

Crisis of wait lists for developmentally disabled people in Ontario

By Dely Farrace

Almost three years ago, the government of Ontario established Developmental Services Ontario (DSO) in its attempt to streamline and improve services for developmentally-disabled adults and their providers, and to make the government more accountable to taxpayers.

Unfortunately, the program seems to have backfired, because current services have been abruptly terminated for the people served who have reached their 18th birthday. In its place, a complicated and onerous process emerged to re-qualify these people for services. Essentially, the new process requires previously qualified disabled persons to prove that they are still disabled, resulting in long wait lists for indispensable service. If someone is born with autism, for example, this disorder remains with them their entire lives and there is a continual daily need for these people to be engaged in meaningful activities in order to offset regression. Requalification is not required and any interruption to their service is detrimental to their health and well-being.

The final, non-partisan report of the Select Committee on Developmental Services Ontario has just been released. Is there a sigh of relief from parents awaiting services for their adult children with developmental disabilities like autism? Possibly. Earlier in July, there was pressure from Committee Vice-Chair Christine Elliott to release the document, and she insisted that the Wynne government begin to implement the recommendations, with an emphasis on properly allocating funds.

So what do the findings of the report mean to those families caring for a developmentally-disabled individual and for that individual himself? The most prominent, paramount piece of the report was the recommendation for immediate dissolution of wait lists; the call of families for more than a decade now. Wait lists are the most damaging component of services, rendering many families ineffective, broken and lifeless.

With the advent of the DSO came the unprecedented influx of adult children drop-offs at the door of their local DSO office. These families, with aging and spent parents of children with developmental disabilities, could no longer cope with the incessant needs of their dependent child. In many cases, families experience breakdown much earlier, from marital breakdown to parental illness and death. Parents of disabled children experience constant stress, both physically and emotionally from the unrelenting needs of their children with severe disabilities.

Clearly, something is systemically wrong, and nothing short of the elimination of the wait lists can address this problem.

Let's take a look at grandparents of typical families. For the grandparents out there, empty nesters, how does it feel when you visit with your children and, more notably, grandchildren? Do you feel exhausted when they leave or when you return home from the visit? Are you relieved that you have had a chance to rest? Now, for all its benefits of spending time with the grandchildren, take this scenario and make it your everyday life, constant and unrelenting. Now make these children bigger, so that they may be stronger than you, yet still require the same types of assistance, such as toileting. Let's say, also, that they cannot speak or understand complex language. How has your world changed now? How long do you think you can live this way? And for parents, whose typical children become more independent, like going out with their friends to the park or to the store, starting at approximately eight to 10 years of age. What a relief it is to be able to complete chores with some peace and quiet and no unremitting demands.

The provincial government has 12 months to eliminate wait lists as per the recommendations of the report of the Select Committee on Developmental Services. With 12,000 developmentally disabled Ontarians waiting for placement in group homes, Community and Social Services Minister Helena Jaczek has committed to building a plan to implement the 46 recommendations and report back on progress in six months.

This may be an indication that the currently elected government is serious about the issues that the developmentally disabled and their families face. They have conceded to the urgency of the situation and have indicated their commitment to providing adequate resources so as to meet the needs of these marginalized persons. However, Jaczek stated that a more realistic timeframe is two years to eliminate the wait lists because agencies need to build up their capacity.

In the meantime, I would expect that those families in crisis will be tended to most immediately. Building capacity is a vital step to eliminating the wait lists. And eliminating wait lists will provide the critical first step in the realization of meaningful lives for some of the most marginalized people in our society.

