

# HOMES FOR LIFE

Peterborough, Ontario

We are a group of parents planning and advocating for appropriate, safe, affordable, accessible and inclusive living options for our sons and daughters who live with disabilities.

We want homes in communities where a spirit of mutual support and a respect for individuality and differences of others will lead to rewarding, interdependent relationships.

Our sons and daughters have value as individuals and must be allowed to express their citizenship through a fully engaged community life.

We are concerned that this discussion paper is too focused on the way things are now, and written in terms of current service system thinking. The whole system needs to be revamped and priorities changed. The needs of the individual must come first, creating a person-centered model of service delivery. Individuals and their families need holistic, flexible supports and integrated services that start with diagnosis, continue throughout school years, on into adulthood and throughout their lifetime.

## Roles and Responsibilities

Government and agencies must work to build stronger, more welcoming communities that are able to provide natural supports to people who live with intellectual disabilities. Most will also need paid supports and agencies must have the funded ability and the flexibility to respond to the individual needs of the people they serve.

Parents, and their sons and daughters who live with developmental disabilities, have the right and the responsibility to make decisions for their own well-being. They need to be able to approach agencies with these decisions and to receive true person-centered support. Agencies need to listen better and to readjust their roles to facilitate, support and assist, as directed by people with disabilities and their families.

The various government ministries (Health, Education, Community and Social Services, Citizenship) must work together to provide a cross-ministry continuum of services and support from birth or diagnosis to death. The federal government must also recognize the need for guaranteed, lifetime funding, transferable from province to province, perhaps overseen by the Ministry of Citizenship.

## Strategies and Resources

Parents often miss out on services because they are not aware of what is available. A government website would enable parents to learn how to navigate the system and to access the resources they need from a comprehensive and complete catalogue of services. Parents need help from the moment of diagnosis. Doctors, who are usually the first contact, should have the information necessary to be able to direct people to appropriate supports in the community.

Flexible funding for supports must be based on the ebb and flow of an individual's lifetime needs, increasing or decreasing as the needs dictate. Flexibility also means having an option to direct individualized funding to a person's parents or support network to purchase the particular services that they require. A provincial auditor has found that "the cost of putting money straight into the hands of parents was as little as one-sixth of the cost of funding the agencies to provide the service," referring to the \$44-million Intensive Early Intervention program for children with autism (Globe and Mail, November 12, 2004). Families must have the option of individualized funding to meet the needs of their family members who live with disabilities.

The province of Alberta recently passed the Family Support for Children with Disabilities Act, which provides funding to cover the cost of services such as counselling and respite to families with a child living with a disability (Globe and Mail, November 12, 2004). Their supports are flexible enough to encompass families as well as individuals. This Act also provides funding to cover the cost of specialized services like personal aides. Ontario needs to provide funding for personal support workers for those individuals who may require assistance throughout their lives. The support person could help a child navigate the school system, then ease the transition into adulthood; act as a facilitator for support circles, be a life-skills coach or a community connector, and advocate for an individual without parents.

Job dignity and decent wages for personal support workers is crucial. A new profession could be developed, based on the European model of a 'Conductor' (of a person's life), who would be trained in a variety of disciplines such as nursing, physiotherapy, education, speech therapy, music therapy, recreation. Again, we stress a holistic approach to support.

The dignity of persons with disabilities in Ontario is also at issue, since current ODSP levels dictate that they must live below the poverty line. The pension must be increased and the claw-back ceiling lifted to allow citizens living with disabilities to make more income and still retain their pension amount.

We look forward to participating in the next round of public consultations as we are determined to help bring about long overdue changes that could greatly improve the quality of life for our families and our sons and daughters. We would welcome the opportunity to develop a pilot project in Peterborough, working with local agencies and

with the Ministry departments that could best serve our family members who live with disabilities.

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