

## **Thematic Analysis of Narrative Survey Comments and Written Submissions**

Parent/caregiver and service provider survey respondents were provided an opportunity to provide additional comments. As well, two people who are neither parents/caregivers nor service providers also took the opportunity to submit personal comments via a feedback form on Saskatchewan.ca. Additionally, government received letters from five of the eight stakeholder organizations that were invited to share their views on Autism Spectrum Disorder (ASD) individualized funding. The following are the major themes from these submissions.

### **Major Themes:**

#### **Accessibility**

Many parents, service providers and organizations expressed accessibility concerns related to the lack of skilled professionals in the province, which may be more pronounced in rural areas, and potentially be impacted by increasing service rates as demand increases, as well as difficulties with navigating the system to access services. Recommendations included making training and orientation available, supporting rural residents to access services and providing navigation support to help families find and access services.

#### **Lifespan supports for individuals with ASD**

Parents, service providers and organizations all noted that individuals with ASD require supports throughout their lifespan. Many noted the benefits of early intervention, but also emphasized that needs increase during school years and continue into adulthood. Some respondents noted the lack of residential options and job opportunities for adults.

#### **Concerns with education system**

Many parents and a few service providers indicated concerns with the education system. Parents spoke about their challenges with having sufficient supports to help their child achieve success at school.

#### **Dissatisfaction with quality and quantity of current public services**

Several parents and a few service providers expressed concerns regarding the quality and/or quantity of public services currently provided to children with ASD. Many of these concerns centered around inadequate amount of public therapy hours available to children with ASD and long wait lists, while a few expressed dissatisfaction with the quality of service available.

#### **Flexible use of individualized funding**

Parents, service providers and organizations emphasized that each child with ASD is unique so individual needs vary. Some responses focused on the concept that every individual has the

right to self-determine what success is for them so they should be able to select services to support their version of success.

### **Diagnostic process may limit access to individualized funding**

Parents, service providers and organizations all recognized that the current ASD diagnostic process could be a barrier to accessing individualized funding and the therapy it can purchase. Many respondents note that diagnostic services are only available in larger centres and that there are long wait lists. In addition, the diagnostic process itself can be a long process that may take two or three years. Respondents are concerned that lack of timely access to diagnosis will be a barrier to accessing individualized funding and result in children not being able to access much therapy before they become too old to access individualized funding.

### **Satisfied with public services and concerned that they could be replaced by individualized funding**

Parents, service providers and organizations all suggest that a comprehensive range of services are needed to meet the needs of children with ASD. Not all parents may have the capacity to access individualized funding and private services may not be available in all communities. Respondents emphasized that individualized funding cannot replace all ASD services. Service providers and organizations also mentioned the importance of service coordination and collaboration among all professionals involved to focus on a family-centered plan.

### **Streamlined application and administration processes**

Many parents, service providers and organizations stressed the importance of streamlined application and administration processes to a successful individualized funding model. Several respondents are aware of the challenges with the Cognitive Disabilities Strategy and do not want the ASD individualized funding program to have the same administration challenges.

### **Loss of family income due to parent not being able to work**

Several parents expressed concerns related to the double financial burden of high expenses related to their children's disability and their inability to work due to having to care for their children. Even when children reach school age some parents are not able to hold a job as they must be available every time the school calls to tell them their child is not manageable and must go home.

### **Adequacy of funding and mode of delivery**

Parents, service providers and organizations all had concerns related to the adequacy of the suggested individualized funding amounts. They recognize that all individuals with ASD have unique needs and require various levels of support that can change from year to year. In addition some respondents suggested that a more appropriate delivery method would be through a disability tax credit.

### **Equity for children with disabilities**

Parents, service providers and organizations indicated concerns related to equity for children with a variety of disabilities. They recognize that children with ASD already have access to more therapeutic services than children with other disabilities. Sometimes children wait a long time for diagnosis, and there may also be cases of inaccurate ASD diagnosis in order to be eligible for services.

### **Accountability through monitoring, regulations and reporting**

Service providers and organizations pointed out that publicly funded programs need to be accountable for the use of funds through an administrative structure that includes program monitoring and regulations to ensure safety and financial reporting. They are concerned that vulnerable families could be enticed to spend their funding on non-evidence based therapies provided by unlicensed practitioners.

### **Individualized funding is not suitable for all families**

Service providers and organizations note that some families are overwhelmed with simply managing their day to day life and would not likely have the capacity to manage individualized funding. Some of these families may never apply for funding, while other may apply and experience difficulties with using the funds for their intended use.

### **Newcomer children's needs**

Addressing the needs of newcomer children with ASD was mentioned by one parent and one organization. Although this emerged as a minor theme in the survey, the issue will grow in the coming years as immigration continues to increase and changes the population demographics of Saskatchewan.