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December 13/2021

Hon. Minister Dr. Merilee Fullerton
Ministry of Children, Community and Social Services
438 University Ave. 7th Floor
Toronto, ON M7A 1N3

Re: SSAH

Dear Minister Fullerton:

We are writing to share the findings of People for Personalized Funding's 2021 survey of Ontario families whose sons and daughters receive Special Services at Home (SSAH) funding.

Our survey shows that SSAH *already* allows children and youth to live the life the MCCSS reform framework Journey to Belonging, Choice and Inclusion envisions on the future for people with developmental disabilities. SSAH *already* supports disabled young people to participate in their own communities (in their own languages and cultures), connect with other kids, access generic community services and live the lives they choose.

Ontario does not have to wait 10 years to test new approaches and get people used to change. As they have since 1982, Ontario families continue to benefit from SSAH, especially to help their children with disabilities live happier, more inclusive lives. Successive governments have seen that SSAH provides excellent and cost-effective support. SSAH *already* helps make Ontario a better place for people of all abilities.

However, as we told your predecessor in a March 9, 2021 Bulletin, provincial SSAH funding is totally inadequate. Thousands of eligible children have been left waiting – sometimes for years – without help to participate in and contribute to their communities. This means families remain isolated and parents must provide all care and so crisis is more likely. Families deprived of SSAH now will go backwards, caught on waiting lists for a service system that MCCSS knows needs to change.

HOW DO FAMILIES USE SSAH FUNDS?

What is especially important is that SSAH funding can respond to individual circumstances and serve multiple purposes, all at once.

Our survey tracked the overlapping purposes for which respondents used SSAH.

- 58% of SSAH use helped respondents' sons and daughters do such things as:
 - go places and do things they enjoyed
 - attend generic child and youth programs (day camps, YMCA, etc.) and
 - learn new skills
- 36% of their SSAH use allowed respondents time away from parenting – which could happen during the time their sons and daughters were supported to participate in those activities.
- Only 6% of the reported SSAH use went to pay for disability-specific programs.

HOW SATISFIED ARE FAMILIES WITH HOW SSAH FUNDS CAN BE USED?

- Very satisfied 29%
- Somewhat satisfied 47%
- Somewhat dissatisfied 15%
- Very dissatisfied 9%

HOW SATISFIED ARE RESPONDENTS WITH AMOUNTS OF SSAH FUNDING THEY RECEIVE?

Although average SSAH allocations are less than \$3000 a year per person, respondents told us the amounts they received made them feel:

- Very satisfied 20%
- Somewhat satisfied 45%
- Somewhat dissatisfied 20%
- Very dissatisfied 15%

HOW LONG ARE FAMILIES WAITING FOR SSAH INCREASES?

- Of those who had applied for an increase, 69% were waiting a year or more.
- Of these families, 28% were waiting more than 3 years.

HOW OLD ARE THE RESPONDENTS' CHILDREN?

- 45% of our survey respondents were parents of children aged 5 to 10 years.
- 34% of their children were aged 11-15
- Only 6% of our respondents had children under age 5.
- However, 15% were parents of 16 and 17 year olds, who are about to “age out” of SSAH. Most survey respondents knew that SSAH stops at age 18 but most did not know how to apply for Passport funding then. *In 10 years, almost all of these people will be adults, and most will require ongoing support.*

HOW LONG HAVE RESPONDENTS BEEN RECEIVING SSAH?

- 51% of survey respondents had been receiving SSAH for less than 2 years

HOW LONG HAD ELIGIBLE FAMILIES BEEN KEPT WAITING BEFORE GETTING ANY SSAH FUNDING?

- 79% of respondents had waited a year or more
- Of them, 16% had waited more than 3 years.

86% OF OUR RESPONDENTS SELF-ADMINISTER THEIR SSAH:

These families are willing to do the paperwork involved in order to have flexibility to make the funding work best for them.

MCCSS should encourage this self-administration in the proposed provincial system reform it calls The Journey to Belonging – so that agencies need not be involved and government money is not lost to administration fees but is used in ways people find most helpful.

WAITING FOR REIMBURSEMENT:

- 85% of families surveyed report that they have waited more than 3 weeks for reimbursement of SSAH expenses
- among those families, 22% have waited more than 8 weeks.

Few families can afford such a disruption in cash flow.

To encourage optimal use of funds through self-administration, MCCSS should ensure families are reimbursed promptly.

FAMILIES VALUE DIRECT FUNDING – HIGHLY:

Our survey shows that families are willing to administer the funds themselves, despite bureaucratic obstacles. They use small SSAH allocations to improve their sons' and daughter's lives, but could do far more if funds were not spread so thin. Outcomes could be even better if children received funding earlier and didn't have to wait so long. Benefits continue to be denied to thousands more eligible children on SSAH waiting lists. When children are denied the benefits of SSAH, they lose important opportunities to take part in their communities early in their lives. If they remain isolated, important opportunities for friendship, education, employment and informal support will be lost. It is vitally important to ensure that children and youth with disabilities are not channeled into segregated services and that their families are well supported.

SSAH needs to be properly funded and responsively administered so it can improve the lives of all eligible children now.

Sincerely,

Alison Ouellette and Susann Palmiere, Co Chairs, People for Personalized Funding

Cc: Chris Beesley, Community Living ON
 Carla O'Neil, Family Alliance ON
 Paula Boutis, Inclusion Action ON