to invest in families and in family organizations to achieve inclusion in the community for people with intellectual disabilities and stronger communities for all.



# Conclusion



Photo: Ulrich Eigner



## Conclusion

**ACHIEVING THE RIGHT TO LIVE AND BE INCLUDED** in the community for people with intellectual disabilities presents a multi-dimensional and complex challenge for a range of actors including families, educators, employers, community stakeholders, governments and people with intellectual disabilities themselves. If we examine the key findings from consultations with self-advocates and families, what emerges is a roadmap for public policy which will lead the process for change in our communities.

### Key Findings and Policy Recommendations:

- **The majority of people with intellectual disabilities have no voice or control in the decisions about where and with whom they live.**

Recognition of the right of each person to make decisions about their own lives will require change in legislation, societal attitudes and the role of families. It is tempting to assume that legislative reform alone will achieve this shift. However, to ensure that real change happens in people's lives, several other important investments need to be made. First, families and people with intellectual disabilities need support to develop personal support networks in their daily lives which will enable adults with intellectual disabilities to express their voice and exercise control in their lives. This support can be developed through investment in self-advocacy and support to family based organizations and training for families. Second, supported decision making structures and processes need to be developed. While some models of supported decision making are being tested in different jurisdictions, there are only a few examples internationally of these models being recognized in law.

➤ **People with intellectual disabilities have limited choice and options for where and with whom they live.**

The public policy response to supporting people to live and be included in the community (where there has been a response) has largely focused on the supply of housing specifically designated for people with disabilities serviced by disability support agencies. While there are good examples of programmes that give individualized or direct funding to be used by individuals to purchase housing and services from the open market, the main approach taken by governments has been to fund the “supply-side”. Too often, the housing models and programmes that receive funding are disconnected from the real needs and demands of people with intellectual disabilities. A more even balance between funding of the “supply” and “demand” sides, would achieve: better accountability for the quality and responsiveness of publicly funded housing; a greater range of housing and support options available; and greater choice, control and flexibility in the lives of people with intellectual disabilities and their families.



There is a risk that in low income countries where little or no public investment has been made to support people to live in the community, increased awareness by governments as a result of the CRDP may mistakenly lead to investments in congregate living (group homes, small or large institutions) instead of demand side investments (income support, housing subsidies, support for daily living activities). When deciding how to best use limited resources, governments should choose policies and programmes that enable individuals to make the best

use of existing mainstream services and supports in their communities.

- **Institutions continue to be a major source of human rights violation and there is evidence in some regions that the admission of children is increasing and that new forms of institutions are being created.**

Without exception governments must commit to closure of institutions and a clear and sustained strategy to invest in community and community supports. The continued institutionalization of people with intellectual disabilities is a direct violation of the

CRPD. Pressure from all human rights actors must force governments to adopt no new admissions policies and no capital investments while individualized plans for people living in institutions to return to the community are developed. We have learned from the closure processes in different jurisdictions of the risks in focusing only on the closure process and not on the corresponding community development required to achieve living and being included in the community. While individualized support plans are critical to ensure successful return to the community,

processes to develop community supports and mainstream inclusion are equally important. Vigilance is needed to ensure that new forms of institutions are not built.



Photo: Ulrich Eigner

- **The vast majority of people with intellectual disabilities live at home with their families with little or no services or support to the individual.**

Children and adults with intellectual disabilities are usually unable to access disability related supports which they require because they live at home with their families. In the case of children, public policies

continue to make more services available to children if the child lives outside the family home (institutions, foster homes, long term care facilities). Despite the rights of the child to a family, public policy continues to force families to give up their children to the state in order to access basic supports. For adults with intellectual disabilities, existing disability and/or income supports are either not available or insufficient to support people to become independent.

There is a clear need for investment in the provision of disability related services and supports to children and adults with intellectual disabilities. In high income countries, these services and supports need to be separated from eligibility for income supports and they must be flexible and portable. In low income countries, few government-funded supports exist and some inconsistent and limited supports are delivered by International NGOs (INGOs).

Governments must develop a clear overarching policy consistent with the CRPD and in particular the right to live and be included in the community which guides development spending and to which INGOs must be accountable.

► **The major source of support and care which people with intellectual disabilities receive is from their families yet families receive little or no support from communities or governments.**

The preamble to the CRPD and Article 23 clearly recognizes that families require supports to assist their family member with a disability to realize their rights. Nowhere is this more important than in the realization of the right to live and be included in the community. Families are the main vehicle through which this right may be achieved. Families are the first and often main advocates for inclusion in education, access to services, employment and housing. Yet public policy in most jurisdictions has

not been developed in “family friendly” ways; they receive little or no information or emotional support in caring for their family member; they do not receive compensation for lost income due to caregiving responsibilities; they have little access to services which provide short breaks in their caregiving responsibilities and as they age and become unable to provide care and support, they have no access to supports to plan for the future of their family member. Many of these supports can be developed in both low and high income countries at the community level through investments in community based organizations and existing mainstream services and programmes. Where some good examples in public policy have been developed to support the role of families, concerns have been raised about reinforcing the dependence of adults with intellectual disabilities on their families. It must be absolutely clear that supports to families are not to be used as a substitute for supports to the individual but rather without both, inclusion in the community cannot be achieved.

► **Even when people with intellectual disabilities live in the community they are often isolated and excluded from the community.**

In high income countries where service infrastructures have been developed they continue to be professionally driven, modelled after institutional care; segregated and isolating. Governments must introduce a reorganization of the service delivery system which requires a paradigm shift by all actors (disability and other service providers, public policy actors, families, employers, educators etc.) towards a system which is directed by the needs and aspirations of people with disabilities. This shift will mean changes in a service industry which has been entrenched in a way of working for many years, but as with the processes of deinstitutionalization and inclusive education have taught us, progress requires

leadership and vision. That vision should come from people who themselves use and require services to live in the community.

In low-income countries the experience of isolation in the community is, in part, the result of lack of services (or limited and poorly directed services delivered by INGOs) but also a result of social and cultural attitudes about people with disabilities generally. While there is clearly a need to develop a consistent and inclusive approach to the delivery of supports, a lot can be achieved through the development of community programmes which raise awareness of the rights of people with disabilities and which demonstrate by example the ways in which people with intellectual disabilities can contribute and participate in society.

- **Communities fail to organize systems to be inclusive (education, health, transportation, political processes, cultural and religious groups, employment etc.).**

The most central and important finding of this report is the clear message from self-advocates and families that no matter how successful we are in providing choice and control to people with intellectual disabilities in their lives and in providing services and supports to them and their families, without a fundamental rethinking about the way that our communities are organized (education, labour markets, health care, political processes, cultural and religious groups etc.) we cannot hope to achieve real inclusion in the community. We know that our communities benefit from and are stronger as a result of inclusive planning and approaches. While the processes for making these changes in our communities are multiple, there are some key



building blocks for governments to use as first steps. Public policies and practices that support the inclusion of children with intellectual disabilities in regular classrooms with their peers and of adults with intellectual disabilities in regular workplaces with others in their communities will result in both improved capacity of individuals to contribute and participate in the community and in better understanding and capacity of communities to support inclusion.

These changes will not be easy, and some may take decades, not years. The CRPD recognizes that some provisions will be subject to “progressive realization” and that each country will proceed in its own way, and at different rates. Some obligations in Article 19 should be considered urgent and immediate action such as the closure of institutions. But all countries can make progress. The CRPD offers people with disabilities and their families hope for a better future. Inclusion International is committed to that better future for all people with intellectual disabilities and their families. We know that by working together, locally, nationally, regionally and globally, we can contribute to a better future and ***better communities for all***.

**Table 12: Using the results of inclusion international’s research on the right to live and be included in the community. Steps to Inclusion**

Research Finding		Strategies
1	People with intellectual disabilities don’t have the chance to decide where and with whom they live.	<ul style="list-style-type: none"> <li>• Encourage and support children and adults who have an intellectual disabilities to speak for themselves and to express their hopes and dreams.</li> </ul>
2	People with intellectual disabilities have few choices about where they can live.	<ul style="list-style-type: none"> <li>• Focus on planning with individuals so they can create futures around their interests and desires.</li> <li>• Take advantage of services, programmes, jobs that are available in the community for all and provide support options there.</li> </ul>
3	Institutions deprive people of their rights.	<ul style="list-style-type: none"> <li>• Don’t build new large centres to house people with intellectual disabilities.</li> <li>• Don’t invest in refurbishing existing large centres.</li> <li>• Start planning for the people now living in large centres so that they can become included in their communities.</li> </ul>
4	Most individuals with intellectual disabilities live at home with their families and receive little or no support.	<ul style="list-style-type: none"> <li>• Remove all incentives that give more support to children or adults if they move away from their families.</li> </ul>
5	Families receive little or no support to help care for a person with an intellectual disabilities.	<ul style="list-style-type: none"> <li>• Provide supports to families AND to individuals with disabilities. Support organizations of families as well as self-advocacy.</li> </ul>
6	Even when people with intellectual disabilities live in the community they are often isolated.	<ul style="list-style-type: none"> <li>• Conduct public awareness about people with intellectual disabilities to reduce stigma and prejudice.</li> </ul>
7	Community systems – education, health, transportation, political processes, cultural and religious groups, employment, etc. – exclude people with intellectual disabilities.	<ul style="list-style-type: none"> <li>• Invest in making community programmemes and services accessible and inclusive rather than in programmes exclusively for people with disabilities.</li> </ul>



## Appendix 1: Contributors to the Report

### AFRICA

#### Country Participants in the Regional Meetings:

Ethiopia, Kenya, South Africa, Lesotho, Malawi, Mauritius, Namibia, Swaziland, Tanzania, Uganda, Zambia, Zanzibar, Zimbabwe, Benin, Ghana

Country	Organization	Representative
Benin	La Chrysalide	Claudine Daizo
Burundi	Association communautaire pour la promotion et la protection des droits de l'homme « A.C.P.D.H. »	Umwana Nk'abandi Programme Partnership – UAPP
Ethiopia	Ethiopian National Association on Intellectual Disabilities (ENAIID)	Gessesse Tadesse Mihret Nigussei
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Lesotho	Lesotho Society of Mentally Handicapped Person (LSMHP)	Kgomoco Motsamai Palesa Mphole
Malawi	Parents of Disabled Children Association Malawi (PODCAM) Mirriam Namanja	Enock Mluka Mithi Hanneck Mdoka
Mauritius	Inclusion Mauritius	Irène Alessandri Mary Margaret Zamudio
Namibia	Namibia Association of Children with Disabilities (NACD)	Pamela Beverly Somses

**AFRICA (continued)**

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Zimbabwe	Zimbabwe Parents of Handicapped Children Association (ZPHCA)	Casper Boriondo
Zanzibar Tanzania	Zanzibar Associations for People with Developmental Disabilities (ZAPDD)	Ali Haji Mwadini Fauzia Mwita Khalid A. Omar

## AMERICA

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**AMERICA (continued)**

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## ASIA PACIFIC

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Hong Kong	Chosen Power People First Hong Kong	Emily Wai Ying Fung
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Japan	Inclusion Japan	Keiko Sodeyama Masahiro Muto Mikako Noguchi
Korea	Korea Institute for the Family of the Developmentally Disabled	
Myanmar(Burma)	Unity Self Advocacy group of Intellectual disabilities	Kaung Htet Naing Min Shwe Htet Salai Vanni Bawi
New Zealand	IHC New Zealand	Claire Stewart Trish Grant
Vietnam	Disability Resource and Development (DRD)	

**EUROPE**

**Country Participants in the Regional Meetings:**

Hungary, Israel, Bulgaria, Croatia, Poland, Austria, Norway, Great Britain and Northern Ireland, Romania, Czech Republic, Slovenia, Spain, Palestine, Moldova, Ireland, Portugal, France, New Zealand, Finland, Germany

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Germany	Bundesvereinigung Lebenshilfe	Ulrich Hellmann
Hungary	Hungarian Association for Persons with intellectual disabilities EFOESZ	Eva Graf-Jaksa Reka Dano
Israel	AKIM	Sigal Peretz Yahalomi Shirley Galor
Netherlands	NGO Foundation Perspectief, expertcentre on inclusion and self determination National Democratic Association Inclusion Netherlands	J.C. Smits
Portugal	FENACERCI	Sandra Marques
Russia	PERSPEKTIVA	Denis Roza
Slovenia	SOŽITJE-The Slovenian Association for Persons with intellectual disabilities	Katja Vadnal
Spain	FEAPS FUNDACION CATALANA SINDROME DE DOWN (FCSD) Cataluña AFANIAS OCUPATIONAL CENTER "Furgonetas Blancas"	Azahara Bustos Daniel Paredes Katy Trias Pep Ruf
Sweden	Riksförbundet FUB	Judith Timoney
Great Britain and Northern Ireland	MENCAP	Ciara Evans Maureen Piggot

## MENA

**Country Participants in the Regional Meetings:**

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Country	Organization	Representative
Bahrain		Christine Gordon
Iraq	Iraqi Down Syndrome Association	Sahira Abed El Latif Moustapha
Jordan	Special Olympics Jordan	Ali Al Shawahin
Lebanon		Fadia Farah
Libya	Altahadey Association for Disability	Mahmoud Etriki
Palestine West Bank	Swedish Organization for Individual Relief IM	Dayana Salah Hamda

## OTHER ORGANIZATIONS

**Organization**

Fundación Saldarriaga Concha

Handicap International

International Disability Alliance

Mental Disability Advocacy Centre

Mental Disability Rights International

Open Society Foundation

Mental Health Initiative

# Endnotes

## Introduction

- 1 Roeher Institute, *Disability, Community and Society: Exploring the Links*, North York, Ont: 1996

## Chapter 1

- 1 [http://ii.gmalik.com/pdfs/Hear\\_Our\\_Voices\\_with\\_Covers.pdf](http://ii.gmalik.com/pdfs/Hear_Our_Voices_with_Covers.pdf)
- 2 [http://inclusion-international.org.cluster.cwcs.co.uk/wp-content/uploads/Better-Education-for-All\\_Global-Report\\_October-2009.pdf](http://inclusion-international.org.cluster.cwcs.co.uk/wp-content/uploads/Better-Education-for-All_Global-Report_October-2009.pdf)
- 3 <http://www.ii-livinginthecommunity.org/>
- 4 The tools and resources used to collect information as well as reports from each of the regional forums are available on Inclusion International website <http://www.inclusion-international.org/>

## Chapter 3

- 1 <http://www.ii-livinginthecommunity.org/>

## Chapter 5

- 1 Letter to Parliament from the minister of Health, Welfare and Sport, 30597, nr 158.
- 2 The Atlas-Global Resources for Persons with intellectual disabilities, 2007, p. 13.
- 3 The World Report on Disability. 2011. World Health Organization and the World Bank page 137
- 4 <http://cupe.ca/developmental-disabilities/a4e09f6875a5cd>
- 5 <http://www.lco-cdo.org/disabilities/joffe.pdf>
- 6 Kirby-McIntosh, Laura. *No, it's not getting better. Sorry.* Autism Canada Foundation, 26 October 2010
- 7 Mental Disability Advocacy Centre (MDAC) Press Release August, 13, 2012
- 8 For a complete copy of this report, covering 28 countries, see [http://www.kent.ac.uk/tizard/research/DECL\\_network/Project\\_reports.html](http://www.kent.ac.uk/tizard/research/DECL_network/Project_reports.html)
- 9 The movie can be seen, with English subtitles at <http://inkluzija.hr/eng/publications/>

## Chapter 8

- 1 Inclusion International Strategic Plan



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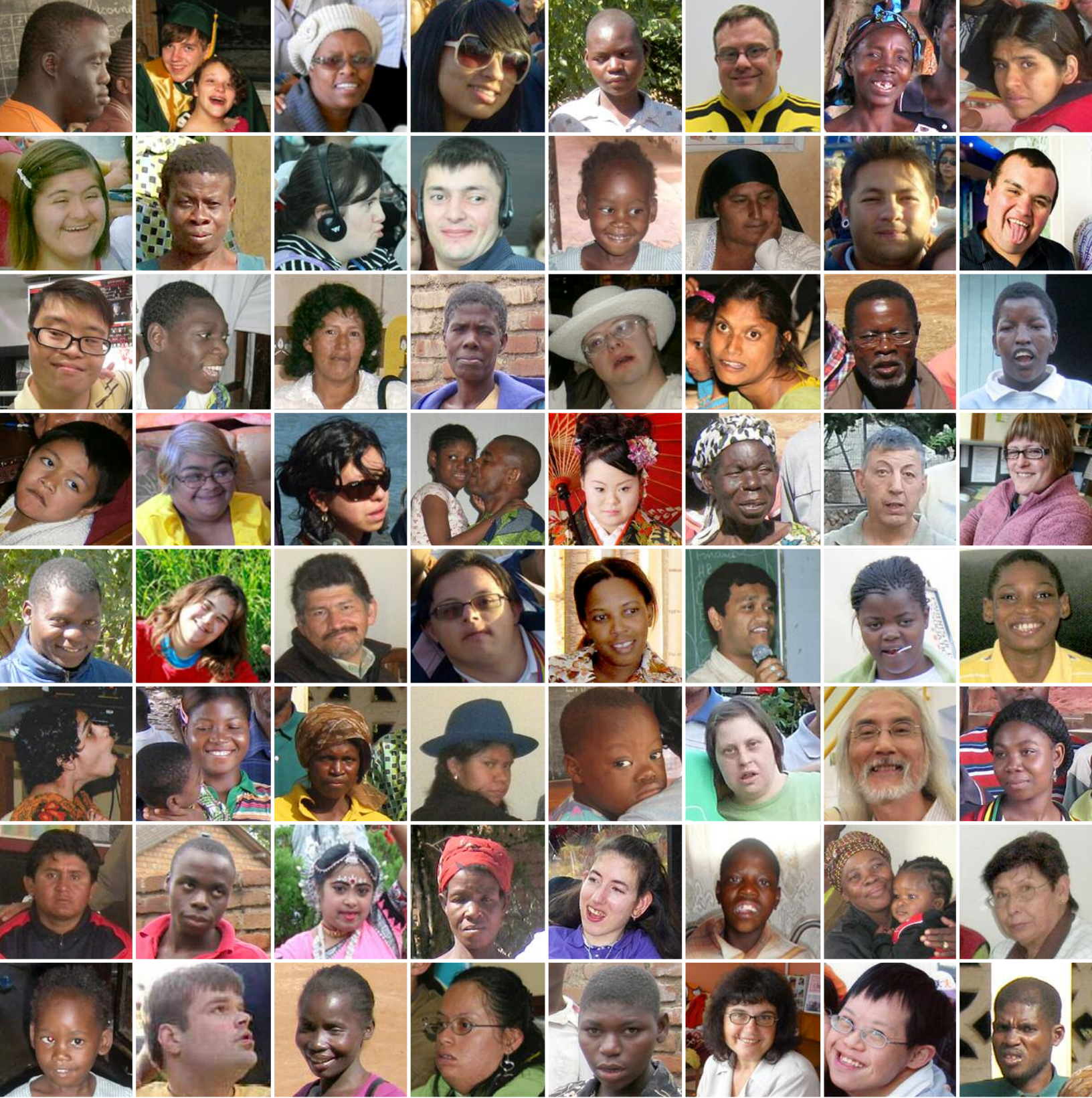
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