



MAPS

MULTIDIMENSIONAL ASSESSMENT
OF PROVIDERS AND SYSTEMS

Phase II Parent Study Update

April 2014

We would like to thank you for your contributions to our project *Parents Seeking Adult Developmental Services for their Children* over the past 18 months. Much has happened since our last Update in July 2013, so we'd like to take this opportunity to share additional findings as well as current and future work being done.

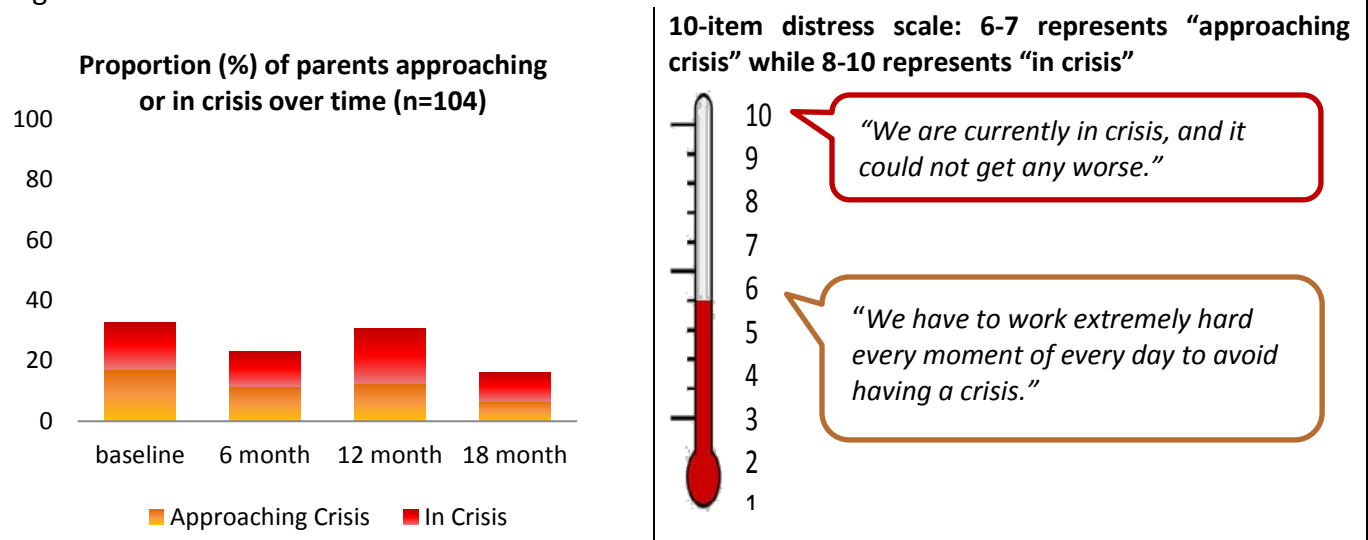
What did we do?

We began this study interviewing and surveying over 200 parents requesting services through Developmental Services Ontario (DSO) for their sons/daughters with an intellectual/ developmental disability (IDD) living at home. We followed 181 of these parents for up to a year to explore their needs, services and supports, and to learn how parents manage over time. We then extended the follow-up to 24 months to better understand how transitions affect families throughout this process, with 148 parents who agreed to stay involved. This update reports on findings up to 18 months, with a focus on how family situations changed over time.

As we reported earlier, few parents received requested services in the first 6 months. In a related study based on extensive interviews with a few families, Robyn Saaltink, a PhD candidate, has found that **parent advocacy** and **resources** may contribute to the likelihood that families will receive formal services. Other factors include positive **relationships** with service providers, parents' **time**, and **perceptions** that services will meet their needs.

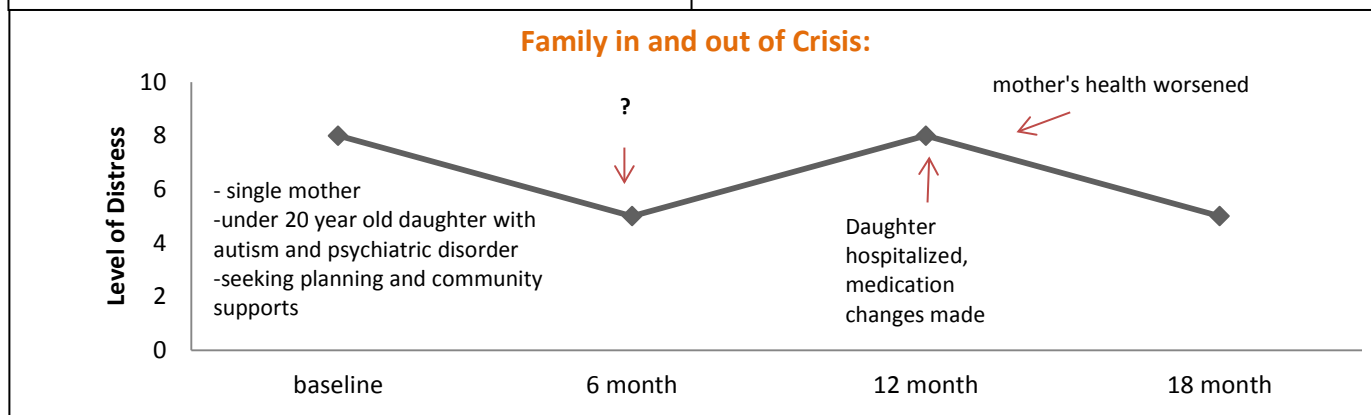
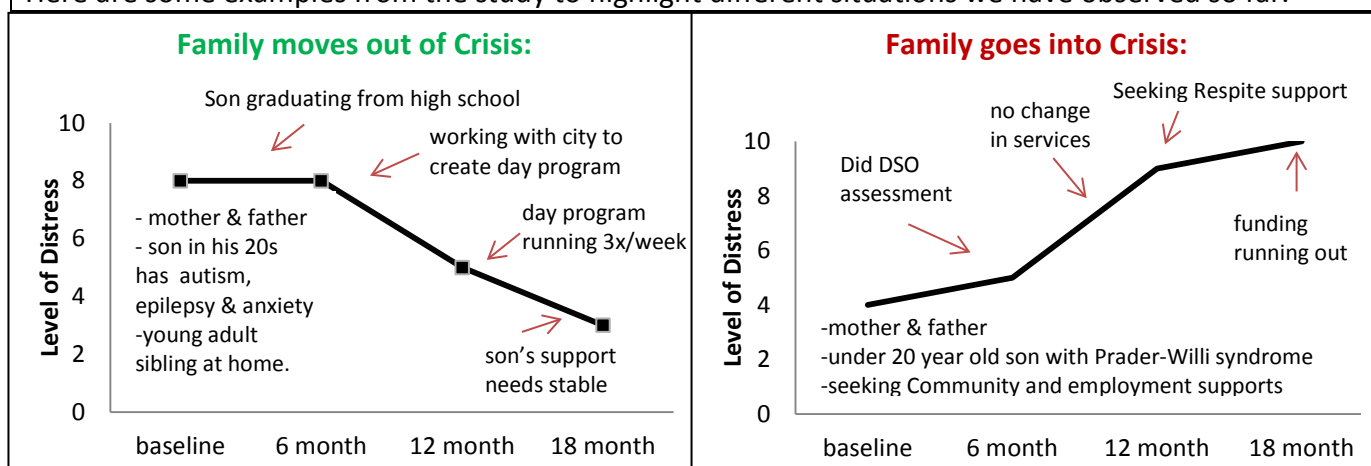
Did the number of families in distress change over time?

We observed fluctuations in the level of distress reported by the 104 parents who completed each time point. The proportion of families reporting that they were approaching or in crisis ranged from a high of 33% at baseline to a low of 16% after 18 months.



What do these families look like?

The level of distress can fluctuate over time, but it can also remain quite stable. All families are unique. Here are some examples from the study to highlight different situations we have observed so far.



Issues surrounding distress of families seeking adult Developmental Services for their sons and daughters are also being addressed by the Ontario government, with the launch of the Ombudsman investigation of DSO in 2012 (www.ombudsman.on.ca) and the work of the Select Committee on Developmental Services (www.ontla.on.ca). MAPS has contributed reports to both, offering up-to-date information, key considerations and next steps including the importance of monitoring families' needs beyond service request and using data collected to gauge system responsiveness.

Current Research:

In addition to the 24-month follow-up that is ongoing, we are studying the experiences of 5 families across Ontario whose son/daughter is going through a life transition. We will produce a **video** highlighting our findings.



Stay tuned for further updates

Want more info?

You can now follow us on **TWITTER!** (http://twitter.com/maps_research) For more information about this project and other MAPS research, please visit our website at www.mapsresearch.ca, email us at admin@mapsresearch.ca or call us at (613) 548-4417 ext.1207. If you are moving or your contact information is changing, please update us so that we can keep you informed.

Thank you again for your involvement!