

An Inadequate Response

On February 24, 2017, the Honourable Dr. Helena Jaczek, Minister of Community and Social Services provided a six-month update on the progress that the government had made in responding to the recommendations of the Provincial Ombudsman's 2016 report *Nowhere to Turn*. The Minister's report provided a long list of positive activities that the government had initiated in response to issues facing people who have an intellectual disability and their families. We thank the government for the work that is underway. We fear, however, that the response fails to match the urgency and the scale of the issues. There is evidence that, despite current efforts, demands for supports and services are outstripping efforts to increase capacity. While some people who have an intellectual disability are benefiting from the additional funding and reform that is taking place, overall, the deep systemic problems outlined in the Ombudsman's report appear to remain or are getting worse. This paper outlines the issues identified by Ombudsman Paul Dubé and considers where our current efforts to respond need improvement.

Background

In 2012, the office of the Ontario Ombudsman was experiencing a significant increase in complaints by families of people who had an intellectual disability and their inability to access the supports and services that their family members required. As a result of growing waitlists, stagnant funding and a frustratingly inadequate mechanism for seeking and accessing services, increasing numbers of families were falling into crisis. Media outlets were reporting on a regular basis about families that were, out of desperation, leaving their family member who had an intellectual disability at Ministry offices or at support organizations that had indicated no agreement to provide ongoing support. Then Ombudsman Andre André soon identified the situation as a "crisis" and launched a comprehensive investigation into the matter.

Following four years of investigation into more than 1,436 complaints, Ombudsman Dubé released his report on the situation in August of 2016. The report titled *Nowhere to Turn*, painted a bleak picture of what his investigators found when they interviewed complainants.

Some of the key challenges identified in the report included:

- The present demand for services far outstrips the supply, leaving thousands stranded on waiting-lists.
- Without adequate safeguards, adults with developmental disabilities are sometimes placed in jeopardy of domestic abuse.

- Individuals with complex conditions or serious behavioural challenges continue to find themselves excluded from their communities due to a lack of support. Institutional care no longer happens through design but by default. With nowhere else to turn, those in crisis can find themselves inappropriately housed in a variety of institutional settings from hospitals to jails.
- Ontario's general hospitals and psychiatric units have become hosts to hundreds of adults with developmental disabilities.
- Long-term care homes have also become providers of institutional care to adults with developmental disabilities, despite the fact that such settings can be wholly unsuitable.
- Individuals who have an intellectual disability, particularly those who also live with psychiatric illness, are in jeopardy of being charged criminally when they act impulsively and aggressively. Incarceration of adults with developmental disabilities has become a "failsafe" alternative to secure and supportive housing in the community.
- Adults who have an intellectual disability and complex medical conditions are often unable to access necessary community supports and services.
- Hundreds of beleaguered families are at the breaking point as they try to cope with immensely complex support needs of their family member without external support.
- Caregiver exhaustion, illness, aging and death have also predictably led to cases of abandonment and homelessness.
- While the government committed in its April 2014 budget to invest an additional \$810 million over three years to strengthen services and supports in the Developmental Services sector, progress has been incremental. Much more needs to be done to bridge the significant service gaps.
- The Ministry's response to urgent situations involving adults with developmental disabilities and its administration of the process to address crisis cases has been unreasonable and wrong.
- The Ombudsman acknowledges that MCSS had begun to make progress in recent years to improve the Developmental Services system and expressed his belief that the Ministry is well intentioned and earnest, but recognizes that systemic flaws persist.

The current state of MCSS wait-lists

In April 2014, the government invested \$810 million over three years to increase services and supports for people who have an intellectual disability. This funding increase, when fully implemented, will increase the annual budget of Developmental Services from \$1.7 billion to just over \$2 billion.

The aim of the funding with respect to Passport and Special Services at Home (SSAH) was to:

- Provide new direct Passport funding to 3,250 adults per year for four years – total of 13,000 by April 2018
- Provide new direct SSAH funding to 4,000 children per year for two years – total of 8,000 by 2016

- Eliminate the 2014 waitlist for both the Passport and SSAH programs

The Ombudsman's report indicated that the April 2014 waitlist for adult residential supports was 12,808 people. The government's 2014 investment committed to providing new supports for 1,400 people on that waitlist.

The Ministry reports that it is on track to achieve all of the targets that it set for the 2014 funding, and in fact, introduced some of the funding more quickly than planned. After a number of years of stagnant funding, the 2014 infusion of funds provided relief for many people and families as indicated by the numbers above.

The reality is, however, that demand for supports and services has continued to grow quickly. At present there are about 70 thousand adults who have an intellectual disability living in Ontario and the prevalence of people with a developmental disability is increasing by 1% more than other disabilities each year. The Ombudsman's report indicated that in December 2014, 33,615 adults accessed some form of Ministry-funded developmental services.

While the 2014 funding, when fully implemented, is expected to eliminate the 2014 waitlist for Passport and SSAH programs, the demand for supports and services has continued to grow. The Ministry anticipates that by April 2018, when the investment is complete, the waitlist for the Passport program which supports adults will be 11,000 with no commitment to additional funding. The Ministry has reported that the SSAH program that supports children has reached more or less a balance of new requests for support and children leaving SSAH services as they become adults. Therefore, the SSAH budget has not increased significantly.

The waitlist for adult residential services is even more alarming than the increases to Passport, given that the 2014 funding was only aimed at reducing the waitlist by less than 11%. While the Ministry reports that the aim of creating 1,400 additional residential spaces with the 2014 investment will be achieved by the end of the four-year implementation period, the waitlist has continued to increase. While the 2014 funding provided for 819 additional spaces over two years (2014 to 2016), the waitlist increased by about 1,300 people in one year alone (2015/16).

Additionally, the majority of the new residential spaces that were created through the 2014 funding were allocated to young people who have an intellectual disability who were transitioning from services funded through the child welfare system. These are individuals that were already in receipt of government residential funding, not those waiting without support. While Community Living Ontario agrees that it was essential that these young people receive the support they need, we challenge the Ministry's contention that it has created new funded services for them, given that they were already in receipt of government funded residential supports. Of the 819 residential spaces that the Ministry reports to have been "created" between 2014 and 2016, 535 were allocated to these transitional aged youth (TAY), who were already funded through the child welfare system:

- 2014-15: MCSS transitioned 297 child welfare TAYs (55%) out of 533 new people placed in adult residential services.
- 2015-16: MCSS transitioned 238 child welfare TAYs (87%) out of 273 new people placed in adult residential services.

While MCSS has not provided Community Living Ontario a projection of what the residential waitlist might be once the 2014 funds are fully implemented, we have been told that as of March 2016, there were approximately 14,900 people on the residential waitlist, about 9,700 of whom were ready to receive service immediately. If the number of new people seeking support each year was to remain the same as it was in 2015/16, the waitlist could be almost 17,000 people by the time the funding investment concludes in March 2018.

Creating a Home in the Community

As the above numbers indicate there is an ever growing need for support to assist people to live in their home in the community. We appreciate the many efforts that the Ministry is undertaking to improve innovation with respect to creating housing and support options. In her update to the Ombudsman, the Minister indicated a range of housing initiatives being undertaken by MCSS including the new Life Share pilot family recruitment campaign, the Ministry's Housing Task Force projects, the Multi-Year Residential Strategy, the work underway with the Intentional Community Consortium (ICC) and, the Housing Forum. While we will not comment in this paper on the merits of each of these initiatives, we accept them as an indication that MCSS is working to make strides with respect to housing and we applaud that effort.

Nevertheless, we are not scaling up efforts quickly enough to address the massive need that exists and is continuing to grow. All of the initiatives currently underway have modest targets with respect to the number of people that will be supported to receive new housing. The 2014 investment with respect to housing was not nearly adequate enough to even address the year over year increase in demand, let alone begin to reduce the massive waitlist that already existed. Housing costs continue to skyrocket in both city centres and remote communities, while rental stocks in many parts of the province are at very low levels. As of 2015, there were 171,360 Ontario households waiting for affordable housing – a number that continues to grow rather than shrink each year. An urgent multi-ministry effort is needed to address these critical needs.

In the absence of an appropriate response to the provision of real homes in the community, increasing numbers of people who have an intellectual disability are ending up inappropriately placed in institutional settings. The Ombudsman identified this trend as “institutionalization by default” and points out the contradiction that “the government has decried the concept of placing those with developmental disabilities in large institutions” while so many are ending up institutionalized.

Almost half of the recommendations made by the Ombudsman (27 of 60) address this issue of institutionalization by default, looking primarily at three key areas of concern:

- Unnecessary and/or prolonged hospitalization;
- Inappropriate placement in long-term-care; and
- Involvement in the criminal justice system and incarceration.

Avoiding Crisis in the first place

The Ombudsman's report provides many excellent recommendations regarding how to respond to people and families who are facing crisis or who are in crisis. Equally important, however, is the consideration of how we might avoid crisis in the first place. This will be achieved only when people have predictable and adequate support throughout their life. At present, supports and services provided to people through developmental services are discretionary; the government is under no obligation to provide them. At present, adults who have a disability are entitled to income supports through the Ontario Disability Support Program, children who are deemed to be at risk have guaranteed access to child protection resources, and all citizens have guaranteed access to a broad range of medical support. No such entitlement exists however with respect to the disability-related supports and services people who have an intellectual disability need to carry on with their daily lives.

While it would require a very significant new investment of government funding in support and services in order to make such a guarantee to people and their families, it is difficult to justify not doing so, given the overwhelming need. Clearly the current discretionary approach is not working; people and families often face a lifetime of stress, uncertainty and crisis, while the support and services when finally provided are often far more expensive than they might otherwise have been. Supports provided to people in crisis are typically much more extensive and expensive than they might have been if delivered prior to the crisis occurring. With adequate planning and consistency of funding for supports and services, people are often able to leverage many of the resources that exist in the community that others rely on to build a meaningful life.

A new approach to funding of supports is urgently needed. Such funding would be available throughout a person's life from childhood to the senior years without artificial transition points such as currently exist and which create significant disruptions in services and supports at critical junctures in people's lives.

Such a funding approach should be designed to help people plan for a full life in community. Such planning should aim to help people utilize the full range of supports and services that already exist in their community and that are available to all citizens. Such an approach will take advantage of the tremendous support a person can receive from family and friends where they exist, while recognizing that there are limits to such supports and that families themselves may require support to carry out their roles. And funding should be adequate to address any

and all gaps in support that a person might require to live in the community once they have fully considered the other resources that they have at their disposal.

Of course, such an approach cannot be implemented or carried out by the Ministry of Community and Social Services alone. Such a broad community-based strategy requires reform within many branches of government, including those that deal with education, housing, transportation, health services, recreation, justice and many others.

Conclusion

We appreciate the light that the Ombudsman's office has cast on the serious issues facing people who have an intellectual disability and their families. We acknowledge as well the work that has occurred on the part of MCSS and the government. Nevertheless, the current data outlined above clearly indicates that these efforts are not adequate to reverse the trends outlined in the Ombudsman's report. At the beginning of the Ombudsman's investigation, Community Living Ontario described the developmental services sector as being "driven by crisis". We pointed out that accessing the support one needed was nearly impossible until one was in a full crisis situation. We stated that crisis was not an unintended consequence of the system, but was a prerequisite to accessing support. Such a situation cannot be tolerated. While the 2014 funding allocation and other actions of the government have provided some much needed funding to people who had been waiting for daily living supports, it is clear that there has been little substantive improvement at a systems level; crisis will continue to drive the developmental services sector until comprehensive steps are taken to address the huge range of issues that exist. Much more work, including policy reform and funding by many area of government is required if we are to make significant improvements in the lives of people who have an intellectual disability and their families.