

FAO Article on Funding Survey for September Newsletter

Earlier this year Family Alliance Ontario conducted a survey on the experiences of families regarding the Passport and Special Services at Home (SSAH) funding they receive or are awaiting, to assist in support for their children and siblings who have a developmental disability.

A total of 386 families responded to the written survey and additional feedback was offered through some telephone, online, and in-person interviews. Two Passport coordinators also provided some thoughts based on their role with families.

People's answers and comments have been very informative. It was mentioned a number of times that having access to some individualized funding through Passport and SSAH helps to make a real difference for the entire family. As expected, the majority of those responding have one child with a disability (282 of the 371 who answered, or 76%. There were 77 (20%) who have two children receiving or awaiting funding, 7 with 3 children, 3 who have 4, and 2 with 5, all with a disability.

Of those replying to the survey, 69 receive Passport only and 288 have SSAH alone. Thanks to People for Personalized Funding (PFPF), previously called SSAH, Passport Coalition) the survey went to significantly more families using the latter. There were also options to check off for additional combined funding sources that included Ministry of Health, Ontario Health at Home, Ontario Autism Program (OAP) and Out of Home Respite. Of the 35 who responded to being on a waiting list , though most did not specify for which services, 14 have been waiting between a month and 2 years, 15 for more than 2 years, and 5 for over 5 years. An overwhelming majority (73 %) said they do not have sufficient support, with 27 % answering that they do, though a good number of those also mentioned that some increase would make a significant difference. Most commented that additional direct funding would be helpful and provide more options for people.

Surprisingly low numbers are receiving any assistance with planning, hiring, and supervision of workers, coordination, or cash flow. Those who do mostly pay an administration fee out of their funding to the organizations offering this help. The majority of families responding self-administer and take care of these functions themselves, though it frequently adds extra challenges.

Many important experiences and ideas were included regarding : *What is Working?; What is Not Working?; and Suggestions for Improvement?* As mentioned earlier, families are in favour of these individualized funding processes and are eager to see them evolve to work as effectively and responsively as possible. People shared a

number of insightful comments and suggestions on issues of: *Processes for Submission and Reimbursement; Finding, Supervising, and Keeping Workers; Communication; and Allowable Uses for Funding and Amounts.*

Families are eager to keep sharing their experiences and ideas to make a good idea even more helpful for people with disabilities, their parents, and siblings in Ontario.

A more detailed report will be shared by FAO in the near future with families, funders, and others who are interested in this topic. We thank all who took the time to respond to this Survey, to help make a difference in people's lives.