

**Response to the Ontario Government Discussion Paper  
'Transforming Services for People who have a Development Disability'  
By Jim and Elgi Johnston, parents of two adult children with intellectual disabilities  
on behalf of Concerned Parents of Toronto Inc.**

We are writing to provide you with our views of some key elements that are critical to providing an accessible system that is safe, fair, accountable, and provides the quality of service, which our adult children deserve.

**1. SERVICE QUALITY**

There are no sector wide effective standards of care for adults living in assisted housing such as group homes or day programs. Despite standards for fire safety and other related items, each of the 370 non-profit and other for profit agencies decides for themselves what standards to apply. The result of this is a wide variety in the quality of residential and day program settings from excellent to those where none of us would send our children if we had a choice. The adults living in group homes are vulnerable, and yet the province allows each agency to decide the standards regarding many issues that affect the quality of life of our children.

The recent deaths and wanderings of clients from an Ontario service facility is just one example of what can happen when standards are not consistent.

We feel that one solution to this is mandatory accreditation with funding penalties if accreditation is not achieved. The standards of accreditation agencies (such as Accreditation Ontario) do focus on the individual and the choices he or she is allowed to make in life. The Government should examine these accreditation agencies, which we in Concerned Parents are doing, decide which has the most effective standards to ensure quality and implement accreditation across the province.

**2. PREVENTION OF ABUSE**

After fire and other physical building safety requirements, the single issue that worries most parents is protecting their children from abuse. This is an extremely vulnerable population.

The recently issued Ministry of Health Policy on the "Prevention, Reporting, and Elimination of Abuse, is an indication of how seriously the government takes the issue in Long Term Care (LTC) Facilities. To quote the policy – "... several factors combine to create an environment in which the potential for abuse exists: the residents are dependent on others, often requiring assistance with the most basic bodily functions, there is an imbalance in physical, social and (often) cognitive power between the residents and those who care for them; staff of the facilities and others often have unrestricted access to the residents, their rooms and their belongings." This applies in its entirety to those who have an intellectual disability and reside in group homes or attend day programs.

**Response to the Ontario Government Discussion Paper  
'Transforming Services for People who have a Development Disability'  
By Jim and Elgi Johnston, parents of two adult children with intellectual disabilities  
on behalf of Concerned Parents of Toronto Inc.**

Despite this risk, there is no standard policy on the prevention, reporting and elimination of abuse for use by service providers. Each agency creates its own policy, and the completeness and effectiveness of the policy is not independently reviewed. A group of agencies and parents in Toronto through the PACT (Prevention of Abuse Through Communication and Training) committee of MARC has developed an excellent standard policy, which could be adopted by all agencies. Unfortunately, there is no requirement for agencies to adopt this policy, and many have not continuing with their own inadequate policies. In addition the PACT committee is developing an education module to help agencies effectively train their staff. Finally, PACT is developing an External Consultation Team, which would be available to agencies to review agency policy and help create best practices in those agencies.

The missing link is a lack of enforcement.. Families and staff should be able to complain about abuse to the government and be listened to with no adverse repercussions. At the moment there are no effective protocols to handle these types of complaints within the government. A commitment by government to investigate these reported incidents of abuse, along with a toll free line to report such abuse would show the resolve of the government to deal with issues of abuse.

### **3. FLEXIBILITY**

No two people are alike, and this certain holds true of people who have an intellectual disability. Each requires an individually created program to best allow him or her to live life to the fullest in the community.

The current system does not do this. Some agencies have tried individual approaches within the agency but there is no sector wide approach. One approach is to connect funding to the individual rather than the agency in cases where this makes sense. A program of agency supports and community supports could be developed with this individualized funding. Moving from one agency to another or one city to another where that was clearly in the interests of the individual would be possible.

For example, someone who does not attend a day program run by an agency, but rather volunteers in the community requires training and support which could be made possible through individualized funding.

In addition, families receive little help in navigating the system. Truly professional and independent case managers who understand the supports in the entire system are key to allowing a family to create the program that is best for

**Response to the Ontario Government Discussion Paper  
'Transforming Services for People who have a Development Disability'  
By Jim and Elgi Johnston, parents of two adult children with intellectual disabilities  
on behalf of Concerned Parents of Toronto Inc.**

their son or daughter. Case Managers can also help in obtaining full assessments of the family member which are essential to help determine the kind of program needed.

**4. FAMILY SUPPORT**

Many individuals with intellectual disabilities live at home. These parents need more than occasional respite such as received through SSAH. Innovative ways of allowing persons to live at home, such as helping with living accommodations and increasing support in the home will often keep these families together longer. There are financial benefits if the family is not forced to seek group home accommodation as the result of a lack of support.

**5. HEALTH CARE**

People with an intellectual disability are more likely to have an increased prevalence of physical disabilities, hearing impairments, neurological disorders, such as epilepsy, and communication disorders, than the general population. Medical treatment is often inadequate. For example, dental needs are often not attended to. Family physicians and dentists are not trained how to effectively treat those with an intellectual disability. This needs to be addressed in collaboration with Colleges and Academic Health Science Centers

Mental Health needs are also more prevalent in this population. A conservative estimate is that 38% of those with an intellectual disability have mental health needs. These often result in behavioral and emotional problems which affect our children's safety and quality of life. Diagnosis is often difficult, resulting in inappropriate treatments. It is extremely difficult for families to find psychiatrists who will work with their sons or daughters.

The Government needs to recognize that a continuum of health and mental health supports is required, and create cross ministry mechanisms to address the problem.

In summary, the Government must examine its current approach to service delivery to ensure that clients are safe and free from abuse, have flexible supports and funding to enjoy the best possible life in the community, are diagnosed and treated effectively for both health and mental needs and are able to live with parents who are supported and helped to plan for the eventuality when they can no longer care for their son or daughter.