



Brief Presented to

**The Deputy Minister
of Community and Social Services**

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ARCH's Brief to Deputy Minister of Community and Social Services, Marguerite Rappolt

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I. Introduction

ARCH has observed an alarming and growing trend of adults with intellectual disabilities being unable to afford vital programs and supports that would facilitate their development, independence and participation in the community. The Ontario government's Passport program is one vital source of funding for such supports. However, Passport remains grossly under-funded, with unwieldy waiting lists, and no program transparency. As a result, young Ontarians with intellectual disabilities and their families are suffering extreme hardship.

II. Promises of Support for Ontarians with Developmental Disabilities

In 2008, Ontario passed the *Services and Supports to Promote the Social Inclusion of Persons with Developmental Disabilities Act* ("Social Inclusion Act").¹ The Act is not yet in force, but when it comes into force it will replace the *Developmental Services Act*. The Act marks a shift in the developmental services sector away from institutionalized

¹ *Services and Supports to Promote the Social Inclusion of Persons with Developmental Disabilities Act*, 2008, S.O. 2008, c.14 [Social Inclusion Act]

care and towards a system of services and supports that are intended to enable people with intellectual disabilities to live and participate fully in communities of their choosing. As part of its strategy to transform the way in which publicly-funded services are delivered to people with intellectual disabilities, the Ministry of Community and Social Services promises that this new legislation will build a modern, fair and sustainable developmental services system that will give people with intellectual disabilities more independence and choice and foster their full inclusion in society.²

The current government has trumpeted an end to institutionalization. The stated goal of the Ontario government is to "...help people with a developmental disability to participate fully as citizens in Ontario communities."³

One vital program in support of these goals is the Passport program. Passport helps adults with intellectual disabilities who have left school find more ways to participate in their communities. According to the Ministry, the Passport Program:

- eases the transition from school to life as an adult in the community,
- encourages independence,
- builds social, emotional and community participation skills, and
- promotes continuing education and personal development.

Through Passport, people can receive funding for activities that help them: grow personally; use community programs; develop work and volunteer skills; join local clubs; and reach their goals.⁴

Thousands of adults with intellectual disabilities and their families have applied to Passport precisely to support these goals. For example, Passport funding is frequently

² Ontario, Legislative Assembly, *Official Reports of Debates (Hansard)* 47 (May 26, 2008) at 2042-2043 (Hon. Steve Peters).

³ Ontario Ministry of Community and Social Services (2010). "Ontario's goal for people with a developmental disability", June 21, 2010. Accessed Online at: <http://www.mcsc.gov.on.ca/en/mcsc/programs/developmental/>

⁴ Ontario Ministry of Community and Social Services (2010). "Services and supports for people with a developmental disability: Passport", June 29, 2010. Accessed Online at: <http://www.mcsc.gov.on.ca/en/mcsc/programs/developmental/servicesAndSupport/passport.aspx>

used to fund participation in day programs that foster community interaction and skills development. However the promise of Passport is going unfulfilled. ARCH hears from many families on waitlists without any indication as to when they will ever receive funding. While the program is intended to be focused on aiding those with an intellectual disability in transitioning from school to community life, funds are not arriving when they are most needed. Teaching such skills and providing the necessary support is extremely time-sensitive. Program participants cannot successfully transition to community life as adults if necessary funding is received *years* after they leave high school, if at all.

Ontario citizens with intellectual disabilities clearly cannot achieve any of their goals if necessary funding for programs that would foster independence, choice, and inclusion in the community, is not made available in a transparent manner. Young adults in Ontario with intellectual disabilities are being left trapped inside their homes watching television, experiencing severe depression, isolation and loneliness because they are not receiving necessary funding to attend vital programs and go out into their communities. In some cases, young adults left without vital Passport funding do not even perceive themselves as adults because they are not given adequate support by the Ministry to participate in their communities, gain independence and skills, and in some cases seek employment. They remain dependent on their families for their supports and services, which they often feel relegates them to a child-like status.

In the Ontario Legislature on March 4, 2009 the Hon. Madeleine Meilleur stated that: “In 2005, we started this Passport program, which has been very successful in helping people like Teddy stay at home with his parents.”⁵ However, ARCH respectfully submits that the Passport program is failing adults with intellectual disabilities because of ever-expanding waitlists, under-funding and the lack of transparency in the program. This is an urgent problem that is known to the government and has been raised in the Ontario Legislature, by the opposition:

⁵ Ontario, Legislative Assembly, *Official Reports of Debates (Hansard)* (March 4, 2009) at 1120 – 1130 (Hon. Madeleine Meilleur).

I've heard from many families over the past year who have applied for funding under the Passport program and have either been denied funding or put on lengthy waiting lists. Families are struggling, and we need to help them now.⁶

After many months, and years, the Patersons and thousands of other families are *still* waiting for funding for which they qualify, while the development, and physical and emotional well-being of these young adults continues to deteriorate.

III. The Impact of an Under-funded Passport Program

These are the stories of three families among thousands who have been negatively impacted due to a lack of Passport funding, as told by the parents of young adults with intellectual disabilities:

Ted's Story

“My son, Ted Paterson, is a 21 year old man who has cerebral palsy. He has limited mobility and requires the use of a wheelchair. In the past Ted has benefited from school-based programs. Now that he has finished high school, in order to be active in the community and continue his development, Ted would benefit from day programs. However, this requires attendant care to facilitate social interaction, mobility, eating and toileting. It is clear that such supported participation in a full-day program would best integrate Ted into the community and continue his personal development.

Although our family currently receives some money through the Special Services at Home (“SSAH”) Program, this is far from sufficient to cover the cost of a full-day program. Such programs for people like Ted who are dependent on others for mobility, feeding, toileting, and general facilitation range in cost from \$50 to \$250 a day.

⁶ Ontario, Legislative Assembly, *Official Reports of Debates (Hansard)* (April 1, 2009) at 1530 – 1540 (Hon. Sylvia Jones)

We have applied for funding through the Passport program, and although Ted has been identified as someone with “significant” needs, and would assuredly be approved for this program, his application in late 2007 continues to languish for lack of funding.

In a letter from Minister Meilleur dated July 14, 2009, the Minister states that the Passport initiative demonstrates the Ontario government’s commitment to people with developmental disabilities, and suggested that I communicate with the MCSS Toronto Regional Office. I was subsequently informed by Ministry staff that no new Passport funding was being released and that Ted’s time on the waiting list would continue.

In a letter sent to Minister Meilleur dated September 23, 2009, I reiterated the situation facing my son, and asked to be informed when new Passport funding would be released, what other sources of funding might be available, and what criteria the Ministry used when deciding to provide Passport funding. The Minister’s reply in a letter dated October 20, 2009, indicated that there is no funding available to meet Ted’s needs. Staff at MCSS have told me that the Passport program is no longer being funded. While it may be the case that a new framework is being put into place, families are suffering while the Ministry’s “Transformation” initiative drags its feet.

The uncertainty and lack of support in our current situation has put a great strain on Ted and us. Ted is deeply saddened that he will be left at home without seeing his friends and without an opportunity to continue learning. We cannot plan for the future, and face great difficulty in supporting him while attending to other needs. As just one example, I recently had to seek out emergency respite support for Ted, in order to attend a job interview, and my efforts to find employment are compromised by my need to stay home and care for Ted. We all struggle to participate in the community and be active, working citizens in the absence of adequate funding.

Sarah’s Story

“Sarah is a 21 year old with severe and profound disabilities and fragile health. Sarah has no functional vision, cannot move herself in any way and can not speak. She

requires 24/7 care with constant intervention day and night. Feeding alone takes several hours each day. Sarah's skin is prone to breakdown if she is not moved frequently. She has 120 degree scoliosis which causes discomfort, has had both hips replaced causing spasms and struggles with daily seizures, and has a sleep disorder. On good days, Sarah is difficult to feed, position, dress, and provide physical care, particularly as she now weighs 90 lbs. On bad days, of which there are many, Sarah cries for long periods for unknown reasons, vomits, experiences blue spells and 'absences'; and chokes on mucous secretions. A day can change from good to bad in seconds.

Sarah's situation has remained the same for many years. She is challenging to care for, unpredictable and one of the few girls with Aicardi Syndrome still alive over the age of 10. Sarah remains alive only through the care of as many as 7 individuals in school and at home who spend some hours with her each week in a caring capacity, making sure that she is safe, comfortable and free of pain. She requires constant supervision, ongoing assessment and appropriate intervention. Despite these challenges, Sarah is not bedridden. She attended school and she graduated this year and is now about to start a new life as an adult. With the right support, Sarah can have an interesting and exciting life beyond school. Current plans for her day include volunteer work in the community, dog-walking, deliveries, continuing education in cookery, art, pottery and gardening, recreation activities such as bowling and swimming as well as music and massage therapy. Initial plans are also afoot for Sarah to help initiate discussion about disability with young children and starting a business where she will be able to shop, pack, deliver and market goods – all with hand-over-hand support.

However, Sarah's care, her life at home and new life in the community is only possible with the right financial supports in place. The funding to support Sarah's care has been a mix of three sources: CCAC, Special Services At Home and my own income. For 14 years I supported Sarah as a lone single parent with no family in Canada, continuing my support through a personal battle with cancer. I continue to work full-time in a demanding job to provide Sarah the quality of life to which she is entitled. When Sarah

turned 18 we lost Enhanced Respite funding of \$3,500 and a further \$6,800 of SSAH support when she turned 20. Now, she has left school with no Passport funding and needs another 40 hours a week of care which could cost over \$30,000.

Clearly it is beyond my abilities to make up the shortfall of \$6,800 on top of the \$3,500 we lost two years ago, and another \$30,000 annually in the coming years. These losses require an unlikely increase in my pre-tax income of \$75,000 a year – impossible in even the best economic times. In terms of providing more care for Sarah myself, I already care for her from when I return from work until 11:30 p.m. five nights a week, stay up one night during which I barely get any rest and for much of the weekend. I am also now 61 years old and cannot continue to support Sarah forever with just my own resources. I am falling off a financial cliff and, without support, will accumulate massive debt as I enter my retirement years.

For Sarah's first 21 years I have been scared of losing the child I love. Now, I am scared that she might live and I will not have the support to take care of her. I am at a loss to understand the decision to arbitrarily cut our funding because Sarah reached 18 and that no support is available for her daytime supports post-school. Sarah's care in any institutionalized setting would far exceed the amount it costs to keep her where she belongs, at home with her family in the community. We have spent 21 years working hard to keep Sarah alive, healthy and happy. Now, as she becomes an adult, we have seen support drop away at an alarming rate, revealing a frightening future where her life does not seem to be valued.

Sarah's case is considered "medically complex" and she was not given a transition plan for leaving school as there were no answers. Even if I wished, she cannot attend a day program as no Toronto day program offers support for medically fragile youth, nor can she travel on Wheeltrans or in a taxi unaccompanied to reach one. In any event, the life we have planned for her is more innovative, creative and appropriate than any day program could offer. Clearly it would be best for Sarah if she can stay at home and enjoy what we have planned. But this cannot happen without sufficient government

support. If she is simply placed in a nursing home, the medical care will not be adequate and she will not survive. And what type of life is living in a nursing home for a 21 year-old?

Despite the fact that Sarah has been identified as being in the highest priority category for Passport funding, she has been on the waitlist for over one year, and I have been told as recently as this week (June 28, 2010) that there is no money available. I am left to wonder: why has everyone invested so much in keeping Sarah alive, only to cast her off when she reaches adulthood?"

Sean's Story

"Sean was born with a developmental disability and autism. Up until he left school, there were programs and places for him to participate in the educational system. Since he left the educational system, everything changed for the worse. The waiting lists for programs are long and the fees are expensive. The daily fees range from \$35.00 per day and up.

Sean needs support in order to participate in a program. We had to hire someone to teach him how to travel to and from his program on public transit. When he was at the program, there was a lack of adequate support for him. Hence, he was not successful in his first round at this program. We have had to suspend his attendance while we figure out what our next steps are. The program has recommended that we hire a worker to go with him, at \$48.00 per day.

While he was there, Sean benefited greatly from the CORE program by participating in arts and crafts activities, learning how to sweep as an employable skill, and learning communication and life skills. However, lacking a support worker to overcome behavioral issues, Sean has been forced to spend his days housebound and has become extremely lonely and feels isolated. Since having to leave the day program

Sean continues to pick at his hands and create open sores. He has lost the structure of a day-to-day routine and feels that his life is falling apart.

We applied for Passport funding two years ago but have heard nothing from the office responsible. Then we heard that there was no more money available. It has been incredibly difficult to navigate our way around the system since Sean finished school. And the hope of getting Passport funding seems to be getting fainter as we go along. All of this has taken a great emotional and financial toll on Sean, our son, his father and I. Caring for Sean has also had a negative impact on my employment, as I have had to take half-days off from work to care for Sean, and must interrupt my work to deal with calls and e-mails related to Sean's care. It is overwhelmingly stressful to consider the future when we will not be here to support him, because he needs to be taught how to transition to a different home."

IV. Lack of Choice

While the current Ontario government has loudly trumpeted the closing of the province's last three institutions,⁷ there is a growing danger that adults with intellectual disabilities will simply be "re-institutionalized" in a different form. If programs like Passport are not adequately funded, the "end of institutionalization" will never be a reality. As stated by the opposition:

We invested a fair amount of time in this Legislature last year on the topic of Bill 77 [*the Services and Supports to Promote the Social Inclusion of Persons with Developmental Disabilities Act*]. Bill 77 was about services for persons with developmental disabilities. As my colleague from the Conservative Party has said, nearly a whole year has gone by and it has not been proclaimed. A whole year has gone by and we've had a budget

⁷ Ontario Ministry of Community and Social Services (2010). "The End of Institutionalization", February 10, 2010. Accessed Online at: <http://www.mcscs.gov.on.ca/en/mcscs/programs/developmental/improving/endingTheEra.aspx>, on June 28, 2010.

that did not put a single penny towards this laudable new goal that the government proudly proclaims at every opportunity. But today, this bill has resulted in the kind of inadequate and inaccessible services that were promised but have never been delivered.⁸

Often, adults with intellectual disabilities would benefit immensely from day programs or other tailored forms of community support, while remaining with their families. In order for services and supports to be effective, they must be individually tailored to meet the specific needs of each person with a disability. This cannot be a case of one size fits all, given the broad diversity among people with intellectual disabilities.

Tanya D. Whitehead and Joseph B. Hughey assert that:

... it is becoming clear that real choice means real options, control of the process of decision making, and control of the resources would move from the system's control to the person's control. If a shift in control of this type should occur, it would have profound implications for the relationship between support people, the organization of services and supports, and the people with disabilities who use those services on a day to day basis.⁹

V. Conclusion

The stories of Sarah, Sean, and Ted clearly illustrate the negative consequences of inadequate and inequitable funding for services. Adults with intellectual disabilities receive more funding when living in group homes or institution-type settings such as long-term care, and nursing homes, but those who wish to continue living with their families may have the same needs but receive less funding. If thousands of adults with intellectual disabilities are forced to enter such residential services because of a lack of

⁸ Ontario, Legislative Assembly, *Official Reports of Debates (Hansard)* (May 26, 2008) at 1530 - 1540 (Hon. Michael Prue).

⁹ Tanya D. Whitehead and Joseph B. Hughey, *Exploring Self Advocacy From A Social Power Perspective* (New York: Nova Science Publishers, Inc., 2004) at 17

financial support, this is simply a decentralized form of institutionalization. Many adults with intellectual disabilities in Ontario are being left with the one “choice” to leave their families. The Ministry’s stated goal is to help Ontarians with intellectual disabilities to have more choice, but a lack of necessary funding from programs such as Passport is leaving them with no real choice.

It is clear that additional funding is needed to support individuals such as Ted, Sarah and Sean. Families have hope in that the new legislative scheme, once in force, will be more responsive and provide new and needed funding. Relevant provisions of the *Social Inclusion Act* will come into force on July 1, 2011. However, the situation is dire for many families and individuals, such as Ted, Sarah and Sean, who simply can not wait another year until the Act comes into force. We urge this Ministry to act and make available sufficient resources and take appropriate measures to ensure that families have access to the supports they require in the interim period.