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Ministry of Children, Community and Social Services
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May 30, 2019

Dear Hon. Minister MacLeod and MPP Fee:

I'm writing to provide feedback from the roundtable conversation with parents, educators, and service providers that I hosted in Guelph on Friday May 24.

As you invited MPPs to hold local consultations on the changes to the autism program in Ontario, we asked four questions based on the Ministries own consultations. We had productive discussions over the course of the afternoon, and enclosed you will find notes from our discussions.

There are three key themes that emerged from the afternoon:

- 1. A one-size-fits-all approach does not work.**
Each child is different, and the needs of the child change over time. Setting arbitrary caps based on age and without consideration for the unique needs of that child simply doesn't work. We need a responsive program that considers the needs of the child and that each child will change over time.
- 2. It's time to deliver.**
Parents and other stakeholders in the autism community have been consulted extensively over the years, and yet program delivery continues to be patchy and insufficient. It is the hope of everyone that the government is prepared to truly listen during this round of consultations, and deliver a stronger program that is communicated clearly to all stakeholders.
- 3. It's essential to support more integration and collaboration.**
Parents, kids, doctors, therapists, advocates, schools and other service providers are all involved in the care an individual receives. The outcomes for children depend significantly on the collaboration between these groups, and yet there is no support for this collaboration to take place. Investments in coordinating services for children with autism are needed.

I also heard about the confusion and fear caused by the lack of communication about the new plan and its roll out. People spoke not only about not knowing what the changes were, but also the difficulty they

had in finding any answers. This confusion is continuing now, even as the new plan rolls out, particularly with the awareness that more changes are coming. Poor communication is causing additional anxiety.

I urge you – after listening carefully to the needs and experiences of those in the autism community – to make sure that when you announce the updated program, that you have the details ready and available at the same time. It is essential for government to provide clear guidance on where people can find answers to their questions.

I know this is an emotional issue. I'm writing in the spirit of working together to find solutions for children with autism and their families. Although I believe that consultations should have taken place last summer and fall, I appreciate that you have now embarked on this consultation. I urge you to listen and to act on what you hear.

Children with autism and their families need to know the Ontario government is here for them.

I also want to touch on an issue that is beyond the scope of this consultation but is very important. Autism does not end at 18, yet most services do. Adults with autism and parents have approached me with real concerns about whether their adult children will receive support. Early intervention must be a priority, but we must also ensure that the government's autism plan provides support for adults with autism and developmental disabilities.

Thank you for listening and for acting in the best interests of children with autism across Ontario.

Sincerely,

A handwritten signature in cursive script that reads "Mike Schreiner".

Mike Schreiner
MPP, Guelph
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cc. MPP Jeremy Roberts

Notes from Autism Roundtable, Guelph Friday May 24

Office of Mike Schreiner, MPP

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Question 1: What feedback do you have about the New Autism Program? (Pros & Cons)

Pros

- More choice and service:
More services covered; ability to chose different services, for example occupational therapy, other than ABA
- If implemented well, extra assistance & supports to navigate system will be beneficial
- Seems like there could be more regulation for services providers; depending on implementation, this could be positive
- Good to reduce waitlists
- Parents feel that they have been heard in sense of old system has wait list and it wasn't working
- Some parents would say an option of direct funding is a pro
- A properly run provider list system will be helpful for parents.
- OAP system over time will be baselines.
- Got rid of income testing; funding not dependent on household income
- It is raising awareness about autism

Cons

Waitlists and funding

- Timelines around waitlists and budgets are delaying kids service
- No new families as of Apr. 1st, 2019 have been added to the list to my knowledge
- No wait list because they're not growing the wait list
- "I should be able to call and ask where I am on the wait list, but that contact does not exist"
- a quantitative number should be given to parents re: wait list so they know where they are
- Financial implications for families is huge, still don't know the \$ value of service
- Funding not consistent
- Geared to therapy only, what about funding for education or electronic needs?

Communications and systems

- System was already complicated, now add lack of information
- Communication roll out was poor- scary for a lot of people, more stress
- Still do not know details
 - o received no info, or letter re: the new program
 - o haven't been told what funding would be
 - o even for people receiving \$5,000 (Passport), that is not enough for service needed
 - o no service until Oct 2019
 - o the goals are always short-term (6 month goals)
 - o no advisory council appointed yet
- Seemed like changes came with a lack of research or planning

Service Providers

- Can't hire service provider because funding is not secured
- Service providers e.g. EA not staying in the trade due to job security
- Caused lay offs in service providers - how does lay offs help the kids?
- Service providers keep changing, kids need continuity with service providers, aka the need the same service provider to build a relationship

General feedback

- Unclear if regulation for OAP services is coming and what it will look like
- Haven't recognized every child is different

- Families moving because of changes
- Lack of community approach
- Lack of accountability
- Not figuring out the root cause of autism rate being so high
- No national autism strategy means that no investment now = more money later
 - o children with autism will not become contributing and functioning adults in society. We will have to pay for them to be in assisted living.
- No interim plan
- Should be under the OHIP umbrella, you need a medical diagnosis to be declared autistic, so why isn't it under OHIP?
- What happens if a child is in Foster care? Does the money follow the child?

Other recommendations:

- Could add more focus on peer support, consultation
- Expand services beyond ABA is good, should de-emphasize ABA as a solution
- Autistic adults and parents should work together
- As there are ongoing updates to psychiatry for a trauma informed approach, opportunity to add an autism informed approach/awareness
- Ensuring medical systems are up to date and how autism presents across gender, race etc.
- Should also treat people with autism for concurrent disorders
- Need to look beyond the autism lens, medical, mental health
- Must have supports for pathways for adults with autism
- All supports end at 18, need to be expanded to 21
- Government does not regulate the price of services. Previous \$55/h, with no regulation, service providers can charge \$110/hour.
- Stricter accreditation for service providers, some service providers "have no qualifications; fraud"

- Unqualified service providers recognize the lack of services, and take advantage of parent's desperation
- Contributions of people with autism to society.
- Should have an annual review/feedback forum of the OAP to assess its effectiveness after every year

Question 2: How should families use additional funding based on need?

- Need a standardized, consistent assessment to determine amount of funding needed
- Need more time put into assessments
- Standardized assessment to be completed by a qualified team including the families, caregivers, educators and healthcare providers
- Family should definitely be involved in the process
- Current program not working to determine needs
- Parents could prioritize which programs are best for their child/children
- Need money to fund assessments
- Have a list of services and therapies available and provide consistent costing throughout the province
- Bring back "family support workers"
- Avoid using labels for autism ie: high functioning/low functioning
- Consult adults with autism to gain insight and get feedback on their experiences
- Funding should be determined by needs of individual and then reviewed regularly
- Decide on how much money is needed based on diagnosis and the consensus of the assessment team
- Community Support *great feedback from the Upper Grand School system group
- Provide community support such as group activities for families with autistic children

- Consult with families to determine needs
- Give the community financial support based on needs and diagnosis'
- Community members to consult with families re: their needs and offer support
- Pool resources within a community to assist families
- Ensure that mental health support systems are in place
- *One person said to look at the 20/20 program in Newfoundland to see how this works

Feedback from Parents

*Question itself is problematic, what amount are we talking about?

Therapies

- Parent based, not ministry based
- Flexibilities: professional, traditional, non-traditional
- Regulated, reliable, consistent
- ABA therapy will make a difference for speech and language
- Regulated therapies - costs/credentials
- Early intervention
- Something FUN for my kid(s) -> not therapy based but normalized activities
- Support teams to help with daily activities
- Therapies that focus on social therapies and community engagement
- Parent/caregiver training

Respite

- Support teams to assist with daily routines
- Lend an extra hand

Educational Systems/Schools

- Money to go towards a variety of learning/educational environments to fit the needs of the child
- School based therapies supervised by non-school board reps
- No age limit on money
- Funding investments in teachers/educators who successfully teach our children to learn
- Educational learning environment should be individualized -> funding to support a variety of educational environments (inclusive, segregated, 1 on 1 specialized)
- AFTER school programs: especially for parents/caregivers who work - ideally someone trained with a specialization in autism

Awareness

- Educate community members about the nature of autism - neighbourhood project

Question 3: What role should the education system play in supporting students with Autism to have meaningful access to education?

Common Themes

- Increase resources; EA's with specialized skills & training
- Increase education and training for teachers and EA's
- Increase collaboration amongst all professionals and family
- Increase choices
- Take a holistic approach
- Increase funding
- More instruction for parents navigating the system
- Awareness

Increase Resources

- Need accountability following legislation
- Principal's discretion to have child stay home; document this and look at real problem
- Must follow the education act; parents forced to pick up child
- Need clarity between education and treatment; fewer treatment centres, Section 23⁺ schools
- Transition, how to bridge between treatment and schools
- Need programs for kids who need treatment and not yet ready to be in school
- Service resolution for one kid at a time (exists in Wellington)
- Boards that are inclusive do not have sectional treatment programs to service students with significant needs
- Treatment homes in community
- A designated specialized group of professionals at each school

Increase Education and training for teachers and EA's

- Quality education - ie. if [there is] ABA, need a full time EA with ABA training
- Appropriately trained support staff in classroom
- Therapists into schools; easier to access, [but] transportation is [a] barrier
- Academic accommodations based on needs, not diagnosis
- Pay attention to physical environment - lights, sounds
- Teacher training about neurodiversity to better understand students
- More EA's with 2nd language training (French)
- School to initiate the diagnosis, sooner they are diagnosed- sooner the supports can be applied for
- Give teachers freedom to speak their opinion

Increase Collaboration amongst all professionals and family

- Meaningful access is not just being in class - focus on strategies that may not be educational especially that fits needs of student supports
- Resistance from school boards & providers; need collaborative agreement for third parties
- Need consistency among schools; hard when families move
- How can education system collaborate better with community service?
- Collective agreements; professional practice; recognizing constraints

Increase choices

- Choice to be in segregated classes or inclusionary
- Have choices to participate with others
- Choice of outings and extracurricular
- Special needs classes need funds for extracurricular, social learning opportunities
- Need flexibility about different placements
- Schools are generic, a one size fits all doesn't work for students with Autism

Holistic Approach

- Team decision: family, school, community supports (OT, speech, mental health) address all needs, look at the whole child
- Transitional supports - i.e. in summer, elementary school to secondary school; resources and staff focussed on transition

Increase Funding

- Funds for staff and families and schools to collaborate and communicate

- Lack of clarity of roles - school? Therapist? Ministry should clarify
- Bring expertise to table - teacher can't be expected to deliver therapy
- Grey zone - what is scope of practice of teachers (sic); parents confused
- Increased funding to service provider
- Money needs to move with the child

More instruction for parents navigating the system

- Families may not know all pieces of intervention; need improved communication; avoid silos of intervention

Awareness

- Adults with ASD to speak to school and students
- Have more inclusive attitude, avoid "them and us" attitude
- More inclusion, inequality, pairing students with and without disabilities
- Sociocultural lens to understand disability, not just medical model
- Support for students dealing with bullying

Question 4 - How should health & social supports for children with Autism be better integrated

Summary

- Worry childhood budgets will put even more focus on autism diagnosis when more integration is needed.
- More integration the better- meds may help at school, but interfere with their sleep
- Focus on the individual, not autism diagnosis (behaviour is due to loneliness, not autism)
- Parents need help navigating, especially between preschool, school, and adulthood.
- Respite should be separate funding from treatment

Notes

- This question is too vague
- Focus on education (children need to be taught differently, as they learn differently)
 - Respite
 - Inclusivity
- Needs more support in the school other than special education teachers, they are not a therapist nor should they be
- Communication program for special needs kids
- Assistance for new parents of autism that are not sure how or where to start
- Programs to help families willing to assist each other- networking, support groups
- Consistent service providers
- Takes too long to fight for medical diagnosis, even after diagnosis, autism is not supported under OHIP like other health conditions requiring diagnosis
- Some children cannot be insured as they have autism, insurers don't want to insure children with autism
- Speech Therapists should be able to medically diagnose autism, not just doctors
- Need a coordinator/caseworker once children enter school system
- Family doctors need to be more aware of autism
- No guidance for parents to understand all the systems
- Parents of autism is a full time job, parents don't have time to work full time.
- ESL for people that do not speak English
- Give service providers more training like workshops
- Had to find out programs available from friends, better communication from ministry
- School system is inconsistent in their approach/help
- Feeling lost in the system, new parents unsure how to navigate
- Not enough support
- Mental health is dismissed in our government, depression for example, is an extension of autism

- Need to treat the whole individual, focus on behavior and education, and also need to integrate mental & physical health as well as social opportunities
- Need autism advocates/caseworkers
- Some individuals fall through the cracks, children in foster care don't qualify for tax credits
- Diagnosed late; diagnosed as adults; had to fight for diagnosis