

Thank you for your participation in the first phase of our study of *Parents Seeking Adult Developmental Services for their Children*. We would like to take this opportunity to tell you about our activities over the past year and share some early findings of the study.

What did we do? –The Recruitment Process

The nine Developmental Services Ontario organizations (DSOs) distributed our Request for Information forms or Consent forms to parents of adolescents and adults (age 16 and above) with intellectual/developmental disabilities (IDD) living at home and seeking services through a Developmental Services Ontario organization between July 4, 2011 and March 31, 2012. The DSOs sent our forms to 1191 parents by mail, email or in-person.

Most of the 250 parents that asked for more information agreed to be part of the study. We mailed them a survey, and scheduled a telephone interview. We completed a total of 207 interviews and received 213 mail-out surveys from the 221 parents who consented to participate.

Who did we hear from? –Parent Description

- Parents ranged in age from 38 to 91 years, with two-thirds between 46 and 60 years old.
- About 60% were married, one quarter divorced/separated, and the remaining single/widowed.
- Most were mothers; around 15% were fathers.
- Half had a college diploma or higher education, while 10% had less than a high school diploma.
- 21% had a household income of less than \$25,000 per year while 22% made above \$95,000.
- One third of the parents interviewed were not currently working (stayed at home, retired, unemployed or received ODSP).
- One in five families lived in a rural area.

Half of the parents reported having **at least one** significant medical, physical or mental health condition.

- 30% identified a medical condition such as heart disease or cancer.
- Around 28% reported physical conditions such as a herniated disc.
- One quarter expressed a mental health condition such as depression or bipolar disorder.



- ★ Nearly half of the parents were also a major caregiver for someone else in the family such as a small child, elderly parent or someone else with a disability.

Who are services requested for? –Adult Children

- There were 216 individuals for whom parents were requesting Adult Developmental Services.
- Nearly two-thirds were male.
- Their ages ranged from 16 to 53 years, with the majority under the age of 35.
 - 46% were 16 to 20 years old and were preparing or recently eligible for Adult Services.
 - 45% were 21 to 34 years old and no longer part of the public school system.
 - The remaining 8% were 35 years or older.

What are common diagnoses?

- 34% had an Autism Spectrum Disorder.
- 15% had Down Syndrome.
- 30% had mobility impairments (some used a wheelchair).
- One quarter had epilepsy/seizures.
- Around 36% had a dual diagnosis (classified as having an intellectual or developmental disability plus one of the following: psychiatric disorder/mental illness, behaviour disorder, drug/alcohol dependency or Alzheimer disease).

What services are requested?

- Nearly 70% requested *Community Participation Supports* to assist with social, recreational, work or volunteer activities.
- Almost half were requesting *Residential Supports* such as a group home, supported independent living, or other residential models.
 - This was the most frequently requested service for children 35 years and older.
- One third of the parents requested *Respite*.



How are they included?

- 2/3 of the individuals with IDD participated in community activities.
- Less than half of the individuals had friends outside of family or staff.
- Most parents felt their adult children were accepted and welcomed by community members.

Who makes decisions?

- Around 1/3 of the individuals made their own decisions about daily activities like routines, spending money and social activities.

Next Steps...

We will be using these findings along with other information you have given us to better understand what it is like for parents across Ontario seeking services for their adult children. Our final report will be presented to the Ministry of Community and Social Services.

A second phase of this study is also under way to see what happens over the year following the request for services. We are currently following 181 parents. For more information about these projects and other MAPS research, please visit our website at www.mapsresearch.ca or call us at (613) 548-4417 ext.1207. Thank you again for participating in our research!