

## **Submission by Family Alliance Ontario**

### **On Bill 77:**

#### **Services for Persons with Developmental Disabilities Act**

*Family Alliance Ontario is an alliance of citizens that offers knowledge, tools and networking opportunities to individuals with disabilities and their families to assist them to realize a vision that includes having valued relationships, choice and control in their lives, and enables inclusion through meaningful contribution and participation in their communities.*

As the people who live with the decisions made by the Ministry of Community and Social Services, we at the Family Alliance Ontario feel we have important information to share and the duty to speak up about the influences on the lives of our family members, especially as it pertains to new legislation.

The Family Alliance Ontario commends the Minister of Community and Social Services for updating the Developmental Disabilities Act. It is our hope that this new Act will embed human rights and end injustice for persons with developmental disabilities. Catherine Frazee writes from the perspective of a person with a disability, "Seen through the lens of human rights, segregation and stigmatization of people with disabilities is a deep wound, not only to people with disabilities themselves, but to society as a whole. This wound can only heal through policy accomplishments, public education and community development."

The transformation of Developmental Services is to be guided by citizenship. Citizenship includes, access, rights, valued status and full [1] participation. We look to this legislation to be the foundation upon which the rights and citizenship of persons with developmental disabilities will rest.

## **Direct Funding**

It is vital that the option of establishing direct funding as a choice for individuals and their families be entrenched in legislation. As the Family Alliance Ontario represents a generation of parents who have raised their children at home, it is imperative that individualized funding be available to these families as they continue to support their adult sons and daughters. The choice to have direct funding offers families increased flexibility, more control over their lives and a freedom from reliance on traditional services. Families who have worked to provide lives of participation and inclusion for their children will have the option for this life to continue into adulthood.

Adequate and secure individualized funding must be available to people with disabilities so they receive sufficient funds to purchase the supports they require to participate. Historical practices of poor or no funding to direct funding programs will not move citizenship rights forward. Rhetoric about policy changes must be matched by adequate funding. The Family Alliance Ontario and its colleagues have been working with government for over 20 years to establish direct funding options and have witnessed those programs stalled or stopped.

Direct funding should be dedicated to the individual. The person with their family and support network would have control over the funds and choose how the money is to be administered. Funding should move with the person so people with disabilities may live and participate where they choose throughout the province of Ontario. The person should have the flexibility to choose direct funding as a primary option. In this way, support and funding is adapted to the changing needs and preference of the person.

There should be no arbitrary caps on amounts of direct funding. Creating programs where people must fit into limited amounts of funding do not respect citizenship or diversity. Historically, funding to families has also been much less than funding to agencies to support an individual. This double standard must stop. Persons living in typical community must be supported to the same extent as they would in traditional service.

## **Waiting Lists**

Enshrining waiting lists in legislation is shocking and leads to enormous strains on families already providing the bulk of support to their sons and daughters. As an example, no funding for Passport direct funding program was provided in 2008, yet \$200 million was provided for agencies enhancements and wage increases. No funding was provided to families with direct funding to increase the pay of their workers. Such imbalances and discriminatory practices must stop. Provision for waiting lists in the Act must be struck from the legislation.

## **Networks of Support**

There is no reference to "networks of support" in the legislation. Networks of support provide people who are vulnerable with more caring people in their lives. Support networks contribute through relationships with the person to safeguard the quality of a person's life. Community development or building community capacity is an outcome of Networks of support. Increased opportunities and on-going problem-solving are further benefits. Networks of support should be unencumbered and kept separate from service provision. Infrastructures, such as facilitators, should be in place to assist people to develop their networks.

## **Planning**

Person-directed planning must be an entitlement. Planning must be available to individuals and their families at all crucial transitions in the life span. Planning options should be open to encourage community inclusion and not a life in service. Planning independent of the service system would enable a person to receive planning support and facilitation without any pressure to select one agency or program over another. By having the facilitator work for the person, conflict of interest would be avoided. Best practices such as models that deliver unencumbered planning support and facilitation should be studied. The individual, her family and friends, need independent facilitation to guide and identify the goals and strengths that will enable her to move more deeply into the typical community. Person-directed planning like this is key to citizenship and self-determination.

FAO strongly believes that planning should precede the application process. A person assessing an individual will need an adequate period of time to fairly and accurately capture the essence of the individual. The process needs to be respectful of the individual and the family. It also needs to be fair. Questions have been raised with regard to who will be assessed first and how often individuals will be re-assessed.

## **Duties of Application Centres**

There is a strong sense of conflict of interest when one centre is doing the assessing, prioritizing, determining the funding and programs, and with no appeal process. Best practices have emerged which include separate independent panels to prioritize and determine funding.

Will adequate information be given if resources are unavailable? Will applications be discouraged if resources are unavailable? Will prioritization be unbiased? Will funding decisions be fair? Will it be possible to present applications anonymously for prioritization and allocation? This conflict of interest could lead to adversarial relationships between families and the application centres.

A history of difficulties with the design of the Application Centres is so strong that FAO strongly recommends that Application Centres be taken out of the legislation completely. More research and development is necessary with more input from family stakeholders. The workings of the Application Centres could be done through the regulations for the Bill.

## **Accountability**

The system needs to be accountable to individuals and their families as well as to the taxpayers. People need to see that they are being treated fairly within a transparent process. Guidelines used for prioritization and funding allocation should be made available as general information and not held as closely guarded secrets. Decisions need to be reviewed on a regular basis and summaries made available.

## **Recommendations:**

1. Implement Individualized funding substantially to make real the values and principles proclaimed in the government's agenda for the transformation of Developmental Services.
2. Include people and their families currently managing their own supports through direct funding, in all distributions of funds for wage increases for support workers. Fairness demands that families have equal opportunity to offer competitive salaries to ensure the long-term viability of individualized supports and the competency of support staff.
3. Application forms for funding would include a section to make people aware that they can choose an independent planner and there will be a funding mechanism to enable up-front hiring of an independent planner. Person-directed planning for self-determined outcomes based on the principles and values of the "Common Vision for Real Transformation" is quite different from planning for traditional programs.
4. MCSS encourages the unbundling of resources by agencies wishing to support families who request individualized funding. The level of individualized funding can be as high as the amount being used for the support of the individual in the service that will be unbundled.
5. Application Centres be removed from the Bill entirely and processes worked out through the regulations.
6. Persons and families have the option of using independent facilitators from a publicly funded organization or choosing their own with public funds. Families have access to an ongoing planning and facilitation process – lifelong, as needed.
7. Accountability that ensures that those involved with the person with a disability are doing what they say they are doing, personally, financially and collectively. People and families are accountable to government for the expenditure of funds, while independent planners and direct service providers (agencies) are accountable to the person by ensuring the person's plan and goals are being met.
8. Adults who have a developmental disability feel secure in their home and are protected, including the requirement that an official entering the home must secure a warrant based on reasonable assumptions of wrong doing in the home. This would apply

equally to all types of residences including supported group living residences, intensive support residences and people's private homes.

9. As the people who live with the decisions made by the Ministry, independent self advocacy groups are invited to be decision-making partners at the various planning and community tables in the province. Representation from People First and family advocacy organizations have an equal voice to paid organizations such as service providing agencies at all decision-making tables, regionally and provincially.

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1. Individualized Funding for Living Supports, Stan Woronko, FAO, 2007
2. More Choice and Control for People with Disabilities, Review of Individualized Funding, Ontario Federation for Cerebral Palsy, 2000
3. Pathways to Inclusion, John Lord and Peggy Hutchison, Captus Press, 2007