

July 2019

The last six months have been challenging times for Ontarians who care about services and outcomes for individuals with autism and their families. Many words have been spoken, much has been written, and yet one truth remains – at the core of everything is the future of children youth and adults with autism and their families.

Ontario families deserve the best service response that our province is able to provide. When a family receives an autism diagnosis, the journey can be challenging and rewarding in so many ways.

KidsAbility Centre for Child Development believes the hallmarks of a strong service delivery system incorporate:

- High quality, evidence based, outcome focused services;
- Services that are based on the need of the individual;
- Services that are universally available, respect family choice and are accountable to families and to funders;
- Services that are integrated, innovative and collaborative – delivered in partnership with providers of all necessary services.

The Government of Ontario intends to budget up to \$600 million annually in autism services. As citizens, we have the right to expect the best possible outcomes for this investment. It is not enough to just spend money – we must see results from our expenditures.

In support of the work underway to improve service experiences for families and to ensure more children receive life-altering services, KidsAbility offers the following recommendations:

Recommendation #1 – That MCCSS (Ministry of Children, Community and Social Services) provide a continuum of choice for families to access services

KidsAbility has always supported a family's right to choose the model of service delivery best suited for their needs. In some cases, that option has been **direct funding (DFO) (families receive funds directly and source their own provider)**; in others it has been **direct service (DSO) (families receive services from an agency funded to deliver the service)**. Families are best served when they can make a true choice. Some families have told us that they cannot or

do not want to manage service provision. Based on the family's priorities, both options should be available if we are truly supporting a family-centred model. Conducting a survey of the existing wait list to determine what families wish to receive would provide valuable information to guide funding model directions.

Recommendation #2 – Consult with families, providers and research experts to determine what a needs based service delivery system is. KidsAbility strongly recommends an average weekly cap of 25 hours, the retention of the Family Support Worker role, effective service navigation and limitation of the Childhood Budget eligible services to Behavioural Supports and Rehabilitation services – all based on clinically recommended needs based plans.

MCCSS has convened an expert autism panel. The mandate of this group is not transparent, however, the panel could advise the government on needs based service. Utilizing the expertise at the table, as well as having access to additional expertise through interested stakeholders, the panel may be in a position to make recommendations to support an inclusive service delivery model. Our recommendation is based on evidence regarding effective and integrated service delivery approaches for children and youth with autism. In particular, MCCSS should seek stakeholder input into the integration of Speech and Language, Occupational and Physio therapies as this has been extremely beneficial for children. The role of the Family Support Worker has been invaluable for families in our community. In addition, MCCSS must review funding for existing respite programs, likely investing in increased resources to benefit all children regardless of diagnosis.

Recommendation # 3 – Ensure that Autism Service delivery is a valued profession with the capacity to deliver results for families.

Serving children and youth with autism **must** be viewed as a valued profession. The skills necessary to ensure effective outcomes **must** be recognized. As a vocation, passionate and caring professionals **must** be recruited and retained. Only then will we be able to make significant strides in achieving the best possible results for children, youth and families. Low levels of total compensation will result in young people not entering the profession and existing staff exiting to pursue other careers – just when families need them the most! Regulation of the industry is critically important to protect families – so is adequately recognizing and compensating staff for their expertise in child behaviour therapy.

Recommendation #4 – That MCCSS undertake a thorough costing review and consult with families, providers, agencies and other stakeholders to truly understand the cost of service delivery and the expected outcomes.

There are multiple formulas under consideration to determine the costs associated with autism services and how to ensure the best possible outcomes for the best price. All would agree that our goal should be to ensure children receive high quality services from highly qualified staff. There has been great debate about hourly rates and cost per child. Given the vast multitude of perspectives on this question, a full and comprehensive review should be undertaken by MCCSS. Financial decisions should be made with evidence based data and study, not rhetoric and hyperbole. This is what investment entails.

In conclusion, KidsAbility stands strong in its commitment to deliver the highest quality, evidence based services to children, youth and families. With over 60 years of experience, we feel we have a great deal to offer the government and our community in how to re-imagine a system that will serve well in our community and beyond. Some might see our views as “self-interest.” As a not for profit and valued member of our community our reputation of working with families to achieve their full potential speaks for itself. If that is our “self interest,” we accept that belief and we are proud of it!