

CRISIS IN THE AUTISM COMMUNITY

CHALLENGES FROM COVID-19
AND CHANGES TO THE OAP



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INTRODUCTION

Four years ago, I became the Minister of Children and Youth Services. At the top of my to-do list was fixing the Ontario Autism Program (OAP). Immediately, we began work to listen to Ontario's autism community – service providers, parents, adults and children with autism, teachers, and other professionals – to best understand what they needed in an OAP. Within 92 days, we put together a new OAP. The plan was not perfect, but it was a marked improvement. It brought stability and predictability to parents, and helped to ensure children were beginning to receive the support and therapy they needed.

In 2018, Premier Doug Ford and then-Minister of Children, Community and Social Services, Lisa Macleod, broke the program, throwing the entire autism community into agonizing chaos. They did not have a plan. They were not listening. I do not need to recount the sorry history of that debacle -- from the accusations of threats against service providers to callous jokes from the minister. The changes set off massive protests in communities across the province. There was real hurt. There was real fear. It was heartbreaking.

Even Conservatives MPPs agreed. In spring 2019, Roman Baber, the Tory MPP for York Centre, wrote in a report to the cabinet that “This has been the toughest and most damaging file of our first year,” he stated. “Regretfully, to add fuel to the fire, our tone has been less than ideal.” He even stated the solution, writing, “a full reset is required, including a retreat from the February/March Plan to a needs based plan, predicated on accurate and non-confrontational messaging.”¹

The autism community was optimistic when Todd Smith was appointed the new Minister in a cabinet shuffle, but other than taking a less confrontational approach and embarking on a listening tour, there has been no meaningful action by this government to fix what they broke. Despite the community contributions from the Autism Advisory Panel and Implementation Working Group, the Ministry has still managed to create more delays and added confusion.

With the COVID-19 pandemic, including the closure of schools and most in-person autism therapies, the situation for parents, children and teens with autism is now particularly dire.

Over the past four years, I have stayed in regular contact with leaders in the Autism community and with parents across the province; during the Ontario Liberal leadership race, countless town hall meetings or meet-and-greets saw me staying after the event to sit down with parents who had come to speak about their particular situations. I felt my job was to listen and to advocate for them.

COVID-19 has brought new and stark challenges to parents across Ontario.

In the North I spoke with mothers and fathers stranded in remote communities, left on their own to try and organize services in an already neglected and collapsing ASD service network. I spoke with single parents -- people who have had to take extended periods off of work, people who are worried they will not have jobs to go back to. They face a future uncertain in terms of how they will support their families. I've spoken to young adults who are on the spectrum who so desperately

¹ “Baber Report,” 13 June 2019, accessed online: <https://drive.google.com/file/d/1GI4DxxFyZ0uFn33mLNxaWyaDnla1XWxj/view>.

want to and are able to make a contribution to Ontario, but need the ongoing support to help them get there. They've watched as this government has let them down repeatedly and they are losing hope that this Ministry is ever really going to show up.

There were parents with two or three young children on the spectrum. One mother had three children in their twenties trying to cope with little or no support, another had a daughter who hadn't slept in forty-eight hours. There were stories about children who communicate well and others who are non-verbal. Some were violent, others were prone to self-harm.

In spite of the circumstances they came to discuss the issues; they wanted their voices to be heard. My hope is that this report sheds light on the everyday challenges of a large group of people in our community who have been forgotten and neglected before and amplified during COVID-19.

This report outlines the findings of those consultations and proposes over thirty recommendations. The Ford government is welcome to implement those recommendations immediately.

If they do not, I will do everything I can to ensure a future Ontario Liberal government will.

Sincerely,

A handwritten signature in black ink, appearing to read 'MC', with a wavy line extending to the right.

Michael Coteau, MPP

Ontario Liberal Critic for Children, Community & Social Services

METHODOLOGY

Over the course of a month, a total of seven meetings took place encompassing nine regions throughout the province: Ottawa, Peel/Halton, Niagara, York, Durham, Northern Ontario, Kitchener/Waterloo, Hamilton and Toronto. The meetings took place over Zoom and each lasted approximately an hour. The COVID-19 crisis prevented meetings from being held in person. Approximate number of participants for each meeting was 10-15 people.

Participants included parents, organizations and other stakeholders in the autism community. Participants were asked to review a draft of this report.

WHAT WE HEARD

1. Clarity, Communications and COVID-19

Following the MacLeod changes to the OAP, the entire autism sector was placed into a state of constant chaos. Parents and children were unable to access funding and services; service providers had their funding upended and many were forced to close or layoff staff.

It is important to note that stability, predictability and clarity are of unique importance to the autism community. The ability to plan is of critical value to parents of children and teens on the autism spectrum so that it can provide some stability around an otherwise extremely sensitive condition. This government is not understanding that open communication in this file is not a courtesy; it is substantively important for children and teens who require routine and predictability.

Parents feel abandoned by this government. The absence of a strategy and consistent communication from the Ministry has essentially left parents and organizations to navigate this crisis on their own.

Then came the pandemic.

Overall, COVID-19 has created an environment of complete uncertainty for the sector, compounding and exacerbating the existing challenges. Services have essentially come to a halt. No one in the community knows the future of the OAP:

- practitioners do not know how to keep themselves, their staff and children safe
- service providers do not know how they can stay in operation as cost-pressures mount
- parents do not know when or the order of priority in which their services will resume
- and application requests for interim funding are consistently going unanswered

Parents and service providers are asking for a centrally coordinated and comprehensive framework and regular communication from the Ministry. What they are getting right now is radio silence, which, in addition to showing a lack of respect, has had a series of additional substantive consequences.

Amidst all of this, Minister Smith has been largely silent. As an example, only after Participation House in Markham – a facility for adults with autism and other developmental conditions – reached over 90% COVID-19 infection rate was there any official response from the Ministry.

For parents and health-care providers, government response to COVID-19 has been slow, decentralized and not practically useful. Again, in the absence of any centralized strategy or lead from the government, most organizations have kept their doors closed. Service providers who would usually come to a client's home are working without clear, useful guidelines that will keep them safe - as a result home visits are not occurring. This means that for most parents, service provision has effectively stopped. Parents have now gone months with no indication of what they can do or where they can go for help.

Parents and families with autistic children are finding ways to manage but it is clear they are facing increasing levels of stress and anxiety due to the COVID-19 crisis. Methods alternative to in-person therapy have had mixed if not outright poor results. Government must understand that virtual therapy (if parents even have access to it) is not a sufficient substitute for most children. Without in-person treatment or effective virtual substitutes, parents are reporting wide-spread regression in the progress of their children. Parents are concerned that over the summer months almost all children will stall their progress and likely set children back months - if not years. Lack of communication of any kind of return to school has caused concern that the Ministry is not prepared for the return of children with autism to schools in September.

As a result, implications for families have been severe. Almost all parents we have spoken to have reported acute regression in their children, sometimes leading to behaviours they have not seen before. Meltdowns happen regularly at times resulting in self-harm and aggressive behavior.

More generally, parents are concerned about the future of the OAP or what program will actually be available for children. Regression will exacerbate the needs for families. Parents do not have confidence that this government has an adequate plan to meet that need given the OAP plan before COVID-19 was already lacking. Moreover, they are concerned this government will use COVID-19 as an excuse to cut programming further and abandon needs-based therapy all together.

There are several particular areas that were commented on, including:

a. Respite services

- The Children's Hospital of Eastern Ontario (CHEO) has managed to develop a respite program tailored to addressing COVID-19. Parents are asking for similar services to be provided in their areas as soon as possible. The Ministry is ideally positioned to learn from CHEO and upscale their model, but this has not happened.
- Parents suggest the Ministry consider smaller units able to manage contact tracing as the situation is urgent with children regressing and aggressive behaviour exacerbated by stay-at-home orders from the pandemic.

b. Virtual Learning

- Virtual learning has been extremely problematic and/or ineffective for some families as a substitute for in-person therapy. While it may have been a necessary and a helpful alternative during the strictest lockdown phase of the pandemic, as a substitute for in-person therapy, virtual learning has been problematic and/or ineffective for many families
- Some children do well with virtual therapy or learning. Many families feel, however, that the virtual services offered can be inadequate for children with higher needs. It also puts an additional amount of stress on parents, who are now expected to implement several of these therapies on their own children which, in the opinion of some professionals, can be considered unethical.
- Remote therapy options that do exist are poorly communicated and not centrally coordinated.

c. Regression and returning to school

- Many children are experiencing moderate to severe regression meaning many children will need urgent attention once services resume.

- There is a lack of confidence that the Ministry is preparing adequately for problems surrounding re-acclimatization in schools.
- Despite the growing number of children experiencing regression, there is no information on what the Minister’s strategy is on how we are going to get children back on track as soon as possible, with parents questioning whether there even is a plan at all.

d. Educational Assistant (EA) services and returning to school

- Some parents report a ratio of one EA for as many as five or six children pre-COVID-19. EAs cannot effectively do their jobs with that many children to supervise.
- The situation for pre-COVID-19 assessment for receiving EA service was already too stringent; policies were treating only the most severe cases, meaning many children who still need help are not getting it.
- The Government must also recognize that some virtual programming requires EA support. During the COVID crisis some parents were provided virtual programming without the necessary EA support instructor. Government must recognize when and where an EA is essential to programming so that it is effective.

e. Gaps in service and long-term consequences

- One high functioning and articulate youth with autism suggested that a lack of investment today may force his peers to rely on services like ODSP or other programs for life. He recognized that early intervention is the most effective way to support autistic children. The lack of support for children and youth with developmental problems is unethical when we know how effective early intervention can be. The burden and additional cost to the government in the long term could be mitigated.

f. Navigating the system with “care coordinators”

- The Autism Advisory Panel advised that “care coordinators” should be made available for families to guide them through available service but these coordinators have not been mobilized; parents have been left on their own to navigate complex choices regarding services and/or devices purchases – often paying out of pocket.
- There is no help coordinating care once a child finally gets a diagnosis, with difficulties navigating the marketplace for occupational therapists, doctors, speech/language pathologists, etc.

g. Parental involvement in decision making

- The government does not understand that parents can be part of the solution. Closing the door on parents in terms of any future planning, information or input is counterproductive.
- As an example, on their own some parents have come up with ideas for group therapy where multiple children can simultaneously receive support thereby saving funds.

h. Long-term changes needed

- There is a real need for a National Autism Strategy at the federal level.
- There was discussion of a Ministry of Disabilities, or a focus provided within a comparable ministry at the provincial level, and for therapy to be brought under OHIP thereby making it widely available and consistently applied.

- The Participation House example highlights that housing availability is going to be a problem for autistic children as they transition into adulthood. The Ontario Government should be forward-thinking. They need to learn from the challenges exposed by the COVID-19 crisis and adapt to a 'new normal'.

2. Funding, Frustrations and Failures

Parents are frustrated that the government's one-size-fits-all approach to funding, particularly bridge funding, runs contrary to the repeated demand that the Autism Spectrum Disorder requires a needs-based approach.

Many families have not received their bridge funding and are not receiving answers from the Ministry, even when local MPPs advocate on their behalf. The Special Service at Home Fund has either not arrived or it is late. There is uncertainty from the Ministry and local officials as to whether the rebate will be fulfilled. Parents are concerned that government spending during the COVID-19 crisis and the Conservative inclination toward austerity will put the OAP in greater jeopardy. Again, lack of communication is doing nothing to abate those concerns.

For many parents, the funding that exists not only does not meet the need, it is mismatched. Parents are having to pay out of pocket for clinically proven therapy while funding for non-clinical diversionary devices like iPads or other electronics is made available. The Ministry must understand that, while diversionary devices are extremely helpful for many families, an overwhelming number of children need Intensive Behavioural Intervention and Applied Behavioural Analysis and other evidence based therapies. Subsidies for non clinical diversionary devices, while useful, cannot be thought of as substitutes for IBI and ABA when kids need them.

Additionally, massive layoffs due to COVID-19 have meant that for many families, both parents are out of work. Payments in the form of rebates will not be helpful when parents' incomes are severely reduced or are having to rely on the Canada Emergency Response Benefit to meet basic needs

There were several specific areas commented on that require simple solutions through a Minister's intervention now, including:

a. Families' needs are not being covered

- Many parents have not received transitional funding and are not being given clear guidance on whether they will receive it or when. Particularly, parents are left unsure if they are eligible for the \$5,000 or \$20,000 funding.
- The Ministry is non-responsive if application problems arise or when parents inquire about the success of their applications.

b. Parents not consenting to childhood budget switch

- There is a lack of clarity on how some families are being transferred to the "Childhood Budgets" model without their consent, often as a default in their renewal contracts. Some parents report ending up on the "Childhood Budgets" model and not knowing how they got there.

c. Special Services at Home (SSAH)

- SSAH funds for 2020 have not been confirmed; families do not know what is going on or if

their expenditures will be rebated. Parents are sending in applications for SSAH and not hearing back. Repeated calls go unanswered - even if local MPPs get involved to advocate for them.

- Parents are not confident that the program will reimburse them as it was designed to or at all; the reimbursement program is already problematic as many parents cannot afford to pay upfront, especially during the economic challenges due to COVID-19, and uncertainty about reimbursement is forcing parents to halt spending because they cannot afford not to be repaid.
- SSAH funding is not properly targeted with parents of children on the old plan unable to spend their funding on alternative therapy during COVID-19, which creates a situation where there are inequities in the services children are able to receive.
- Some parents would like to carry over unused SSAH funds from the previous year or transfer funding for diversionary devices such as iPads to instead cover therapy costs. Some parents are worried they will be penalized if they do not use the full funding amount or request a carry-over arrangement.

d. Honouring service hours that have been committed

- What is going to happen to funding on the old program now that 10 weeks of programming has elapsed? Will these hours still be honoured? How are children on the old program going to bridge this breach in service while organizations are closed? Without services, their budgets are essentially frozen. Will there be interim funding for them to find alternatives (diversionary devices, psychology, etc.)?

e. Ministry of Labour concerns

- A suggestion was made that there needs to be better coordination and allowances for parents returning to work so that they may take time off to care for children who have regressed due to complications caused by the pandemic and school absences.

f. Timeline considerations

- Given the closure of so many businesses and service providers, it is taking longer to acquire receipts to claim reimbursement, so the government should extend deadlines as necessary.

3. Challenges for Service Provider Organizations

From a clinical perspective, the Ontario government has failed to provide a coordinated response to the pandemic which results in regulation that is of little value to practitioners or parents. If the Ministry has provided any kind of guidance it has come late or lack of clarity. This means that doors to service organizations have remained closed.

Service providers have largely been left on their own in terms of how to ensure safety in a COVID-19 environment. This has led to disasters like Participation House where over 90% of residents were infected before the Minister provided guidance.

Parents are questioning why the government did not designate IBI or ABA treatments as essential services. Not designating these therapies and not providing any direction as to how continuity of service can be made safe has meant most organizations have had to close their doors. The consequent lack of revenue has meant that these organizations are at risk of insolvency. This is a major concern, especially in remote communities where there are less agencies to choose from.

There were several specific areas commented on, including:

a. Organizations having to close their doors

- Service providers are worried about staying afloat with the government 75% wage subsidy. Commercial rent relief is simply not enough to compensate for substantial decrease in revenue.
- Service providers are facing burnout as they are being forced to develop solutions and answers in a vacuum with concern over how many specialists will want to return to this environment once regular provision returns. There is a sense the government does not recognize the level of preparation a resumption of services will need.

b. Lack of immediate preparations

- There are no transition teams or guidelines coordinating how service providers will resume service considering issues such as: the availability of PPE, how home-based service providers will be able to engage multiple clients, what cleaning services will be required, and how to accommodate COVID-19 distancing in densely populated neighbourhoods with small retail rental spaces, etc.

c. Urgent Response Service

- What is the status of the proposed “Urgent Response Service” recommended by the Ministry Task Force as one of four pillars that will define what is meant by needs-based therapy? This unit would have been ideally suited to deal with the likelihood of high volume acute care needs due to regression.

d. Capacity and conflating mental health resources with ASD resources

- There is a concern that there is a clinical conflation of mental health and psychological services with Autism Spectrum Disorder services, which will water down necessary funding for both types of therapies and render both ineffectual.

e. Direct Funding Organizations and Direct Service Organizations

- There are inconsistencies in the level of regulations required and funding provided for DFOs versus DSOs that should be rectified.

f. Diagnosis and funding gaps

- There are critical gaps between diagnosis, the required therapy needed and what the Ministry will fund.

g. Ministry reporting problems

- There is confusion about how the Ministry publishes and presents monthly numbers regarding how many children are receiving invitations for interim funding against those who have received funding. Each month the data keeps changing, obfuscating what the overall picture is. The criteria of “Funding Invitation Letter Sent” as a barometer of the Ministry’s success in addressing the waitlist is misleading and insufficient as it does not reflect when a child begins therapy.
- There should be a standardized model (like the organ transplant list) for reporting metrics.

4. Challenges in The North

There are unique challenges encountered by families and service providers in The North that require interventions by the government to address.

a. Getting to in-person care

- There needs to be a strategy to subsidize travel expenses outside OAP budgets for Northern families who must travel long distances for therapies. The Ontario government must recognize that capacity has fallen apart. People have no choice but to travel large distances for care and travel is prohibitively expensive, eating up whatever funding that is allocated almost immediately.

b. Building capacity

- The system supporting subsidized diagnosis has almost completely collapsed and the situation needs urgent attention. Parents are having multi year delays in getting a diagnosis and private diagnosis is both prohibitively expensive and provided by an almost non-existent number of service providers.
- There needs to be a strategy to recruit and retain qualified professionals in the North. This should include incentive programs for those willing to relocate and stay in Northern Ontario.
- There needs to be a model to support organizations, especially where agency revenue has collapsed even before COVID-19. Specifically, what current assets exist that can be used to bridge service while capacity is being built?
- There needs to be work done to build capacity in the North, including a respite network. Respite care should be classified as an essential service. The mental health of parents depends on the ability to access respite services when they are needed.
- There also needs to be a Residential Behavioural Unit in the Northeast and Northwest for those with multiple diagnosis and complex needs, as well as the creation of a Single Plan of Care Coordination program for those with complex needs.

c. Regional Representation

- There needs to be representation from Northwest, Northeast and from the Far North including remote First Nations, as part of any groups, panels etc. that are put in place for any matters related to autism or developmental services now and in the future in order to service as an advocacy base to highlight inequities for the network in the North.
- 3-5 individuals from each region should be represented and should serve on a group that identifies inequities for networks in the North and advocates on behalf of the North. Waitlist Management and the Social Determinants of Health (particularly geography) should be standing considerations.

d. Culturally appropriate services for First Nation and Francophone families

- There needs to be particular focus on language and cultural competencies. For instance, in the Thunder Bay region, there is only one known Registered Behaviour Therapist who offers services in French. Francophone families who are not fluent in English are forced to either try to receive services in English or go without therapy for their child.

RECOMMENDATIONS

The following are our recommendations arising from these consultations:

Emergency Respite Services:

1. Study the Children's Hospital Eastern Ontario (CHEO) model and develop a set of standard guidelines for upscaling an Emergency Respite Services model based on their successes.

Sector-wide Reopening Strategy:

2. Work with parents, service providers and the Ministry of Health to develop a new COVID-19 Standard of Care for practitioners. Use service users' input to ensure the standard is comprehensive enough for organizations so that they can open their doors and keep parents and children safe.
3. Establish a COVID-19 task force within the Ministry with a centralized point of contact for organizations specifically in order to urgently assess the equipment needs (e.g. PPE, etc.) of service provider organizations, solicit requests from organizations for information on the help they need and coordinate addressing equipment shortfalls across the sector.

Dealing with Regression:

4. Liaise with the Ministry of Education and develop a strategy to address cases of regression and how an abundance of cases will affect the return to school. This must consider improving the EA-to-student ratio and considering how to adapt physical distancing, handwashing and other safety measures for those with autism.
5. Resume work on initiating the Urgent Response Service. Direct their work toward treating children and families dealing with regression now, as well as preparing to mitigate regression in preparation for school resuming in September.

Better Ministry Communication:

6. The Minister must assume responsibility for constant and respectful communications, beginning with clarifying to parents during what stage of COVID-19 reopening will IBI/ABA be allowed to open.
7. The Minister should schedule regular updates for autism parents online and/or by email, including sending status updates on the development of the new OAP.
8. The Minister should publish the agendas and minutes of the Ministry's Autism Working Group.
9. Transparency and regular communication is also required from the Ministry of Education as they are responsible for aspects of accrediting Speech/Language Pathology, Occupational Therapy and Physical Therapy.

Collaborating with Parents:

10. The Minister should develop standing bodies and regular town hall opportunities that allow parents who are day-to-day service users to provide input into planning the new OAP, with opportunities to provide input and adjustments as a new plan is announced and implemented.

Better Allocating Funding:

11. The Ministry should allow for greater flexibility in funding, including for those families on the old program to adjust their needs, ensuring additional costs for incidental assistive devices are covered independent of therapy funding.
12. The Ministry should create a Directorate with a mandate that includes, but is not limited to, working with the Ministry of Health to explore opportunities for including Autism Services under OHIP.
13. The government should advocate, actively participate and cooperate with the federal government on a National Autism Strategy.

Improving Applications:

14. Clarify the timelines of communicating application information to families in Ontario, specifically ensuring that regions are not given conflicting information so that parents receive accurate information and standardized timelines.
15. Explain to parents what the timeline for Special Services at Home rebate will be as soon as possible.
16. Redesign the Special Services at Home funding so that at least 25% of funding is upfront and not a rebate.
17. Ensure that parents who have had their services halted due to organization closures have their lost service hours honoured.
18. Liaise with the Ministry of Labour and enact legislation that makes it illegal for employers to fire parents for taking time off of work to prepare their children for a return school, especially if their children have suffered severe regression as a result of a halt in services due to COVID-19.

Organizations:

19. Develop and communicate a strategy to support organizations that are at risk of permanent closure due to capacity loss from COVID-19. The government should prioritize regions where there are few alternative options available if service providers go into bankruptcy because of the pandemic.

Metrics and Reporting:

20. Standardize reporting and metrics: do not shift methods of reporting or metrics from report to report. To ensure clarity and maintain transparency in terms of trends, create and maintain one standardized model (like the organ transplant list) and assign one agency to administer reporting.

Funding:

21. Ensure the new OAP is truly a needs-based program.
22. Remove age-based funding to instead focus on need.
23. Families require choice to ensure the services they receive work best for them and their children. Monies should be able to be used for more than just ABA. This includes other evidence-based therapies, such as speech therapy, occupational therapy, etc.
24. Families require choice in terms of public services or a direct funding option. However there should be standard fees charged by private providers set by the government (such as the OHIP model for physician billing).

Programming:

25. Programs and services must be culturally appropriate.
26. Tools for assessment should include information that focuses on needs, gifts, and strengths and not just deficits. Current assessment processes can be devaluing and traumatic for families.
27. Continue face-to-face consultations across all of Ontario as the new program rolls out so that the program can be monitored to remain responsive to the needs of children and their families.
28. Transition programming for children entering school, leaving school, or moving from the child system to the adult system is not effective and/or nonexistent. Work with the Ministries of Education and Health as well as communities, agencies and family networks to develop a comprehensive plan that meets the needs families have expressed at all stages of life.

Recommendations Specific to the North

1. Understand the degree to which travel costs will dominate any expenses families are facing. Therefore, cover the costs of travel, special equipment, communication tools, etc so that remote/virtual therapy and staff training does not come out of the OAP funding allocated for a child, but rather a separate funding stream. All monies in the OAP need to go to direct services.
2. Develop and communicate a strategy for reducing wait times for diagnosis, especially in Northern Ontario where subsidized diagnosis has become a multi-year wait and private diagnosis is prohibitively expensive for most families.
3. Recognize that there is a capacity crisis in the North and develop a separate, comprehensive Northern plan. Such a plan must include a strategy to address untenable diagnostic wait times and prohibitively expensive private diagnosis options. The plan should also include strategies to incentivize, recruit and retain qualified practitioners to the area.
4. End any further defunding of current programs and continue with a single point of access (regionally or locally) such as Child Care Resources who can work with local partners in each community (i.e. provide training).
5. Expand the Single Plan of Care Coordinator program for those with complex needs (i.e. multiple diagnosis).
6. Regional representation must be ensured, comprehensive with clear expectations. The Northwest, Northeast, Far North and remote First Nations must be included on any decision making bodies with at least 3-5 individuals from each Region
7. Decision making for the North should always be done through the lens of the “Social Determinants of Health”. This should include but not be limited to considerations based on Geography as well as culturally appropriate services for First Nations and Francophone families

Conclusion:

Captured in this report are the voices of parents, service providers and young people who need their voices to be heard, especially in light of the world's unrelenting focus on COVID-19. We have to remember that they are the ones who will face some of the most intense challenges due to this virus, and they deserve their government's support.

The message received from these consultations is that there are two streams of problems the government must urgently address: immediate challenges due to the pandemic and long-term changes to fix the OAP. The infuriating factor is that many of those immediate challenges should be addressed by the basic services expected of a competent and caring Ministry.

Fixing what was broken by this government, addressing the pandemic and transitioning to a better model in the future will take deliberate, conscientious work. The recommendations outlined in the report will go a long way to stabilizing the sector, helping parents and families through the pandemic, and putting in place a reliable new OAP.

Parents are feeling as though they are coming last. They feel the government does not realize that in difficult times like COVID-19, vulnerable sectors like this need more help and attention as they will suffer the consequences more severely than others. Stress levels on families are extremely high; parental mental health is suffering. They feel disrespected.

These are complex issues, to be sure. But some of the solutions are relatively simple, and require basic, competent government and basic human decency and respect. The Minister can fix many problems by being conscientious, communicative, attentive and respectful. A better tone and respectful interactions with the autism community will not fix the systemic problems in the MacLeod OAP or deal with the unprecedented challenges of COVID-19, but it would help parents to know their government is not indifferent to their real suffering.

Children with autism deserve our support. I will continue to do whatever I can to help.

ACKNOWLEDGEMENTS

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