

January 24, 2020



Via Email: comm-financeaffairs@ola.org

Amarjot Sandhu, MPP, Chair
The Standing Committee on Finance and Economic
Affairs Pre-Budget Consultations
Room B-304, Whitney Block
Queen's Park, Toronto, Ontario
M7A 1A2

Dear Mr. Sandhu,

Regarding: 2020 Pre-Budget Consultations

Thank you for the opportunity to present our challenges and ideas as part of your consultation and preparations for Ontario's next provincial budget.

As a developmental service agency, Extend-A-Family Waterloo Region (EAFWR) supports 2,229 children and adults in Waterloo Region. Our annual operating budget is approximately \$12.8 million, which includes \$7.2 million in individualized budgets that we administer on behalf of families with Special Services at Home (SSAH) funding, or on behalf of adults who have Passport funding.

EAFWR is a member agency of OASIS. We concur whole-heartedly with the issues, cost pressures and solutions identified in the OASIS Submission to the Standing Committee on Finance for the 2020 budget. We wish to highlight similar concerns, and also provide reference to systemic issues such as children aging out of the MCCSS-funded Special Services at Home program only to wait in some cases for years for the MCCSS-funded Passport program. I have attached copies of the OASIS submission for your reference.

In 2018 the Ontario Developmental Services Housing Task Force published their Final Report entitled, **Generating Ideas And Enabling Action: Addressing the Housing Crisis Confronting Ontario Adults with Developmental Disabilities**, they reported that, "there are more than 15,000 adults with developmental disabilities in need of housing in Ontario". In the Waterloo Region alone, the Developmental Services Ontario (DSO) agency tells us there are more than 500 individuals in current need of residential services. We need an investment of funds to expand residential services and address this crisis. The above-noted report contains many ideas for systemic change and modernization of the system for efficiency and effectiveness, while simultaneously requesting a ten year plan of increased funding to address this ever-growing waitlist.

I received a letter from a parent who, several years ago faced a decision no parent should have to face. Here is part of the story that she shared with me:

After 3 1/2 years of violent behaviour, and supports dwindling, I abandoned my daughter with Family and Children's Services, in order to force them to help me find her a children's bed. We signed a Special Needs Agreement where I retained my parental rights. Many family and friends supported me in this, however, other than my Father's sudden passing at the age of 57, it was the hardest thing I have ever faced in my life. I never knew a person could cry so many different 'kinds' of tears while I prepared to let Laura go. Laura was placed in a behaviour group home in Brampton for 1 year. This was not a good place, she was hurt there, and so I demanded FCS remove her. She ended up at CPRI in London for an emergency stay, and then back to another group home in Scarborough - even further away. There she remained for 2 1/2 years. This was a very difficult time in my daughter's (and my) life. I visited every weekend.

This single-mom has remained a strong advocate for her daughter, who now lives in Kitchener-Waterloo. Mom has fought hard for the supports that Laura needs. For example, Laura was blind for two years due to cataracts, until mom was finally able to find a doctor who was willing to perform the much-needed surgery. Fortunately, while still a young adult, Laura got her sight back. This is an example of the extreme actions parents have to take to fight their way to the top of the prioritization process to gain access to services for their loved one. This should never happen.

We currently support two men who have moved from our Family Home program into long-term care. They could very easily be supported within a developmental services group home, but there are no options available. Wayne is in his 40's. He absolutely should not have to live in an institution because he needs more support than the Family Home (where he lived for over 20 years) can provide. We are desperately trying to get Wayne and Gord placed within developmental services and hope this LTC arrangement is temporary. We continue to support Wayne and Gord to attend day programs, and continue to have an active life but they are suffering. Wayne's day program is now in jeopardy because he is so stressed about his living arrangements that he is disruptive at the day program. This is entirely new for him. Our system has done this to him. If he loses his day program, we will see him heavily sedated and living 24/7 in an under-staffed long-term care facility for the next 30 years before he reaches the average age of the others in the home. This is not the life we envision for a person who relies on our Ministry of Children Community and Social Services funded developmental services.

Many of the Waterloo Region families who desperately need residential services for their loved one face dire circumstances with seemingly no way out. We need to show them a way out. Our province can do much better. We need an influx of funding to ensure that adults are able to access suitable housing supports before their family hits a crisis point.

Families who have Special Services at Home (SSAH) funding typically receive a funding approval/renewal letter in March, ahead of the start of the fiscal year. Unless their circumstances change, families are not required to have their children re-assessed for the next fiscal year. This past year, in 2019, families did not receive the letter, and in fact anyone who inquired were told that the approvals would not come out until after the budget was announced April 11. Families had no assurance that the SSAH program was in fact continuing or when the confirmation would be provided. Agencies were asked not to communicate with families about this delay, as the province did not want to raise alarm bells. The news media picked up the story, creating panic amongst the families who feared their funding would be cut. It was not cut, but rather approved before the end of April. The delayed notice served no significant purpose. Yet thousands of families experienced a loss of service and great distress for weeks. Please make the decisions early and communicate with the families ahead of the fiscal year, ensuring continuity of service and a stress-free transition to a new fiscal year.

SSAH was once a program for children and adults, but in 2012, SSAH was eliminated for adults. They now have to apply for Passport funding, which is, in many ways, similar to SSAH. Yet, the waiting period can be years, even though both services are funded by MCCSS. Why should an 18th birthday result in the loss of services, just as the youth is finishing high school? The answer is "because MCCSS changed the system". The OASIS submission addresses this in their first and third recommendation. A parent told me that her daughter lost her SSAH funding after close to 15 years of eligibility. Mom reports that,

This has made a large impact on Marie as they would do a lot in the community as "buddies" (the SSAH worker was only 8 years older). This was a great benefit to Marie as she felt she was doing things (as other teens do) in the community without her parents, but with a friend.

She is now 20 years old and has had no word about when she will receive funding. The DSO has simply confirmed Marie's eligibility. So, she remains eligible for this much-needed funding, but her 18th birthday marked the beginning of her waiting period and the loss of her worker, a key link to her community, at a time of significant transition from high school to adult life. How long is it appropriate for Marie to wait for services?

Another mother shared a similar story with me. Her son is a young adult, has completed high school and is eligible for Passport funding:

It is a reality for us that although my young adult child has life goals and is determined to be a valued member of society, he will continue to need the support of his family and paid persons to ensure his safety and well-being. Passport funding would aid in the costs associated in providing my adult child continued social, emotional and educational opportunities to reach his ultimate goal of independence.

These stories demonstrate the heart and real-life behind the fact that 14,800 Ontarians are on the Passport waiting list. And, 15,000 people in our province require residential services with 500 of them being in Waterloo Region. Please provide funding to expand the services that these folks need so desperately.

In 2018 a minimum of \$5,000 Passport funding was announced for all eligible adults, ensuring a successful transition from SSAH funding for children up to age 18 to Passport funding upon their 18th birthday. OASIS references this as Passport Bridge. Then, beyond this bridge, based on assessed need level, additional Passport funding could be approved. Yet, there are consistently gaps and waiting periods, and costs associated with eligibility assessment in order for people (who were eligible for SSAH until their birthday) just to receive the Bridge funding allocation. In many cases, months of parental advocacy is required to access these supposedly guaranteed Passport funds of \$5,000 annually. Please ensure changes to the process such that the transition is seamless and does not result in a gap in services for these families. And, please invest sufficient funding such that the funding level can match their assessed need, and not linger at the insufficient \$5,000 level.

We recognize that we need solutions that go beyond simply "more money". I would urge you to introduce a systems change to help ensure the much-needed funding is used efficiently and effectively. Our 12 month fiscal cycle is simply not working. It is common for MCCSS to make funding approvals in February or March and require the resources to be spent prior to the end of the fiscal year. Our sector would benefit from multi-year budgets with the ability to reserve funds (subject to ministry spending approval), rather than rush spending at the end of each fiscal year, creating a cycle of spending that is inefficient, ineffective and, ultimately, predictable every March.

Finally, a mechanism to monitor and adjust funding levels annually is urgently required. Statistical information such as the annual Cost of Living Allowance (COLA) should be used to assist in determining if funding levels are up to date. We cannot receive 2009 funding levels and expect to survive in the current economy. Services have been eroding for a decade, while costs go up and, in many cases, people's support needs increase as they age. Again, this is math that simply does not work.

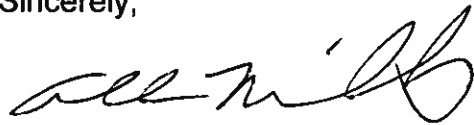
After ten years of zero increases, our first increase (Stabilization in 2018-2019) has not been annualized. This "Agency Stabilization Funding" was communicated via letter as "annualized funding", intended to address cost pressures. The following fiscal year, we received confirmation halfway through the budget year that we were again receiving our Agency Stabilization Funding, but it remains fiscal, with no commitment to it continuing. Rising costs such as Pay Equity obligations and rising benefits costs, utilities, groceries, rent, etc. cannot be addressed with fiscal funding as these are ongoing costs. We need the assurance that this base increase is indeed a base adjustment, so that we can plan ahead and use the funds strategically and efficiently. This essential funding, in the way it

has rolled out, has been *de-stabilizing* funding, not providing the results that were intended. Please annualize it and provide clarity on our budget early in the fiscal year.

Systemic improvements such as these two examples will most effectively be found in consultation with the agencies that deliver the services, as noted in the OASIS submission as recommendation one.

I thank you for hearing our concerns, and I look forward to good news in Ontario's next budget for Ontarians who live with developmental disabilities.

Sincerely,



Allan Mills
Executive Director

Encl.: Julia Douglas, Clerk
OASIS Submission of Standing Committee on Finance, 2020 Budget
Amy Fee, MPP Kitchener South-Hespeler
Catherine Fife, MPP Waterloo
Mike Harris, MPP Kitchener-Conestoga
Laura Mae Lindo, MPP Kitchener Centre
Belinda Karahalios, MPP Cambridge



**Ontario Agencies Supporting Individuals with Special Needs
Agences ontariennes de soutien pour les personnes qui ont des besoins spéciaux**

**Pre-Budget Submission
Ontario Agencies Supporting Individuals with Special Needs
January 2020**

Ontario Agencies Supporting Individuals with Special Needs (OASIS) is a volunteer-run, member-driven provincial organization. Our member agencies support children and adults with developmental disabilities in every corner of the province. We provide services to over 65,000 of Ontario's most vulnerable citizens and employ 25,000 full and part-time staff. Our 190+ member agencies currently provide more than 85% of all developmental services funded by the Ministry of Children's, Community and Social Services.

OASIS is eager to work with government to help address the challenges being faced by families and individuals with developmental disabilities and the opportunities to modernize the sector. We recognize the fiscal challenges facing the province and believe that only in working together can we resolve these challenges. Our member agencies are lean and efficient organizations, and understand the need to extract value from every dollar of public or donor funds.

We know that the government has difficult decisions ahead to restore balance and confidence in public finances. OASIS has continually made clear our desire to work with the government to modernize how developmental services are delivered across the province and we are eager to help identify solutions to make the sector more efficient and sustainable. OASIS is seeking productive and meaningful engagement with government as decisions around service transformation for individuals, families, and agencies are made.

1. Formal and meaningful consultations with individuals, families, and the DS sector bringing all of us to the table before decisions are made

The government has confirmed that a third-party consultant has been engaged since September 2019 to complete a review of the DS sector and to recommend ways to maximize efficiency and modernize the sector, looking to other jurisdictions for ideas and solutions. OASIS has not been advised of the timelines for the final report or when the report and recommendations will be made public. Looking ahead, we would urge the

government to learn from other jurisdictions to ensure that modernization is properly funded, avoiding disruption to critical services and ensuring a smooth transition.

OASIS is asking that the government work with our sector and engage in substantive and meaningful formal consultations with people with developmental disabilities, their families, and the agencies that support them, before any decisions are made.

We have concrete suggestions that we are eager to share through this process. We have developed and previously shared ideas that could save time and money, as well as free-up our sector to deliver higher-value work more efficiently. These include removing unnecessary bureaucracy by streamlining Quality Assurance Measures and allowing accreditation instead, creating more choice for families and agencies. This allows transitions to individualized budgeting solutions and lets agencies develop opportunities for amalgamations and sharing of back office functions, such as HR and IT.

There is a unique opportunity to seize-upon the merger of the former Children and Community and Social Services ministries into MCCSS by eliminating repetitive eligibility tests and streamlining the age-based direct funding programmes Special Services at Home (SSAH) and Passport into one programme. These reforms would help address the “cliff” families fear when their children turn 18.

These ideas are meant simply as a starting point for discussion. Given the opportunity to participate in substantive consultation, we are prepared to work together to develop these and other ideas further.

Consultation is a must with the individuals, families and service providers directly impacted by publicly-funded developmental services. No one understands the challenges and opportunities of our sector better than those who provide and receive supports.

2. Maintain funding allocations at current levels

While we are not asking for new money as part of this Budget submission, OASIS is calling on the government to maintain agency budgets at current levels by annualizing stabilization funding. After over a decade of frozen budgets, the DS sector received \$57 million in new funding in Budget 2018 to help address increases in both need and basic operating costs, such as hydro bills, food, and property. This stabilization funding accounts for 0.35% of the overall budget of MCCSS in 2019. Stabilization funding is vital to all DS agencies budgets and helps keep people out of crisis, as well as out of hospitals and correctional facilities.

Cuts to this funding would mean job losses, with some agencies needing to permanently close their doors, leading to even longer wait lists for services. It would lead to people and their families losing the services they count on, which means more parents and care-givers working part-time or not at all to support their family members with developmental disabilities. Cuts to these direct services put individuals and families at imminent risk and

tax the whole system greatly, not only those individuals directly impacted. It would mean higher costs to other government sectors, including our already strained health system, due to some of Ontario's most vulnerable people with complex care needs being placed in hospital beds, for want of more appropriate settings. OASIS is committed to working with government to modernize the sector and improve the services to individuals and families. Learning from other jurisdictions, modernization must be funded properly to avoid disruption to critical services. At a minimum this must start with a commitment to maintaining current budget allocations, including the critical stabilization funding.

3. Maintain the Passport Bridge

Currently, some individuals with developmental disabilities receive direct funding when they turn 18 through the Passport programme. They use these funds to purchase services in their communities, such as employment training opportunities, cooking classes to increase independence, and public transit training to help people navigate their communities. This is real money in people's pockets that they can direct however they see fit.

The waitlist for Passport funding is over five years, and often does not become available until well after youth-focused SSAH funding expires. In Budget 2018, the Passport Bridge was introduced, which provides \$5000 per year to families on the waitlist while they wait for their full allocation to become available. Families who have received this funding have reported significantly improved access to community services and quality of life.

To date, the government has not communicated regarding the future of Passport generally or the Passport Bridge in particular. Many individuals and their families are unable to make critical decisions about services in the community without assurances about their eligibility. Many families who should be eligible for the Passport Bridge have not received word about their future. Absent clear information, many are assuming the worst and expecting cuts to Passport. Removing this programme would mean pulling money out of family budgets and real cuts to the services these families purchase. OASIS is calling on the government to publicly commit to maintaining both Passport and the Passport Bridge and communicate a timeline around full implementation of the \$5000 allocations for families on the waitlist.

Conclusion

The key areas outlined here should in no way be seen as encompassing all of our sector's priorities. For example, there is a desperate need for more and adequate housing for people with developmental disabilities, a need that will only continue to grow as family caregivers age. We look forward to participating in forthcoming engagement opportunities on this critical topic.

Despite these other pressing issues, OASIS is advocating for the inclusion of the key areas articulated above in Budget 2020.

To reiterate, OASIS is advocating for:

1. Commitment to stabilize the sector by maintaining funding;
2. Substantive consultation around transformation and modernization, and;
3. Continued support for the Passport programme

Working together, we can provide better and more efficient services while protecting the vulnerable people we serve.