INDEPENDENT BUT NOT ALONE

2014

A GLOBAL REPORT ON THE RIGHT TO DECIDE

Inclusion international

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LIST OF ACRONYMS

AKIM	National Association for the Habilitation of children and adults with intellectual disability, Israel
CIS	Commonwealth of Independent States
COAMEX	Coalición México por los derechos de las personas con discapacidad
CONFE	Confederación Mexicana de Organizaciones en Favor de la Persona con Discapacidad Intelectual, México
CRPD	Convention on the Rights of Persons with Disabilities
DPOs	Disabled People's Organizations
FEPAPDEM	Federación Ecuatoriana Pro Atención a la Persona con Discapacidad Intelectual, Autismo, Parálisis Cerebral y Síndrome de Down, Ecuador
GC	General Comment
IDA	International Disability Alliance
II	Inclusion International
NFU	Norsk Forbund for Utviklingshemmede – Norwegian Association of the Disabled
NGO	Non-Governmental Organization
NHS	National Health Service, United Kingdom
MENA	Middle East and North Africa
RDSP	Registered Disability Savings Plan
UK	United Kingdom
UN	United Nations
USA	United States of America

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Finally and most importantly, to all of our member organizations and the many individuals with intellectual disabilities and family members, we thank you for sharing your stories and pictures with us (see full list in Appendix 1) as well as 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 the right to decide and all of your efforts to make our communities stronger for all.

Connie Laurin-Bowie (Editor)
Executive Director
Inclusion International

FOREWORD

Over the past two years Inclusion International's Global Campaign on the Right to Decide has facilitated an international discussion about the right to make decisions in the lives of people with intellectual disabilities.

The message from self-advocates is clear. ***We want to be heard and we want to make decisions about how we live our lives. Sometimes we might need help in making decisions but that does not mean we can't decide.***

We heard from families: **we need help in supporting our family members with intellectual disabilities to have the right to decide.** As the main source of support to people with intellectual disabilities, families often feel isolated and worried about the future.

Our member organizations told us of the challenges they face in **providing support to people with intellectual disabilities in ways that respect the "will and preference" of a person.**

The historical and systemic denial of the right to make decisions experienced by persons with intellectual disabilities is a reflection of societal prejudice and a failure of communities to understand and respect one's personhood.

Underlined by Article 3 of the UN Convention on the Rights of Persons with Disabilities (CRPD) which calls for respect of the individual autonomy of persons with disabilities including the freedom to make one's own choices, Article 12 creates an obligation by governments to reform their legal frameworks to shift from substitute decision making to supported decision making. However, these reforms will require fundamental transformations of the way that people are supported to participate in the economic, social and political life our communities.

For Inclusion International the messages from this report will shape our own agenda for the future. We hope others will use the report to shape a shared agenda for governments, advocates and policy makers.

Our commitments to advancing the right to decide are to:

- support our members to keep pressure on **governments** to implement Article 12 of the CRPD through monitoring and advocacy at the national level and through reporting to the UN CRPD Committee of Experts;

- strengthen the voice of people with intellectual disabilities in their own lives and collectively as **self-advocates**;

- provide **families** with assistance in building support networks for their family members; and,

- support **member organizations** in their efforts to provide supports to people that enable self-determination and the realization of the right to decide.

This report provides a clear vision and roadmap for achieving the right to decide, set out by people with intellectual disabilities and their families. We invite global leaders from government and civil society to work with us in advancing a shared agenda for reform.

Klaus Lachwitz
President
Inclusion International

EXECUTIVE SUMMARY

Article 12 of the Convention on the Rights of Persons with Disabilities (CRPD) reflects a fundamental shift in thinking: it asserts that with support all people with intellectual disabilities are able to make decisions and have control in their lives. This Global Report presents the perspective of people with intellectual disabilities and our families on the right to decide.

Over the past two years, over 600 self-advocates, family members, disability advocates, and professionals participated in discussions motivated by our Global Campaign on the Right to Decide. Additionally, we heard from more than 80 organizations from more than 40 countries worldwide.

Self-advocates said: we want to be heard and we want to make decisions about how we live our lives.
Families said: we need help in supporting our family members with intellectual disabilities to have the right to decide.
Family based organizations said: we face challenges in providing support to people with intellectual disabilities in ways that respect the will and preference of a person.

Having the right to decide means being able to make decisions in all aspects of our lives: health decisions; financial and property decisions; and, personal life and community related decisions. The Right to Decide has been identified as the heart of the UN CRPD, as we heard that having the right to decide is important for securing all other rights. In order for the voices of persons with intellectual disabilities to be heard around the tables where policy decisions are made, their voices must be heard and acknowledged in their daily lives.

We heard that people with intellectual disabilities are usually denied the opportunity to make decisions for two reasons: first, because of preconceived ideas, myths and prejudices about their "capacity" as well as sometimes their communication barriers, and second, because the network of people in their lives has been limited to immediate family or service providers. A number of questions and challenges were identified in implementing the right to decide: awareness, accessibility and understanding of Article 12; the capacity to act, that is the legal power to put decisions into practice; appropriate safeguards; communication; supported decision making in difficult situations; supports in the community; and, progressive realization, that is the move from current practices of substitute decision making where another person decides for the individual who has an intellectual disability to supported decision making.

Building on our earlier global reports – on ending poverty, inclusive education, and the right to live in the community - the findings in this report demonstrate that these other widely shared goals cannot be realized without recognizing, respecting, and supporting the equal right of people with intellectual disabilities to direct their own lives in the context of their families and communities.

For people with intellectual disabilities the realization of this fundamental right will require: attitudinal change; transformations in the way supports are provided by governments and communities; legislative reform; public policy transformation; and, the development and recognition in law of supported decision making networks and processes. Simply

eliminating all forms of substitute decision making without providing the necessary support for decision making would in effect deprive people with an intellectual disability of the power to make decisions.

Inclusion International makes the following recommendations and conclusions in advancing the right to decide:

- Invest in empowerment, self-advocacy and strengthening a collective voice
- Recognize our interdependence
- Families have a critical role to play in building the social connections necessary for supported decision making
- Family based organizations must play a leadership role as agents of change in community
- The right to decide cannot be achieved without community inclusion
- The right to decide is about more than the removal of guardianship and substitute decision making
- Legal reform must go hand in hand with strategies for building community supports and supports for decision making

This report is our contribution to advancing the right to decide in the real everyday lives of people with intellectual disabilities.

INTRODUCTION

Many years before the adoption of the Convention on the Rights of People with Disabilities (CRPD), Inclusion International (II) identified ***self-determination*** as one of the fundamental principles to guide our work. Self-determination refers to the concept that all people should have control over decisions that affect our lives. Generations of people with intellectual disabilities – wherever they live in the world – have been and continue to be denied the right to make decisions about where they live, whether they get married, have children, work, spend money, participate in political processes and about countless other day to day issues. With the adoption of Article 12 (Equal Recognition Before the Law) of the CRPD, governments, disabled persons organizations (DPOs), community organizations, judges and lawyers, families and self-advocates have all become increasingly aware of the importance of the right to make decisions.

Article 12 of the CRPD reflects a fundamental shift in thinking: it asserts that with support all people with intellectual disabilities are able to make decisions and have control in their lives. Support can take many forms: the provision of information in plain language, support to understand the options and consequences of decisions, extra time to make decisions, etc. For people with more significant support needs and/or difficulties in communicating, support could be a network of people who express and articulate decisions based on the will and intent of the individual. All of these options were what Inclusion International considered when we introduced the concept of supported decision making into the negotiations of the CRPD. Many other DPOs advocated that the CRPD simply had to assert the right of all individuals to make their own decisions and to eliminate any limitation on this right, such as guardianship where another person has the legal authority to make a decision for the individual concerned (substitute decision making). As we outline in this report, simply eliminating all forms of substitute decision making without providing the necessary support for decision making would in effect deprive people with an intellectual disability of the power to make decisions.

Inclusion International is the international organization that represents the voice of people with intellectual disabilities and their families. Our members are family based organizations in 115 countries around the world that work to promote the inclusion of people with intellectual disabilities in their communities. Our members identified ***legal capacity*** and the right to make decisions as one of four priority issues in the negotiations of the CRPD. It was clear to us that a human rights Convention that did not recognize the fundamental right to have control over the decisions that affect our lives would do nothing to advance the human rights of people with intellectual disabilities in any other area of life (the right to live in the community, the right to inclusive education, employment etc.)

As governments and communities struggle to understand the implications of implementing the "shift" that the Convention requires, we felt it was important for our voice to be heard as the *real experts.*

Defining Ourselves – People with Intellectual Disabilities and Our Families

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

First, we are people with intellectual disabilities. We are your neighbours and community members, your schoolmates, your co-workers and fellow citizens, and we are redefining how we all view the world. We are calling on others to recognize that people learn in different ways and make their own unique contributions to families and communities. We want to make our own decisions about our lives and want the support to do so. As self-advocates we no longer want to be referred to as 'mentally retarded', a term that has been used to devalue, segregate, and discriminate against people.

Self-advocates are challenging those who would define intellectual disability as simply slower or poor ways of remembering, thinking and communicating. We are calling on others to respect and understand differences and to treat

us with equality – just as we call on others to respect equally people defined by their religious, gender, ethno-racial-cultural, sexual orientation, and other differences.

This does not mean that people with intellectual disabilities do not want to develop. On the contrary, we want support to develop to our maximum potential and to pursue our unique life path. We want to thrive with other members of our families, communities, schools, and places of work.

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

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

Overview of the Report

The Report will present the perspective of people with intellectual disabilities and our families on the right to decide. We want to share our experiences of having – or not having – voice and control in our lives, of having decisions made about us for us, of being supported to make choices that reflect our will and preference, and the impact that these experiences have had in our daily lives in community and in securing all other rights.

Part I of the report sets a global context for the analysis, explores what exactly is the right to decide and explains the implications of Article 12 and the right to decide across all areas of a person's life, including health decisions, financial and property decisions, and personal life and community related decisions. In Chapter 1 we describe how we developed the

report and how participants from around the world contributed their stories, information, and knowledge through discussion groups, webinars, interviews, surveys, regional forums, and member submissions. Understanding the regional and cultural contexts of decision making is critical to advancing the right to decide in all communities. Chapter 2 describes how decision making is treated in law and how the right to decide includes decisions that are both formal and informal. In Chapter 3 we discuss the impact of the denial of the right to make decisions and how this denial can affect all areas of life, from sterilization to employment to voting.

In Part II we discuss the shift from substitute decision making to supported decision making and examine the importance of decision making for people with intellectual disabilities, their families, and the community organizations that provide support. Chapter 4 explores the idea and mechanisms of supported decision making and reviews existing supported decision making models. In Chapter 5 people with intellectual disabilities explain why the right to decide is important and what supports are needed to make daily decisions small and large. In Chapter 6 we consider why the right to decide is important for families, as well as highlight some of the challenges for families and their need for support in "making the shift" to supported decision making. Chapter 7 explores why the right to decide is important to the work of family based organizations and their role in advancing Article 12.

Part III begins the discussion on how we can move forward in our work as change agents. We examine the practical issues in implementing Article 12 and supported decision making in Chapter 8 and finally, in the Recommendations and Conclusion we explore the implications of our findings and point toward directions for the future for governments, families, self-advocates, and family based organizations in advancing the right to decide for persons with intellectual disabilities around the world.

This report is our contribution to advancing the right to decide in the real everyday lives of people with intellectual disabilities. It provides a roadmap for the realization of Article 12, which we believe is the heart of the Convention on the Rights of People with Disabilities.

PART I
THE GLOBAL CONTEXT

CHAPTER

1

About the Global Study

CHAPTER 1:

About the Global Study

Inclusion International uses global campaigns to provide a platform for the collective voice of people with intellectual disabilities and their families around the world on issues of importance to us. Since 2006, our members have raised our voices on Poverty[1] (2006), Inclusive Education[2] (2009), and Living and Being Included in the Community[3] (2012). Through these global campaigns and reports, people with intellectual disabilities and their families and friends have identified the exclusion, isolation and discrimination that is experienced. We have also identified innovative solutions, policy and legislative reforms, and strategies to promote inclusion.

A common message in each of our global campaigns has been the lack of voice and choice that people with intellectual disabilities and their families have. Without voice, our members told us, we are invisible and powerless. For people with intellectual disabilities, too often their voice is restricted because they are denied the right to control their own lives and make decisions about how they want to live their lives. Informally or formally they are deemed "incapable" or "incompetent"; they are penalized if they need support to make decisions.

"At 20 I was told, 'Shut up when the adults are talking, do not interrupt our conversation.' My cousin, who was the same age, was also there and they did not say anything to him. I felt a little bit discriminated. I did not like what they told me – we were family."
– Self-advocate, Spain

In our 2012 campaign on living and being included in the community, this was particularly clear. People with intellectual disabilities do not have control about where and with whom they live; landlords or other third parties would not allow them to sign rental agreements or utility contracts. People are institutionalized against their will or living in places not of their own choosing. In all regions of the world, people with intellectual disabilities say that having control in their lives is essential to being seen and treated equally in community.

Over the past few decades, the direct engagement of people with intellectual disabilities and the development of a self-advocacy movement have provided adults with intellectual disabilities a platform to express their priorities. Consistently, adults with intellectual disabilities have told us that having a voice and control in their lives is a top priority. Increasingly, we have heard that having the right to decide is important for securing all other rights. The development of the UN Convention on the Rights of Persons with Disabilities (CRPD) represented an opportunity to secure this right in international law. Over the past two years, Inclusion International's Right to Decide campaign looked at how we make this right real for people with intellectual disabilities.

A Different Approach

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.

We needed a methodology and process to capture the diversity of perspectives and the complexity of the issues. Having the right to decide means different things in different places. There are real and vast 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 "capability" with respect to decision making.

Building on what we heard 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 at a country level from our member organizations; and to engage groups of people at regional, national and community levels in interactive discussions.

In contrast to previous campaigns, Inclusion International found that beyond gathering information, more awareness and conversation was needed – simply not many people were talking about decision making. During the campaign Inclusion International developed a framework to support people around the world to begin a conversation on the Right to Decide with people who have an intellectual disability; family members; community organizations; service providers; and other stakeholders. Tools – including webinars, presentations, and discussion guides – were developed to create a space to provide information and help people understand the meaning and implications of Article 12 and the Right to Decide. The tools also helped to mobilize and engage communities around the issue of decision making and legal capacity.

"In my home my husband is the one that makes the decisions; he decides about the family holiday without asking any of our children, or me."
– Mother, Honduras

In developing these tools, we sought to:

- Share information to increase knowledge on issues related to the Right to Decide and Legal Capacity of people with intellectual disabilities.
- Provide expertise, materials, and presentations to support discussions on the issue around the globe.
- Support facilitators leading discussion groups on their knowledge and understanding on the Right to Decide and its implications for people with intellectual disabilities and their families in different parts of the world.

- Explore the challenges and opportunities for people with intellectual disabilities; their families; civil society organizations; service providers; governments; and, society to achieve the Right to Decide of people with intellectual disabilities.

Table 1: Tools Developed[4]

Background Materials	• The Right to Decide: Campaign Overview[5] • The Right to Decide: Why does it matter?[6] • The Right to Decide: Background Information on Decision Making[7]
Facilitation Guides	• The Right to Decide Discussion Groups: A Guide for Facilitators (available in English, Spanish, and Japanese)[8]
Webinars & Presentations	• Webinars for Beginners • The Work of Inclusion International • The Global Campaign: Background • The Right to Decide: Why is it Important? • What does it mean for people with an intellectual disability? • What does it mean for families? • The Right to Decide: An Everyday Reality • Substitute Decision Making vs. Supported Decision Making
Video Testimonials	• A Personal Perspective: Self-advocate • A Personal Perspective: Family Member
Reporting Guide	• The Right to Decide: Reporting on Organizational Activities[9]

How Information was Collected

Inclusion International collected and shared knowledge, information, stories, and experiences, building on the knowledge and findings from previous Global Campaigns and learning about The Right to Decide for people with intellectual disability through regional conferences and by hosting webinars.

Inclusion International also mapped global initiatives on Article 12 and reviewed the CRPD Committee's approach to, and interpretation of, Article 12. Analysis allowed inter-country commonalities to be discovered: for example, many organizations in the Americas, Australia, and Europe raised similar questions related to the Draft Response by the Committee of Experts[10]. These findings are documented in Chapter 8.

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

Discussion Groups – We asked organizations to host regional and national discussions with families and self-advocates, to hear their perspectives on the impact of the denial of the right to decide, and their first hand experiences of how people can and are supported to make decisions in their lives.

Country Surveys – Available online and in hard copy, the survey was designed to collect information on initiatives around decision making that are happening at the national level and to help provide a snap shot of key issues, challenges and successes in promoting self-determination.[11]

Sharing stories – We asked people with intellectual disabilities and their families to share their personal stories with us. Through the submission of oral and written stories, pictures, and videos, we learned of innovative practices that assist people to make decisions for themselves and to have control in their lives.

Regional Forums – Regional meetings provided an opportunity to hear from families and people with intellectual disabilities about issues that were specific to each region of the world.

Organizational Reports – Member organizations reported on the work they are doing with families and self-advocates at the community level to ensure that people with intellectual

"Thanks for such an important contribution to this work and the effort to share enriching experiences; a work that cannot be postponed."
– Webinar participant

disabilities are directing and controlling their own lives with the supports they need.

Case Studies – We asked members to submit case studies on supported decision making as well as national reviews of current legislation reforms and the implications for people with intellectual disability.

What We Heard

In Mexico, decision making for people with intellectual disabilities is an emerging topic of discussion. The Confederación Mexicana de Organizaciones en Favor de la Persona con Discapacidad Intelectual (CONFE) created a discussion strategy using the Right to Decide Campaign tools, resulting in 13 associations hosting over 65 focus groups of families, self-advocates, teachers, and service providers. Facilitated discussions and CONFE's plain language and picture participation tools helped to keep the conversation focused.

Discussions were centered around five statements regarding decision making and participants would use text and picture cards to identify how they felt about each statement. Afterward, the facilitator would ask participants to explain why they chose that answer. Outcomes from the discussions provided information for an analysis report, which is being used by CONFE to enhance their work.

The Zanzibar Association for People with Developmental Disabilities (ZAPDD) told us that people with intellectual disabilities are systematically denied the right to self-determination in Africa; however, there have been some recent moves to models of support that enable supported decision making. The organization hosted training workshops for families and youth with intellectual disabilities to equip them with necessary knowledge and skills around decision making. Muhammed Kesi Sadik, a self-advocate attending the workshop, shared his story: *"I am 20 years old and single. I am a livestock keeper. I started to keep one cow, which I had been given by my mother's sister, and now I have four cows. I make money by selling milk. In addition, I am employed in a vegetable farm. My role here is watering the vegetables. My money is kept by my mother and whenever I want to spend it, I have to ask her. She respects my decision."*

"Accept your sons and daughters and believe in their capacities. Deal with them as you would their brothers and sisters. Don't deny their rights."
– Parent, Lebanon

In Bulgaria, the Bulgarian Association for Persons with Intellectual Disabilities (BAPID) shared their experiences, lessons learned, and personal stories from participants regarding their pilot project *'Empowering people with intellectual disabilities – Next Steps'*. Through this work, BAPID is establishing a supported decision making model, implementing supported decision making as an alternative to guardianship for persons with intellectual disabilities that are currently under guardianship or at risk to be placed under guardianship. *"We found in implementing supported decision making that it is appropriate to establish the main areas of human life for each participant – at home, at school, at work, in leisure time. To create a personal history: important life events; changes; health issues; good experiences; sad memories; relationships. Who is the one that the person spends the most time with during the day? Who are the beloved people of this person? Who does the person rarely see? In preparing individual profiles, we developed a sample questionnaire in easy to read text and additional materials that*

we continuously improved based on the facilitators' feedback. The success depends on acknowledging the person and the commitment of all participants."

The Lebanese Association for Self Advocates (LASA) hosted discussion groups that included parents of self-advocates as well as their children: *"Parents who attended said that they didn't believe in their children's abilities. They have made decisions on their own because they assumed their children would not be able to know better. After their children attended the training, parents realized they have underestimated their children's abilities. The parents are amazed by the growth their children have shown. They have finally discovered their child's true self. They have found out what how much they can fight to make their children's lives easier, more productive, and more valuable."*

When discussions started with a group of students in a school for persons with disabilities in Myanmar, it was identified that the students needed an opportunity to practice decision making and independence away from their parental homes, where many parents admitted they were doing "everything" for their sons and daughters. A weekend sleepover at the school was suggested to facilitate the students making simple daily living choices on their own, including which groceries to buy and what to cook for meals. After the weekend, students took pride in their skills: *"I went shopping at the Supermarket. I washed the dishes, too." "I peeled an onion, chopped garlic, and took a shower by myself." "My brother told me not to stay overnight, but it was so nice to stay with friends."*

Table 2: Sources of Information

Group Discussions at the country level	Argentina; Bolivia; Cambodia; Chile; Colombia; Costa Rica; El Salvador; Guatemala; Honduras; India; Japan; Lebanon; Malawi; Myanmar; Mexico; New Zealand; Nicaragua; Paraguay; People First of the United Kingdom; Peru; Spain; United States; Zanzibar
Regional Meetings	Self-Advocate conference hosted by Inclusion Europe in Croatia: Belgium; Bosnia and Herzegovina; Canada, Croatia; Czech Republic; Finland; France; Hungary; Lebanon; Macedonia; Republic of the former Yugoslav Republic of Moldova; Norway; Poland; Portugal; Romania; Serbia; Slovenia; United Kingdom; United States Hosted by Inclusion Africa in Kenya: Kenya; Zimbabwe; Ethiopia; South Africa; Namibia; Uganda; Zanzibar; Canada; Lesotho; United States; Ghana; Mauritius; Benin; Malawi Hosted by Inclusion MENA in the United Arab Emirates: Bahreïn; Dubai; Egypt; Iraq; Jordan; Kuwait; Lebanon; Libya; Mauritania; Palestine; Sharjah; Tunisia; Yemen
Supported Decision Making Initiative Contributions from Member Organizations	Barcelona; Bulgaria; Hungary; India (2); Spain; Taiwan, United States (2)
Personal Stories	Argentina; Bulgaria; Cambodia; Colombia; Egypt; Hungary; Japan; Mexico; New Zealand; Peru; Spain
Structured Interviews with Member Organizations[12]	National Association for the Habilitation of children and adults with intellectual disability (AKIM), Israel Alberta Association for Community Living Community Living Ontario Confederación Mexicana de Organizaciones en Favor de la Persona con Discapacidad Intelectual (CONFE) Mexico Intellectually Handicapped Children (IHC) New Zealand Inclusion British Columbia Lebenshilfe Germany MENCAP United Kingdom National Association of State Directors of Developmental Disability Services USA (NASDDDS), United States New Brunswick Association for Community Living The Arc USA

Webinars	Over 100 individual participants in from: Argentina; Belgium; Bolivia; Canada; Chezk Republic; Colombia; Ecuador; Mexico; Nicaragua; Panama; Peru; Portugal; Spain; Switzerland
Surveys	Association for Persons with Intellectual Disabilities, Spain (AFANIAS) AKIM, Israel National Agency for Evaluation and quality of institutions and social and medico-social (ANESM), France Association for Help to People With Intellectual Disability in Slovak Republic Centro de Investigación para el Desarrollo Socioeconómico (CEINDES) CONFE Mexico Association d'Entraide Médico-Sociale, Democratic Republic of Congo (AEMS-ASBL) Chosen Power (People First Hong Kong) Excellence in Action Federation of Associations in favor of Persons with Intellectual Disabilities located by the four Galician provinces (FADEMGA FEAPS GALICIA) Fundación de Asistencia Psicopedagógica para Niñas Adolescentes y Adultos con Retardo Mental (FASINARM) Spanish Confederation of Organizations for Persons with Intellectual Disability (FEAPS) Federación Ecuatoriana Pro Atención a la Persona con Discapacidad Intelectual, Autismo, Parálisis Cerebral y Síndrome de Down (FEPAPDEM) Federación Nacional de Padres de personas con Discapacidad de Honduras Fundación Amanecer Fundown Caribe IHC New Zealand Inclusion Japan Kenya Association for the Intellectually Handicapped MUSKAAN, India Parents' Association for Persons with Intellectual Disability, Taiwan (PAPID) Parents Association for empowering persons with intellectual disability

The Right to Decide has been identified as the heart of the UN Convention on the Rights of Persons with Disability and we increasingly have heard that having the right to decide is important for securing all other rights. In order for the voices of persons with intellectual disabilities to be heard around the tables where policy decisions are made, their voices must be heard and acknowledged in their daily lives.

People with intellectual disabilities and their families and friends told us they engaged in this dialogue because it is critically important for persons with intellectual disabilities to have control in their own lives. Over 600 self-advocates, family members, disability advocates, and professionals participated in discussions motivated by our Global Campaign on the Right to Decide. Additionally, we heard from more than 80 organizations from more than 40 countries worldwide – with stories continuing to arrive as in many places the discussion is only just beginning.

CHAPTER

2

The Right to Decide

CHAPTER 2:

The Right to Decide

People with intellectual disabilities, wherever they live in the world, continue to be isolated, excluded and often vulnerable in their communities. The isolation and marginalization means that people do not have the natural supports and relationships that would enable them to be supported to make decisions and have control in their lives. The right to decide is about having control and choice in our lives and having support to make choices that reflect our will and preference. To exercise the right to have control over one's life, people with intellectual disabilities have been subjected to questions about whether they are "human" as well as attitudes and misconceptions of their abilities (capacities). By rejecting these long-standing assumptions, Article 12 of the UN Convention on the Rights of Persons with Disabilities (CRPD) marks a fundamental shift in the social, legal, and political recognition of people with disabilities as well as how we make choices in our lives.

The denial of such rights is often cloaked in language of "protection" and best interests. It may be assumed that a person with an intellectual disability cannot make or express choices. But underlying much of the prejudice against persons with intellectual disabilities is far more than a paternalistic attitude – it is a failure to recognize their humanity and personhood.

Some people have seen the challenge of implementing Article 12 of the CRPD as simply the need to change laws to eliminate substitute decision making and provide supports to people to make or express their decisions. But more than that, Article 12 calls on society to be open to seeing the humanity in persons with significant disabilities, to find ways to understand their wishes and dreams, and to make them come true. Discovering our common humanity contributes to building a better society for all.

The experience of people with intellectual disabilities, in their everyday interactions in the community, too often reflects this dehumanization by society. We heard stories from people in every part of the world about how they were treated as if they were not "people".

"When L passed away the doctor came to certify her death; the doctor took one look at her then looked at my mother and asked '...mongoloid?' As if losing my precious sister wasn't bad enough a member of the NHS then insulted her..." – Sister[1]

The most destructive view is expressed by the Princeton University professor Peter Singer who actively advocates the killing of babies and others with significant disabilities, claiming that "killing a disabled infant is not morally equivalent to killing a person." Singer argues that membership in the species "homo sapiens" doesn't entitle anyone to better or worse treatment than a member of another species with a similar mental level.

The complete opposite view is articulated by Jean Vanier, founder of the l'Arche movement, who not only recognizes the equal value and humanity of people with significant disabilities, but goes further in his witnessing of how such individuals can help those who don't have disabilities to discover their own humanity. In his book, *Becoming Human,* he recounts many incidents of people who don't have a disability discovering their own humanity though developing relationships with people who have significant disabilities. These stories mirror the experience of members of Inclusion International who have witnessed the contributions that people with intellectual disabilities have made to classrooms, to workplaces, to communities.

Recognition by the law

The way in which a society recognizes or denies the personhood or humanity of a person with an intellectual disability is reflected in the way in which decision making is treated in law.

The legal term for being able to make decisions is "legal capacity". All countries have laws and practices that relate to legal capacity. These laws apply to all people and have been used to determine who can make decisions and what kinds of decisions they can make. These laws can be used to take away the "legal capacity" of people with intellectual disabilities. We know that many countries have laws that prevent people with intellectual disabilities from making decisions because they are perceived by others to be "incompetent" or "incapable".

"For someone to be born without seemingly a capacity to be fully human is seen as something horrible, and therefore these people are hidden away. People don't realize that the secret of being human is the capacity to understand, but more than that, it is the capacity to love. To be human is to bring the head and the heart together. Individuals with severe intellectual disability have the extraordinary capacity to enter into relationships, to trust, and to love, and that is maybe the great secret of the human being. It is love that will unify the human family. We need to learn to love each other, not just to have a good head where we're proving that we're better than others. The fundamental thing for human beings is to accept ourselves as we are, with our strengths and also with our weaknesses. And weakness is not something bad. It implies: 'I need your help.' That brings us together, because I'm not able to do everything myself. I'm calling out: 'Can you help me?' Fundamentally, we human beings, what we need most deeply is to know that we are loved and accepted. All of us have to go through this tension between showing we are capable and accepting ourselves with our weaknesses."
(Jean Vanier, *Becoming Human*)

Article 12 UN CRPD

Article 12 of the UN Convention on the Rights of Persons with Disabilities (CRPD) focuses on legal capacity. It guarantees that all people with disabilities "enjoy legal capacity on an equal basis with others in all aspects of life." This means that ALL people with disabilities have the right to make decisions.

Article 12 also recognizes that some people may need support to make decisions (to exercise their legal capacity) and requires that governments "take appropriate measures to provide access... to the support..." a person needs to make decisions. This means that no one should be denied the right to decide just because they need help to make decisions.

Article 12 CRPD:

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.

While Article 12 of the CRPD articulates the right to be recognized before the law, this right is recognized in international human rights law more generally. *The Universal Declaration of Human Rights, the International Covenant on Civil and Political Rights and the Convention on the Rights of Persons with Disabilities each specify that the right to equal recognition before the law is operative "everywhere." In other words, there are no circumstances permissible under international human rights law in which a person may be deprived of the right to recognition as a person before the law, or in which this right may be limited. This is reinforced by article 4, paragraph 2, of the International Covenant on Civil and Political Rights, which states that no derogation from this right is permissible even in times of public emergency. Although an equivalent prohibition on derogation from the right to equal recognition before the law is not specified in the Convention on the Rights of Persons with Disabilities, the provision in the International Covenant covers such protection by virtue of article 4, paragraph 4, of the Convention, which states that the provisions of the Convention on the Rights of Persons with Disabilities do not derogate from existing international law.*

The right to equality before the law is also reflected in other core international and regional human rights treaties. Article 15 of the Convention on the Elimination of All Forms of Discrimination against Women guarantees women's equality before the law and requires the recognition of women's legal capacity on an equal basis with men, including with regard to concluding contracts, administering property and exercising their rights in the justice system. Article 3 of

the African Charter on Human and Peoples' Rights provides for the right of every person to be equal before the law and to enjoy equal protection of the law. Article 3 of the American Convention on Human Rights enshrines the right to juridical personality and the right of every person to recognition as a person before the law.

[General Comment on Article 12 – UN CRPD Committee of Experts]

Types of Decisions

Having the *right to decide* means being able to make decisions in all aspects of our lives:

- **Personal life decisions** – the day to day decisions like personal care, what we wear, where we shop, what we eat, and what we do for fun. The right to make these day to day decisions is also very important to people with intellectual disabilities. Also the more substantive personal decisions like having a boyfriend or girlfriend, getting married, taking post secondary schooling or training, where we want to live or the kind of work that we might like to do.

- **Health decisions** – People want to be able to understand and learn more about their health issues and proposed medical interventions, so that we can make informed decisions around health care. We may also have to give consent for certain medical procedures.

- **Financial and property decisions** – It is important that people can decide where they want to live and who they want to live with. Everyone wants to be able to have control over their own money and be the one who decides how to spend it: having access to pensions, inheritances and managing other

financial affairs, being able to sign contracts such as leases or employment contracts. We may want to apply for a credit card, or purchase bigger items like cell phones, a computer, or a new television.

In each of these areas of life there are decisions which are made informally and those which require some formal or legal mechanisms.

Table 3: Informal and Formal Decision Making

Areas of Life:	Informal	Formal/Legal
Health Decisions	Exercise; diet; hygiene; smoking; birth control; etc.	Medical procedures; sterilization; consent to treatment; etc.
Financial/Property Decisions	Spending money; budgeting	Bank accounts; wills and estates; investments; credit
Personal Life Decisions	Where to live; relationships; employment; education; civic participation	Housing (rental or purchased); employment contracts; voting

Legal Decisions

In legal decisions the traditional test of a person's "capacity" or decision making "abilities" are:

- Do they understand information about the decision?
- Can they understand potential consequences of the decision?
- Can they communicate their decision?

Often for people with intellectual disabilities, these tests result in courts, banks, doctors, employers or landlords denying their legal capacity. This is the old formula of legal capacity, one that equates the right to decide with certain mental and communication capacities.

Article 12 of the Convention offers a new formula for legal capacity. It recognizes that each person has unique abilities and capacities, which for some is simply the ability to be known as a full person by others who know and love them. People may have a significant or 'profound' disability but their presence and being is valued and understood by their family and friends. Others may clearly express what they like or don't like, even though they may not understand and appreciate all the information and consequences that might come with different choices. Their wishes are clearly understood by those around them.

In the new formula for legal capacity, Article 12 recognizes that when you add supports to a person's unique abilities – whether the support is plain language assistance from a doctor, or an

In the Czech Republic, Inclusion Czech Republic and Quality in Practice (QUIP) are working together to pilot a method to build circles of support and provide support in decision making for people with intellectual disabilities living with their families or in institutions. A new legislation on legal capacity in the new civil code and its related Acts entered into force in January 2014[2] and abolished plenary guardianship. While partial guardianship is still included in the new legislation, new models – including representation by a household member and contract for support - have been included. However, no efforts have been made to prepare for the introduction of these new models; to change public and family perception; or, to prepare professionals, judges, families or people with intellectual disabilities for these new models as described in the law. Due to this gap in legislation and practice, Inclusion Czech Republic and QUIP have decided to test methodologies for the use of these new mechanisms, in line with the concepts of Article 12. In addition, through litigation, the organizations pushed for strategic decisions of courts on all levels (local, regional, supreme) to restore full legal capacity to people with intellectual disabilities, creating legal precedents for the future practice of courts, guardians, families, etc. Although precedents are not obligatory in the Czech legal system, lower courts should respect decisions of Constitutional and Highest Court, and decisions of any court can be a source of inspiration and empowerment for others.

independent advocate, or a person's support network which helps represent that person to the world – you can produce legally valid decisions.

While *legal capacity* refers specifically to formal or legal decision making, the *right to decide* includes decisions in all areas of life, both formal and informal.

Our global consultations with self-advocates and families makes it very clear that without recognition by families, communities and societies of a person's right to decide in all aspects of life, tackling legal mechanisms that deny legal capacity will not achieve the "paradigm shift" promised by the CRPD.

The right to decide for the purposes of our report refers to the way in which decisions are made from everyday choices like what to wear and eat to more complex decisions about money and medical issues including both informal and formal (legal) decisions.

CHAPTER

3

Implications of Article 12 Across All Areas of Life

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Implications of Article 12 Across All Areas of Life

When people with intellectual disabilities and their families were asked to discuss the impact of the denial of the right to make decisions on their lives, the response was to talk about restrictions in the ways day to day decisions are made about where to live; support needs; and very personal choices. Often the limited control that people have in their lives is a result not of formal substitute decision making but rather of policy and legislation (voting and marriage laws, financial and medical policies etc.) or social attitudes of service providers, family members and others in the community.

Since the Convention on the Rights of Persons with Disabilities (CRPD) came into force in May 2008, there has been significant discussion among governments, academics and policy makers regarding Article 12 and the right to legal capacity. Much of this discussion has focused on addressing the formal legal structures that remove a person's power to make decisions about their own lives. Legal mechanisms – such as guardianship, "interdiction", and other forms of substitute decision making – formally remove a person's right to make decisions and give that right to a third party. (We discuss the shift from substitute to supported decision making in Chapter 4). Because of this globally entrenched denial of the right

> State parties must holistically examine all areas of law to ensure that the right of persons with disabilities to legal capacity is not restricted on an unequal basis with others. Historically, persons with disabilities have been denied their right to legal capacity in many areas in a discriminatory manner under substitute decision making regimes such as guardianship, conservatorship and mental health laws that permit forced treatment. These practices must be abolished in order to ensure that full legal capacity is restored to persons with disabilities on an equal basis with others.
>
> (CRPD Committee of Experts, *General Comment on Article 12*)

to legal capacity, advocates around the world have emphasized the need for legal reforms to eliminate guardianship and substitute decision making laws, as well as other reforms related to mental capacity and mental health laws. While these discussions are certainly necessary, they have not addressed how people with intellectual disabilities are denied the right to make decisions whether or not they are under formal substitute decision making, nor have they included the ways in which the right to decide impacts all areas of decision making in a person's daily life.

The areas of life that are affected by the right to decide can generally be placed into three categories:

1) Health decisions;
2) Financial and property decisions; and,
3) Personal life and community related decisions.

These areas of life are not completely separate of course: there is often overlap between the different categories. For example,

decisions relating to the right to choose where to live can be identified as both a property decision and a personal life decision. Health care decisions include sexual reproduction decisions, which are inherently linked to personal decisions regarding family life. Still, the point remains that the right to decide affects all areas of a person's life.

Health Decisions

People with intellectual disabilities are often denied the basic right to have control over what happens to their bodies. Health care decisions can include informal decisions such as nutrition, physical activity, hygiene, smoking and alcohol use, and birth control, as well as formal decisions such as whether to undergo medical procedures and consenting to medical treatment.

Persons with intellectual disabilities are often excluded from participation in health care education and programs, including sexual and reproductive health programs. When they are included in these programs, the information is often not clear or easy to understand. Therefore, when it comes to making health care decisions, people with intellectual disabilities often lack adequate information to be able to make an informed decision. Choices about nutrition, exercise, and other health and wellness concerns are often made by service providers or family members with the good intentions of augmenting a person's health.

In a discussion with United Kingdom People First members, one participant indicated that when it comes to receiving medical treatment *"it is not explained why things are happening."* Another participant stated it would be helpful if easy to read information about health issues was available, and yet another participant spoke of the need for good information about how to achieve a healthy lifestyle.

A study carried out by Mental Disability Advocacy Center (MDAC) in Kenya[1] found that many people with intellectual disabilities were simply *"not being told about health care procedures and not being invited to consent to treatment decisions, which were often made on their behalf by relatives or carers."*

Doctors and medical professionals also may discount the person's opinions, concerns and choices. In Ghana, a report produced by Inclusion Ghana[2] found significant differences in the beliefs held by health care professionals concerning whether or not people with intellectual disabilities could adequately express what they wanted regarding treatment. Though the majority of health care professionals interviewed believed persons with intellectual disabilities should be allowed to express their choices, it was not because they thought their opinion was credible or valuable. Rather, the health care professionals interviewed thought it would be rude not to allow them to express themselves: *"We should allow them to talk even if it does not make sense, so that persons with intellectual disabilities do not feel left out."*

Health care professionals in Ghana who disagreed with allowing persons with intellectual disabilities to choose their own medical treatment named a number of reasons, including:

- *"I think since their brain is not functioning or they have a low IQ they cannot be allowed to make any decisions."*
- *"They lack a lot of knowledge about everyday life."*
- *"No mental patient can tell you what is wrong with them."*
- *"I think they have nothing important to tell us."*

The Right to Decide: Sterilization

The sterilization of persons with intellectual disabilities, primarily but not limited to females with intellectual disabilities, has historically been performed without regard for the person's decision making rights, reproduction rights, and right to have control over their own body. Sterilization has often been performed with the – false, however sincere – belief that it will prevent expressions of sexuality, decrease the chances of sexual exploitation, or reduce the likelihood of acquiring sexually transmitted diseases.

"I decided I had to sterilize her…and I did it for her safety." – Parent, Mexico

"In the institution where my daughter goes [a 3 year old girl], I was told to place her under guardianship so we can have her sterilized, and told this is better for her because she can be abused and girls have the added risk of becoming pregnant in the future." – Parent, Colombia

In direct conflict to both Article 12 and Article 23 1(c) of the CRPD, laws in some countries have upheld decisions made by families and health professionals to sterilize persons with disabilities. In 2013 in Colombia, the Constitutional court approved the sterilization of minors with intellectual disabilities with parental consent, following the challenge of a law[3] that prohibits surgical sterilization for contraceptive purposes on all minors. The court went on to state that *"when it comes to minors with disabilities for whom there is a proven impossibility to give consent in the future to undergo sterilization procedures, the parents, or in any case, the legal guardian, must request judicial authorization to allow surgical sterilization.[4]"*

In Kenya, a young woman in her 20s who had been sterilized without her consent shared her story: *"I will tell you something, you see here [lifts up her blouse and reveals a scar on her stomach], here I had an operation. This is contraception, all of us have been done like this. We cannot have children. Nobody asked me if I wanted it. They should have asked me, because I love children. I feel bad, but what can I do now?"*

Sterilization, without informed consent, removes an individual's right to choose to have children of his or her own.

"I wanted to sterilize my daughter but what helped me decide was that one of her friends was sterilized when she was a girl. When she later had a partner and wanted to have a child, it was very painful for her to learn that she had been sterilized. That is why I decided not to sterilize my daughter – because as people with disabilities, they also have the ability to have children and be responsible." – Parent, Mexico

Supreme Court of Canada Decision on Sterilization (E. (Mrs.) v. Eve, [1986] 2 S.C.R. 388)

Shortly after our committee of self-advocates was created, the Canadian Association for Community Living (CACL) was approached to see if we wanted to intervene in the case of a young woman known as Eve. Eve's mother had asked if she had the legal right to authorize a non-therapeutic sterilization for her daughter, and the case had made its way to the Supreme Court of Canada, where third parties which have an interest in the results of the case are able to present a position.

The debate about whether CACL should intervene produced a storm around our board table. Many parents on the board focused on their ability to know what was in the best interests of their sons and daughters. However, the self-advocates took the position that persons who were able to give informed consent to sterilization should be allowed to do so, but that no one else should be given that power in situations where informed consent could not be given.

When the Board could not achieve consensus, they agreed to support the self-advocates to hire their own lawyers, and the Inclusion Advisory Committee sought intervener status on their own. In a surprise decision, the Supreme Court accepted in full the self-advocates' argument and decided that for non-therapeutic procedures, if an individual cannot give informed consent, then no third party can be authorized to do so.

The decision was a turning point for CACL. For the first time, it pitted parents against their own sons and daughters. The issue was human rights, and the highest court in the land said that parents did not have the right to make decisions for their adult children.

The Eve case was the beginning. The victory by self-advocates gave them a new confidence to speak out on their own, and gave many members of the association the humility to listen. The next message was about the name of our association, which then was still known as the Canadian Association for the Mentally Retarded. The message of self-advocates was clear. Labels hurt. Labels lead to discrimination. The problems in achieving inclusion of people with intellectual disabilities in their communities had less to do with the nature of the disability and more to do with the barriers that excluded them.

Diane Richler

Financial and Property Decisions

People with intellectual disabilities are frequently denied the right to control their personal finances and make property decisions. Making financial and property decisions includes both informal decisions such as how to spend money and how to budget, and more formal decisions and transactions such as opening a bank account; the purchase or inheritance of property; will and estate planning; and, access to credit facilities such as getting a loan, opening a bank account, or making financial investments.

There is often no formal court process involved in denying an individual their right to decide regarding financial decisions, as illustrated by the following stories from self-advocates in Zanzibar:

"My name is Hafidhi Seif Suleiman. I am 21 years old. I am a shop keeper, selling kitchen and household effects. The idea of opening the shop came from my family and myself when I went on a self-advocate trip to the United States. I saved enough money and with additional contributions from my family I managed to open the shop. My father is the one who looks after the shop and I work with him to give products to the customers. The money is kept by my father and whatever I want to spend it on, I have to ask him."

"My name is Maryam Bakari Ali. I am a baby sitter. The money which I receive from my job is kept by my mother and whenever I want to spend something I have to ask her."

In many countries, people with intellectual disabilities do not inherit land in practice and have no power to make decisions concerning land that is legally theirs. Often, even if a person does inherit land through a will, a family member will "look after" the asset on behalf of the individual, sometimes with grave consequences: *"After my mother gave birth to my brother who had Down Syndrome, she ran away. My father remarried and before his death, he allocated a piece of land to my brother and instructed the family to look after the land on my brother's behalf and ensure that he does not suffer. After my father's death, my stepmother chased my brother away and sold his piece of land. This action could not be challenged and my brother lost his property in that way."* – Sibling, Kenya

The Right to Decide: Employment

Persons with intellectual disabilities are often prevented from seeking employment and denied the right to make decisions about where they will work and the skills they have to offer.

"I wanted a paid job and my family stopped me from getting one because the job would not pay as much as my benefits. If I lost some of my benefits it would be hard for me to claim the lost benefits back."
– Self-Advocate, United Kingdom

In Japan, we heard from self-advocates experiencing barriers to employment that include 'falling through the cracks' in government rules and regulations for persons with intellectual disabilities: *"I can't get support that the government offers because I became disabled after I was born and my IQ is higher than the criteria for intellectual disability. When I go out with my peers, they get discounts on public transportation; I don't because I don't have the identification booklet for the intellectually disabled. When I went to the public job office, I was told that I should find work at job placement office for the disabled. So, I went there but they told me they can't do anything for me because I don't have the identification booklet."*
– Self-advocate, Japan

Participants in a discussion in Kenya shared that it is very difficult both to get employment and to keep it, due to prevailing stereotypes that people with intellectual disabilities cannot be trusted. A large number of Kenyans with intellectual disabilities do not go to school and therefore are only considered for manual work. Ali, a participant, shared that his mother did not consult him when she looked for a job for him and placed him in a sheltered workshop for people with intellectual disabilities, something he did not want to do. Ndungu's story is similar. He shares: *"My grandma had gone to ask them because she had heard they needed a watchman. She did not consult me, she just told me we needed to go there to get a job and that would help in getting money to buy food. She is the one who knows best, so if she tells me something, I have to obey her. It was okay, only the nights were very cold, and at times no matter how I covered myself, it was too, too cold. But now I am laid off, because they said I have a problem with my head. I don't know what that means. I felt very bad because that is the money I was taking home to feed my brother and my grandmother, so when I was fired, that meant that we had to struggle for food, or go borrow from my uncles."*

Personal Life and Community Related Decisions

The final area of life that is impacted by the right to decide is the area of personal life and community related decisions. This includes informal decisions such as where and with whom to live, who to date or marry, where to work, what to study in school, and what to do as leisure and recreation activities. It also includes formal decisions such as signing a lease for an apartment, utility contracts, purchasing a house, signing employment contracts and participating in civic activities such as voting, standing for election to public office, and being included in a census.

Families often decide where and with whom persons with an intellectual disability should live. Decisions about living in an institution, as opposed to living in the community, are often made on the individual's behalf.

"We don't have a choice. We don't have money. The choice is either to keep them at home or send them to institutions."
– Parent, Lebanon

People with intellectual disabilities are often prevented from getting married and/or having children by their families, carers, health care professionals or social service workers. While disability does not legally prevent someone from getting married, in practice, the high levels of stigma make it difficult for someone who has an intellectual disability to get married.

A 22-year-old woman with an intellectual disability told us that she would like to get married and have a family like other people, but her relatives told her that she cannot take vows at the church or at the District Commissioner's Office. A mother of a young man with an intellectual disability told us about how her son loved a young woman who also has an intellectual disability and wanted to marry her, but the woman's parents were reluctant to allow the marriage.

"I have told my daughter, do not let him touch you. You cannot have a family because you cannot work." – Parent, Spain

In the United Kingdom, we heard that families and carers of persons with intellectual disabilities with more significant support needs or who do not communicate in traditional ways – for example, persons who may use gestures or certain behaviours to communicate – have difficulty supporting their family member's decision making for even the 'simplest' of personal decisions, such as whether to have coffee or tea in the morning. As persons with intellectual disabilities are supported to express their decisions through new communication techniques – and families and carers are supported to understand these techniques – these decisions are becoming realized for the first time, building the foundation for future supported decision making in other areas of life.

The Right to Decide: Voting & Political Participation

Persons with intellectual disabilities are often prevented from voting, standing for election to public office, and civic participation.

In Kenya, people with intellectual disabilities are only able to exercise their right to political participation if certain conditions are met:

- The person must have an interest in politics and be supported either by family or an NGO;
- The person must not be perceived by the polling station officer to be of "unsound mind". (The meaning of this term has not been clearly set out).
- The person must be able to access the polling station physically and either be able to write on his/her own or have someone assist them to do so in casting the ballot.

One workshop participant shared his experience with voting capability tests, stating that *"we have to prove ourselves worthy of the right."*

In Europe, a 2011 proposal by the Venice Commission on electoral law[5] states that *"universal suffrage is a fundamental principle of the European Electoral Heritage. People with disabilities may not be discriminated against in this regard. Nevertheless, a court, in an individual decision, may consider that the lack of proper judgment of a disabled person may prevent him or her from exercising his or her right to vote or to stand for elections."* Member organizations in Europe continue to push for the abolishment of voting tests, asking that tests of voting capability not be enforced, as they would not be imposed upon any other citizen and clearly discriminate against people with disabilities.[6]

Attaching conditions to the right to vote and enforcing voting tests are not in line with Article 12 nor Article 29 of the CRPD, the latter of which states that *"persons with disabilities regardless of their impairment, legal status or place of residence have the right to vote and participate in public life on an equal basis with others."*

The right to vote and to political participation is currently denied to people with intellectual disabilities in many countries around the world. Stereotypes about the ability of people with intellectual disabilities to make decisions are huge barriers to participating in elections for many citizens with intellectual disabilities who are prevented from exercising their right to vote.

In most countries around the world, much of the discussion regarding Article 12 of the CRPD has focused on addressing the legal processes that formally remove a person's power to make decisions about their own lives; however, the denial of the right to decide pervades all aspects of life. There are real barriers in legislation and policy which prevent people from having a say about how they live their lives (voting and marriage laws etc.) and there are significant cultural and attitudinal barriers to the full realization of the right to decide. Strategies for addressing these barriers must include broad review of family law; medical consent; contract law; financial regulations; access to justice; political participation, etc. Still, reform of legislation and policy alone will not change the informal ways in which people are denied the right to have control and voice in their own lives. Community support, awareness raising, the empowerment of self-advocates, and other strategies for enabling people to have the right to decide go hand in hand with strategies for legislative reforms.

Table 4: Implications of the CRPD on All Aspects of Decision Making

Area of life:	CRPD article:	People with Intellectual Disabilities are often denied the right to make decisions in areas of their life that impact other rights:	Implications of Article 12 for governments:
Health	15 Freedom from torture or cruel, inhuman and degrading treatment	• Medical procedures and treatment are given without informed consent, e.g. sterilization. • Persons with intellectual disabilities have been subjected to scientific experimentation.	• State must ensure that support is given to guarantee informed consent; Third parties must be held accountable for performing procedures without informed consent.
	25 Health	• Persons with intellectual disabilities are often excluded from participation in health care education and programs, e.g. sexual and reproductive health programs. • Doctors and medical professionals discount the person's opinions, concerns and choices. • Families are often in the position of making medical decisions for the person. • Choices about nutrition, exercise, and other health and wellness concerns are made by service providers or family members.	• Health care education, programs, and services must be made accessible and support must be provided for the participation of all. • Health care workers require training to effectively communicate with people with intellectual disabilities and their supporters. • Support to families is required to develop supported decision making networks for their family member. • Support to self-advocates, families, and service providers is required to enhance decision making knowledge and skill development.

Area of life:	CRPD article:	People with Intellectual Disabilities are often denied the right to make decisions in areas of their life that impact other rights:	Implications of Article 12 for governments:
Financial and Property	12(5) Equal recognition before the law	• Decisions about buying or selling property, such as land, are often made on the individual's behalf by family members or carers. • Persons with intellectual disabilities often do not inherit property on their own. Instead, someone else is given control of the inherited property. In cases where a person does inherit property, they often cannot choose who will inherit their property. • Persons with intellectual disabilities are often unable to open a bank account, obtain a bank loan or obtain a mortgage. • Permission to spend their own money often has to be obtained from relatives and carers who control the individual's finances.	• Persons with intellectual disabilities must be recognized by all parties involved as the primary decision-maker, and enabled to make decisions either directly or through supported decision making mechanisms about their property and finances. • Laws and legal processes must ensure the equal right of persons with intellectual disabilities to own or inherit property, to control their own financial affairs, and to access bank loans, mortgages and other forms of financial credit. • Governments must provide access to supports required by a person to understand and exercise their legal rights. • Training is required to ensure professionals, e.g. banks, lenders, lawyers, and brokers, understand and respect the equal rights of persons with intellectual disabilities.
	28 Adequate standard of living and social protection	• When families have limited resources, the member with a disability may be denied adequate food and personal belongings.	• Government support programs must recognize the extra costs to a family of a person with a disability and provide financial support. • Support to families is required to develop supported decision making networks for their family member. • Information about available and alternative housing options must be given in a manner accessible to the person.

Area of life:	CRPD article:	People with Intellectual Disabilities are often denied the right to make decisions in areas of their life that impact other rights:	Implications of Article 12 for governments:
Personal Life	13 Access to justice	• Persons with intellectual disabilities are often perceived as unreliable, and are therefore denied the opportunity to be witnesses in court. • Persons with intellectual disabilities are often prevented from bringing a complaint before the courts.	• Persons with intellectual disabilities must be allowed to initiate legal proceedings and fully participate in the justice system either on their own or with support from others. • Legal professionals, as well as police personnel, require training to effectively communicate with and understand the rights of people with intellectual disabilities and their supporters. • Information about accessing the criminal justice system must be made accessible so persons with intellectual disabilities can make informed decisions regarding restitution for wrongs suffered.
	14 Liberty and security of persons	• Persons with intellectual disabilities are often detained without their consent.	• Consent must be obtained either directly or through supported decision making mechanisms. • Consent must informed – it should be obtained only after objective information has been relayed in a manner accessible to the person. • Governments must ensure persons with intellectual disabilities have equal access to supports required to challenge any unlawful deprivation of liberty.

Area of life:	CRPD article:	People with Intellectual Disabilities are often denied the right to make decisions in areas of their life that impact other rights:	Implications of Article 12 for governments:
Personal Life	18 Liberty of movement and nationality	• Families and carers often decide where they should go and when. • Decisions about which country to live in and be a national of are often made for them by families and carers.	• Governments must ensure persons with intellectual disabilities are registered at birth and receive the identity cards required to confirm legal status. • Countries must not prohibit persons with intellectual disabilities and families who have a family member with an intellectual disability, from immigrating on the basis of disability support needs. • Persons with intellectual disabilities must be recognized as the primary decision-maker in their own lives, and enabled to make decisions either directly or through supported decision making mechanisms about where to live, travel to, and their national identity.
	19 Living independently and being included in the community	• Families often decide where and with whom persons with an intellectual disability should live. • Decisions about living in an institution, as opposed to living in the community, are often made on the individual's behalf and their wishes are often not respected.	• Persons with intellectual disabilities must be respected as the primary decision-maker in their own lives, and be enabled either directly or through supported decision making mechanisms to make decisions about where and with whom to live. • Housing and community programs, services, and practices must be made accessible and support must be provided for the inclusion of all. • Support to families is required to develop supported decision making networks for their family member. • Information about available and alternative housing options must be given in a manner accessible to the person.

Area of life:	CRPD article:	People with Intellectual Disabilities are often denied the right to make decisions in areas of their life that impact other rights:	Implications of Article 12 for governments:
Personal Life	23 Respect for home and family	• People with intellectual disabilities are often prevented from getting married and/or having children by their families, carers, health care professionals or social service workers.	• Persons with intellectual disabilities must be respected as the primary decision-maker in their own lives, and be enabled either directly or through supported decision making mechanisms to make decisions about whether to get married and/or have children. • Support to families is required to develop supported decision making networks for their family member. • Training is required to ensure health care and social service professionals, understand and respect the equal rights of persons with intellectual disabilities.
	27 Work and Employment	• Persons with intellectual disabilities are often prevented from seeking employment. • For those that are in employment, they are often not permitted to participate in trade unions.	• Employment programs and services, including trade unions, must be made accessible and support must be provided for the participation of all. • A person's choices must be respected when considering the kind of work that they might like to do.

Area of life:	CRPD article:	People with Intellectual Disabilities are often denied the right to make decisions in areas of their life that impact other rights:	Implications of Article 12 for governments:
Personal Life	29 Participation in political and public life	• Persons with intellectual disabilities are often prevented from voting, standing for election to public office, and civic participation.	• Government policies and practices must ensure persons with intellectual disabilities are registered at birth, to facilitate their civic participation vote. • Governments must ensure voting processes are accessible to allow persons with intellectual disabilities to contribute as equal citizens. • When required, supports and safeguards must be provided to allow persons with intellectual disabilities to engage in political practices without influence.
	30 Participation in cultural life, recreation, leisure and sport	• Persons with intellectual disabilities are often prevented from participating in mainstream sporting activities and organizing cultural and recreational events.	• Recreation and cultural programs, activities, and events must be made accessible to allow people with intellectual disabilities to fully participate, and support must be provided for the participation of all.

PART II
MAKING THE SHIFT

CHAPTER 4

From Substitute Decision Making to Supported Decision Making

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From Substitute Decision Making to Supported Decision Making

During the negotiations on the Convention on the Rights of People with Disabilities, Inclusion International, represented by a delegation of self-advocates and families, played a central role in shaping Article 12.

One of the four key priorities identified by Inclusion International, legal capacity[1] was also one of the most difficult Articles to negotiate. There were vastly differing perspectives among our members, within the disability community, and between the disability community and governments. For our members, this was not a clear-cut issue. We were committed to challenging the traditional boundaries of competence and incompetence entangled in the notion of legal capacity, in particular the capacity to act. At the same time we recognized the very real challenges facing people with significant support needs – those who do not communicate traditionally or may be perceived by others to not communicate at all; those who are extremely isolated (possibly living in institutions); those who have no existing support network; those who are vulnerable to abuse and exploitation. Our objective was to ensure that Article 12 did not ignore or leave out these individuals while tackling out-dated assumptions about decision making capacity.

> The capacity to act refers to the capability to engage in a particular transaction or enter into or maintain a particular relationship with another individual (for example, to enter into a binding contract, to inherit, to sue or be sued, to marry, or to adopt a child), and in general, to exercise one's rights by way of one's own actions[2].

Government representatives involved in negotiating the Convention struggled with the idea that the concept of legal

capacity includes the capacity to act. In other words, the idea that all people have rights was accepted but that all people had the right to act on those rights was more difficult to understand. The concept of supported decision making grew out of the recognition that some people may need support to exercise their legal capacity but they should not be punished by being deprived of any rights because of their need for this support. As well, some people with intellectual disabilities may want to make decisions without supported decision making; they may only require some accommodation to make decisions (for example, more time or plain language information), while

While the negotiations of the CRPD supported the participation of a number of articulate and impressive self-advocates, for whom minimal support was required to enable their capacity to act, Inclusion International also had an obligation to ensure that the Convention reflected the realities of those who are unable to communicate in traditional ways. For this group, families, friends, and other supporters were essential to the realization of the capacity to act. Many other disabled peoples organizations (DPOs) were suspicious of the role that families play in a person's decision making, fearing from their own experiences interference and an undermining of a person's autonomy. The participation of Sue and Charlie Swenson and Susan and Rebecca Beayni was pivotal in establishing mutual respect and understanding between Inclusion International and other members of the International Disability Caucus and the International Disability Alliance. At one side event on legal capacity, Sue Swenson said, *"You told me I should bring my son to speak for himself. This is Charlie, please ask him what he thinks about this Convention. When this meeting is over I invite you to take Charlie to lunch and to determine what Charlie would like to eat."* This challenge and the reminder that the Convention was being developed for all people with disabilities helped to build an understanding of the challenges of understanding the will of some individuals, developed some trust among members of the caucus and helped to deepen the understanding of what supported decision making meant for people with intellectual disabilities. The model of supported decision making was able to garner support from community and UN member states. It became central to the Article and helped broker consensus. For the first time ever, the right to use support in exercising legal capacity had been secured[3].

others may require support for complex decisions but not for day to day choices, and still others will require significant support for even the simplest decisions on a day to day basis. Article 12 recognizes that support in decision making includes a range of supports: from assistance in decision making (including communication supports like assistive technologies, interpretation, and translation), to assistance in expressing a person's will and choices (including peer support, advocates, and self-advocacy), and assistance in communicating to others someone's personal identity (including a person's hopes, expectations, and life plan).

The Case of Ricardo Adair Coronel Ramos

Mexico ratified the Convention with reservations on Article 12 (Declaration of interpretation), introducing a national discussion where numerous human rights groups supported a coalition of disability organizations (COAMEX) to advocate for the removal of the reservation. The discussions brought some awareness of the implications of the recognition of the right to legal capacity of persons with intellectual disabilities and their active participation in decision making on matters pertaining to their own lives, but it has not been enough to reach a wide range of stakeholders, including families, people with an intellectual disability, professionals, service providers, government officials and society in general.

Ricardo Adair Coronel Ramos is a self-advocate supported by CONFE who went to the Mexican court requesting an injunction against Mexican laws that conflict with Article 12 of the CRPD. The case was heard by the Supreme Court of Justice after a Family Court judge ruled that Ricardo had the ability to make "certain kinds of decisions" for himself. The Supreme Court did not remove the protection measures, but recognized the right of all persons with disabilities to have an accessible judicial hearing and, more generally, to have both the right of access to justice as well as support in decision making: "decisions must be taken in an individualized way, i.e. from a particular analysis of each case."

Ricardo is now deciding whether to pursue additional legal proceedings before the Inter-American System and the CRPD Committee, to monitor the implementation of the CRPD for the elimination of compulsory substitute decision for all people with intellectual and psychosocial disabilities in Mexico[4].

What is Supported Decision Making?

Informally, we all make decisions in our lives with input, information and support from our friends, family, work colleagues, teachers, doctors, role models etc. People with intellectual disabilities are usually denied the opportunity to make decisions in this way for two reasons: first, because of preconceived ideas, myths and prejudices about their "capacity" as well as sometimes their communication barriers, and second, because the network of people in their lives has been limited to immediate family or service providers.

In legal or formal situations, supported decision making can be recognized in law through various mechanisms such as representation agreements; adaptations within the justice system which recognize supports; financial and estate plans; person centered planning; etc. Many existing legal and financial mechanisms can be used to recognize the will and preference of the person. These are all tools that can facilitate and recognize the way in which people use supports in their lives to make decisions and express those decisions.

Supported decision-making can take many forms. Those assisting a person may communicate the individual's intentions to others to help him/her understand the choices at hand. They may help others to realize that a person with significant disabilities is also a person with a history, interests and aims in life, and is someone capable of exercising his/her legal capacity.

While some good models of support networks exist, there is generally no clear policy framework; guardianship laws and practice still dominate. It is sometimes difficult to designate support networks, particularly when an individual cannot identify a trusted person or people[5].

Table 5: Examples of Accommodations and Supports in Decision Making

"Independent" Decision Making	• Extra time to make decisions • Information in plain language or Easy to Read • Information in multiple formats, including visual or audio • Communication supports like assistive technology, interpretation, or translation • Informal assistance • Support to build self-advocacy capacity
Supported Decision Making	• Peer support • Advocacy • Personal support networks, formal representation agreements, or key supporters for assistance with some or all decision making • Communication supports like assistive technology, interpretation, or translation
Decision Making in Complex Situations	This is an area many struggle with. Some have suggested "facilitated decision making[6]" as a support when decisions are complex or when a person requires significant support or does not use traditional communication.

Supported Decision Making Models

There are very few jurisdictions in the world that have made a serious effort to develop and put in place these mechanisms. However, there are some examples and pilot projects that help us understand how supported decision making looks in practice and how to build those supports in the community.

British Colombia

In British Colombia (Canada) a series of legislative reforms were made to ensure that people could move from substitute decision making to supported decision making. A key piece of the reforms was the introduction of the Representation Agreements Act. Representation Agreements are legal plans that say to whom you give authority if you need assistance to

A Representation Agreement is a legal document available to adults in British Columbia for personal planning. It allows a person to authorize one or more personal supporters to be his or her representative to help manage their affairs and, if necessary, to make decisions on their behalf in case of illness, injury, or disability.

A Representation Agreement is the only way a person can appoint someone to assist them or to act on their behalf for health care and personal care matters. It can also cover routine financial affairs.

The Representation Agreement Act is the result of law reform initiated by citizens and community groups. The purposes of the Act are to: 1) provide a legal alternative to adult guardianship for adults who need help today, and 2) enable planning for the future. The Representation Agreement Act came into effect in February 2000[7].

manage your affairs. They can cover financial, legal, personal care and/or health care matters. There are two kinds of Representation Agreements: limited agreement – to cover straightforward, everyday decisions; and, general agreement – to deal with complex legal, personal care and health care matters.

The Representation Agreements Act presumes capacity:

(1) Until the contrary is demonstrated, every adult is presumed capable of making, changing or revoking a representation agreement, and making decisions about personal care, health care and legal matters and about the adult's financial, business and assets.

(2) An adult's way of communicating with others is not grounds for deciding that he or she is incapable of understanding anything referred to in subsection (1).

The experience in British Columbia provides an important example of mechanisms designed to recognize and formalize supported decision making. However, parents and self-advocates tell us that their experiences with such tools are only as true to the principles of supported decision making as the people who are in the support network. The mechanism, in this case Representation Agreements, does not answer the difficult questions about how to interpret and understand the will and preference of the person nor is it immune to misuse.

In other jurisdictions such as Bulgaria, India and the Czech Republic, community organizations are working with governments to develop personal support networks and strategies for inclusion in community for people who are under guardianship (or other substitute decision making mechanisms) or at risk of being subjected to it. Building the social and personal networks that have been denied to

people because of isolation and segregation is the core function of supported decision making, and also the main challenge.

In Bulgaria and the Czech Republic, projects designed to develop support networks for people who have been estranged from their families, institutionalized, or otherwise marginalized are exploring how to facilitate and build those networks. A demonstration project in India is working across a number of communities to help individuals to speak up for themselves and develop community supports. Parivaar's approach to advancing supported decision making has demonstrated the importance of focusing on individuals, families and communities to help people who have been marginalized (in their communities and sometimes also in their families) to develop a personal identity and build social capital. Not unlike Inclusion Europe's TOPSIDE project (see Chapter 5), Parivaar's project has demonstrated that peer support is a significant element in building personal identity and demonstrating that an individual can make their own decisions. Furthermore, the project's efforts suggest that it is important to start with small day-to-day decisions and build decision making capacity from there.

Bulgaria

The Bulgarian Association for People with Intellectual Disabilities (BAPID) is working to address the legal capacity and citizenship rights of people with intellectual disabilities in Bulgaria by introducing the alternative system of supported decision making.

BAPID has implemented two projects focusing on developing individual planning and personal support networks, a new approach in Bulgaria based on the principles for supported decision making: a support network is not appointed without the adult's consent; there is a relationship of trust between the adult and the support network; the support network does not act on behalf of the adult; the support role provides the adult with support and assistance in making and communicating decisions; and, there are safeguards in place to protect the adult against abuse and exploitation. BAPID hopes to both develop and test approaches to support people with intellectual disabilities in exercising legal capacity as well as develop the capacity of people with intellectual disabilities, their families, supporters and organizations to promote the right to legal capacity and implement practical, community-based approaches for supported decision making. The projects also aim to identify policy and program conditions and key issues in transforming the current policy, program and service delivery framework in Bulgaria.

India

The activities through the supported decision making projects being carried out nationally by Inclusion International's member Parivaar and in the state of Kerala both focus on peer support and are proving to be a critical component in establishing the personal identity of a person with a disability. Through implementation of the projects, it is clear that until an individual is seen as a person and treated with respect the leap to seeing the individual as a decision maker is too wide for many to make.

There is a marked difference in the dialogue about legal capacity law reform efforts at the national level with Parivaar's leadership and at the local level with families, individuals and community stakeholders involved in the supported decision making project. Participants involved in the national law reform discussions are better equipped to use rights-based language and concepts of supported decision making; however, their knowledge and understanding about deeper issues and community-based solutions is not as strong. The families, individuals and community stakeholders involved in the supported decision making project in Kerala do not always use rights-based language; however, they demonstrate a deep understanding of the importance of supported decision making and the conditions that need to be in place to make it work than participants involved only in law reform efforts.

Self-advocates involved in the projects talked about wanting to have control in their lives. "I want to speak up," said one young woman. "When I get my salary, I will handle it myself." Another self-advocate said, "I want to marry a girl that is employed." A young woman explained how her mom has listened to her decision to live more independently and is helping her to do this.

Parents and professionals expressed their shift in understanding. One parent said, "Before this project people didn't know [people with intellectual disabilities] had rights."

The supported decision making policy reform efforts have the benefit of being deeply informed by the realities of individuals and families. Globally, a key challenge for establishing supported decision making networks has been identifying people to be part of the support network. The proposals moving forward in Kerala are exploring ways to begin the development of support networks through government. Concerns have been expressed about the risk of over-formalizing or professionalizing support networks that could come with this approach; however, it is an innovative approach that – with monitoring and a risk mitigation strategy – could address this key barrier that has been identified.

Czech Republic

Inclusion Czech Republic's Black and White pilot project aims to create long-term mechanisms of support in life and decision making of people with disabilities. The work focuses mostly on strengthening relationships and improving communication with people who have circles of support and with people who are facilitating circles of support. On the basis of a person's interests and hobbies, Inclusion Czech Republic has been mapping where these interests can be experienced and shared; how the individual can take part in community life, meet new people, do new things together, and realize their wishes. The most successful stories happen when the creation of a circle of support coincides with the need for change, when the person is not satisfied and is looking for something different.

For some participants, a support circle can be built on pre-existing relationships. In creating support mechanisms, the main obstacle is often the attitude of the person or their family – they are not always ready for change or making decisions. Creating mechanisms for support in decision making does not make sense if it remains theoretical. At the same time, even mechanisms for every day decisions may not currently exist in the individual's life.

Inclusion Czech Republic encounters some circles in the project composed only of social workers; even if they are trusting relationships and they are friends, it is unbalanced. Other circles are composed only of family members. In both real friends and peers are missing. Fewer circles of support are well balanced, composed of family members, friends, peers and professionals. **The goal is to establish support circles that are well balanced, strong and independent.**

During the project, it was realized that it would be beneficial to expand the activities to be able to work with more people, and the project was opened up to other organizations. Inclusion Czech Republic is currently cooperating with eleven organizations that are interested in working with their members in the framework of the project, including organizations that support people with psychosocial disabilities. This sharing provides the opportunity to test the methodology and to produce a useful tool to train more people in the future. The involvement of community connectors from different horizons also secures the stability and the effectiveness of the circles of support. It is of course the most difficult part of the project, as the 'matching' between people or life events cannot be planned, which may influence the relationship or the absence of it.

While the adoption of Article 12 as a central concept of the Convention on the Rights of People with Disabilities reflected a fundamental conceptual shift, the realization of that shift will require complex social changes. In some jurisdictions this shift has been initiated by legislative reforms which eliminate or limit substitute decision making provisions in law, in others the process has begun through cultural and grassroots awareness raising, community education, and the development of supported decision making mechanisms. While the path towards realizing the right to make decisions will start in different ways, what is clear is that building supports for decision making at both the community and policy level must be a priority.

CHAPTER 5

Why is the Right to Decide Important for People with Intellectual Disabilities?

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Why is the Right to Decide Important for People with Intellectual Disabilities?

Making choices and decisions for ourselves is an important part of who we are. It is fundamental to having control over our own lives and important for securing all other rights: if we are not allowed to make our own decisions, how can we have a voice in anything else that is important to us? The opportunity and support to make decisions is important for persons with intellectual disabilities for a number of reasons:

- It helps us develop a sense of control over our own lives;
- It teaches us that we are responsible for ourselves and that we often have a responsibility to others;
- It helps us become more assertive and therefore, less vulnerable to exploitation; and,
- It helps us develop positive and healthy relationships with others.

When people are supported to make decisions for themselves, they are seen as more capable by others. When we are not allowed to make our own decisions or when someone else makes our decisions for us, we are seen as less capable and as having less value in community.

People with an intellectual disability say:

- We want to have our voice heard and acknowledged
- We want to be accepted for who we are
- We want to make our own decisions
- We want to be asked for our view and opinion on things
- We want to be treated the same as other people
- We want to have the same rights and opportunity to do things, with support only when needed

As we engaged in an international dialogue on the right to decide, people with intellectual disabilities said:

➢ We do not have control about where and with whom we live. Landlords or other third parties do not let us sign rental agreements or utility contracts. We are institutionalized against our will or living in places not of our own choosing. Even those of us who live in the community often feel lonely and isolated.

➢ Realizing our right to make decisions is essential for being seen and treated equally in community. In all regions of the world, persons with intellectual disabilities say that having control in their lives is essential to achieving the right to live and be included as valued and contributing members of community.

"I would like people to hear what I have to say, and for them to realize that I am capable. When I do not understand something or do not know how to do it I ask my mom and she helps me."
– Self-advocate, Colombia

- Our voice is restricted because we are denied the right to make decisions in our lives. Informally or formally we are deemed "incapable" or "incompetent"; we are penalized if we need support to make decisions.

- Having voice and control is a priority.

"I was promised more time, with my own guide, and papers with large print; but come the day none of these promises were met and so I did not perform at my best."
– Self-advocate, Malawi

Table 6: We Asked Self-Advocates: What are the barriers when trying to make decisions for yourself?

Tools	• Not knowing what choices are out there for me • Not being told the information • The information is not accessible to me – it is too complicated if it's given to me at all
Skills	• Lack of knowledge on how to communicate my choices • Lack of confidence • Fear
Relationships	• Families and other people make it hard to let me make my own decisions: they are overprotective • People still see me as a child and treat me as such • People think I won't understand • The staff are supposed to support me, but they run my life • People around me do not believe I can decide
Opportunity	• Bad past experiences • Other people don't want me to make mistakes • I am ignored or excluded • I want to be able to go out at the times I want, shop where I want, and make decisions on what time I do things – not when or where it suits the staff

"When I go to the doctor, he talks to my parents and always wants to talk about me with them in the room. I would like to be left alone with the doctor so he can explain to me how to take my medicine."
– Self-advocate, United Kingdom

Why Do People Need Support?

People with intellectual disabilities say that support is needed to develop decision making skills and to make decisions for a variety of reasons:

"I make my own decisions. That does not mean that I disagree when they give me advice. I seek support, but not permission."
– Self-advocate, United Kingdom

- Some of us have difficulty making decisions independently – it may be that we don't understand what we are being asked or the implications of our decisions.
- Some of us have a hard time making our wishes or choices understood by others if we don't communicate in traditional ways. Some people do not use words to communicate – pictures, assistive technology, gestures, or certain behaviours may be used.
- Families and others often have concerns about the decisions we are making; they may not understand how to support us to make decisions.

Table 7: We Asked Self-Advocates: What helps you make your own decisions?

Tools	• Information that is: clear, accessible, and easy to read, with simple language and no jargon • Information in video or audio format • Lists of possible choices • 'Tester sessions' when I can practice making decisions • Time – to understand, to express myself, and to make decisions
Skills	• Confidence!! To say yes and to say no. • Knowing where I can go to get advice • Learning how to talk to my support workers, social worker, and family members about my decisions
Relationships	• I need good trusting relationships with the professionals in my life • I need to be able to talk to people about the problems I have in order to know the options, and then I can make my decision • I need a key worker to support my decisions around specific things • I need someone to come with me when I go to the bank or rent an apartment for the first time • I need the person who comes with me to insist that the professional or third party speak to me directly
Opportunity	• I need to see and try new things to find out what I want and like to do

"I won't know if I made the right decision or not until I take the risk." – Self-advocate, Lebanon

Choice and Inclusion

People are social beings; our identity and the decisions we make about our lives are shaped by our relationships with the world around us. This means that true autonomy derives from inclusion in the wider community. Social embeddedness – the achievement of an inclusive life through living and growing alongside peers and progressing towards the same life goals – is critical to achieving self-direction.

The Dignity of Risk

"When we decided to go and live together we discussed it with our families, who supported us. With friends and others that were couples, people we trusted, they told us about responsibilities that family life has, how to care about our emotions and our health, and we made our decision."
– Self-advocates, Costa Rica

Self-advocates from around the world express fear that if they make a "bad" decision or fail, no one will let them make their own decisions again. The Dignity of Risk describes the right to choose to take some risk while engaging in life experiences. Every endeavour has some element of risk, and every opportunity for growth carries with it the potential for failure. Everyone learns through a process of trial and error, often learning as much from mistakes as from successes.

People in the lives of individuals with intellectual disabilities – usually with the best of intentions – often try to eliminate all of life's risks and prevent any opportunities for failure. What can result is a life where an individual has never had the opportunity to develop new skills and learning, and has never experienced the satisfaction of achieving something that was not certain to be achieved from the beginning.

Dignity of Risk is not equivalent to encouraging recklessness; supporting a decision does not mean supporting a person to be unsafe or setting people up to fail. Rather, by supporting each other in informed risk-taking, and utilizing the many teaching opportunities it reveals, we are provided with the opportunity to try new things, test our limits, and discover capabilities we never knew we had, helping us to achieve goals that further enrich our lives.

Table 8: We asked Self-Advocates: What kind of decisions do you have to make in your life?

How do you make those decisions now?	
Personal Care	
➢ Grooming and hygiene ➢ What to eat ➢ Organizing my schedule	• I make my own decisions! • I go shopping with Mum to choose clothes. I try them on in the changing room and put them back if I don't want them. I pick out shoes I like, I pay the person and they give them to me in a bag. • I go to the fish and chip shop by myself and to the supermarket to help the staff in the home where I live. • The staff gets different clothes out for me to choose between. • People in the house decide what groceries to buy. • My parents will tell me when I can bath or shower. • My parents refuse to buy us new clothes, claiming we are careless. • The staff decides everything.
Social Life and Activities	
➢ Planning my holidays ➢ Going out with friends ➢ School and learning ➢ Spiritual decisions ➢ Hobbies	• I always feel that I am listened to and I can go out when I want to. • I chose whether I work or not. • I can't see my good friend anymore because my family has moved and it is difficult to travel to see her. • I go to a day centre even if I though I don't want to. • My mam worries so she won't let me do things. • I am told I have to go to college and the college decides what courses I can do. • We are not given time to play both at school and at home. Some of us are confined to homes when we are not at school; we are not allowed to go out for sports.
Relationships	
➢ Having a boyfriend/ girlfriend ➢ Having children ➢ Getting married	• Staff stopped me from having a girlfriend; they wouldn't let me see her anymore. • People try to stop you from having sex because they think you cannot cope with a child. • They don't want us to have children because they don't want more people with disabilities. • I am seeing someone but I have no plans to get married, it wouldn't be allowed.

How do you make those decisions now?	
Where to Live	
	• I was shown different places so I could choose where I wanted to live. • I was told that I had to live wherever there was availability. • In a group home most of the things are decided. • In an institution meals are cooked and served like school meals. Your choices get smaller as more people live together.
Money and Finance	
➢ Where to put money ➢ Budget ➢ Paying bills ➢ How to spend money ➢ Where to get money ➢ Where to invest money	• I put my money in a tin after I have paid bills and done my shopping. • My sister administers my pension and she writes it down in a notebook. I asked her to do that because I trust her. • I have to ask my parents for money and they give me what they think I need. • I don't know what benefits I get; my mam deals with all that. • Some parents refuse to pay school and exam fees, saying it is a waste of money for children who will not succeed in school. • My money has gone missing several times even though my room is locked.
Health and Well Being	
➢ Going to see medical professionals ➢ Reproductive decisions ➢ Pregnancy care ➢ Medication	• I decide to go to the doctors when I feel unwell. • I decide on my women's health care. • I chose to take my own medication. • Sometimes it is not explained to me why things are happening. • I don't have a say at all in making appointments. • I have been told that if I do not have sex I do not need a women's health exam. • When I go to the emergency room, the doctors call my parents as if I was a minor or incapable.

The Role of Self-Advocacy

"Being a self-advocate helped me speak for myself and make my own decisions."-
– Jean, Scotland

In most parts of the world, the idea of people with intellectual disabilities being empowered to speak on their own behalf is not yet supported by society. This action of an individual expressing their own voice – self-advocacy – is critically necessary for persons with intellectual disabilities to reclaim the power to have control in their lives and to rebuild the skills to exercise their rights, skills that have not developed or have been taken away by society due to decades of exclusion.

Self-advocacy supports individuals to share their voices and seeks to reduce the isolation of people with disabilities. Self-advocacy *"refers to a process of individual empowerment. The promotion of self-advocacy involves building self-esteem and*

An Emerging Support Model: Peer to Peer Support

Many adults with intellectual disabilities are denied the right to participate as active citizens in their societies. Since most adults with intellectual disabilities in Europe have only limited access to formal or informal adult education and training, one of the main challenges lies in providing the education necessary to enable adults with intellectual disabilities to make their own decisions, to take control in their lives, and to realize their role as valued and contributing citizens.

Inclusion Europe's Training Opportunities for Peer Supporters with Intellectual Disabilities in Europe (TOPSIDE) project has developed a peer support model and peer training for adults with intellectual disabilities that has been implemented in many countries throughout Europe, including the Czech Republic, Finland, the Netherlands, Romania, Scotland, and Spain, building the capacity of adults with intellectual disabilities to provide support and training to their peers.

As Peer Supporters, adults with intellectual disabilities receive training and go on to work or volunteer in a variety of places: in self-advocacy organisations; counseling services; or family-based or service organisations, to complement the support provided by others. Adults with intellectual disabilities who receive training and support from Peer Supporters access new opportunities of informal education that reinforces both the capacity of persons with intellectual disabilities to be included in society as well as their role as valued and contributing citizens.

the acquisition of skills that allow a person to take life in his/her own hands."[1] Often, family based or community organizations provide this self-esteem and skills training for persons with intellectual disabilities to develop self-advocacy capacity. While this is certainly necessary, there is also a need to develop processes that enable the collective voice of people with intellectual disabilities to be heard and to effect change.

Over the past few decades, the development of self-advocacy groups in some parts of the world has provided adults with intellectual disabilities with a platform to express ideas for advancing an agenda for change. The role of self-advocacy groups in expressing the need for investment in supports that enable self-determination is essential to having a meaningful impact on public policy and systems change. In uniting individual voices, self-advocates are a powerful collective voice to government and community organizations about the issues that are important to us and the changes we want to make in our communities.

CHAPTER 6

Why is the Right to Decide Important for Families?

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Around the world, families are often the first and main source of support for people with intellectual disabilities.

While parents and family members are sometimes seen as a barrier to people with intellectual disabilities being able to take control of their own lives, we heard very clearly from families that it is isolation, exclusion and lack of support that results in families acting in controlling and protective ways.

For many people with intellectual disabilities, particularly those with more significant support needs and those living in countries with few resources and services, it is their families that facilitate their inclusion in community and the expression of their wishes. Yet the reality for families is that they recieve little or no support from their communities to enable their family members to participate and be supported in the community. As a result, their family member does not have relationships and networks in community through employment, neighbours, friends, etc.

In order to help families make the shift to support their family members in decision making, it is important to understand the reasons that families feel the need to make decisions on behalf of their family member. We asked families to tell us why their family member with an intellectual disability might be denied the right to make decisions and how they might support their family member to make and act on decisions in their own lives.

While we heard about significant challenges in enabling people to realize the "right to decide", families also told us that finding

ways to support their family member to express their opinions and make decisions is critically important in planning for a secure and inclusive future.

Challenges for Families

Some of the issues that families face in being able to support their family member with an intellectual disability to exercise their right to make decisions include:

Isolation and Exclusion from the Community

The most fundamental challenge for families is that they are often the only source of support for their family members. People with intellectual disabilities who are systematically excluded from mainstream education, employment, political participation, and religious and cultural participation are denied the opportunity to build relationships that are a natural part of people's lives. As a result, parents are often left to make decisions on behalf of their sons and daughters or to interpret the will and preference of their family member.

Families expressed frustration at the lack of appropriate accommodation and support in their community so that people can exercise their right to make choices, take risks, and participate. We heard that *"lack of awareness has put us in a position where we are making the decisions on behalf of our children ."*[1]

Perception of Capacity

The attitudes and perceptions of families about their family member's ability to make decisions is a direct result of the way their family members are treated by the societies and communities that they live in. People with intellectual disabilities are often not afforded the opportunity to make decisions because of the misconception that they are incapable of making 'good' decisions or that they do not have valid opinions. Sometimes, this misconception is reinforced by the individual's family: *"We do not feel that our sons and daughters are mature enough. They have limited capacities, and no matter how we teach them, they will always need our support."* – Parent, Lebanon

"When my sister was born, my mom said she had a problem. I thought she looked beautiful. I said, 'She has hands, she has feet, she is complete.' I grew up with the idea that she was not well and could not do things and that everything had to be done for her, but I have learned better; she is very clever." – Sibling, Mexico

From the time that their family member is born, professionals, doctors, teachers and community have emphasized to families what their family member could not do. The result is that some parents of children and adults with intellectual disabilities simply do not believe in their child's abilities. These parents make decisions on behalf on their son or daughter, because they assume their son or daughter does not "know better".

Fear and Protection

One of the biggest barriers families spoke of is fear: fear that their family member will be hurt, abused or taken advantage of; fear of legal implications if something goes wrong; fear of failure.

Families often make decisions on behalf of their family member with an intellectual disability due to a sincere belief that they are protecting their family member from harm, or to avoid unwanted consequences.

"They do not let me go anywhere alone, not even to the park by my house. They think I can't do anything alone, so if no one can take me then they will not let me go. I would like for them to let me go outside but they think that something may happen to me." – Self-advocate, Colombia

Many families worry that if their family member takes a risk and fails, it implies they are doing a bad job. Parents also note that they have a lot of anxiety about their sons and daughters making the 'wrong' choices.

"We didn't believe in their capacities to make decisions, because we did not give ourselves the chance to discover who they really are and what they can really achieve. We always underestimated them and feared that they will fail in their decisions." – Parent, Spain

Families are also concerned about the safety of their sons and daughters in communities that have not demonstrated acceptance and inclusion. We know that in many parts of the world these fears of vulnerability are justified given the experience of violence and abuse faced by people with intellectual disabilities in care facilities and in the community. As one parent from Lebanon stated, *"It is true that I believe in my daughter, but I cannot let go from my fears. I trust her but I cannot trust society. So I will be always following her to make sure no one is taking advantage of her."*

Cultural beliefs

In many countries (for example, Kenya, India, and Lebanon) we heard that gender and age have an impact on the informal denial of decision making rights with respect to financial and property decisions. Older persons, and older men in particular, are much less likely than younger people, and young women in particular, to have their decision making rights denied. This is a reflection of cultures that demand more respect for both elders and males.

Time and Convenience

As the primary and often only support available to people with intellectual disabilities, families play multiple roles as caregivers, therapists, and advocates while providing financial and emotional support for the whole family. For many, it is easier and often quicker to make decisions for their family member than to collaborate and support their family member to make their own decisions. Believing they know "what is best" for their sons and daughters, parents will simply make choices that work best for the family.

The Right to Decide in Lebanon

Lebanon is a Middle Eastern country that is part of the Arab world. Although it has always been viewed as a democratic place, people are still engulfed by the traditions inherited from their Lebanese ancestors – traditions that have been the essence of Lebanese law since it was written in the early 19th century by a group of feudal lords. Most of the laws written have reinforced the culture's perspective about gender, rights, and responsibilities.

The Right to Decide in Lebanon is not exempt from tradition. The guardian of a family or a person is the oldest man in the family. The decision maker is the oldest man in the family, or the father. In cases of dispute, the religious man settles the issue. The religious man will listen to the man in the family and the family members who are allowed to speak to him. The final decision is usually the option that follows the norms and traditions of the family and the religious man.

Being in charge of the family's finances and being the decision makers, men are perceived as the most important gender. Their needs, aspirations, and whims are given more attention. Parents and carers will try hard to foster the independence and ambitions of their male children. They will try hard to support their boys with tools that lead to a prosperous and dignified life, even if the boy has a disability. On the other hand, a female is perceived as a dependent, a weak burden that is to be taken care of until the time comes where she moves to a husband's house to be a mother and a wife. The problem continues to be with girls who have a disability: the ones who are unable to "learn", "produce", or "get married", let alone "handle property" or "run a business".

With the enforcement of international laws on the government, many amendments have been introduced to the Lebanese law. Nevertheless, these amendments have not reached implementation. Carers in Lebanon still believe the father or the oldest man in the family is the wisest and the best decision maker. The Right to Decide is his at all times, especially in the time of crises, which is the situation these days.
– Farah, Parent

"The decisions of our sons and daughters are usually simple decisions that have to do with what to wear, what they want to eat, etc. Many times we do not let them make these decisions because of our own convenience." – Parent, Spain

Pressure to Seek Guardianship (or other forms of Substitute Decision Making)

The decision to formally seek plenary or partial guardianship is often made because of financial planning, medical or support needs. In dealing with third parties such as doctors, financial institutions or care providers, families are sometimes obligated to obtain legal recognition of their status as substitute decision makers in order to put in place the financial or care supports needed by their family member. For example, the Registered Disability Saving Plan (RDSP) is a savings plan for persons with disabilities created by the federal government in Canada. Its legislation requires that a "qualifying person" who is "legally authorized to act on behalf of the beneficiary" must open the plan on behalf of a person with an intellectual disability[2]. Parents in Canada frequently cite this legislation as a barrier that prevents them from opening the savings plan for their family member. They report feeling caught between their desire to assure the future financial security of their son or daughter, and the stigma and restriction of basic rights they feel comes with formally placing their son or daughter under a substitute decision making or guardianship order[3].

What Families Need to Build Decision Making Supports

In addition to the many roles families play in the lives of their family member with an intellectual disability, shifting from substitute to supported decision making often asks families not only to change the way they support their family member, but also to mobilize supports that currently do not exist in their communities. Families around the world reported that they need support in order to support their sons and daughters including: supports for inclusion in the community; communication tools; alternatives to substitute decision making; and appropriate safeguards in implementing supported decision making.

Table 9: We Asked Families: What is needed for you to support your family member to make his/her own decisions?

Knowledge and Information	• We need to understand the implications of guardianship models on the lives of people with intellectual disability • We need to information on the concept and practices of Supported Decision Making • We need information about what support means and what it looks like in a variety of situations • We need a way for people working on this issue to link to and communicate with one another for the purpose of building momentum and advancing practice • We need access to tools and documents on the rights of our family members with a disability • We need information on what is available in the community, both for us and for our sons and daughters
A Transformation of Values and Beliefs	• We need all families and professionals to recognize that people with intellectual disability are people first; have equal rights; and need to participate and be part of community

Family Supports	• We need support to address our own fears about decision making • We need family support groups and family organizations to share success stories • We need the opportunity to use peer to peer support strategies and parent to parent support groups • We need support to understand what is required from us to help our children and others to respect their right to make decisions
Community Awareness	• Stakeholders, including persons with intellectual disabilities, families, policy makers, professionals, and the general public, need education on the right to decide • We need community to focus on a person's rights and have high expectations for our sons and daughters • We need real-life examples of people taking different paths and using different decision making methods so the discussion moves away from being hypothetical • We must share stories that illustrate what worked and what did not work in different situations • We need strategic partnerships to address and advocate for supported decision making in everyday life decisions and formal policy
Support for Complex Issues	• We need to identify and implement ways to help people explore different issues and circumstances, so that everyone can understand how people with very different abilities can take charge of their lives • We need to address the most complex issues for families: safety, protection, and "the big decisions"

Families *"Making the Shift"*

As a result of global discussions around the right to decide, many families are making the shift from substitute to supported decision making, both formally and informally. In India, a supported decision making project has demonstrated to parents the importance of their sons and daughters having a personal identity and being able to build social capital. These families have found that until someone is seen as a person and treated with respect, the person will not be seen as a decision maker

in their own life. Parents are now consulting with their sons and daughters who have disabilities on decisions, just as they would their sons and daughters who do not have disabilities. One father shared that he changed his will to include his son with an intellectual disability. A mother asserted, *"When people are supported from a young age, they grow to be strong, confident adults."* In expressing the impact having the right to decide and control in one's life has, one father said *"it allows me to make him free."*

Some family based organisations, particularly in Canada, told us about how they are using 'an inclusive definition of family' in their daily work. An inclusive definition of family is one that gives equal status to people with intellectual disabilities as part of a family, rather than as a 'dependent' to parents. These organisations see this definition as necessary to overcome a common 'false dichotomy', or false contradiction, between family (often meaning parents) and individuals. This false contradiction between families and individuals often risks limiting parents from being involved in decisions in their child's day to day life, while also limiting the recognition of family as being at the core of an individual's natural support network and instrumental to an included life.

"I would love for my son to make decisions, the issue is how."
– Parent, Kenya

In a few areas, we heard about how excluding families completely from decision making has sometimes placed individuals with intellectual disabilities at risk. In the United Kingdom, an analysis of the treatment of people with intellectual disabilities in healthcare settings[4] found that families had been excluded from decision making by medical professionals on grounds of protecting the individual's autonomy, often without any equal efforts to listen to the individuals involved. In one case, these factors were associated to the death of a young man who was left unsupervised while bathing.

In many other countries, we heard how it is difficult in daily life to honour the decisions made by people with intellectual disabilities, as plenary guardianship gave all priority and rights to an individual's parents. In Israel and Mexico, for example, family based organizations are now working to repeal their country's guardianship laws to remove this emphasis on the parent and place the individual back in control of their decision making.

Adults who have an intellectual disability – wherever they live in the world – continue to be isolated, excluded and often vulnerable in their communities and continue to be denied the right to control their own lives and make decisions about how they want to live their lives. While families represent the main source of support for people with intellectual disabilities, parents worry about what will happen to their family member when they are gone or when they are no longer able to provide care. Strategies to build networks of support for people with intellectual disabilities enable a person to direct their own lives and be supported to make decisions for themselves (supported decision making). Having these supports to make decisions means that people who have an intellectual disability are less vulnerable, less isolated and less dependent on their families to live the lives they choose.

CHAPTER 7

Why is the Right to Make Decisions Important to the Work of Family Based Organizations?

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Why is the Right to Make Decisions Important to the Work of Family Based Organizations?

In many countries around the world, Inclusion International's national member organizations have been supporting people with intellectual disabilities and their families for over 50 years. The organizations were founded to respond to a need — at the time, for services and public attention. Over time the role of these organizations has evolved, reflecting the needs and priorities of people with intellectual disabilities and their families. Some organizations developed into service delivery organizations to fill gaps in community, some became strictly advocacy voices, and others have tried to play both roles.

While these family based organizations and groups vary significantly in size, structure and mandate, they often are the only organizational source of support for families who have a family member with a disability and for people who have an intellectual disability. They provide advocacy support to families struggling to get their children into school, to access health care, to access the justice system, etc. They also provide direct support to people with intellectual disabilities for employment support, personal assistance, housing support, developing self-advocacy capacity, and much more.

As we learned through our Global Campaign on the Right to Live and Be Included in the Community[1], many of these family based organizations continue to struggle to change the way they provide support to people in the community.

We Asked Senior Leaders of Family Based Organizations[2]:

- How does your organization define inclusion and independent living?
- Give examples of the way your organization, as an advocate or provider of services, embeds respect for the will and preferences of people with intellectual disabilities in your ethos and conduct?
- How and by whom are you held accountable in doing so?
- How do you measure your effectiveness in doing so?
- Has your organization gone through a process of change in ensuring respect for the will and preferences of the people you support?
- What were the past deficiencies in your approach? What have you changed and what were the steps to getting there?
- What have been/continue to be the chief challenges your organization faces in respecting the will and preferences of the people you support?
- What do you do when the will and preferences of people with intellectual disabilities contrast with those of their families or legal guardians? Do you have policies on this issue?
- What have been/continue to be the key factors that have improved your organization's capacity and success in respecting the will and preferences of the people you support?
- If you are an advocacy organization, are there times when your organization advocates for what is in a person's 'best interests' where that might conflict with what the person is saying that they want? What policies and practices have you developed to deal with this?
- If you are a service provider, are there times where your organization is making 'best interests' decisions which might conflict with what a person wants, or might restrict their freedom of movement? What policies and practices have you developed to deal with this?
- Do you consider social connectedness as being relevant to whether people with intellectual disabilities successfully lead independent lives in the community?
- In what ways do you promote social connectedness? How do you measure success?

We know that while the majority of adults who have an intellectual disability live at home with their families, the services and supports people receive (where they exist at all) continue to segregate and exclude them from real participation and inclusion in community. Our members are often the delivery agent of those services at the same time as they are advocating for supports that respond to the "will and preference" of the person and working as agents of change in building inclusive communities. In order to understand how these organizations have either shifted their purpose and mandate or adapted new approaches in the way they support people with intellectual disabilities, we asked senior leaders of some of those organizations about the way their organizations

embed respect for the will and preferences of people with intellectual disabilities in their ethos and conduct.

Over the past five decades family based organizations have experienced two overarching shifts:

From Substitute to Autonomous to Supported

The gradual move from the legal mechanisms of substitute decision making which allowed parents to decide for their sons and daughters (and was seen as a way to protect people with intellectual disabilities from abuse and exploitation), to the focus on independent decision making (which ignored the fact that most people do not make decisions in isolation but rely on advice from families and friends), to supported decision making and the recognition that naturally, most people make decisions with support from others.

From Institutionalization to Living in the Community to Real Inclusion in the Community

The shift from institutionalization of people with intellectual disabilities, to people living in but not belonging to their community, to people with intellectual disabilities being part of an inclusive community through which individual choices can be supported.

Family based organizations have been challenged to adapt their mandates and strategies to manage these transitions:

- From being paternalistic and assuming that families always know best, to being 'person-centred' and respecting the will and preferences of people with intellectual disabilities;
- From being 'custodians' on behalf of parents, concerned above all else with safety and physiological well-being, to becoming 'facilitators' of participation of people with intellectual disabilities in the community according to their own choices and preferences;
- From providing specialist services, usually in separate programs and facilities, to harnessing social supports and building inclusive communities.

> The idea of choice raises the question of 'self-segregation', whereby adults with intellectual disabilities actively seek out one another for mutual support, sometimes choosing to live, work, or engage in social or recreational activities with other persons with intellectual disabilities. How much are such choices an expression of limited options or a sense of isolation or exclusion from mainstream society versus a genuine desire for connection or private space with others who share a particular characteristic? What does the answer to this question mean in terms of how organizations should respond?[3]

For many of our member organizations – whether they are newly formed or were founded 50 years ago – there are significant challenges in shaping their purpose and vision to be 'person-centred facilitators' and community change agents:

Principles and definitions

There is sometimes a lack of clarity and understanding regarding what is meant by supported decision making and how is it distinguishable from substitute decision making. In practice, there is a risk that organizations providing support to people with intellectual disabilities will simply adopt the language of 'supported decision making' without fundamentally making a change to the way in which supports are organized to enable people to determine the way they want to live their lives.

Some organizations view "choice" as more important than inclusion, supporting individuals and families to select

non-inclusive options for education, work, living, or leisure time when individuals and families express this as a preference. This raises the question of whether real choices are being offered to people. This also raises the question of whether the limited experience and isolation of people who have been segregated their entire lives results in fear of change or fear of losing the security of being in a "protected" environment.

Other organizations take the view that inclusion is more important than "choice" or rather that real "choice" is only possible in the context of inclusion. Therefore, these organizations will not support individuals and families to select non-inclusive options that may limit people from being connected in community. For example, in communities where there is not good support for inclusive education, some families may "choose" to send their children to a special school. Some organizations maintain the importance of supporting families to make that choice. Others commit themselves to improving the regular school system so that students with disabilities are well supported in quality, inclusive settings.

Changing the relationship with parents and families

There are differences of attitude and practice with respect to where parents and/or families fit in when pursuing a person-centred approach and with respect to what is meant by 'family'. Some organizations have developed an 'inclusive concept of family', designed

Through experiences of international exchange, the **Parents' Association for Persons with Intellectual Disabilities (PAPID), Taiwan** witnessed that people with intellectual disabilities in other countries and regions were enabled to express themselves and "do more" than people with intellectual disabilities in Taiwan. What made the difference? PAPID observed both local and international experiences and developed a program, along with other local associations and service providers, to support people with intellectual disabilities in self-advocacy and living in community. Beginning with seven local associations in 2008, there are now 16 local associations participating in the program. The program has changed the relationships between self-advocates and service providers and has also changed ways of providing services: self-advocates are the main participants and the social workers or staff are supporters. PAPID encourages the delegates to discuss their dreams, their concerns, their goals in life, as well as strategies for facing difficulties or challenges. Program participants know they can make decisions on things that impact them by themselves.

Some activities the program participants are involved with include: participating in the election of the Service Users' Rights Committee in Institutions; advocating for setting the traffic light close to their office; visiting the Ministry of Labour and the Legislative Yuan of the Republic of China; advocating with the Ministry on Higher Education for their right to go to college; participating in international art exhibitions; and, advocating for support for the Right to Decide.

AKIM, Inclusion International's member in **Israel**, has embarked on a process to promote more person-centred and inclusive approaches. This has involved staff training – over 650 staff members, beginning with senior staff – and support to parents to build their confidence in allowing their adult children to make decision about their lives. AKIM has established a taskforce involving parents and staff from employment, housing and community centres to identify the need for change and support the change process. They are playing an active role in a major deinstitutionalization initiative and plan to support hundreds of people moving out of institutions and into the community. AKIM is also part of a process with other Israeli advocacy organizations to reform Israel's guardianship laws, in line with Article 12 of the CRPD.

to challenge what is viewed as a false contradiction between individuals and their families, and emphasize that families *include* people with intellectual disabilities. Families and self-advocates should not be seen as competing groups. Other organizations take a rigid line, placing more significance on the will and preferences of the individual above any other considerations. Some organizations are seeking to look beyond 'blood ties' towards 'people that matter' in their conception of family, encompassing friends, neighbours, colleagues, and significant others.

Theories of change

Some family based organizations view inclusion as a precursor to self-determination, believing it to be the means through which individuals establish their identities, and via which our will and preferences develop. In this sense supported decision making and inclusion are synonymous. Some organizations believe cultural change must come before law reform with respect to supported decision making and prioritize creating practical alternatives to guardianship and other modes of 'protection' as well as building the confidence of families, professionals, and businesses such as banks, whereas other organizations prioritize changing legislation to comply with Article 12 of the UN CRPD.

Photo: Markus Hippmann

The German Experience in Making the Shift

From the beginning, the implementation of the CRPD was discussed in close connection with the term inclusion and the question was asked nearly everywhere: "What does inclusion mean?" In particular, persons with disabilities started to discuss: "What does inclusion mean for us, for our well-being, for our rights, for our status in society?"

In German language the term "inklusion" is a word of foreign origin, not historically used to describe the need to recognize persons with disabilities as full citizens as described in the CRPD. Today nearly all politicians talk about "Inklusion" and the German media use the term in a very broad sense, referring not only to persons with disabilities, but also to immigrant workers, refugees and other minorities who are not treated equally in society.

The public attention to the term inclusion has had a lot of positive impact on persons with intellectual disabilities in Germany. While many people still live segregated from their community, are educated in special schools, or work in sheltered workshops, a growing number of people have learned that the term "inklusion" describes a fundamental change: people with intellectual disabilities are no longer "objects" of discussions led only by professionals but citizens entitled to participate in all decision making processes regarding their lives.

As a result, the voice of people with intellectual disabilities is now at the centre of organizational leadership. It is not only parents and family members who run associations and groups for persons with intellectual disabilities and their families, but a growing number of self-advocates are included in the governing bodies of these organizations.

An example of this is Lebenshilfe Germany, guided by a federal council of mostly parents. At the last General Assembly, three self advocates were elected as full members of the council, assisted by persons of their choosing and by *Länder,* an advisory board of self-advocates from all German provinces. Many local Lebenshilfe branches now operate in a similar way; the self-advocacy movement within Lebenshilfe Germany consists of more than 10,000 self-advocates today. All that sounds very positive; however, there are still conflicts. Parents who belong to the founding generation of Lebenshilfe claim that the legal capacity of some of their sons and daughters is limited. The question "whether a person with an intellectual disability – who requires significant support and does not communicate traditionally – still needs to be legally represented by a third party" causes much discussion.

Germany abolished its guardianship law in 1992 and replaced it with a custodianship law. The German Ministry for Justice takes the view that the custodianship law is progressive and "fully in line with the CRPD", even though custodians are entitled under certain conditions to make substitute decisions for persons under custodianship. For instance, if a custodian has been appointed to represent a person in *all* affairs, the person under custodianship is automatically not allowed to take part in political elections.

The custodianship law still requires fundamental change to be in compliance with Article 12, but one thing is real: unlike a former guardian, a legal custodian is obliged usually to observe the will and preferences of the person represented.

– Klaus Lachwitz

Organizations such as **Asdown (Colombia), Asociación Azul (Argentina), CONFE (Mexico), and FEPAPDEM (Ecuador)** in the Americas are building ways to support people with intellectual disabilities to decide on the issues that impact their lives. Initiatives and activities include: promoting individual self-advocacy; raising awareness with people with intellectual disabilities about their rights; involving people with intellectual disabilities in the organizations' governing bodies; understanding the role of supporters and personal helpers; and, increasing participation in political and civic engagement.

IHC in New Zealand is engaging in a layered educative program of work with families, disability support providers, legal professionals and community organizations to encourage an increased understanding of human rights obligations that support decision making and facilitate best practice innovations based on common sense approaches. Families have shown a great need for accessible, reliable and relevant information and to have discussions about advocacy issues impacting on their lives. IHC heard repeatedly that locating appropriate and accurate information is difficult.

"Advocacy to the Heartland Forums" is part of the ongoing advocacy work of IHC. In 2013-2014, the advocacy team has delivered a total of 37 family, staff and community forums in 18 towns and cities across New Zealand to a total of over one thousand people. The goal is to educate families, people with intellectual disabilities, and community organizations about alternative approaches to formal legal orders, e.g. having joint signatories on bank accounts, or becoming an agent or nominated person for benefits or tax issues. IHC encourages families to ask "What is the problem I am trying to solve?" before they seek substitution decisions and provides alternative ways to support people without invoking the formal legal provisions[4].

Processes, Practices and Protocols

It is not always clear how organizations assure themselves and others that they are respecting the will and preferences of people with intellectual disabilities, despite their professed commitment to do so, other than the pursuit of person-centred planning. For example, many organizations do not appear to have developed specific policies or protocols for managing conflicts between the stated will and preference of individuals and those of the individuals' families. While organizations may recognize the value and need to help build inclusive communities, the practical tasks involved in doing so are relatively under-developed compared with those involved with providing support to individuals.

'Being the Change'

Organizations are striving to implement often deep and profound changes: at the level of governance (in particular to increase the involvement and influence of people with intellectual disabilities); organizational culture; in redefining organizational purpose and role; developing new operating models; investing in new staff skills; building new external relationships; and, finding ways to measure effectiveness and impact in order to align with the new paradigm outlined earlier in this chapter. These organizations are very often seeking to entirely reform themselves. Such change requires strong and visionary leadership, including the management of multiple competing interests from parents, self-advocates, staff, the community, and politicians. Sometimes it may be that such change is unachievable, in which case there may be reason to establish entirely new entities.

The Influence of Government, Funders, the Law and Public Attitudes

Organizations do not work in a vacuum and cannot work entirely against the grain of government policy, the priorities and preferences of funders, outside the structures of the law, or, without regard to prevailing social attitudes. Learning how to influence these is critical if organizations themselves do not wish to become a block to progress.

While some organizations have been successful at reinventing themselves and responding to both the changing needs and context of our work, for others the challenge has been to even understand the need for change. Achieving the right to decide for people with intellectual disabilities will require transformation of the way in which family based organizations provide support. Whether a service providing organization, an advocacy organization, or some combination of both, community organizations have a key role to play as change agents in achieving the Right to Decide.

Table 10: The Role of Family Based/Community Organizations in Advancing the Right to Decide

In Advancing the Right to Decide, the Role of Family Based/Community Organizations includes:	
Support to families	• Information and learning opportunities • Respite • Access to community supports and services • Advocacy
Support for self-advocacy	• Empowerment • Information and learning opportunities • Facilitation and support to self-advocacy groups
Community facilitators/change agents	• Community connectors: bringing people together • Building networks and relationships with employers and professionals in education, health, finance, and legal systems • Opening doors • Public Awareness
Campaigning and advocacy for policy change	• Public policy engagement • Litigation and grievance advocates

While these organizations that were founded by families have evolved in different ways, they have a unique and critical role to play in both creating decision making supports and in acting as community change agents. In order to be effective, this role requires investment and support from Governments. The implementation and realization of the right to decide will require the transformation of supports and investment in organizations that can help to build and strengthen inclusion in the community.

PART III
MOVING FORWARD

CHAPTER

8

Issues in Implementation

CHAPTER 8:

Issues in Implementation

There is increasingly wide spread acceptance of the idea that people with intellectual disabilities can make decisions in their lives and have the right to act on those decisions. At the same time, we heard from self-advocates, families, friends, and organizations that provide support about their concerns and confusion regarding how to respect the right to make decisions in difficult situations.

In response to the Draft General Comment on Article 12 prepared by the UN CRPD Committee of Experts, governments, disabled persons organizations, academics, and family led groups submitted comments[1]. A number of questions and challenges were identified in these submissions that echo the concerns raised by our members as we contemplate our role in the implementation of the right to decide:

Awareness, Accessibility and Understanding

Since the effective implementation of Article 12 depends on families, self-advocates and communities making changes to the way people are enabled and supported to exercise their decision making, there is a need to make the text of the Article more accessible and understandable and to develop practical examples of supported decision making in everyday life. Beyond the technical language of legal capacity and substitute decision making rights, how do self-advocates and families understand this right? What tools exist to provide support in decision making? How do we scale up practical understanding, to include local governments, employers, policy makers, service providers, community organizations, etc.?

In most parts of the world there are few, if any, supports to develop and raise up the voice of people with intellectual disabilities. Development of self-advocacy groups is important both to help individuals become empowered to express their own preferences and to have control in their lives, and to ensure that the collective voice of people with intellectual disabilities can be heard in processes that impact on their lives. Families also are looking for tools and supports to build support networks that enable their family member to grow and take charge of their lives. Sometimes there are very basic ways in which families can recognize the will and preference of their family member, but they need help to build networks and supports in the community and also struggle to figure out how to support more complex decision making.

As people with intellectual disabilities increasingly live in community, models and examples of support are developed and become more prevalent. Yet there are few processes for sharing these models and examples or having them recognized as legitimate by others in the community (e.g., doctors, employers, service providers).

The Capacity to Act

Governments and policy makers require further clarification on the distinction between legal capacity and mental capacity: the legal standing to have rights and the legal protection to act on those rights. The very status of people with intellectual disabilities as persons before the law has been challenged through laws that directly exclude them from the right to vote or to sign an employment agreement, for example. (This concept of "personhood" is explored in more detail in Chapter 4). Even where the right of persons with intellectual disabilities to hold rights is established and respected, people continue to be denied the right to act.

The Committee of Experts points out that legal capacity and mental capacity are often combined and that limitations in a person's decision making abilities are often used to deny the right to make decisions.

In most of the State party reports that the Committee has examined so far, the concepts of mental and legal capacity have been conflated so that where a person is considered to have impaired decision-making skills, often because of a cognitive or psychosocial disability, his or her legal capacity to make a particular decision is consequently removed. This is decided simply on the basis of the diagnosis of an impairment (status approach), or where a person makes a decision that is considered to have negative consequences (outcome approach), or where a person's decision-making skills are considered to be deficient (functional approach). The functional approach attempts to assess mental capacity and deny legal capacity accordingly. (Often based on whether an individual can understand the nature and consequences of a decision and/or whether she/he can use or weigh the relevant information.) This functional approach is flawed for two key reasons. The first is that it is discriminatorily applied to people with disabilities. The second is that it presumes to be able to accurately assess the inner-workings of the human mind and to then deny a core human right – the right to equal recognition before the law – when an individual does not pass the assessment. In all these approaches, a person's disability and/or decision-making skills are taken as legitimate grounds for denying his or her legal capacity and lowering his or her status as a person before the law. Article 12 does not permit such discriminatory denial of legal capacity, but rather requires that support be provided in the exercise of legal capacity[2].

While the Committee clearly explains that a person's decision making skills are not legitimate grounds for denying his or her legal capacity, many governments and support providers are seeking further clarification and direction on how to support people to exercise legal capacity in different ways.
In their submission to the Committee, the Canadian Association for Community Living offers one approach:

"we believe there are substantially different ways of exercising legal capacity and that States parties must recognize these. We believe that maintaining in law a distinction between exercising one's legal capacity legally independently and exercising it with the support of others who are legally recognized to provide that support, is crucial. ...[]...

First, some people with intellectual disabilities make their decisions legally independently, provided they have the supports (plain language, informal assistance, communication technologies, etc.) and accommodations in the decision making process by third parties that may be required to demonstrate they can understand and appreciate the nature and consequences of a decision. This group can be vulnerable in exercise of their legal capacity because they lack the supports and accommodations needed to demonstrate to others that they can act independently.

Other people with more significant or 'profound' intellectual disabilities will require other persons (decision-making supporters) who can understand their unique forms of communication to assist them in developing their will and preferences, and to translate them into particular actions and decisions which enable the person to exercise legal capacity. We attach the term 'supported decision making' uniquely to these types of arrangements. This group is particularly

vulnerable to the imposition of decisions by others whom they require to interpret their will and preference. Such persons may be trusted family, friends and service providers – who provide support with the best of intention but in a way that may end up reproducing paternalism in the interests of protection[3]*."*

Recognition of the difference between people's decision making abilities is not discriminatory, just as it is not discriminatory to recognize people's different sensory or mobility abilities and needs. The challenge is to ensure that people's rights are not compromised in meeting needs in different ways.

For example, in our consultations many self-advocates expressed the need to distinguish between situations when a person can clearly say that they can make their own decisions 'by themselves' and situations where support persons play the primary role in interpreting a person's unique form of communication. In formal or legal relationships and transactions, doctors, lawyers, bankers, and other professionals will need to be assured that the individual understands the nature of the decision and can appreciate the consequences. For situations where people require support persons to interpret their will and preferences and translate those into legal agreements or informed consent, governments must ensure access to legally recognized decision making supporters and safeguards to protect against and respond to financial and other forms of abuse.

Safeguards

As different tools (both formal and informal) are developed to enable supported decision making, concerns have been raised about the potential for misuse or abuse, or situations where there are conflicting interpretations of the person's "will and preference", or where those providing support impose their own will on a person.

Article 12 (4) specifies that *"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*

Where, after significant efforts have been made, it is not practicable to determine the will and preference of an individual, 'best interpretation of will and preference' must replace 'best interests' determinations. This respects the rights, will and preferences of the individual, according to Article 12 (4). The 'best interests' principle is not a safeguard which complies with article 12 in relation to adults. The 'will and preference' paradigm must replace the 'best interests' paradigm to ensure that persons with disabilities enjoy the right to legal capacity on an equal basis with others.

All people risk being subject to 'undue influence' yet this may be exacerbated for those who rely on the supports of others to make decisions. Undue influence is characterized where the quality of the interaction between the support person and the person being supported includes signs of fear, aggression, threat, deception or manipulation. Safeguards for the exercise legal capacity must include protection against undue influence – however the protection must also respect the rights, will and preferences of the person, including the right to take risks and make mistakes[6].

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[4]."

While Article 12 outlines the nature of the safeguards to be put in place, there is a need to elaborate and share specific mechanisms and safeguards to ensure that supported decision making arrangements are recognized, accommodated, and supervised:

- ***Legislated duties for support persons***
  While informally people may chose supporters who help interpret their will and preference, a process for recognizing in law or policy the role and duties of support persons will ensure recognition of the legitimacy of decisions made with support and provide a measure of protection to individuals from misrepresentation or imposition of the will of the support person(s).

- ***A process of appointing support persons***
  By establishing a formal process for appointing support persons (or a circle/network of support) we can ensure that the appointed support person(s) is in a trusting relationship with the individual.

- ***Processes to adjudicate disputes***
  In order to address situations where there are disputes about who is to be a decision making supporter or how to interpret will and

preference, a process for adjudication is needed. A dispute resolution process may take different forms but should be independent and mandated to resolve disputes on the basis of interpreting the will of an individual rather than "best interest"[5].

Communication

One of the major challenges identified by families in our focus group discussions was how to determine the "will and preference" of individuals who do not (or cannot at specific times) speak nor communicate through other means. This demonstrates a need for:

- expanding and sharing models and training in assisted communication;
- building a profile and record that reflects the will and preferences of a person over time; and,
- advocating for the use of the best interpretation of will and preference as opposed to the best interest test.

Supported Decision Making in Difficult Situations

Families and supporters also expressed the need for further guidance on how supported decision making can be practically applied, particularly in 'difficult situations'. We heard that these 'difficult situations' sometimes include: co-occurring disabilities or mental health; involuntary treatment; restrictive practices; detention; psychiatric treatment; complex health situations; persons with significant support needs; etc. In our consultations with communities that were developing innovative approaches to supported decision making, we heard about different ways in which a person's "will and preferences" were recorded, tracked and illustrated through different parts of their lives. This "life record" provides a "living expression" of the person by those who know him or her and can be a tool for support networks to use in interpreting their will and preference in different circumstances. However, for most people these tools have not yet been developed and even where they exist they may not

provide clear direction in difficult circumstances. In recognition of these types of situations, some have proposed the "best interest interpretation of will and preference".

In recognizing the reality of such situations, we recommend that GC advance the notion of 'best interpretation of will and preference' to replace the best interest test for application in these situations. Such a test would recognize that will and preference cannot always be interpreted with certainty, but that there are always better interpretations than others. Further, to guide that States parties abide by such a test in facilitating the making of needed decisions for a person in such a situation. In effect, this would be a third way that persons could exercise their legal capacity where no provision of support is available that could enable a person to clearly direct decision making. CACL has termed this way of exercising legal capacity 'facilitated' decision making to provide a basis on which to terminate substitute decision making regimes, and at the same time provide for the greater safeguards States parties should be obligated to provide in such situations[7].

While it is critical that processes for adjudication and facilitation be established to assist in these situations, these examples of exceptional circumstances cannot be used as the basis for denying the legitimacy of supported decision making processes.

Supports in the Community

For people who have been isolated and segregated either in institutions, in segregated programs, or because of supports in the community that continue to "institutionalize", the removal of substitute decision provisions such as guardianship alone does not automatically result in the realization of the right to decide. For the majority of people with intellectual disabilities, the supports that are required to enable decision making have been denied over time. The development of relationships beyond family and/or service providers in the community will require community development strategies and investments. This will mean significant changes to the way direct supports are provided and funded by governments and investments in processes to build and recognize the support networks in people's lives.

While there have been several important legal decisions that reinforce the right to exercise legal capacity in different jurisdictions, the expansion of the right to legal capacity and recognition of alternatives to substitute decision making by courts must be accompanied by practical strategies to demonstrate supported decision making in practice.

The protection of legal capacity under the CRPD is beginning to carry weight in the courts even in countries which have not yet ratified it. For example, in the Surrogate court of New York, United States, Justice Kristen Booth Glen terminated the guardianship of a woman with an intellectual disability after being convinced that the woman's husband, extended family, neighbours and community agencies were providing with sufficient support for her to make her own decisions. With that support, Dameris, L. had blossomed from a retiring young woman lacking confidence to become a successful and caring wife and mother. In terminating the guardianship Judge Glen wrote that "While the CRPD does not directly affect New York's guardianship laws, international adoption of a guarantee of legal capacity for all persons, a guarantee that includes and embraces supported decision making, is entitled to "persuasive weight" in interpreting our own laws and constitutional protections."[8]

Progressive Realization

Legislators and community activists have debated whether Article 12 should be subject to "progressive realization" which would allow for the gradual implementation of the right to legal capacity. The disability community is suspicious of calls for "progressive realization" as it implies governments are avoiding or postponing reforms of a fundamental right. In some countries legislative reform of substitute decision making laws has been touted by governments as meeting their immediate obligations, but these reforms often fall short of the full realization of Article 12 or have been instituted without corresponding investment in supported decision making mechanisms. In other jurisdictions where the process of reform is being initiated through changes at the community level in the refusal of guardianship applications, development of support networks, development of self-advocacy, and/or awareness raising with families, there is a still a lack of recognition in law of supported decision making.

As governments, policy makers, community organizations, families, and self-advocates themselves have begun to contemplate their role in the implementation of Article 12, there is increased recognition of the complexity of the reforms which are required to realize these rights. There must be a process in place to create a shared agenda for reform and establish benchmarks and monitoring for implementation.

Recommendations and Conclusion

Recommendations and Conclusion

In the short time since the CRPD has come into force, there has been a significant increase in the awareness of governments and communities of the human rights of people with disabilities and specifically, of the right of people with disabilities to make decisions about their own lives. As we heard from self-advocates, families, friends and allies around the world in our Global Campaign on the Right to Decide, for people with intellectual disabilities the realization of this fundamental right will require: attitudinal change; transformations in the way supports are provided by governments and communities; legislative reform; public policy transformation; and, the development and recognition in law of supported decision making networks and processes.

Key Findings and Policy Recommendations:

Investment in Empowerment, Self-Advocacy and Strengthening a Collective Voice

The fact that people with an intellectual disability are denied the right to decide in their own lives also means that the collective voice of people with intellectual disabilities is not heard in broader public policy decisions. While we have seen increased attention by civil society organizations and governments toward "self-advocacy", there has been little discussion about the different strategies needed to support the empowerment of individuals who have never been given the opportunity to express their "will and preference", to give people a voice in decision making about their lives, and to enable the collective voice of people with intellectual disabilities to be heard in public

policy, community action and organizational governance. The kinds of support and facilitation required to enable a person to express their own likes, dislikes and preferences is very different from that required to build the collective voice of groups of people.

Recommendations:

- Develop decision making supports
- Support choice and control in services and supports for persons with intellectual disabilities and their families
- Expand supports for engagement and inclusion in the community
- Increase support and facilitation for the collective involvement of persons with intellectual disabilities: "self-advocacy"

Independence Does Not Mean "Alone"

So much of the emphasis in the negotiation and promotion of the CRPD by the cross disability movement has been on the concept of independence and autonomy. A result of the disempowerment experienced by people with disabilities and the need to reclaim control in their lives, this is also a result of a cultural bias that values individualism. The effect on people with intellectual disabilities and their families has been to create an artificial standard for "acting alone".

Article 12 (3) requires governments to *"take appropriate measures to provide access by persons with disabilities to the support they may require in exercising their legal capacity*[1]*."* Yet we heard from self-advocates and families that there is little understanding by legislators, policy makers and community that those supports are in fact relationships that need to be fostered and developed and ultimately recognized in law.

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[2].

For our member organizations this underlines the importance of their role in supporting individuals to access and develop relationships in the community, and facilitate community development (building relationships with educators, employers, etc.).

Recommendations:

- Invest more time in developing social relationships by organizations which provide supports to people with intellectual disabilities

- Recognize in law supported decision making mechanisms and processes

Families have a Critical Role to Play in Building the Social Connections Necessary for Supported Decision Making

For the majority of people with intellectual disabilities, families are their first and primary source of support in being enabled to exercise the right to make decisions. Yet families have been cast in the role of caregivers, substitute decision makers, and protectors. For many, the experience of being rejected by their communities, turned away by schools, and denied supports and services has left families suspicious and distrustful. Some families have sought guardianship orders to plan for the financial future of their family member, access services and supports from government, and protect "the best interest" of their family member with an intellectual disability. Making the shift from being protectors to enablers – from substitute to supported decision making – is more than semantics. It is both a fundamental change in the role that families are expected to play and provides potential reassurance to families that their family member can be supported to have control and choice in their life.

Recommendations:

- Increase information and support for families to learn how to build and maintain support networks
- Assist in the facilitation of support networks
- Prevent guardianship as a professional default for access to financial, legal, and/or medical services

Community Family Based Organizations must play a Leadership Role as Agents of Change in Community

The organizations that were formed by families at the community, national and regional levels over 50 years ago to fight for needed supports and services have evolved into a global network of organizations that play an array of roles: advocacy; awareness raising; campaigning; human rights; service provision; community development; family support; and self-advocacy groups. At their heart, these organizations – our members – have as their mission the goal of supporting people

to be included in society and to have their will and preference respected. Financial support for family based organizations received from governments, where it exists, is often tied to the provision of services: in some countries we have seen restrictions by governments on the advocacy and campaigning activities of these organizations. At the same time as services available to people are being cut back, the capacity of the organizations who support and act as the voice of people with intellectual disabilities is being eroded. In countries where there is little or no publicly financed social support infrastructure, organizations rely on charitable giving and development funding to play complex roles as both support and advocacy organizations. For all family based community organizations there is a delicate balance to be struck in responding to the demands of funders in order to sustain the capacity to provide supports while serving the needs of people with intellectual disabilities and their families. While this tension is not new, the adoption of Article 12 creates an obligation on governments to provide access *"to the support [people with disabilities] may require in exercising their legal capacity."* The best resource available to governments in shaping and providing this support is through the organizations that were established by families and self-advocates themselves.

Recommendations:

- Governments must invest in the multiple roles of family based organizations: supports to individuals; family support; community development; advocacy; and public awareness

- Develop training for support workers to shift from "care givers" to "facilitators/community outreach workers"

- Invest in on-going training of support workers to provide person-centred planning and supports

The Right to Decide Cannot be Achieved Without Community Inclusion

Throughout the campaign we heard from professionals, parents and service providers who believed it was necessary to continue to provide segregated services because people who have an intellectual disability might "choose" those settings and might be "more comfortable" in environments with other people who have a disability. In fact there were people who have only experienced segregated settings who said, "I like my workshop" or "I like my group home". However, there was no one whom we spoke to who was living in a more inclusive environment and wanted to be segregated. In places where we have little or no say about when we eat, when we go to bed, what we wear or how we spend our money, there is no opportunity to build our capacity to express our preferences.

In these circumstances, simply removing someone from guardianship does not resolve the problem – the person also may have no support network. Increasingly we are seeing the misuse and appropriation of the language of Article 12 to justify existing practices or to "rename" substitute decision making practices as supported decision making. One very dangerous example of this has been the introduction of the term "person-centred guardianship". Without the opportunity to live and be included in the community, real choice and support in decision making is not possible. The actual challenge is to develop strategies that support people who have been segregated and isolated in building networks, relationships, and support in the community.

Recommendations:

- Restructure segregated housing, employment, and other services and supports which group people with intellectual disabilities together into inclusive and individualized supports using person-centred planning

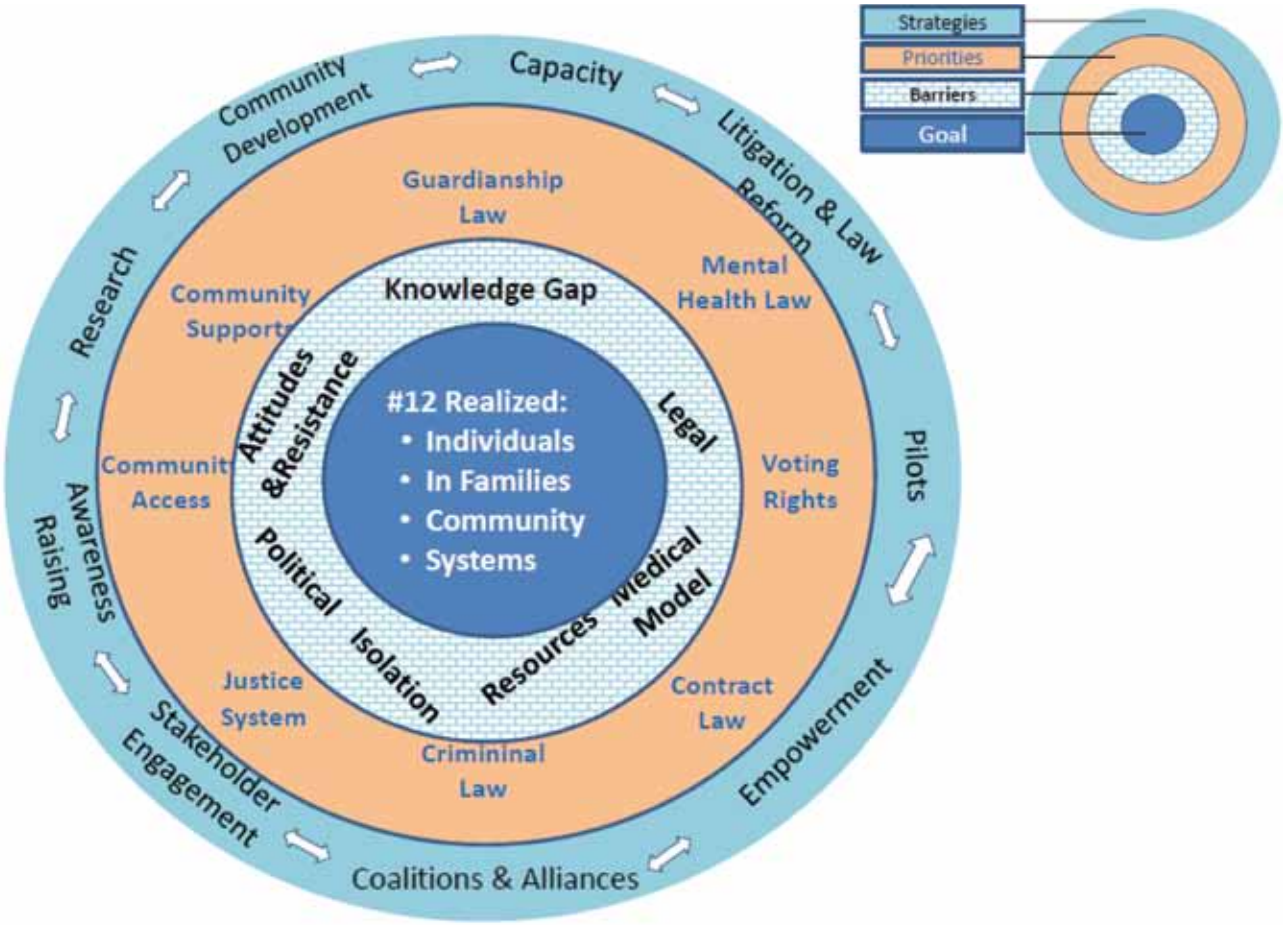
- Families, service providers, and policy makers develop strategies to build networks for persons with intellectual disabilities in community

The Right to Decide is about More than the Removal of Guardianship and Substitute Decision Making

In addition to the significant legal reforms and the corresponding development of supported decision making mechanisms, there is a much broader set of implications of the right to decide. As outlined in Chapter 3, Article 12 of the CRPD requires a broad reform agenda which includes: access to justice; employment law and practices; access to health care and training of medical practitioners; reform of finance sector (banking and contract law) practices; education systems; direct support services systems, etc. In countries where formal substitute decision making mechanisms do not exist, there is an informal acceptance of substitute decision making practices. In those countries and in countries were substitute decision making mechanisms are recognized in law, the removal of both formal and informal provisions alone will not achieve the transformation required to realize the right to make decisions.

Figure 1 was developed from a facilitated discussion of experts from countries around the world regarding advancing the implementation of Article 12[3]. Showing the numerous strategies, priorities, and barriers in realizing the right to decide, it also affirms the need for broader agenda.

Figure 1: Change Framework for Advancing Article 12



Recommendations:

- Establish processes of legislative and policy review at the national and state/provincial/municipal levels to develop a reform agenda, in consultation with disabled persons organizations and other community stakeholders

Legal Reform Must Go Hand in Hand with Strategies for Building Community Supports and Supports for Decision Making

The experience of our members in promoting the right to live and be included in the community over the past twenty years has taught us that closing institutions is only one part of a larger process, which requires also the transformation of communities and the way in which supports are provided. **Likewise we know that the abolishment of plenary and partial guardianship and other forms of substitute decision making without corresponding investment in the development of supported decision making networks cannot achieve real progress toward the right to make decisions.** A legal reform agenda which includes the prevention and elimination of plenary guardianship must go hand in hand with a comprehensive, multi-stakeholder strategy for building supports in the community to develop support networks that are recognized in law, appropriate safeguards, and community development and outreach processes.

Recommendations:

- Restrict guardianship orders
- Develop a policy agenda to legally recognize personal support networks and supported decision making supporters
- Develop and enforce safeguards to protect against misuse or grievances within support networks
- Develop community outreach processes to work with employers, financial institutions, medical practitioners, lawyers, judges, and other identified professionals and community members

Table 11: A Shared Agenda for Achieving the Right to Decide

Governments
• Support choice and control in services and supports for persons with intellectual disabilities and their families • Increase support and facilitation for the collective involvement of persons with intellectual disabilities: "self-advocacy" • Recognize in law supported decision making mechanisms and processes • Support the restructuring of segregated services and supports to inclusive and individualized supports • Establish processes of legislative and policy review at all levels to develop a reform agenda, in consultation with disabled persons organizations and other community stakeholders • Place restrictions on new guardianship orders • Develop a policy agenda to legally recognize personal support networks or supported decision making supporters • Develop and enforce safeguards to protect against misuse or grievances within support networks • Prevent guardianship as a professional default for access to financial, legal, and/or medical services • Invest in the multiple roles of family based organizations • Invest in on-going training of support workers to provide person-centred planning and supports
Family-Based Organizations
• Support choice and control in services and supports for persons with intellectual disabilities and their families • Develop decision making supports • Expand supports for engagement and inclusion in the community • Increase support and facilitation for the collective involvement of persons with intellectual disabilities: "self-advocacy" • Become actively involved in building the social capital of the people they support • Restructure segregated services and supports to inclusive and individualized supports using person-centred planning • Develop strategies to build networks for persons with intellectual disabilities in community • Participate and support families to participate in the development of a reform agenda and other processes of legislative and policy review

Family-Based Organizations (continued)

- Develop and implement community outreach processes to work with employers, financial institutions, medical practitioners, lawyers, judges, and other identified professionals and community members
- Participate and support families to participate in the development of a policy agenda to legally recognize personal support networks and supported decision making supporters
- Participate and support families to participate in the development and implementation of safeguards to protect against misuse or grievances within support networks
- Provide information and support for families to learn how to build and maintain support networks
- Assist in the facilitation of support networks
- Develop training for support workers to shift from "care givers" to "facilitators/community outreach workers"
- Provide on-going training for support workers to provide person-centred planning and supports

Families

- Contribute to the development of decision making supports based on the needs and abilities of their family member
- Help to build networks for persons with intellectual disabilities in community
- Demand choice and control in services and supports for persons with intellectual disabilities and their families
- Work with support workers to shift from "care givers" to "facilitators/community outreach workers"

Self-Advocates

- Contribute to the development of a collective voice for self-advocates at the national and international level
- Provide leadership and direction in setting an agenda for reform that respects the voice of people with intellectual disabilities

Inclusion International undertook the development of this report as part of a broader campaign to bring our voices and aspirations for the right to decide in our own lives – as people with intellectual disabilities and families – to broader civil society organizations in the disability and other sectors, and to governments and international agencies. For too long, our voices and our possibilities to contribute to society have been denied. Building on our earlier global reports – on ending poverty, inclusive education, and the right to live in the community – the findings in this report clearly demonstrate that these other widely shared goals cannot be realized without recognizing, respecting, and supporting the equal right of people with intellectual disabilities to direct their own lives in the context of their families and communities. This requires going beyond the usual notions of autonomy as isolated individualism and independence to fully grasp the essential *interdependence* of all of us. It requires shared effort, resourcing, responsibility, and accountability to build the culture, organizations, community supports and government policies and practices that will enable people with intellectual disabilities to take their rightful place in society, in their own voice and on their own terms. We look forward to working with partners local to global to make this vision a reality in law, policy and practice in communities and nations around the world.

APPENDIX 1

Contributions to the Global Report on The Right to Decide

EVENT	COUNTRY/REGION	ORGANIZATION	CONTRIBUTION
Inclusion Africa Regional Meeting Nairobi, Kenya	Kenya, Zimbabwe, Ethiopia, South Africa, Namibia, Uganda, Zanzibar, Canada, Lesotho, USA, Ghana, Mauritius, Benin and Malawi	Inclusion Africa Members	Discussions on the Right to Decide and a Roundtable on Access to Justice
Inclusion MENA Regional Meeting Sharjah, United Arab Emirates	Bahrein, Dubai, Egypt, Iraq, Jordan, Kuwait, Lebanon, Libya, Mauritania, Palestine, Sharjah, Tunisia, Yemen	Inclusion MENA Members	Discussions on the Right to Decide and citizen engagement
Inclusion Europe Self-advocates Conference Zagreb, Croatia	Belgium, Bosnia and Herzegovina, Canada, Croatia, Czech Republic, Finland, France, Hungary, Lebanon, Macedonia, Republic of the former Yugoslav Republic of Moldova, Norway, Poland, Portugal, Romania, Serbia, Slovenia, United Kingdom, United States	Inclusion Europe self–advocates	
Webinar on The Right to Decide	Argentina, Bolivia, Canada, Switzerland, Colombia, Ecuador, Nicaragua, Mexico, Peru, Spain	Inclusion Inter Americana	
Webinar on Self-advocacy	Argentina, Bolivia, Canada, Colombia, Check Republic, Ecuador, Nicaragua, Mexico, Peru, Portugal, Spain	Inclusion Inter Americana	**Best Practices from:** Asdown Colombia, CONFE Mexico, Asociación Azul Argentina, FEPAPDEM Ecuador and Inclusion Europe

EVENT	COUNTRY/REGION	ORGANIZATION
Group Discussions	Argentina	APAD – Asociación de Promoción y Ayuda al Discapacitado, Argentina ASDRA – Asociación de Síndrome de Down de la República Argentina Asociación Azul
	Bolivia	CEINDES – Centro de Investigación para el Desarrollo Socio Económico
	Cambodia	Rose
	Chile	Colegio Educación Especial la Espiga Comuna Puente Alto
	Colombia	Asdown/Bogota Fundown Caribe/ Barranquilla
	Costa Rica	ASCODI – Asesorías y Consultorías en Discapacidad, Costa Rica CNREE – Consejo Nacional de Rehabilitación y Educación Especial de Costa Rica
	El Salvador	Paraíso Down Centro de Estimulación y Terapias
	Honduras	FENAPAPEDIS – Federación Nacional de Padres de Personas con Discapacidad de Honduras
	India	Parivaar – National Confederation of Parents' Organizations India
	Japan	Inclusion Japan
	Lebanon	LASA – Lebanese Association for Self-Advocacy
	Malawi	PODCAM – Parents of Disabled Children Association of Malawi
	Mexico	CONFE-Confederación Mexicana de Organizaciones a favor de la Persona con Discapacidad Intelectual, A.C Asociación para Autismo y Desarrollo Integral, A.C. Centro Cultural Xalostoc Centro de Adiestramiento Personal y Social, A.C Centro de Atención Múltiple del Estado de México No. 10 Centro de Educación Especial e Integración Social Kandinsky. S.C Centro de Habilitación e Integración para Invidentes, I.A.P. Construyendo Puentes Fundación Por Una Inocencia Feliz, A.C. Grupo Integración, A.C Integración Down Kadima Olimpiadas Especiales

EVENT	COUNTRY/REGION	ORGANIZATION
Group Discussions	Myanmar	School for Disabled Children, Yangon, Myanmar
	New Zealand	IHC
	Nicaragua	ASNIC – Asociación Nicaragüense
	Paraguay	APDIR – Asociación de Personas con Discapacidad,Padres y Amigos,Paraguay Asidown – Asociación Síndrome de Down, Paraguay FEPANE – Federación Paraguaya de Padres de Personas con Necesidades Específicas
	United Kingdom	People First UK
	Peru	Asociación Aquí Estamos, Patronato Peruano de Rehabilitación, Sociedad Peruana de Síndrome de Down
	Spain	FEAPS – Spanish Confederation of Organizations for Persons with Intellectual Disability, ANFAS-Asociación Navarra en favor de las Personas con Discapacidad Intelectual, FEAPS Cantabria, Ampros-Alumnos de Programa de Capacitación Profesional Inicial, ÁVASO-Autogestores veteranos, Grupo LÚPAR, Centro de Educación Especial Dr.Fernando Arce, FEAPS Comunidad Autónoma de Ceuta
	USA[1]	
	Zanzibar	ZAPDD – Zanzibar Association for People with Developmental Disabilities

EVENT	COUNTRY/REGION	ORGANIZATION
Personal Stories	Argentina	Asociación Azul
	Colombia	Red de Familias por el Cambio
	Bulgaria	BAPID – Bulgarian Association for Persons with Intellectual Disabilities
	Ecuador	FASINARM – Fundación de Asistencia Sicopedagógica para Niños Adolescentes y Adultos con Retardo mental
	Egypt	Help Center
	Hungary	ÉFOÉSZ – The Mental Disability Advocacy and the National Association of Helpers, Hungary (Értelmi Fogyatékossággal Élök és Segítöik Országos Érdekvédelmi Szövetsége)
	Japan	Inclusion Japan
	Mexico	CONFE
	Spain Barcelona	Fundación Catalana de Síndrome de Down SOM, Fundació catalana tutelar Aspanias
	Peru	Patronato Peruano de Rehabilitación

EVENT	COUNTRY/REGION	ORGANIZATION
Supporting Decision Making initiatives	Barcelona	Fundación Catalana de Síndrome de Down
	Bulgaria	BAPID
	Hungary	ÉFOÉSZ The experience gained in the supported decision-making pilot project in Tapolca
	India Kasargord and Kochi, Kerala	Parivaar
	Spain	FEAPS
	Taiwan	PAPID – Taiwan Parents' Association for Persons with Intellectual Disability
	USA	The Arc of Michigan
	USA	The Arc of San Angelo Texas

EVENT	ORGANIZATION
Survey	IHC KAIH – Kenya Association for the Intellectually Handicapped Chosen Power (People First Hong Kong) PAPID – Parents' Association for Persons with Intellectual Disability Taiwan AKIM – Israel Family and Community Services Inclusion Japan CONGO HANDICAP ASBL FADEMGA FEAPS GALICIA – Federation of Associations in favor of Persons with Intellectual Disabilities located by the four Galician provinces ANESM – National Agency for Evaluation and quality of institutions and social and medico-social France, Excellence in Action FEAPS Association for Help to People With Intellectual Disability in Slovak Republic MUSKAAN India Parents Association for empowering persons with intellectual disability Fundación Amanecer Fundown Caribe AFANIAS – Association for Persons with Intellectual Disabilities Spain FENAPAPEDIS CEINDES – Centro de Investigación para el Desarrollo Socioeconómico FASINARM FEPAPDEM CONFE

EVENT	COUNTRY/REGION	ORGANIZATION
Interviews	Canada	Community Living Ontario
	Canada	Inclusion British Columbia
	Canada	New Brunswick Association for Community Living
	Canada	Alberta Association for Community Living
	New Zealand	IHC
	United Kingdom	MENCAP
	Germany	Lebenshilfe Germany
	Mexico	CONFE
	USA	The Arc
	USA	NASDDDS National Association of State Directors of Developmental Disability Services
	Israel	AKIM

APPENDIX 2

Inclusion International Position Paper on Legal Capacity

The Convention on the Rights of Persons with Disabilities recognizes:

- that persons with disabilities have the right to recognition everywhere as persons before the law;
- that persons with disabilities enjoy legal capacity on an equal basis with others in all aspects of life;
- that States Parties shall take appropriate measures to provide access by persons with disabilities to the support they may require in exercising their legal capacity.

Background

For people with intellectual disabilities self-determination and full citizenship are fundamental principles that underlie the potential enjoyment of human rights. It is the presumption of legal capacity that makes it possible to exercise self-determination and full-citizenship.

Guardianship laws assume that some people do not have the capacity to make legally binding decisions and put in place substitute decision making provisions.

Supported Decision Making means a person may accept help in making decisions without relinquishing the right to make decisions. Supported Decision Making helps a person to

understand information and make decisions based on his or her own preferences. A person with an intellectual disability might need help with reading, or may need support in focusing attention to make a decision. A person who has no verbal communication might have a trusted person or people who interpret(s) their non-verbal communications, such as positive or negative physical reactions, or uses Alternative and Augmentative Communication.

Position

Inclusion International demands the right of every person with an intellectual disability to have their right to make decisions recognized and to receive the support they require in making those decisions.

The right to legal capacity includes the capacity to have rights and the capacity to act on those rights, i.e. the capacity to make legal agreements with others. The capacity to act is not only part of the legal capacity guaranteed in Article 12, it is the most defining part: the right to make decisions. The following provides some overarching principles and key elements to help guide the work of II members in their work to support the development of supported decision making models and in their work with their governments to advance the implementation of Article 12.

- Article 12 must be implemented as a part of the whole Convention. Other articles of the Convention impact on the right to exercise legal capacity
- All persons have a will which, with adequate support, can be discerned
- The right to support is required to exercise legal capacity
- Having support does not negate a person's full legal capacity
- Other parties have a duty to accommodate (doctors/lawyers/bankers/contractors, etc.)

- Appropriate measures means supports can take various forms both informal and formal and these must be tailored to the person's circumstances

- Presumption is that all people can exercise their legal capacity independently

- If the capacity to act independently is challenged in the context of legal relationships and contracts then the tests that would be applied on an equal basis with others should be disability neutral. Any test would question whether support and accommodations have been put in place and the responsibilities of other parties have been met.

In situations where supported decision making measures are not yet in place and a person's right to exercise their full legal capacity is not realized, states must take measures to develop and put in place supports to build capacities of communities to enable people to make decisions in their lives.

Where substitute decision making currently exists, reforming laws, policies and practices to be consistent with Article 12 and to implement supported decision making may take time. Immediate steps should be taken for law reform and provisions to limit substitute decision making including:

- Safeguards shall ensure measures taken respect the rights, will and preferences of the persons
- Acknowledge that all people have legal capacity
- All steps demonstrated to provide support
- Least restrictive to persons
- Only made for specific matter and that decision/moment
- Free of conflict of interest
- Apply for the shortest time possible
- Distinguish between the kinds of decision (financial/personal) and decision making processes
- Provision for the abolition of incapacity and a procedure to provide support in the exercise of legal capacity

APPENDIX 3

CONVENTION ACTION GROUP ON LEGAL CAPACITY

Designing Supported Decision Making Systems: A Guide For Dialogue

February, 2009

Introduction

Article 12 of the UN Convention on the Rights of Persons with Disabilities provides that States Parties shall recognize the full and equal legal capacity of persons with discrimination on the basis of disability. It also provides that States parties shall recognize the right to support in exercising legal capacity.

Recognizing the right to support may require putting into place new laws, policies, programs and administrative systems that make supported decision making available to people with intellectual and other disabilities. There are examples of some elements of a supported decision making system now in place in a few jurisdictions, and much that can be built upon.

Designing more comprehensive systems that fully implement supported decision making raises a number of practical design questions. Inclusion International wants to encourage public dialogue about how to design these systems and encourages experimentation and demonstration. We believe that culturally appropriate and context specific designs are necessary to respond to the unique legal traditions in different countries, and a range of civil society and governmental contexts.

To help foster public dialogue about the development of supported decision making systems, Inclusion International adopted a framework of principles and directions for development of supported decision making at its General Assembly in November 2008. The following document is

intended as a complementary 'Guide for Dialogue' in designing supported decision making systems. The purpose is to assist our member organizations, allied disability organizations, other civil society and professional groups, and governments to engage in public dialogue about how to design a supported decision making system. We believe that open dialogue is needed to ensure that such systems promote and respect the full and equal legal capacity of people with intellectual and other disabilities.

This Guide provides a set of questions that can be used to structure policy dialogue, analysis, research and design of effective and accountable systems for supported decision making.

Dialogue Questions

1. **What are the criteria in law and public policy for ensuring recognition of legal capacity and the right to support in personal decision making?**

   Article 12 requires States Parties to put into place measures that recognize full legal capacity without discrimination on the basis of disability. It also requires measures that recognize the right to support in making personal decisions. How is this recognition institutionalized in law and public policy? Is it through legislated statements of principle and recognition of these rights, revised criteria of legal capacity, and/or specific policy statements?

2. **How does support to exercise legal capacity, including the support provided through a personal supported decision-making network, get recognized?**

   Support should be provided appropriate to the support a particular individual requires to exercise their legal capacity. Appropriate supports can take many forms – like an interpreter, a communications device, information in plain language, or a trusted individual or network of individuals who assist a person in making decisions about personal care, health care, finances and property. Such individuals or networks can help to represent a person in making

agreements with others to give effect to these decisions (like a rental agreement to give effect to a decision to live in a certain place).

Because entering agreements with others is an exercise of legal capacity that brings rights and obligations to all parties involved, it is important to ensure that the particular individuals designated to assist a person in exercising legal capacity can themselves be officially and legitimately recognized. Other parties to the agreements need to know that it is a particular individual or network that is designated – to avoid any conflicts over who is authorized to assist and/or represent a person with a disability in making a legal agreement with others.

In designing a supported decision making system, therefore, it is important to ask how a supporting individual or network will be recognized. Is the recognition made informally, through an agreement between an individual and his/her network? Or is a more formal approach used – i.e. going to a lawyer or the court to have the supporting individual/network officially recognized.

3. **Where does a person, or their supporters, go to get assistance in developing a supported decision making network?**

People with disabilities who may require assistance in decision making are often isolated in their communities, or are living in institutional settings with little contact with others. Many live with aging parents or family members who are concerned about the future of their family member with a disability, after they are no longer able to provide any assistance at all. Developing a network of trusted people to provide decision making assistance and representation in a way that supports and maintains a person's legal capacity usually takes intentional effort.

Having people who are 'trusted' by a person with a disability is essential to good representation and supported decision making. For people who have been isolated much of their lives, the first step may be to develop trusting relationships with others. Some kind of facilitation of such relationships is

needed, and this takes time and resources to make happen. Once these relationships are in place, people will also need information and back-up about how to put supported decision making in place, how to mediate conflicts that might arise in a supported decision making network, and how best to represent a person and assist them in making decisions, without becoming a substitute decision maker.

What are the options for providing this kind of facilitation and assistance in developing and maintaining trusting personal relationships and supported decision making networks? Is an existing community resource available? How would this resource be funded and made widely available to meet States' Parties obligations to ensure such supports are in place? Ideally, such a resource would be non-governmental and free from any conflict of interest in providing assistance.

4. How is a support network monitored?

Ideally, a supported decision making network is based on ongoing trusting, caring relationships of support and assistance. However, in designing a system it is important to acknowledge that such human relationships can break down. There is much evidence to suggest that people with disabilities are much more likely than most other groups to experience violence and abuse at the hands of others, and that this is most often by people who are close to them. It is important therefore to put in place a system of independent checks and balances, so that people with disabilities can be protected from support network members who would use their status in a recognized support network to abuse a person or take advantage of their property or financial resources.

How are support networks monitored? How are monitors appointed, and what is the range of their authority? What is the system of checks and balances?

5. **Where do people go when they have concerns that a person is being neglected or abused by a support network?**

   To what body does a monitor go, when they are concerned that a person may be at risk of abuse by one or more supported decision making network members? Beyond formally designated monitors, what options, and what responsibilities, do others have in reporting suspected abuse of a person by their network? Is reporting of suspected abuse mandatory, or voluntary? And what steps are taken, by what authorities, to respond to these reports?

6. **Where does a third party (like a physician, bank, etc.) go when they are concerned that they are not getting a valid consent through a supported decision making process?**

   Supported decision making enables full legal capacity. However, this way of making decisions may be new for physicians, housing authorities/landlords, lawyers, or financial or other professionals who are used to entering an agreement with or receiving consent from an individual who are seen to act by themselves. When a support network is involved, which may be required to represent a person and interpret their unique form of communication, third parties in these decision making processes may legitimately wonder if the agreement they enter with a person, via the representation of a supported decision-making network, is indeed a valid one.

   Where do third parties go when they want validation that the representation by the supported decision making network of an individual's wishes and intentions is an adequate basis for entering an agreement with the individual? Third parties have a legitimate interest and concern in doing so, in order to protect against any liabilities in entering an agreement that might later be declared null and void on the basis that the individual was misrepresented by their network. Individuals with disabilities also have an interest in making sure that the other party is fully confident in making an agreement with them.

7. **How are the liabilities of the support network members protected, for the advice they give to an individual, or the representations they make on behalf of an individual in entering an agreement with others?**

   Potential support network members may feel hesitant to become formally recognized as supported decision-making network members, if they feel that they may become personally liable for an agreement entered on behalf of an individual. What are the ways in which support network members can protect against such liabilities?

8. **How does a person revoke a representation agreement with a support network, or a member of a support network (i.e. terminate the role of a supporter in representing an individual)?**

   Relationships with support network members may change over time. Some members may pass on, or leave the network for personal reasons. An individual may wish to end the relationship with one or more of the network members, or an individual may develop new relationships with other people whom he/she may want to include on the network. Therefore, it may be necessary to change from time to time the individuals who are recognized members of the supported decision-making network. How does an individual revoke the designation of some or all network members and appoint new ones? What are the steps required?

9. **What is the way/the process by which someone that is under guardianship can shift to a supported decision making status?**

   Supported decision making provides a person with a legal status (i.e. full legal capacity) that is distinct from substitute decision making. Therefore, it is important to ask in designing a system how people who are currently under the legal status of guardianship, can regain full legal capacity by having a supported decision making network in place. What are the steps? At what point does the transition from one legal status to the other take place, and how is it authorized?

10. What happens if a person with a disability wants to be recognized as capable of exercising legal capacity without assistance or support of others?

Some people with disabilities may feel they do not need others to assist them in making decisions, and do not want a formally recognized supported decision making network. It is essential to respect the right of individuals to exercise their legal capacity individually – that is, without the formally recognized assistance of others. A supported decision making network should not be forced on anyone. This would violate the basic principle of respect for autonomy that the right to legal capacity is based upon.

At the same time, the banker or physician with whom a person with a disability may want to enter an agreement or give legal consent to, may feel that the person cannot exercise their legal capacity without the support of others. They may be unwilling to enter an agreement with that person, or accept their consent for health care, unless others are also involved to support and represent the person in making that decision. It is important to recognize that no one can force another party to enter an agreement with them, or force a physician to accept their consent for health care, if that party firmly believes the person requires decision making assistance to exercise their legal capacity.

What are the ways in which these differences can be resolved? Where does an individual go to seek recognition that they can exercise their legal capacity individually, if others refuse to enter agreements with them? What happens if the appointed authorities disagree that a person can exercise their legal capacity without support from others? Can arrangements be made so that a person can access support on a one-time basis, for a particular decision, in order to enter a specific agreement?

11. **What are the administrative systems for managing supported decision making at a state-level (registration of representation agreements, court proceedings, authorities, etc.)? What authorities are responsible for design, implementation and management? Who is responsible for what costs?**

    Questions 1-10 above will be answered in different ways depending on the context. However, they do make clear that various systems will be required for designating, authorizing, monitoring, validating, and changing relationships and decision making processes associated with supported decision making. As these questions make clear, there will be many interacting elements in the design of a supported decision making system. Some broad administrative guidelines will be needed. As well, forms and systems for managing the various activities, documentation and authorizations associated with the system will be required.

    What are the various administrative structures in place for the various steps and interactions associated with supported decision making? What is the budget required, and who is responsible for designing and implementing the needed systems?

END NOTES

Chapter 1

1 http://inclusion-international.org/hear-our-voices-people-with-an-intellectual-disability-and-their-families-speak-out-on-poverty-and-exclusion

2 http://inclusion-international.org/better-education-for-all

3 http://inclusion-international.org/living-in-community

4 http://inclusion-international.org/the-right-to-decide-about-the-campaign

5 http://inclusion-international.org/the-right-to-decide-campaign-overview

6 http://inclusion-international.org/the-right-to-decide-why-does-it-matter

7 http://inclusion-international.org/the-right-to-decide-background-information-on-decision-making

8 http://inclusion-international.org/the-right-to-decide-discussion-group-facilitators-guide

9 http://inclusion-international.org/reporting-on-organizational-activities

10 http://www.ohchr.org/EN/HRBodies/CRPD/Pages/DGCArticles12And9.aspx

11 For more information, see Chapter 7.

Chapter 2

1 Michael, J. (2008). *Healthcare for all Report into access to healthcare for people with learning disabilities.*

2 Czech Republic, Civil Code, 1 January 2014, Art. 49–55.

Chapter 3

1 Mental Disability Advocacy Center. (2014). The Right to Legal Capacity in Kenya, page 46.

2 Inclusion Ghana. (2013). Access to health care for persons with intellectual disabilities in Ghana: Mapping the issues and reviewing the evidence. http://www.inclusion-ghana.org/reports.php

3 Decision C-133/14 – Press Release No.08

4 Decision C-133/14 – Press Release No.08

5 European Commission on Democracy Through Law (Venice Commission). (2010). *Information Note Concerning the Interpretative Declaration to the Code of Good Practice in Electoral Matters on the Participation of People with Disabilities in Elections.*

6 Inclusion Europe. (2011). *Opinion on the limitation of the right to vote in the case of "proven mental disability" of the Venice Commission.*

Chapter 4

1 Inclusion International. (2010). *Position Paper – Legal Capacity.* See Appendix 2.

2 United Nations. (2007). *Handbook for Parliamentarians on the Convention on the Rights of Persons with Disabilities.*

3 Sabatello, M. and Schulze, M. (Editors). (2013). *Human Rights and Disability Advocacy.* Penn Press: University of Pennsylvania.

4 Retrieved from: http://www.dis-capacidad.com/nota.php?id=2221#.U4ZWk17YjDN

5 United Nations. (2007). *Handbook for Parliamentarians on the Convention on the Rights of Persons with Disabilities.*

6 Canadian Association for Community Living. (2014). *Response to Draft General Comment No.1 on Article 12 UN Committee on the Rights of Persons with Disabilities*

7 Representation Agreement Act [RSBC 1996] Chapter 405.

Chapter 5

1 Camille Latimier. (2014). Webinar: *Qué es e implica la autogestión para las personas con discapacidad intelectual?* Retrieved from: http://inclusion-international.org/videos-webinars-sobre-el-trabajo-con-autogestores/

Chapter 6

1 Quote from parent in Global Campaign discussion group, Lebanon.

2 Government of Canada. Retrieved from: http://www.cra-arc.gc.ca/tx/ndvdls/tpcs/rdsp-reei/menu-eng.html

3 From Global Campaign discussions with the Canadian Associated for Community Living (CACL) and Planned Lifetime Advocacy Networks (PLAN).

4 Care Quality Commission. (2013). Retrieved from: http://www.cqc.org.uk/directory/rw11v

Chapter 7

1 http://inclusion-international.org/living-in-community

2 Crowther, N. (2014). *The Right to Decide: Snapshot of and reflections on the practice and activities of eleven 'Inclusion International' member organisations.*

3 Adapted from: Crowther, N. (2014). *The Right to Decide: Snapshot of and reflections on the practice and activities of eleven 'Inclusion International' member organisations*.

4 Referencing The Protection of Personal and Property Rights Act 1988 (PPPR Act).

Chapter 8

1 Submissions can be found at: http://www.ohchr.org/EN/HRBodies/CRPD/Pag-es/DGCArticles12And9.aspx

2 United Nations Committee on the Rights of Persons with Disabilities. (2013). *General comment on Article 12: Equal recognition before the law.*

3 CACL submission to the Draft General Comment: No. 12. Retrieved from: http://www.ohchr.org/EN/HRBodies/CRPD/Pages/DGCArticles12And9.aspx

4 United Nations General Assembly. (2006). *U.N. Convention on the Rights of Persons with Disabilities and Optional Protocol.* Reference Article 12.

5 Adapted from: CACL submission to the Draft General Comment: No. 12. Retrieved from: http://www.ohchr.org/EN/HRBodies/CRPD/Pages/DGCArticles12And9.aspx

6 United Nations Committee on the Rights of Persons with Disabilities. (2013). *General comment on Article 12: Equal recognition before the law.*

7 CACL submission to the Draft General Comment: No. 12. Retrieved from: http://www.ohchr.org/EN/HRBodies/CRPD/Pages/DGCArticles12And9.aspx

8 Booth Glen, K. (2014). *In re Guardianship of Dameris L 38 Misc. 3d 570, 956 N.Y.S.2d 848 (Sur. Ct. 2012)* Retrieved from: http://caselaw.findlaw.com/ny-surrogates-court/1619828.html

Recommendations and Conclusion

1 United Nations General Assembly. (2006). *U.N. Convention on the Rights of Persons with Disabilities and Optional Protocol.* Reference Article 12 (3).

2 Steven M. Eidelman – June 1, 2012 H. Rodney Sharp, Professor of Human Services Policy and Leadership

3 Open Society Foundations. (2011). *Article 12 Implementation: Emerging Lessons in Moving From Theory to Practice.* Report of a Workshop Convened by Disability Rights Initiative.

BIBLIOGRAPHY

Attorney General of British Columbia. (2014). *Representation Agreement Act.* Retrieved from: http://www.bclaws.ca/civix/document/id/complete/statreg/96405_01

Convention Action Group on Legal Capacity. (2009). *Designing Supported Decision-Making Systems: A Guide for Dialogue.*

Inclusion Ghana. (2013). *Access to health care for persons with intellectual disabilities in Ghana: Mapping the issues and reviewing the evidence.* Retrieved from: http:// www.inclusion-ghana.org/reports.php

Inclusion International. (2006). *Hear Our Voices: A Global Report* Inclusion International: United Kingdom. Retrieved from: http://inclusion-international.org/hear-our-voices-people-with-an-intellectual-disability-and-their-families-speak-out-on-poverty-and-exclusion

Inclusion International. (2009). *Better Education for All: A Global Report: When We're Included Too.* Inclusion International: United Kingdom. Retrieved from: http://inclusion-international.org/better-education-for-all

Inclusion International. (2012). *Global Report on Article 19: The Right to Live and Be Included in Community.* Inclusion International: United Kingdom. Retrieved from: http://inclusion-international.org/living-in-community/

Jean Vanier. (2008). *Becoming Human.* Paulist Press.

Judgements of the Supreme Court of Canada. (1986). *E. (Mrs.) v. Eve, [1986] 2 S.C.R. 388* Retrieved from: http://scc-csc.lexum.com/scc-csc/scc-csc/en/item/170/index.do

Mental Disability Advocacy Center. (2014). The Right to Legal Capacity in Kenya. http://mdac.info/sites/mdac.info/files/mdac_kenya_legal_capacity_2apr2014.pdf

Michael, J. (2008). *Healthcare for All: Independent Inquiry into access to healthcare for people with learning disabilities.* Retrieved from: http://webarchive.nationalarchives.gov.uk/20130107105354/http:/www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/@dh/@en/documents/digitalasset/dh_106126.pdf

Sabatello, M. and Schulze, M. (Editors). (2013). *Human Rights and Disability Advocacy.* Penn Press: University of Pennsylvania.

The Kenya National Commission on Human Rights and the Open Society Initiative for Eastern Africa. (2013). *How to Implement Article 12 of Convention on the Rights of Persons with Disabilities Regarding Legal Capacity: A Briefing Paper.* Retrieved from: http://www.knchr.org/Portals/0/GroupRightsReports/Briefing%20Paper%20on%20Legal%20Capacity-Disability%20Rights.pdf

United Nations Committee on the Rights of Persons with Disabilities. (2013). *General comment on Article 12: Equal recognition before the law.* Retrieved from: http://www.ohchr.org/EN/HRBodies/CRPD/Pages/DGCArticles12And9.aspx

United Nations. (1948). *The Universal Declaration of Human Rights.* Retrieved from: http://www.un.org/en/documents/udhr/index.shtml

United Nations. (2007). *Handbook for Parliamentarians on the Convention on the Rights of Persons with Disabilities.* Retrieved from: http://www.un.org/disabilities/de-fault.asp?id=242

United Nations General Assembly. (2006). U.N. *Convention on the Rights of Persons with Disabilities and Optional Protocol.* Retrieved from: http://www.un.org/disabilities/convention/conventionfull.shtml

Wolfensberger, W. (1972). *The Principle of Normalization in Human Services.* Toronto: NIMR.

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