



## **THE ISSUE**

There are approximately 70,000 people in Ontario with developmental disabilities and their family members who require support.

## **ABOUT OUR ORGANIZATION**

We are an autonomous alliance of citizens who offer knowledge, tools, and networking opportunities, to individuals with disabilities, their families and friends. Our mission is to assist people in realizing a vision that includes valued relationships; choice and control over their lives; and enables inclusion through meaningful contribution and participation in community. <https://family-alliance.com>

## **OUR VISION**

**A society where people and their families are fully supported to live a regular life.**

Family Alliance Ontario defines “a regular life” as, having an affordable home of one’s own, having opportunity for meaningful contribution in one’s community, having the opportunity to build meaningful relationships and having access to the support resources needed to have that regular life.

## **BACKGROUND**

Canada has signed and ratified the United Nations Convention on the Rights of People with Disabilities (UNCRPD). Article 19 recognizes the right for all people to live in community; to choose where and with whom they live; not being made to live in a specific living arrangement; and having access to the supports to enable that life in community.

The developmental service system has been undergoing transformation for 15 years, with a goal of an “*accessible, fair and sustainable system of community-based supports*”. December 9, 2013, saw the Government of Ontario issue an apology to the men, women and children of Ontario who were failed and harmed by a model of institutional care for people with developmental disabilities, adding “today, **we strive to support people with developmental disabilities so they can live as independently as possible and be more fully included in all aspects of their community.**”

Yet 5 years later, the largest proportion of investment in developmental services continues to be to group programs directed and managed by agencies, which originated as an alternative to large institutions. In many ways, the model remains similar—continuing the practice of “placement and care”. This model does not allow for people to be fully included in all aspects of their community and is contrary to the UNCRPD.

The average annual cost of a Group Home exceeds \$120,000 per person and the average annual cost of a Day Program exceeds \$35,000 per person. Despite the large investment in group programs, people continue to languish on growing wait lists for service--there are simply not enough “places” to meet the current demand, not to mention the growing demand. This clearly indicates the unsustainability of the current system.

For many years, Family Alliance Ontario has been asking that a significant portion of all new investment in the Developmental Sector be individualized funding--directed to people and families, to provide adequate and equitable supports to everyone who chooses not to ‘give up’ their loved one to the current “placement and care” system. While there has been some new investment, a significant portion of that investment has created added levels of bureaucracy which divert desperately needed resources away from people and families.

In *Nowhere to Turn*, Ontario's Ombudsman Paul Dubé states: "Ontario's systemic failure to help desperate families who are unable to care for loved ones with developmental disabilities has left vulnerable people in dire and often dangerous circumstances." The current reality for people and families can be described as:

- A great black hole when school is over.
- A harmful negative characterization of people, required for eligibility for and access to supports.
- A confusing maze trying to access supports, where rules, policies, and procedures get in the way of an everyday, ordinary life.
- A perception that people are a burden to society.
- A forfeiture of authority to agencies around how resources are used and managed.
- A lack of choice, voice, and control, in needing to conform to "spots" and vacancies.
- An experience of isolation and depression, where relationships are stagnant or lost.
- A life of poverty due to inadequate support funding.
- A lack of consideration, priority, and value for planning.

There are an estimated 50,000 people in Ontario waiting for adequate funding and supports to assist them to have a regular life in community.

## **POSSIBLE SOLUTIONS**

### **I. New Developmental Disability Legislation**

- Cultural change away from a one-size-fits-all approach to a more person-centred approach, as identified by David Carter-Whitney (MCSS Assistant Deputy Minister of Social Policy Development) in the deposition to the Select Committee on Developmental Service, October 30, 2013.
- Shift in societal norms and attitudes around the full inclusion of people with developmental disabilities.
- Core vision to support adults with developmental disabilities to live as independently as possible in the community and to support their full inclusion in all aspects of society.

### **II. Moving to a Person-Directed, Individualized Community First Model**

- Assistance for people and their families to have control over their lives and the supports they receive.

<b>Individualized Funding</b>	<b>Personal Support Networks</b>	<b>Everyday Relationships</b>	<b>Help to Imagine a Regular Life in Community</b>
<ul style="list-style-type: none"> <li>- Goes directly to people/families</li> <li>- Provides portability or the freedom to choose where and how supports are delivered</li> <li>- Not dependent upon agency "spaces"</li> <li>- Provides opportunities to use existing, natural community supports as a first resource</li> </ul>	<ul style="list-style-type: none"> <li>- Provide safeguards for vulnerable people</li> <li>- Provide support for families as their children moves through various life stages</li> <li>- Help people to find their voice</li> <li>- Help people explore their gifts and talents</li> <li>- Gain strength through knowledge and experience by connecting to others through autonomous family networks</li> </ul>	<ul style="list-style-type: none"> <li>- Maintaining relationships with family, friends</li> <li>- Developing relationships with people in neighbourhood and community</li> <li>- Developing relationships with systems people</li> <li>- Freely given parent to parent mentoring via well-resourced autonomous family networks</li> </ul>	<p>This help comes in various forms for example:</p> <ul style="list-style-type: none"> <li>- Assists people and families to explore gifts, talents, and contributions to create a full life in community</li> <li>- A 'start from scratch' effort that incorporates a dynamic, step-by-step planning process</li> <li>- Involvement in autonomous family networks where people learn to dream and see what is possible</li> </ul>

## **WHAT WE WANT TO EXPLORE WITH MPPs**

The importance of continuing the transformation of developmental services in a more coherent equitable way; away from the current expensive "placement and care model", towards a regular life in community. This requires listening to and consulting with people and families **FIRST**...we are the essential part of the solution!

## **CONTACT INFORMATION**

Cindy Mitchell

alliance@family-alliance.com

905-723-8111