

# Inclusion International Discussion Paper: Focus on Families of Persons with Intellectual Disabilities

*(x) Convinced that the family is the natural and fundamental group unit of society and is entitled to protection by society and the State, and that persons with disabilities and their family members should receive the necessary protection and assistance to enable families to contribute towards the full and equal enjoyment of the rights of persons with disabilities.*

- Convention on the Rights of Persons with Disabilities

## **Introduction**

Families are the cornerstone of our communities. Strong and vibrant families are built on healthy reciprocating relationships. They are built on trust and respect for each family member. The wellbeing of the family unit has significant impact on all family members. For all people, families should be a source of support and strength. For us, “families” refers not only to parents and siblings but to the extended family and those with whom a person chooses to share his or her life. It includes families where the parent is a person with intellectual disability. It does not refer to paid caregivers or service providers or people one may be living with but with whom one has not chosen to have a relationship (e.g.: roommates in a group home where a person is “placed”).

Around the world, families are the main source of support for people with intellectual disabilities. Often, it is families that are the key to facilitating their sons’ and daughters’ inclusion in community and securing their rights. Families value this role and reject a charitable approach that views them as being “burdened” by disability. They embrace their role but lack support, networks and supportive communities. This leaves them feeling isolated and alone.

Families need support to address the unique challenges they experience. Strong family-based public policies and valued recognition of the role families will enable families of people with intellectual disabilities to have ‘typical’ lives like other families. Supports to families should not be seen in isolation or as a replacement to supports to individuals. For families supporting a family member with an intellectual disability, the best support is ensuring the inclusion, starting in the early years, of our sons and daughters in all aspects of our communities – specifically inclusive education for children and employment opportunities for adults.

For Inclusion International, **family supports** refers to a “broad range of social, economic, community and personal goods, services and benefits that enable families with family members who have an intellectual disability to maintain typical family caring relationships while advancing the full inclusion, self-determination and citizenship of persons with intellectual disabilities.”<sup>1</sup>

## **A snapshot of families**

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<sup>1</sup> Canadian Association for Community Living

Through our global reports, the work of our members and country-level research, we have a consistent picture of the issues faced by families around the world. Families share a common experience of isolation, increase economic and social stress wherever they live in the world. This is not a result of disability but the result of a lack of support and barriers in community. Recent studies by our members in the United Kingdom (MENCAP), New Zealand (IHC), the United States (The Arc) and Canada (Canadian Association for Community Living) reflect an alarmingly common reality for families supporting a family member with an intellectual disability in resource rich countries. In lower and middle income countries where supports to people with disabilities are less available and access to mainstream systems (education, health care etc) is limited, the pressures faced by families are exasperated. Due to a lack of support, families experience:

### ***Increased stress***

- Globally, the majority of adults with intellectual disabilities live at home with their families with no support to the family.
- In the absence of adequate supports and services, families worry about the potential for their sons and daughters to be exploited and abused. In Zanzibar, we heard *“Too much freedom exposes our children to grave danger, they are prone to assault by bad people, sexually abused, over-dependent on parents, excluded, don’t feel good about themselves, people look down upon them, they are called names.”* Families report feeling extra pressure and responsibility to keep our sons and daughters – whether as children or adults – safe. The instinct to ensure safety has at times led to overprotection.
- In the UK<sup>2</sup>, research found that 72% experienced ... anxiety, depression or emotional breakdown due to isolation. Almost half had felt so unwell that they had asked their GP for medication or had seen a counsellor, and one in five reported that isolation had led to the break-up of their family life.
- In the US, 46% of parents/caregivers report that they have more caregiving responsibilities than they can handle. Around the world, families report stress about keeping their children safe and concern about what will happen when the parents are gone.

### ***Lack of support***

- In Lebanon we heard *“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.”*<sup>3</sup>
- In the US<sup>4</sup>, more than 75% of families report they can’t find afterschool care, non-institutional community services, trained reliable home care providers, summer care, residential, respite and other services.
- In New Zealand<sup>5</sup>, families highlighted that as a result of a lack of support *“many parents found that their expectations were lowered... [and] families less likely to push for better things because they have already dealt with so many barriers.”* In many places, the only supports available are specialized.

### ***Financial impacts***

- In all regions of the world, families report on the financial impact of disability related costs and lost economic opportunities as a result of caregiving responsibilities. Disability associated costs included communication devices, specialized foods and/or equipment.

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<sup>2</sup> Relate, Relationships Scotland and MENCAP. *The Way We Are Now: Under pressure*. February 2017

<sup>3</sup> Unless otherwise noted, country and regional data are drawn from II’s global reports. [www.inclusion-international.org](http://www.inclusion-international.org).

<sup>4</sup> The Arc. *Still in the Shadows with Their Future Uncertain*. 2011

<sup>5</sup> IHC New Zealand, *What’s important for family wellbeing?* April 2016.

- In the UK, households with a disabled family member are more likely to not be working, or to work fewer hours, and the level of “worklessness” is much higher for households with disabled children: 38% of disabled children live in workless households, compared to 16% of all children.
- In the USA, 1 out of 5 families (20%) report that someone in the family had to quit their job to stay home and support the needs of their family member.
- In, Canada: 27.8% of parents of children with intellectual disabilities have to turn down employment opportunities; 33.6% have to work less hours per week; and 17.1% decline promotions.<sup>6</sup>

Parents who have an intellectual disability, “experience additional disadvantages in getting supports to care for their children and/or being able to stay involved with their children if legal processes have removed them from parental care.”<sup>7</sup> Where supports do exist they are often “not equipped to provide the intensive and ongoing supports that parents with intellectual and/or developmental disabilities and their children are likely to require.”<sup>8</sup>

### ***It's an issue of support not of disability***

Families are clear that the challenges they experience are not a result of disability but a result of the barriers in communities and lack of supports to individuals and families. The challenges are rooted in society’s failure to support children with disabilities and their family unit – not the disability. In Colombia, we heard “*It is generally assumed that children and young people with disabilities are better cared for by specialists, in special schools, so they are not given the same opportunities as their peers without disabilities.*” The research shared with us by MENCAP highlights: “the extra pressures on the relationships of parents who have a child with a learning disability experience are not simply inevitable corollaries to parenting a child with a learning disability. They’re often the same common stressors we all face from time to time – different in quantity more than quality – which are intensified by a lack of support in the face of extra need. We must be careful not to ‘pathologise’ the condition of parents with a child who has a learning disability who in many cases will be coping as well as other parents, especially where sufficient support is in place.”<sup>9</sup>

In IHC’s report *Making citizenship and rights real in the lives of people with intellectual disabilities*, a mother succinctly asked: “(Government agency) said I couldn’t fill in a form on behalf of my son even when I explained he was non-verbal and couldn’t read or write. They wouldn’t speak to me (his mother), so I took my son into the office and when it was his turn said to them you wanted to speak with him, I’ll be waiting outside the office. What does it take for common sense to prevail?”

### ***What families need:***

Consistently, families around the world have told us they need: information – including help navigating systems, opportunities to connect with other families, short breaks from care-giving duties, and help with disability associated costs. For example, in the UK, MENCAP families are calling for:

- Good quality information for parents on what support is available to them;
- Effective identification and assessment of parents and family carers of people with a learning disability;
- Increased take up of benefits which ‘passport’ you to other benefits for parent carers and disabled children;

<sup>6</sup> Canadian Association for Community Living. *Position Statement on Income Security for Families*. 2010

<sup>7</sup> IHC. *Making citizenship and rights real in the lives of people with intellectual disabilities*.

<sup>8</sup> The Arc. *Still in the Shadows with Their Future Uncertain*. 2011

<sup>9</sup> Relate, Relationships Scotland and MENCAP. *The Way We Are Now: Under pressure*. February 2017

- Short ‘respite’ breaks for parents;
- Better childcare support for families of children with a learning disability; and
- Targeted relationship support for parents of children with a learning disability.

Too often families are invisible or not valued for the expertise they have. Yet families are often the ones with innovative solutions. In India, we heard about the role of families in helping people with intellectual disabilities to start their own businesses. Research we received from MENCAP, in the UK, indicates: “parents of disabled children have talked in research, for example, about the way in which people outside the family (particularly public services professionals) viewed them primarily as *carers* rather than *parents* – which parents felt had the effect of de-personalising the relationship.” Similarly, families are often invisible – or excluded – from the disability community. For us, self-advocates and families work together for inclusion. The voice of one does not negate the voice of the other. Independence does not mean being alone – this is particularly important for people with intellectual disabilities with significant support needs and people who do not communicate in typical ways. It is often families who are able to express the will and preference and needs of people who are not easily understood by others.

### **Public Policy Options**

We have some good examples of public policy options that address the needs of families. It is initiating an exchange of knowledge and best practices with our members to collect and gather comprehensive examples of family-friendly policies. To-date, some policy options identified include:

- Cash transfers/Tax relief/benefit programs
- Short breaks for parents
- Supports for working parents
- Information/Capacity building of parents and their organizations

Some examples to explore include: Panama has given grants to families of persons with intellectual disabilities to help them start small businesses to reduce family poverty. The United Kingdom has given support to families to take short-term breaks. The Canadian tax system compensates families for some of the additional costs of caring for a child with a disability. Costa Rica includes a disability targeted transfer as part of its family allowances. South Africa has a means-tested programme that provides support to families who have a child under the age of 18 with a disability. The United States has a federally mandated system of family resources centers to support parents to access education.

### **Supporting family wellbeing**

In New Zealand, IHC has identified 4 themes and corresponding indicators as important for family well-being. The following is an excerpt from *Making citizenship and rights real in the lives of people with intellectual disabilities*:

<b>Themes</b>	<b>Indicator areas</b>
Attitudes	<ul style="list-style-type: none"> <li>• Feeling welcomed and accepted</li> <li>• Being seen as part of the community of all children and families</li> <li>• Reasonable accommodations are made without a fuss – it is just the way things are done</li> </ul>
Belonging and inclusion	<ul style="list-style-type: none"> <li>• The family is seen as a unit, whatever the family structure is</li> <li>• Families feel welcomed and connected with their communities</li> <li>• Children with intellectual disability and their families have the same opportunities and take part in family and community activities, at the same rates and similar ways, as non disabled children and their families – spending time with friends, invited to birthday parties, joining clubs, going on holidays</li> </ul>

	<ul style="list-style-type: none"> <li>• Children with intellectual disability participate in early childhood education and schools on an equal basis as their non disabled peers, school and communities</li> <li>• All family members feel safe</li> </ul>
Fair systems and being able to plan with confidence	<ul style="list-style-type: none"> <li>• Family preferences and culture are respected</li> <li>• Families are aware of their rights and entitlements</li> <li>• Transparent and fair processes for resource allocation</li> <li>• Equal access to universal services – health, education</li> <li>• Timely access to quality disability support and specialist services</li> <li>• Seamless transition across preschool, school age and post school systems</li> <li>• Adequate income and housing</li> <li>• Families with disabled children not over represented in those living in poverty</li> </ul>
Good support and connections	<ul style="list-style-type: none"> <li>• Family preferences and culture are respected</li> <li>• Professionals and services work in partnership with families</li> <li>• Families have good information so they can make informed choices</li> <li>• Families have timely access to reliable supports and services</li> <li>• Families have a key contact person</li> <li>• Supports and services are responsive to changed needs or circumstances</li> <li>• Workforce with the right attitudes and skills</li> </ul>

### Recommendations for Action

During the CRPD negotiations, Inclusion International advocated for the recognition of the role of families. Despite the preamble (paragraph x) and references in Articles 23 (Respect for home and the family) and 28 (Adequate standard of living and social protection), the role of families as advocates for the human rights of people with intellectual disabilities and their need for support continues to be ignored by policy makers and human rights advocates. Inclusion International makes the following recommendations for action:

- CRPD committee draft a General Comment on the Role of the Family
- The UN and Member States commit to:
  - Exchange data and knowledge about public policies that support families.
  - Provide information in plain language.
  - Support family-based DPOs to provide progressive training and rights-based knowledge to families.
  - Support family-based DPOs to provide opportunities for families to network and connect.
  - Invest in inclusive education – beginning with early learning and childhood education – to establish meaningful patterns of inclusion.
  - Invest in employment – stable and secure employment is critical for reducing the ongoing reliance of people with intellectual disabilities on their families.
  - Ensure public policies – in particular those related to sexual and reproductive rights, sterilization, forced marriage, violence against women, decision-making – are reflective of the rights of persons with disabilities and consistent with the CRPD.
  - Recognize and support family members and their organizations to secure human rights and advance inclusion.