**Draft GC No.7:**

**Defining ‘Representative Organizations’ under the UN Convention of the Rights of Persons with Disabilities (CRPD)**

**By: People First of Canada (PFC)**

**&**

**Canadian Association for Community Living (CACL)**

**Background**

CACL and PFC are both national not-for-profit organizations dedicated to advancing the rights of people with intellectual disabilities. CACL is one of Canada’s largest not-for-profits and has a membership of over three hundred local associations, as well as provincial and territorial associations across the country, which work within their communities to advocate for the interests of people with intellectual disabilities. PFC, with approximately 3300 members nationwide, is a self-advocacy organization with a membership made up of people who have been labeled as having intellectual disabilities and has about 3,300 members nationwide.

**Introduction: Representative Organizations**

The UN CRPD calls on governments to make sure that people with disabilities and their ‘representative organizations’ are involved in:

* developing policies and laws affecting people with disabilities
* finding out if the Convention is being put into action.

But how should ‘representative organizations’ be defined? The UN Committee on the Rights of Persons with Disabilities is asking for ideas.

People First and CACL commend the committee’s thorough clarification on articles 4.3 and 33.3 of the convention and its implementation and monitoring. Expanding on the draft, we recommend that Paragraph 14 (a) – Definition of ‘representative organisations’ of the draft general comment should highlight the importance adding family in the definition of ‘representative organizations’ of persons with disabilities.

**PFC and CACL recommend that:**

1. **Representative organizations include organizations of people with lived experience of disability.**

The lived experience of persons with intellectual disabilities and their families contribute to positive policy outcomes. Historically, everyday lived experiences have not been embraced. These experiences have already played an essential role in the creation of the UNCRPD. They serve to build capacity and leadership within representative organizations ensuring that the voice of persons with disabilities and their families are heard.

1. **Lived experience comes with having a disability, or being a family member of a person with a disability.**

Families are the driving force in furthering inclusion for their family member. They have unique insight from long-term observation, of caring personal relationships with their family member who has a disability, it is essential to recognize this knowledge. Family members are often crucial to the inclusion and protection of rights of persons with intellectual disabilities and underscore the value of the lived experience of families of persons with intellectual disabilities.

1. **Family-based organizations should be included to help represent the voices of their family members, who others may not understand.**

Families are the very threads of our social fabric and as such are the cornerstone of inclusive communities. They are necessary for protecting the human rights of persons with intellectual disabilities, and caring families have natural authority. An authority that comes from knowing their family member the most fully and over the most extended period and are often best positioned to see how everything, in its entirety, adds up in the life of the person who has an intellectual disability. Given that families are the driving force in promoting inclusion for their family member, policies, initiatives, processes, and actions must be designed to acknowledge that fact We recommend that the text of general comment recognize the authority of the family.

1. **For family-based organizations to be included, they must state their commitment to the principles and rights recognized in the Convention**.

Enhancing the role of families within the frame of the UNCRPD contributes positively to the disability movement. Families provide us with a sense of belonging, are a real lasting source of support, and offer the highest degree of continuity in the lives of family members with intellectual disabilities. However, it is essential that family-based organizations are rooted and committed to the principles and rights recognized in the UNCRPD. Principles that that strengthen the family, respect and honour the family and facilitate inclusion in all aspects of family and community life.

1. **‘Family’ is defined as: two or more people, living together or apart, related by blood, marriage, adoption or a commitment to support one another.**

Families themselves are composed of two or more people, living together or apart, related by blood, marriage, adoption or a commitment to support one another. This definition of family is broader than the traditional criteria of the parents of persons with intellectual disabilities because it encompasses natural scenarios where the parents of persons with intellectual disabilities pass away. In these circumstances, its family members (siblings, cousins and other relatives) usually step in as persons in whom the surviving sons and daughters with intellectual disabilities have the confidence to receive the support required by them.