



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

### *What did we do?*

Our project focuses on parents requesting services through Developmental Services Ontario (DSO) for their sons/daughters with an intellectual/developmental disability (IDD) living at home. In the first phase of the project, we described a group of parents during the process of seeking services. In this second phase of the project, we are following parents for up to two years to explore the association between needs, services and supports, and to learn more about how parents manage over time.

Of the 211 parents from across Ontario who completed the first phase, 181 agreed to participate in phase II. These parents were similar to the parents in phase 1 in terms of their initial situation. This report includes findings from phone interviews and surveys over six months.

### *Who received supports & services?*

- In the first six months of follow-up, 18.3% of individuals reportedly received at least some of the services they had requested through DSO.
- The most commonly received services were **Community Participation Supports** (17 of 130 requests), **Caregiver Respite** (9 of 61 requests) and **Agency Residential Supports** (7 of 86 requests).
- Parents whose sons or daughters had a dual diagnosis (a mental health or behavioural issue in addition to their disability) were more likely to receive services within the 6 months than other parents.
- Advocacy efforts and resourcefulness of parents, as well as changes in family situation appear to be important in understanding why some families received services and others did not. Most parents were seeking the same services as originally requested, six months later.



- 61% of parents reported changes in supports to their family, most commonly reporting a gain or loss of paid workers.
- **Transitions** resulted in significant changes in supports, both positive and negative. This includes the individual aging out of the educational system or child services, or the movement into a new residence.
- ★ *Parents talked about how helpful it was to feel heard and get oriented to how the services system works, and what they can expect from the DSO.*

## *How did support needs of sons and daughters change over 6 months?*

- 53% of individuals with IDD were identified as having **medical support needs**.
  - Nearly a third of parents reported that these needs were increasing.
- 44% of individuals with IDD were known to have **behavioural support needs**.
  - Over one third of parents said these were increasing; sometimes requiring specialist attention or crisis support.

## *How did parents change over 6 months?*

- A quarter of parents reported being less distressed after 6 months, while over 60% of parents did not perceive distress any differently.
- When the study began, 53% of parents reported having at least one significant medical, physical or mental health issue.
  - The health challenges improved over time for 10 to 18% of parents, but worsened for 32 to 38% of parents, depending on the condition.
- Parents' perception of **burden** and **support** in caring for their son/daughter did not change over time.
- Parents' whose sons or daughters had medical support needs experienced poorer **emotional well-being** over time.
- Of parents involved in both phase I and II, fewer reported being 'in or approaching **crisis**' after six months (34% at baseline, compared to 23% at six months).



## *What are we recommending?*

- It is important to maintain contact with families after they have requested services to confirm their current support needs.
- Efforts should be made to help parents cope by getting practical support from others and keeping them informed throughout the process.
- Identifying what is needed for both individuals with IDD *and* their parents will lead to the development of better, more proactive responses and improvements for the sector.

## *Next Steps...*

This phase of the study continues until June 2014. Through analysis of interview and survey data collected every 3 to 6 months for 2 years we will gain a clearer understanding of the needs of families and how the system responds to them. For more information about this project and other MAPS research, please visit our website at [www.mapsresearch.ca](http://www.mapsresearch.ca) or call us at (613) 548-4417 ext.1207. Thank you again for participating in our research!

