Autism Services in Ontario:
Impacts on Family and Child Well-Being

Research Summary

Janet McLaughlin & Margaret Schneider
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The final contents, and any errors are the responsibility of the authors alone.

ABOUT THE AUTHORS

Janet McLaughlin is an Associate Professor of Health Studies at Wilfrid Laurier University (WLU) and the mother of a child with autism. She researches and teaches in the areas of health policy and health care, social determinants of health, and autism policy.

Margaret Schneider is an Associate Professor in the Department of Kinesiology & Physical Education at WLU. She previously worked as a support worker to families of children with ASD, and teaches and researches in the areas of disability, caregiving and adapted physical activity.

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List of Acronyms

AAC – Augmentative and Alternative Communication

ABA – Applied Behaviour Analysis

ADHD – Attention Deficit Hyperactivity Disorder

AIP – Autism Intervention Program

ASD – Autism Spectrum Disorder

BCBA – Board Certified Behaviour Analyst

BCBA-D –Board Certified Behaviour Analyst-Doctoral

CASDA - Canadian Autism Spectrum Disorder Association

CCAC – Community Care Access Centres

DFO – Direct Funding Option

DSO – Direct Service Option

EA – Educational Assistant

ESL – English as a second language

IBI – Intensive Behavioural Intervention

IEP – Individual Education Plan

IPRC – Identification, Placement, and Review Committee

OAP – Ontario Autism Program

OT – Occupational Therapy

PPM 140 – Policy/Program Memorandum No. 140

SES – Socioeconomic Status

SLP – Speech and Language Pathology

SSAH – Special Services at Home

I. INTRODUCTION & OVERVIEW

This report provides a summary of key findings and recommendations from a survey with Ontario families who have children or youth with autism conducted in the summer of 2018.

The purpose of this study was to explore the impacts of autism policy and any barriers and facilitators to accessing private and publicly funded services (including those provided within the education system) in Ontario for children and youth with autism spectrum disorder (ASD), in a climate of limited capacity resources.

This study occurred when the Ontario Autism Program (OAP), as devised by the former Liberal Government, had been in place for approximately one year but was still in a period of transition. Surveyed families would have encountered a range of service delivery offerings, including the former Autism Intervention Program (AIP)/Intensive Behavioural Intervention (IBI), limited blocks of Applied Behaviour Analysis (ABA), and/or the OAP, while others had not yet received services. Survey findings, particularly regarding experiences accessing services, must be read with this diverse range of experiences in mind.

After considering all of the findings this research summary provides basic, point-form data that summarizes the key findings of the study for the

The purpose of this study was to explore the impacts of autism policy and any barriers and facilitators to accessing services in Ontario.

Given that the Ontario Government has been in an ongoing process of evaluating and redesigning its services, our study aimed to:

1. Identify any barriers and facilitators experienced by families when accessing services, including OAP, education and others
2. Explore how barriers and outcomes may differ based on social determinants of health, diagnostic factors and other variables
3. Understand impacts on family health and well-being
4. Make recommendations for the development of policy that is evidence-based and reflective of the specific needs of those families affected

immediate use of participants, policymakers, and the public. It highlights significant quantitative (statistical) findings, summarizes the most common themes in open-ended responses, provides a sample of demonstrative quotes from participants and highlights key recommendations from participants and the researchers.

The report first provides a list of overarching key recommendations to holistically address the needs of families identified in the research. It then gives an overview of methods and the demographic profile of those surveyed and provides key findings and recommendations (as suggested by both the respondents and the researchers) for the current Ontario Autism Program.

This is followed by an examination of other services, including diagnosis, and financial implications of paying for services for families. Next, the report highlights areas of challenge in the education system. In the final section, physical, mental and emotional health impacts of service challenges are explained. This includes an examination of the time families spend navigating services and advocating for their children, and how investing time, energy and money in these activities impacts their personal and professional lives and it identifies the different implications for men and women.

Our key recommendation is that the Ontario Government devise an OAP that responds to the individual clinical needs of each child.

The key conclusion from examining these various aspects of caregivers' lives is that autism families in Ontario, as elsewhere, are struggling to manage with a vast amount of stress, financial and other demands in their lives related directly to insufficient supports for their children. Better access to meaningful services and supports for their children, including high quality education, therapy and respite services, would not only benefit their child or youth with autism, but also the entire family unit.

BUILDING A NEEDS-BASED, MULTI-PRONGED ONTARIO AUTISM STRATEGY

Why a Needs-Based Therapy Program Makes Sense and is Fiscally Responsible

The following recommendations outline a model to address the needs of all children and youth with autism that draws on wrap-around supports from Ontario's Ministries of Health, Education, and Social Services as well as other levels of government. The model builds on the findings of the research presented below, and integrates feedback from community stakeholders, expert clinical reviewers and evidence-based research.

Our key recommendation is that the Ontario Government devise an OAP that responds to the individual clinical needs of each child.

Such an OAP would not include arbitrary caps or cutoffs, since these would be antithetical to an evidence-based clinical approach[1], but, like Ontario's health and education systems, it would aim to be fiscally prudent and responsible so as to ensure continued sustainability and inclusion of all children and youth with autism in Ontario.

The guiding premise is that **the high cost of investing properly in autism supports and therapies for children and youth is not only the right thing to do, but it is offset by much lower**

costs for public services throughout childhood and into adulthood.

A recent University of Calgary report estimates that it costs $5.5 million over a lifetime to care for an autistic person requiring constant support in Canada. Much of this financial burden falls squarely on Canadian families. As the report makes clear, “Lifelong family caregiving is extremely stressful and can be financially devastating. Families often suffer the emotional, social and financial consequences.”[2]

Given the high cost of delivering effective, individualized, evidence-based autism interventions[3], it is important that Ontario invest now in shouldering this burden over the long-term so that the Ontario children who need this help are able to access it across the spectrum of need.

We believe that an Ontario Autism Program should not sacrifice clinical service quality and outcomes to fiscal pressures. Furthermore we believe that Ontario’s foundational principles on this issue should be that access to autism therapy is a basic need and it is possible to ensure that public dollars are targeted towards the most cost-effective treatments and supports without forgoing standards, as we do in health care and public education.

Numerous studies have shown that when young children receive appropriate therapeutic intervention it is a long-run public cost-savings to education, health, social and other public services, as well as an amelioration of the children’s quality of life (Chasson, Harris, & Neely, 2007; McClean, Grey, & McCracken, 2007; Peters-Scheffer, Didden, Korzilius, & Matson, 2012).[4]

Early intensive behavioural intervention, more specifically, can improve children’s scores on IQ testing, their ability to speak and understand what others are saying, and perform typical day-to-day tasks that, prior to therapy, were beyond their ability and not likely to be learned in time (Peters-Scheffer et al., 2011). Other forms of comprehensive ABA[5] and complementary therapies are often the only way in which some children and youth at the high needs (“severe”) end of the spectrum are able to learn the key skills, such as toileting, eating a diverse diet, basic communication, safety, and self-help skills, that they will need in life to have even the most basic levels of independence, dignity, health and well-being.[6]

Providing needs-based services not only benefits children, however. As our research suggests, doing so also improves the physical health, mental health, well-being and productivity of their families and unpaid caregivers. In order to provide essential supports in the absence of adequate public programming, many of them have had to quit or downgrade their jobs, or work part-time. By enabling parents to return to the workforce, Ontario can maximize its tax-base as well as its return on investment for the education and training received by its citizens. In so doing, Ontario will also be acting to increase the health and well-being of children and their families.

Assessing Demand for OAP Services

It is critical to understand the clinical needs of children and youth in order to assess the amount of money a needs-based program would cost and in order to design a system that is fiscally sustainable. Without access to OAP data, it is impossible to know the profile and needs of children receiving or waiting for OAP services.

The first step in any modelling should be to carefully assess this data and understand the scope of clinical need and the nature of the variance across this population. In the absence of this data, we drew on other available sources to provide some reasonable starting points for assumptions.

There may be concerns that eliminating caps will mean the system is unsustainable. This is understandable if we believe that every child was likely to require an intensive therapy program and/or if intensive therapy programs were never-ending. Importantly, however, most children with autism never require intensive therapy and most of those who do only require it for a relatively short period of time. It is fair to say, however, that most children may benefit from a range of therapeutic interventions including targeted programs, such as social skills or life skills groups, OT, SLP support, or focused ABA, which are significantly less expensive.

In Missouri, where families are allowed to claim up to $46,000 per year in a needs-based autism therapy system with regulated ABA professionals, the average annual claim is just US $4,800.[7] As another point of comparison, a 2015 investigation revealed that under the former Ontario autism programming, which was divided between a more comprehensive "IBI" program called the Autism Intervention Program (AIP), and focused ABA programs, e.g. sessions for two hours a week, called the ABA Services and Supports, 2,192 children were waiting for IBI services while 13,966 were waiting for ABA services.[8]

This means that 14% of waitlisted children were deemed eligible for intensive behavioural services, while 86% were deemed eligible for the much less expensive focused ABA services (e.g. two hours/week or group-based ABA).

Although the range of needs is much more complex and fluid than these two previous programs allowed (e.g. many families indicated this former program with two hours a week in short blocks was not sufficient to meet their children's goals), this breakdown still provides insight into the likely share of Ontario children requiring intensive versus focused treatment. Based on these data, less than one in six Ontario children who have autism is likely to require intensive intervention.

Participants in our research also indicated that the average weekly hours of ABA received (at the maximum level provided, as these hours fluctuated over time) in the former needs-based OAP was 13 hours. (By comparison, comprehensive ABA is typically delivered at an intensity of 25 to 40 hours per week.) An average of 13 hours per week suggests that, even in a needs-based program lacking caps, most children do not require intensive supports.

Moreover, it is generally expected that, after receiving a period of intensive therapy, the need for the same level of intensity will ebb over time as children reach their therapeutic goals and as their day increasingly includes other child-appropriate activities, such as school and community-based programming. The length of time to reach these goals will vary by child (e.g. 1-5 years), but intensive therapy programs are designed to be time-limited and to fade the need for continuous support so that the child may enjoy increased independence and be able to continue to learn in different ways and in other environments.

To this end, a child's clinical needs and responsiveness to therapy are two factors that influence the duration of therapy.[9] In a needs-based system, children's clinical needs should be regularly re-evaluated (e.g. every six months) with the expectation that the level of intensity (i.e. number of hours per week) will fluctuate as their needs change but, generally, will diminish over time as skills and core competencies are developed, key deficits are remediated, and children are able to integrate into appropriately supportive educational settings.

Regulation of ABA as a profession, with careful monitoring of adherence to established clinical guidelines,[10] will be important to ensuring consistent, ethical, and clinically efficacious treatment programs. Treatment plans that fall outside of the normal expectations could be reviewed by an independent clinician or body to ensure adherence to guidelines.

In our research sample, 58.4% had either received behavioural services in the past and had been discharged, or were in OAP service at the time of our survey (32.7% had received AIP (IBI) and/or ABA services in the past and 25.7% were currently in the OAP). Of the remaining 41.6% who had never received government-funded behavioural services, 57% were on the OAP wait list; 8% were awaiting intake; 5% were previously denied service; 19% had never applied for service; and 11% aged out of services. **Only 23.7% of our sample was both on the OAP waitlist AND had never received past service**.

In short, **the demand for intensive services may be much lower than imagined**. However, until more Board Certified Behavior Analysts (BCBA) and other therapists are trained, in the short-term if everyone has full access to funding for needed therapies without caps it is still likely that there will not be sufficient properly trained service providers to meet the demand of all potential clients.

As a way of balancing the limited number of therapists and available public funding with the clinical needs of children with autism — and to provide families with wrap-around, inter-ministerial supports — we propose the following model to support children and youth with autism. This model could also be adapted as appropriate for children with other disabilities.

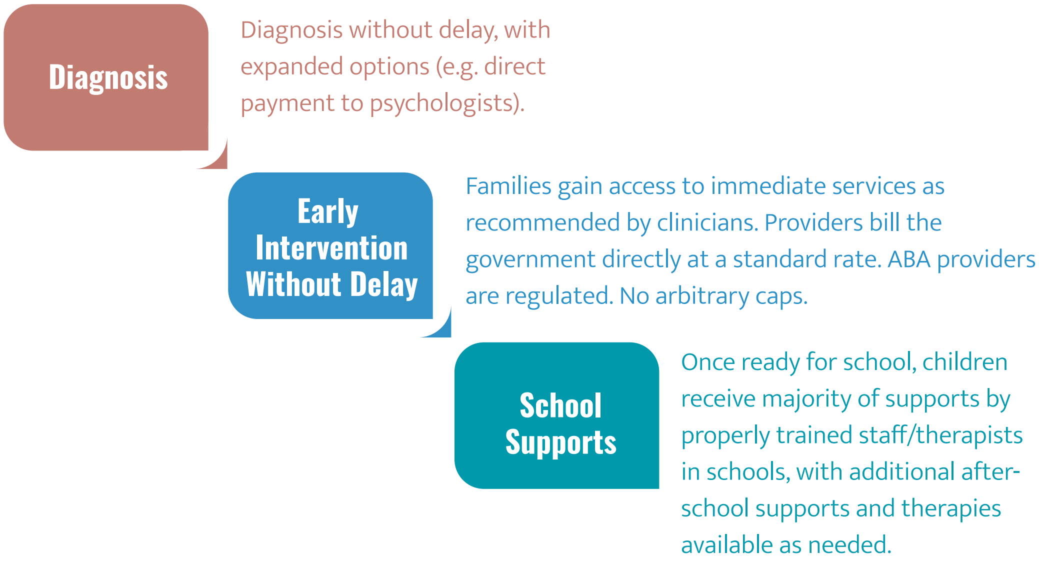
II. RECOMMENDATIONS

OUR OVERARCHING RECOMMENDATION is to invest wisely and sufficiently in each key area of service — early diagnosis, respite, therapies, AAC where required, and education — rather than diminishing any one of them by combining funding envelopes, while working collaboratively across silos to better integrate these services and create seamless supports for children and their families.

BASED ON OUR FINDINGS, we believe one of the factors driving up OAP costs has been the insufficient programming for respite and education. If these other programs received sufficient support, demand for more costly individual OAP services would likely decline, as children could be more readily and safely integrated across other domains once their therapeutic goals are achieved. This is why a strategy that sufficiently supports all of these areas can ultimately be more cost-effective as well as more responsive to children's diverse and ever-changing needs.

THE KEY TO SUPPORTING ALL CHILDREN with autism in an evidence and needs-based system within the available budget is to find ways to make the OAP more fiscally responsible, including wrap-around meaningful supports in the health and education systems; providing children with the exact amount of therapy they clinically require (no more and no less) without conflating additional non-therapeutic services, such as respite and technology, into the budget; and ensuring the services provided are done so ethically and at reasonable rates through further regulation and standardization.

Figure 1: Road Map to Ontario Needs-Based Autism Services



Diagnosis without delay, with expanded options (e.g. direct payment to psychologists).

Families gain access to immediate services as recommended by clinicians. Providers bill the government directly at a standard rate. ABA providers are regulated. No arbitrary caps.

Once ready for school, children receive majority of supports by properly trained staff/therapists in schools, with additional after-school supports and therapies available as needed.

1. DIAGNOSIS

Early diagnosis is important to maximize the chances of obtaining early intervention. As our research demonstrates, many families are paying over $2,500 out-of-pocket to private psychologists in order to obtain a diagnosis early and move on to treatment, creating a two-tiered system as well as inequity in outcomes. The costs for receiving an autism diagnosis whether attained through a diagnostic hub, pediatrician, or a qualified private psychologist should be covered by the government. This expansion of funding options will shorten wait times for assessment and diagnosis and act to further support the government's current investment in front-line diagnostics. Family doctors could refer patients suspected of autism to qualified pediatric specialists or psychologists. The clinician should, then, be able to bill the government directly.

Parents with private insurance plans, which cover psychology and other services, can use these first with the government paying any difference. Parents without private plans should be fully covered by the government. In either scenario parents should not have to pay out-of-pocket to receive diagnostic and other health services for their children, especially as even short wait times for diagnosis and treatment can impact directly on each child's therapeutic outcomes. Upon clinical confirmation of signs of autism and/or diagnosis, parents should be referred to appropriate health professionals who can further support their needs.

2. REGULATION OF ABA PROFESSIONALS

To ensure ethical and standard treatment of clients, ABA therapists (BCBAs, BCBA-Ds) should become regulated health professionals under the Regulated Health Professions Act, which includes the establishment of a regulatory college. “Health regulatory colleges are responsible for ensuring that regulated health professionals provide health services in a safe, professional and ethical manner. This includes, among other things, setting standards of practice for the profession and investigating complaints about members of the profession and, where appropriate, disciplining them.”[11] Oversight mechanisms should work to protect the public and ensure ethical practices, such as complaint mechanisms and standards for billing practices, including protection against over-billing.

3. DIRECT BILLING TO REGULATED HEALTH PROFESSIONALS FOR ALL NEEDED SERVICES WITHOUT ARBITRARY WAIT TIMES

The OAP should cover only evidence-based services from regulated health professionals, such as ABA, SLP, OT, psychology and social work (for those who need counselling or navigation supports) without caps or restrictions, based on qualified clinician recommendations.

The precise therapies funded could be determined by an interdisciplinary expert committee that takes into account the best available evidence and families’ diverse needs and experiences. In addition to direct treatment, supervision and programming hours, family training to ensure generalization of skills should be included in potential billable hours. Ideally, these evidence-based, regulated services would move under OHIP, through the Ministry of Health. Regardless of the ministry and funding program, there should not be a wait list to be eligible to receive funding for needed therapies at the appropriate level of intervention, as determined by a clinician and with the parents’/primary caregivers’ consent. If a regulated health provider/clinician deems a child needs therapy, they should provide an immediate referral to a specialist in the field. The provider should then bill the government, who reimburses them directly, as currently occurs in OHIP.

The burden of upfront payment and receipt reimbursement should not be placed on parents/caregivers, most of whom are already overburdened and some of whom may not have disposable income, strong English/French skills, and/or financial or bureaucratic literacy to successfully navigate these systems for their children. To further maximize OAP budget dollars for all families, families with private insurance for any of these services could first maximize these benefits before utilizing government funds, but, crucially, no family should be forced to pay out-of-pocket expenses due to their insurance access or lack thereof.

4. STANDARD RATE FOR SERVICES

Children who require therapy (any combination of approved services, e.g. ABA, SLP, OT, psychology) should receive it without delay, either through a directly funded government-to-provider OAP, or through OHIP cards if the program changes ministries. Currently, reported charges for ABA therapy range from $39 to over $100 per hour. Payment discrepancies have long existed, as noted in the Auditor General's report, which found that fees were 66% higher on average in the former DSO program than the former DFO program (Auditor General, 2013). Services should be provided at a standard rate negotiated between providers and the government. The rate should balance cost efficiency with fair wages to attract and retain high quality therapists and account for adequate supervision, supplies, rent, geographic region, etc. Services could be provided through private clinics, through government-funded treatment centres or through private home- or community-based supervised programming, but there should be greater standardization between the costs. This would help to improve consistency in treatment and the efficient use of funds to enable the maximum number of children to benefit from therapy. Additional funding could be provided to government-run treatment centres or grants made available for the specific goal of running targeted programs to ensure inclusion of vulnerable or under-served clients (e.g. Indigenous, refugee, low socioeconomic status, rural/remote, non-English speaking, recent immigrant), as is done for health care services in Ontario's Community Health Centres.

5. NO ARBITRARY CAPS ON HOURS

Governments must work to balance the competing demands of wait list reduction (serving all children who need therapy as quickly as possible) with children receiving therapy at clinically recommended intensity and duration. Doing so will help to increase the likelihood that children who undergo therapy will make meaningful, long-term gains.[12] To ensure therapy effectiveness, there should be no artificial caps on hours based on age, family income or severity level. In order to ensure more children can receive supports among a limited number of providers, a reasonable maximum cap (e.g. 36 weekly therapy hours)[13] could be implemented in consultation with clinical experts (although there could be a petition process for extenuating circumstances, reviewed and approved by an independent clinician). The therapeutic needs of children should be established by a clinician, in consultation with parents, without artificially imposed non-clinical restrictions.[14]

6. SERVICES AND SUPPORTS IN SCHOOLS

Our research findings document that most families are dissatisfied with their school placements, and many children are attending public school only part-time or not at all because they cannot be safely and meaningfully integrated in the schools. The proper provision of supports in schools is important both for the success of all children in schools, as well as to alleviate pressures for children to continue receiving OAP services outside of schools due to inadequate education supports. Further oversight is necessary to ensure school boards (and individual principals) are meeting their commitments according to the regulations set-out by PPM 140.

Once children have acquired sufficient core skills in treatment (e.g. communication, reduction in challenging behaviour, learning readiness) that enable them to access the curriculum in the natural environment, then continued supports should be provided in schools. When these core skills are not sufficiently honed, school boards should work with practitioners and families to reach educational solutions that recognize the extent of the need, and support the child in accessing the curriculum in a way that is appropriate for his or her learning level.

In all cases, key support services (tiered/supervised ABA as defined by the Behaviour Analyst Certification Board, OT, SLP, etc.) should be provided as needed, to support children in accessing the curriculum in a meaningful way.[15] This would free up the bulk of services outside of schools for younger children. Schools must hire EAs with the appropriate skillset and training as well as therapists, when needed, to support children in these settings. EAs should receive additional and ongoing training in supporting children with autism. Some could be trained as registered behaviour technicians and receive ongoing supervision from BCBAs/psychologists.

Public (including publicly funded Catholic) schools should quickly work to increase capacity of properly trained and resourced professionals so that, in the near future, these services can be provided safely and effectively to all in the public school system.[16] Innovative education models that work to integrate children with complex needs in meaningful educational environments could be examined for how similar successful practices could be integrated into Ontario's public education system.[17] Safe and compassionate strategies for calming and self-regulation, such as sensory rooms and breaks, should be developed in consultation with autistic people and experts. Therapeutic services should only be provided with the consent of parents/legal guardians.

7. THERAPIES OUTSIDE OF SCHOOL

Children who require extra supports for therapies after school hours should be provided these services as needed, with the goal of diminishing and/or eliminating the need for additional support over time, as skills are acquired.

8. RESPITE PROGRAMS

Our recommendation is that the OAP remain a needs and evidence-based therapy only program, but respite services are still critical for many families. Funding should also be provided for extra supports for after-school respite and support programs that safely and meaningfully integrate children with special needs. All families should receive adequate funds for respite and recreational programs (e.g. adapted sports, accessible summer camps, etc.) through SSAH with no waiting times (aside from the time to administer applications, maximum three months). Funding envelopes should be reassessed to reflect changing needs and rising prices within the community for the costs of many key services, such as summer camps with one-to-one supports.

9. AUGMENTATIVE AND ALTERNATIVE COMMUNICATION (AAC) PROGRAMS

All clients who require it should receive AAC supports and devices through the existing AAC program with minimal wait times. Experienced clinicians should be available to assess clients' needs, make recommendations, and support training. Full costs of needed technology for communication should be covered, as should the cost of repair and updating of these systems over time. Professionals who have expertise in AAC could work collaboratively with other professionals (e.g. BCBAs, SLPs, OTs) to support the child's development of functional communication skills and create efficiencies.[18] AAC intervention should be integrated across home, educational and therapeutic settings as appropriate to enhance success.

10. TRANSITION PERIOD (SPECIAL/TEMPORARY MEASURES)

There should be special measures to allow for a smooth transition period while supports and capacity are being developed in schools. Until the 2020 or 2021 school year, depending on how long the transition to provide meaningful supports in schools takes, all children currently in the OAP should continue to receive therapy under their current programs (or as modified by clinicians in charge, and/or under newly established guidelines arising from the expert panel recommendations). Many families have their children at home or in private schools because there is no safe and meaningful placement available to them in the public system or because their children have been excluded from public school.

Parents in such situations should be able to apply their OAP funding to cover needed supports (e.g. tuition for private specialty schools for children with exceptionalities, or in home educator/therapists) at least until public schools are properly equipped to safely and meaningfully educate their children. A job retention and transition strategy should be implemented to ensure current ABA therapists retain jobs so that capacity is not lost during this time of change within the OAP. If current OAP contracts are extended during the period of transition, this would help to secure these jobs through this difficult period.

11. BUILDING CAPACITY FOR ALL

If funding is released to all families, in many regions there will likely be more demand than there is supply available of therapists trained in evidence-based therapies, effectively creating new provider-based wait lists. It is particularly important that the practice of behaviour analysis is regulated and that only regulated professionals are allowed to provide therapy so that untrained therapists do not take advantage of available funds and put clients at risk.

Training capacity should immediately be expanded in ABA programs as well as for related professions (e.g. SLPs and psychologists specializing in autism) to ensure that supply can meet demand as soon as possible and into the future. Incentive programs should be implemented to attract appropriate therapists to rural and remote regions, Indigenous communities, and for those requiring Francophone services or the use of AACs, to ensure equal access for all communities across the province. For example, the existing Grant Assistance Program could be enhanced with these targets in mind.[19] To increase the likelihood of attracting and retaining northern-based therapists, training programs in these regions could be particularly targeted (as is done for physicians in the Northern Ontario School of Medicine).

Until capacity in northern, rural and remote regions is fully developed to provide services in all regions, families who must travel a far distance to receive therapies should receive travel cost reimbursement. Even better, funding programs could be put in place to allow therapists to travel to families. Families who require services in languages other than English should receive adequate supports to enable them to access these services. The Ministry of Training, Colleges and Universities should expand doctoral level ABA programs where appropriate throughout the province.

12. OTHER FINANCIAL AND SOCIAL SUPPORTS

Considering the enormous costs that many families incur out-of-pocket for therapies and supports, there should be expanded disability tax benefits and tax deductions for medical/therapeutic and respite expenses of parents' choice that are not fully covered by the government. Programs should be developed and funded to provide support groups, system navigational supports and counselling for families. Strategies should be developed to better support families in order to retain optimal hours of work/income while caring for family members with complex needs, considering the findings and recommendations made throughout this research report.

13. TRANSITIONS INTO ADULTHOOD

As children grow into teens, appropriate programs should be developed to support their life and social skills, employment training/counselling, etc., with seamless transitions planned for wrap-around adult supports. Student co-op programs and workplace support programs could assist in gaining practical experience to transition into adulthood. Many programs and supports, such as safe and affordable housing, employment, mental health, recreation and day programs, need to be considered for transition age youth and adults. These were not the focus of this research and warrant separate study and commentary.

14. EXPANDED ROLE OF THE FEDERAL GOVERNMENT

Given the fiscal restraints of provinces/territories, and the variable and extremely inconsistent services across the country, the Federal Government through a National Autism Strategy should play a greater role in leading and supporting provinces and territories. A starting point is the recent Canadian Autism Spectrum Disorder Association (CASDA) blueprint.[20] Ideally, the Federal Government would also provide fiscal transfers to help provinces pay for autism therapies. This could be done through an amended and expanded Canada Health Act that recognizes autism and other disability therapies as medically necessary. Alternatively, other innovative funding strategies could be developed to provide needed federal support. For example, autism/disability therapies could become a "shared health priority" and funded under a bilateral agreement, as is done with the Canadian mental health and addiction strategy.[21] Another possible model is the proposed Catastrophic Drug Transfer.[22]

III. METHODS AND DEMOGRAPHIC OVERVIEW

METHODS

A survey was developed by Drs. McLaughlin and Schneider, and then further refined using solicited feedback from parents, clinicians, and other community stakeholders. It was distributed online with the help of a number of autism organizations, practitioners, and community members.

654 parents/primary caregivers of children and youth with autism in Ontario completed the 179 question online detailed survey, with closed and open-ended responses, in the summer of 2018. (There were 719 participants, when combined with initial/partial responses.)

With this sample we assume a 95% confidence level, with a margin of error +/- 3.8%. Supplementary qualitative interviews were conducted with limited participants. All statistical data were analyzed using Qualtrics and SPSS software. Qualitative data were analyzed using thematic analysis coding. Research ethics clearance was received through Wilfrid Laurier University's Research Ethics Board.

STUDY LIMITATIONS AND FUTURE RESEARCH

This study only involved parents and primary caregivers of children and youth with autism in Ontario who reported about their children and their own experiences.

As the focus of the study was on parent/caregivers' experiences raising children and youth, autistic self-advocates and other stakeholders were not invited to participate, however, a number of participants identified as autistic themselves as well as parents to autistic children.

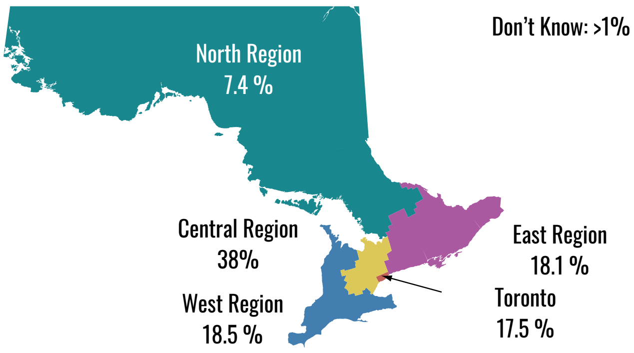
Future research projects are being planned to examine issues facing autistic youth and adults from their own perspectives. Given that the issues examined only focused on those under 19 years of age, the transitions to adulthood, including housing, recreation and employment supports, were not included, and also merit separate examination.

Our sample of parents and primary caregivers represents, on a whole, more privileged families (higher socioeconomic status) and proportions or percentages should be interpreted as not being representative of the full Ontario population.

Due to budget constraints, the survey was only available in English, limiting the number of ESL participants. The average family income of our participants was significantly greater than the Ontario average.

There were few Indigenous and new immigrant families, and there were unfortunately no refugee or on reserve Indigenous participants.

Figure 2: Percentage of Survey Respondents From Each of the Five Ontario Service Regions



Even though this study reflects a more privileged segment of society, the findings demonstrate that most are struggling to adequately support their children.

More acute barriers and resulting impacts would be anticipated for the under-represented and marginalized groups listed above. In recognition of the importance of having their voices be heard, further research is being planned to specifically target facilitating the participation of these traditionally hard-to-access groups.

We anticipate that the same challenges which led to the under-reporting of such groups in this survey would also amount to additional barriers to these families when accessing autism services and supports.

PARTICIPANT DEMOGRAPHICS

Caregivers

- The average age of respondents was 42
- Most were women (92%)
- 86% of respondents had a spouse, and 74% were married
- Families' total annual income (before taxes) was $96,144 on average (Ontario median family income in 2016 was, in contrast, $86,081)
- 86% had one child with ASD; 14% had 2-3 children with ASD
- Just over half of respondents indicated having a major mental or physical health challenge in their family in addition to autism (e.g. cancer, dementia, depression)
- All Ontario regions were represented, with the Central Region having the most respondents (38%) and the Northern region having the fewest (7%)

Children/Youth

- 80% of the children/youth were male
- Ages 2-18, with an average age of 10
- **Autism Severity Levels (Diagnosed or Believed):**
  - Level 1 – 29.8% (Requiring support)
  - Level 2 –34.6% (Requiring substantial support);
  - Level 3 – 23.9% (Requiring very substantial support)
  - Don't know – 11.7% (Note: Many families had not received a diagnostic "level," so these results should be interpreted with caution.)
- **Most Common Co-Occurring Challenges/Diagnoses:**
  - Speech & Language Disorder – 70%
  - Anxiety – 65%
  - Sensory Challenges – 58%
  - Sleep Disturbances – 48%
  - Limited Food Intake – 48%
  - ADHD – 43%
  - Elopement – 42%
  - Intellectual Disability – 41%
  - Aggression – 38%
  - Gastrointestinal Disorder – 34%
  - Phobias – 30%
  - Self-Harm – 29%
  - Depression – 20%
  - Pica – 16%
  - Physical Disability – 11%
  - Seizures – 7%
  - Vision Loss / Blindness – 5%
  - Hearing Loss & Deafness – 5%
  - Other – 22%

IV. FINDINGS

A. ONTARIO AUTISM PROGRAM

Background

The purpose of this portion of the study was to seek parents' and primary caregivers' input on the OAP and other services, and provide evidence-based feedback to the Ontario Government in its design of future autism services and supports. Important to note again, this study was conducted in the summer of 2018, when the previous Ontario Autism Program (OAP) had only recently been implemented.

Only 23.7% of our sample was both on the OAP wait list and had never received past service.

Thus, participant feedback and recommendations are related to the previous funding models (not just pertaining to the OAP, but the previous ABA and IBI programs as well). Recommendations and feedback were not sought on the childhood budget model introduced by the Progressive Conservative Government in April 2019.

Inclusion in the OAP

At the time of the survey:

- 58.4% of respondents were either in the OAP or had received past government-provided behavioural services under a previous program
- 25.7% of respondents were enrolled in the OAP
- 32.7% of our sample had received AIP (IBI) and/or ABA services in the past
- Of those currently enrolled, 53% were in the DFO program and 47% in DSO (Note: This may reflect the higher socioeconomic status of study participants—those with higher SES were more likely to be enrolled in the DFO program)
- Of those who reported having received services in the past, most were discharged due to: child's age, child doing "too well", completed block and put on wait list again, "mild-moderate" ASD being deprioritized, and waitlist being so long that they gave up
- 41.6% were neither in the OAP nor had received past service. Of those never having had OAP/ABA/IBI service, 8% were waiting for intake; 57% were on the OAP wait list; 5% were denied service; 19% never applied for service; and 11% aged out of service
- Only 23.7% of our sample was both on the OAP wait list and had never received past service
- Respondents reported waiting on average 23 months, from time of diagnosis to receiving behavioural services provided by the Ontario Government
- They reported receiving, on average, 13 hours of government-funded behavioural services per week (at the highest level received)
- **Location of Services:**
    - » 34% at home
    - » 32% at a government-run centre
    - » 16% at a private clinic
    - » 10.6% at school
    - » 7% other

Positive Impacts of the OAP

- On the whole, respondents indicated receiving the OAP was "very influential" for their lives
- Most reported significant, positive gains from the program
- **The reported benefits of the OAP were assistance with:**
  - » Social skills (68%)
  - » Communication (62%)
  - » Self-help skills (e.g. eating, toileting, dressing) (61%)
  - » Play skills (52%)
  - » Aggression/behaviours (51%)
  - » Reduced stress on family (50%)
  - » Increased child's confidence and/or self-esteem (40%)
  - » Assisted with academic skills (40%)
  - » Provided a means of respite (33%)
  - » Other (13%)

Four percent of respondents indicated that they did not receive any benefit from ABA services. In some cases, this was because they were enrolled in short blocks of services under the previous ABA program that were perceived to not be effective. A few respondents (less than 1%) indicated that ABA was not a desired method of therapy for their particular child.

Themes Cited in Open-Ended Responses

- Couldn't have afforded that level of service otherwise
- The OAP has been life changing /saving for the child and the family
- ABA has taught child key skills that have made a huge difference in their life

Challenges with OAP

The top challenges or areas for improvement of the former ABA, IBI and/or current OAP services, as identified by respondents (in order of frequency), included:

1. Not enough funding for the amount of ABA therapy needed (44%) (previous ABA/IBI programs)
2. Frustration with inconsistent or insufficient information from ministry/government officials (42%)
3. Lack of control over time and location of services (42%)
4. Stress related to advocating for the services my child needs (40%)
5. Cut-off from therapy prematurely (previous ABA/IBI programs) (34%)
6. Would like to use other forms of therapy not currently funded (30%)
7. Frustration dealing with paperwork and management of services (25%)
8. Too much family stress to arrange and/or transport child to services (24%)
9. High amount of therapist turn-over (22%) (this trend appeared especially common among therapists in DFO, where providers were often incentivized to leave for better paying DSO positions)
10. Disappointment with therapy quality or approach (21%)
11. Disappointment with service providers/ therapists (21%)
12. Costs and/or logistical challenges relating to providing space and resources for home-based therapy (18%)

Of the 30% of respondents who wished to see other types of therapy funded, by far the most common types of services were SLP and OT. Smaller numbers of respondents were interested in physiotherapy, psychology/counselling and music therapy.

Very few numbers of respondents (less than 1%) indicated desire for a variety of other therapies, such as Relationship Development Intervention (RDI), HANDLE, horse therapy, osteopathy, Floortime, son-rise, natural medicine, pharmaceuticals, social groups, tutors, homeopath/natural medicine, vision therapy, listening therapy, stress management, play therapy, and a variety of other methods, as listed in their open-ended responses.

Themes Cited in Open-Ended Responses

- Provide more services in Northern locations
- The changeover to OAP has been stressful
- Wait lists are too long
- Parents should be able to use a variety of programs, not just those deemed acceptable by the government (i.e. ABA) – a small number of respondents felt ABA was harmful or not helpful for their child
- Increased time commitment getting children to and from appointments
- 'High-functioning' kids being discharged despite the fact that they have learning needs too (previous program)
- Need transitional programs from childhood to adulthood and between various contexts (e.g. therapy, school, adolescence and adult services)
- Ineffectiveness of group settings (in [previous] ABA program)
- Need more focus on social skills
- Lack of coordination among branches of the government and with schools
- Frustration that ABA therapists not allowed into schools
- Onerous paperwork (particularly DFO)
- DFO parents forced to pay for extra fees when kids are sick or for consultations with professionals above the $55 rate (e.g. SLP)
- Difficulty coordinating therapy times with work
- Distance and time to travel to therapies
- Too much time between ABA sessions, and hours too few to be effective (previous ABA program where ABA services were offered in temporary blocks)

Areas of Stress

Issues respondents' reported being "very stressful" or "extremely stressful" for their families included:

- Emotional aspects of navigating various services and supports for autism (e.g., managing staff, determining the best type of therapy, etc.)
- Time involvement of navigating various services and supports for autism
- Financial aspects of autism (personally funding various therapies and services)
- Confusion surrounding how to navigate the therapy and support systems
- Insufficient funding for ABA, so child goes without adequate level of service
- Long wait times

Respondent Suggestions for OAP

When asked what the government could do to improve its OAP, the respondents answered in support of the following (in order of frequency):

- Reduce or eliminate wait times for support (98%)
- Provide ABA services in schools (89%)
- Expand its range of therapeutic options (i.e. beyond ABA) (87%)
- Provide direct funding to all children who need support (81%)
- Provide a regulatory framework for ABA professionals in Ontario (57%)
- Increase amount provided per hour (from $55) (53%)
- Provide more guidance and support to parents regarding hiring and training staff under the DFO program (48%)
- Provide more specialized support to assist with children's limited eating patterns (44%)

Themes Cited in Open-Ended Responses

- Integrate fuller ranges of necessary services in OAP (especially evidence-based services that parents report using most—ABA and intensive ABA, OT, SLP, Psychology)
- Some respondents would like experimental/alternative and natural therapies funded, while others prefer only evidence-based standard models
- Some prefer DFO for flexibility, while others prefer DSO for convenience
- Provide equal choice of DFO / DSO and better equity between systems, especially:
    - More support for DFO, including assistance with billing
    - Cover all true costs of program (e.g. do not penalize parents for missing shifts due to sick children; fully cover costs of professionals needed – e.g. ABA, SLP, OT, etc.)
    - ABA therapists should be regulated health professionals
    - Increase in capacity of ABA and other professionals
    - Ensure adequate professionals in rural/remote/Northern regions
    - Provide greater supports with service navigation

Conclusions and Recommendations for the OAP

The Ontario Government is currently restructuring its OAP. Unfortunately, our survey was set up in a different context, and the questions were geared towards issues with the previous system in place.

Nonetheless, we can extrapolate some insight from the findings to inform the current consultations. First, the government's changes to expand the OAP to services such as SLP and OT were advocated among our respondents. Reducing wait times, both for diagnosis and for service, was also a key recommendation which the government also identified.

While opinions were not directly sought on the issues of imposing age caps, arbitrary restrictions on funding, or the utility of moving towards a childhood budget model, our survey respondents did not suggest any of these as desired revisions to the OAP model in question.

Indeed, those receiving services in the OAP were generally very happy with a flexible, needs-based system and one which allowed for the funding of intensive therapy when needed. Further, while private ABA services are enjoyed by many families, direct services offered through government-funded treatment centres provide unique wraparound supports for families, with multiple professionals working together to provide integrated care on-site.

Some clients, especially those in more marginalized circumstances or living in remote regions, particularly benefit from this approach. The choice for this service has been removed as an option with the new program.

Informed by these survey results, our key recommendations for the new OAP include:

1. Provide evidence-based services, such as ABA and IBI, OT, Psychology and SLP based on clinical need and parent preference, but not limited by arbitrary age caps or funding cutoffs. This could be through an OHIP model or a similar model in which the providers directly bill the government for services, reducing the time, paperwork and stress for parents.
2. Implement better oversight of providers, including regulation of ABA professionals.
3. Generate program cost savings by providing a standard rate card for ABA services, whether provided through government treatment centres or private clinics. Additional funding or programs could be provided to government treatment centres to ensure timely, equal access for Northern, rural/remote, Francophone, refugee, new immigrant, Indigenous and other marginalized populations.
4. Improve therapies and supports in schools and better coordinate services between schools and OAP. Doing so will have multiple benefits: improving the experience of education for all students; allowing parents to work without being called home; and reducing pressure on OAP budget outside of schools.
5. Enhance respite supports under SSAH and eliminate wait times for this service, which does not require implementation/oversight by qualified/regulated professionals.
6. Expand capacity of ABA training programs and other needed therapies to reduce wait times for service. Work with providers to ensure current therapists are not laid off, which will only further reduce capacity.

Further detailed recommendations on the OAP can be found at the beginning of this report.

RESPONDENT COMMENTS: ONTARIO AUTISM PROGRAM

OAP POSITIVE IMPACTS

"ABA has given dignity to my child and has kept our family together. It has given my son with autism chances at eating, toileting and finding ways to communicate."

"Excellent and effective. We saw great results and were taught how to use it in our daily lives. Waited too long and it was too short, but it really worked."

"ABA has given my son a life with opportunity and it has kept our family stable."

OAP CHALLENGES

"It's an uphill battle. You have to prove over and over again that your child has challenges- schools and ABA program work against each other. So exhausting. ...There is zero understanding - many days crying and worrying I did paperwork wrong. Spent hours on monthly paper work- waste of time. Time I should have been with my son."

"School boards must allow schools as a setting for government-funded IBI/ABA services and allow our therapists/providers into the schools. Otherwise - OAP program and funding may be great ... But if we can only access services by removing our child from school - to either be in the home (DFO) or anywhere else (DSO) then nothing else matters."

"The system needs more money. I know there's a move to privatization over centre based agencies but I prefer to work with an accredited agency rather than getting direct funding & then having to do all the vetting & quality control myself. Parents have way too much on their plates. We need more hands on help, not 'consultation & direction' on how to do things at home."

"There are no DFO centres in our area. I must drive 4 hours a day to get my child to his centre. I have had to leave my job in order to do so."

SUGGESTION FOR OAP

"Put money back into Direct Service models. Don't abandon this approach. Not everyone wants DFO. I have enough stress without having to worry about that."

AREAS OF STRESS

"Don't make announcements and "roll out" a program that is not planned out, ready or even understood by the workers who will carry it out again. The rollout of the OAP has been a fiasco for workers and an ever-changing bundle of mystery to parents. Ridiculous. It's caused stress and hardship to those it claimed to be helping."

"Don't use it as a wedge issue. Take the politics out of it and just meet the kids' needs. Stop making us have to fight tooth and nail. Take him home with you for a week and then get back to me on what you're going to do for him."

"Direct pay service providers no matter whether you get DSO or DFO."

B. OTHER SERVICES AND FINANCIAL IMPLICATIONS

Context

Given their varied diagnoses and co-morbidities, families normally access a range of health and support services. While some of these are provided publicly, many parents spend significant amounts of money out-of-pocket in order to provide the extra supports and services their children need. This begins even with the process of diagnosis, as long wait times compel some families who can afford it to pay out-of-pocket to access a private assessment, allowing them to enter wait lists for therapy programs faster.

Diagnosis Issues

- Families waited an average of two years between suspicion of signs and attaining a diagnosis
- Primary reasons for delay:
  - » It took long to get an appointment with someone who could offer a diagnosis (33%)
  - » Doctor/practitioner didn't believe there was an issue (20%)
- 24% of respondents paid out-of-pocket to receive a diagnosis, with the average payment being $2,551

Other Services

Most families received a variety of services through public and private programs, although it is important to note that the amounts spent by individual families may not necessarily reflect the amount of support needed by the child, but likely also reflects the amount of money the family felt they could afford to spend. With this in mind, the top six reported services are included in Figure 3.

Implications

- Families with higher levels of income are able to access more and earlier services for their children. This amounts to a two-tiered system of care, in which the poor go without and the rich gain access faster and longer. As a result, children's outcomes are likely correlated to families' socioeconomic status.
- Across all income groups, parents are pressured to work extra jobs, quit jobs to support children, sell homes or make other major financial sacrifices.

Respondent Suggestions to Improve Services/Supports Outside of the OAP

- Provide more social and recreation programs for children with autism (100%)
- Provide more financial supports for parents and family members (97%)
- Fund a more diverse array of services (e.g. SLP, OT, etc.) for those who need it (95%)
- Improve disability tax benefits (93%)
- Provide more support for families to navigate the health and social services systems (88%)
- Provide more housing and employment services to adults with autism (82%)
- Provide more emotional supports for parents and family members (82%)
- Improve training of health care providers to better recognize and support autism (80%)
- Provide education to families on how to support children's development while waiting for therapy (76%)
- Support a National Autism Strategy (75%)

Figure 3: Top Services Used by Parents

	Avg. Amount Spent Out-of-Pocket in Past 12 Months	Receiving Privately (%)	Receiving Publicly (%)
Behavioural Therapy	$ 8,688 (max $60,000)	44 %	26 % (OAP)
Specialized Sports and Recreation Programs	$1,613	42 %	18 %
SLP	$2,797	39 %	29 %
Respite	$2,884	37 %	31 %
OT	$1,686	25 %	29 %
Psychological Services	$2,415	24 %	8 %

- Improve and expand respite options (71%)
- Provide more education to families on savings programs that may benefit them (69%)
- Education campaigns for other Ontarians to have a better understanding of autism (68%)
- Provide better funding for augmentative communication systems (51%)

When asked "How confident are you that your child(ren) has/have received all possible supports and therapies you would have wanted for them to fulfill their potential in life?" most respondents indicated "not at all confident" to "slightly confident" (the lowest two responses on a five-point scale).

The main reasons why participants felt this way included:

1. Lack of adequate publicly available supports
2. Lack of ability to pay for privately available supports
3. Experiencing "burnout" related to dealing with my child's behaviours and/or from having to spend so much time advocating for my child
4. I didn't know what therapies or supports to provide

Respondent Recommendations by Theme

- Provide immediate supports and early intervention for families who have children with delays/concerns, regardless of diagnosis
- Significantly shorten wait lists
- Create simpler service navigation and more supports
- Address needs of whole child and family (health, well-being, counselling, employment, etc.)
- Provide more respite and financial supports
- Provide appropriate services for families with varying contexts – not a "one size fits all" (considering different diagnoses, needs, ages, etc.)
- Increase supports for families with multiple diagnoses and additional challenges

RESPONDENT COMMENTS: OTHER SERVICES AND FINANCIAL IMPLICATIONS

FINANCIAL IMPLICATIONS

“We shouldn’t have to pick between paying the bills and paying for treatment for our children. I think a lot of children go without therapy because of the cost.”

OTHER SERVICES

“Have ONE place where families can get information- right now it is a maze of confusion. One website. One phone number to start. This is hard. Please don’t make it harder.”

“Outside of school, it is ridiculous that I am to be expected to not only be a single mother in charge of all aspects of their care, but also be fully aware of the health and government agency system as to what is available to them, and how to access that. I desperately need help.”

“After diagnosis there is no clear next steps and families need to be better guided to figure out what to focus on.”

“My children have been on the wait list for SSAH for almost a decade. Moreover, I learned that unless the child is deemed a “high priority transition” before entering public school, the wait list for the school board provided or CCAC provided supports (i.e. speech, physio, and OT), are minimum 4 years. This is unacceptable.”

“It’s so frustrating that we have to wait so long for a diagnosis (2 years in our case), and then another year for [an] intake meeting, and probably another year before we actually get services. Absolutely unacceptable for a condition that can benefit so much from early intervention.”

C. EDUCATION

Context

According to the Ontario Human Rights Commission (2018), the Education Act states that the "Ministry of Education is responsible for ensuring that all exceptional children in Ontario have available to them appropriate special education programs and services without payment of fees" (para. 2).

To this end, the Ontarians with Disabilities Act (1990) claims that the "Ministry of Education, as well as school boards, are required to prepare, update and make public accessibility plans that address the identification, removal and prevention of barriers to people with disabilities" (as cited in Ontario Human Rights Commission, 2018, para. 5).

More specifically, the Ministry of Education is further guided by Policy/Program Memorandum No. 140 (PPM 140), which states that, "School boards must offer students with ASD special education programs and services, including, where appropriate, special education programs using ABA methods" (Ontario Ministry of Education, 2012, para. 13) and additionally that, "School board staff must plan for the transition between various activities and settings involving students with ASD" (Ontario Ministry of Education, 2012, para. 20).

In sum, all children have the inalienable right to an equal and appropriate education, responsive to their particular educational needs. Despite this, many challenges and barriers to education continue to exist for children with ASD and their families, and these were clearly identified by survey respondents.

Key Findings

- 68.5% of respondents reported that their children were attending school full-time and 13.9% part-time, with a breakdown in settings of 57% public; 26% Catholic; 12% private/other; and 4% in preschool
- 17.6% did not attend school at all. Among those not attending, 35% were too young, 10% were receiving ABA instead, and the remaining 55% were home because they couldn't find a school with adequate supports and/or the student was excluded for other related reasons
- 61% of those respondents who reported that their children were attending school (either full-time or part-time) indicated that they were being educated in an inclusive classroom, with varying degrees of support (23% - specialized consultation only; 30% - specialized instruction within the regular classroom; 8% - specialized instruction outside of the classroom), while 10% were being educated in a segregated, special education classroom, with partial integration; and 19% were in a full-time, segregated, special education classroom
- Of those respondents reporting their children were enrolled in school (full-time or part-time) and when asked, "What services has your child received (within the past 12 months) in their education?", only a small proportion of the respondents reported receiving services (35% reported that their child received full-time EA support; 31% part-time EA support; and 39% and 36% reported their child received OT and SLP respectively).

  These were particularly interesting findings considering that approximately 60% of respondents reported their child's severity level rating (diagnosed or believed) to be at a Level 2 (35%) or Level 3 (24%), or in other words, the higher end of the needs spectrum

Challenges with Education

Despite some children receiving EA support, there were a number of challenges reported.

- Of those in school, 27% indicated their child had been sent home in the past 12 months because the school could not properly support the child, with the average being 10 times.
- 55% of respondents reported spending just over $10,000 out-of-pocket (on average) per year, for such services as ABA specific to education (31%), tutoring services (24%), private schools (10%) and home school expenses (10%) in order to meet their child's educational needs
- Over 78% of all respondents reported that their child did not have (or they did not know of) anyone who worked with their child on a daily basis in school, who had specialized training in ABA or autism
- Over 80% reported frustrations or challenges with respect to their child's treatment within the education system
- The top 5 frustrations included: 1) lack of EA support; 2) teachers not being properly trained with respect to autism; 3) no option for ABA in current school; 4) communication problems with schools; and 5) safety while at school
- When asked whether they felt their child was "receiving an education in a safe & supportive environment", they reported feeling "neutral" (on a scale from "very dissatisfied" to "very satisfied").
- They also reported feeling "somewhat dissatisfied" with the "meaningfulness" of the education their child was receiving.
- With respect to restraints & seclusion, 10% of those who responded to experiencing challenges in the education system, reported the use of "improper restraint from school staff", and 18% reported the use of "improper segregation by school staff". When asked, "What could be done (if anything) to improve the education experience for your child (check all that apply)?", 40% of the respondents checked off "Properly train staff in regard to restraint and/or segregation practices".

Themes Cited in Open-Ended Responses

- Education does not match child's learning needs
- Children are being "warehoused" and/or "baby sat" at school
- School system is designed to "push these kids through"
- Students engaging in self-harm due to school stress and bullying
- Not allowing ABA therapists in schools (for those who want it) is a breach of human rights
- Frequent calls to pick child up or tend to child while at school
- Dissatisfaction surrounding the IPRC process, referring to it as a "rubber stamp process", that is a "waste of time" and a "useless exercise". With respect to the actual IEPs themselves, respondents stated that they were neither standardized nor consistent, and were "not worth the paper it's written on".
- Not enough EAs or support for EAs within the school system
- Staff/administrative people are not properly trained

Respondents reported being dissatisfied with the "inclusive" model of schools, citing numerous issues that in fact make this learning environment particularly "exclusive" for their child.

When asked "What could the Ontario Government do to improve its Ontario Autism Program (OAP)?", 89% of respondents said, "Provide ABA in schools".

Without access and the ability to choose from an array of meaningful supports in schools (for example: ABA, OT, SLP, etc.), children are not able to meet their full potential, and the school environment becomes one of exclusion rather than inclusion.

Recommendations for Improving Education

Parents report experiencing a number of frustrations when trying to access equal and appropriate education services for their children with ASD, sometimes having to pay exorbitant amounts out-of-pocket to meet their specialized education needs. This continues to occur, despite the Ministry of Education's mandate to provide "appropriate special education programs and services without payment of fees" (Ontario Human Rights Commission, 2018, para. 2).

Because there is no effective mechanism for oversight to enforce PPM 140, it would appear that the experiences of families are entirely dictated by their respective school boards, or in some cases, their principal.

Informed by these survey results, our key recommendations for improving education include:

- Design and implement a meaningful oversight mechanism, in order to address disparities within school boards and at individual schools
- Offer ABA and other meaningful supports in schools, to help alleviate the burden upon school boards and families, and to ensure that ALL children with ASD receive those services to which they are entitled as a basic human right
- Hire more EAs and provide them with better supports and training
- Provide better autism training for teachers
- Establish and enforce significant penalties for school boards / schools which violate provincial education regulations, holding them accountable for the services they provide to children and youth with ASD

RESPONDENT COMMENTS: EDUCATION

EA

"An EA has been assigned for a couple of hours per week but I don't know that he actually spends any time with the EA. I get the sense that his EA entitlement has been spread around to 'share the wealth' with others who are not eligible. He certainly doesn't get what he needs to actually learn anything in school."

CHALLENGES

"We, as parents, are fighting a battle with school for extra help for our kids, which is not fair. They are entitled to help and support, to grow and learn like regular kids. They are not sick. [They] just need extra help and attention, and it's a battle getting our kids the help they require."

"We hire a full time worker....we are opting not to fight the school board and instead keep our son safe at home and learning in his own way. It's a fortune, but it's so much better than the stress of school (which he can't do). So, basically, we've given up on everything government-funded because it doesn't exist for us. There is literally no help. My autistic son can't go to school. No one knows he's not in school; no one cares; no one finds anything despite us trying."

RESTRAINTS & SECLUSION

"[My son] has been through Catholic school in which they were locking him in a locked room. I changed to public [and] he was picked on, segregated from children, made a mockery, suspended every other week, rude comments made to him by principal. ... and at [the] end of [the] school [year], she asked us to leave the school."

"When my kids were younger, both were excluded as "safety risks", subject to frequent restraints, constantly sent home by 10 in the morning, denied transportation services, excluded from events and trips, subject to poorly trained, angry staff, with no understanding of autism, ABA, "behaviour management."

"I've filed two human rights complaints and taken legal action against the school board. That was a big waste of time and money. The government does not enforce provincial regulations.... In my experience, school personnel ignore PPM 140, do not file incident reports, do not know even the DEFINITION of a restraint, forget about how to apply one safely. Principals can send any student home at any time, with no mechanism for parents to protest, except to hire an expense [sic] lawyer."

IEPs

"IEPs are just a formal piece of paper with a whole bunch of goals and responsibilities nobody looks at until it is report card time, and then they realize they didn't hold up their end of the bargain. It's meaningless. You have to be equipped to actually achieve the goals and meet the needs to make it a worthwhile process."

MEANINGFUL EDUCATION

"School boards do not understand the difference between equal right to education and equitable education. My child has equal access but not teaching approaches that support the child to learn in a way that aligns with their learning needs."

"We are advocating for 'schools as a setting for government-funded services'. For the OAP, we need to have our child in school all day, every day—which is his right. He should not have to miss school to go anywhere else to receive his IBI/ABA therapy services."

"I just wish I could drop him off at school and trust that, like any other kid, he's going to learn something that he can build on and use to improve his life. Then, I would like to pick him up, do what I need to do at home to meet his needs at home and in the community. It really shouldn't be this hard."

D. HEALTH IMPACTS

Context

There is a growing consensus that families raising children with ASD face heightened levels of stress with emotional, physical and social well-being implications.[23]

What is less understood, particularly in the Canadian context, is what factors contribute to families' stress; what factors contribute to, or undermine, families' resilience and their ability to manage stress; how family stress relates to (is mitigated or worsened by) available programs and services; what impacts do extra parenting demands have on work patterns, and how do these vary by gender; and ultimately, what policy and program changes could be implemented to better support and improve the well-being of Canadian families with ASD.

Such questions are particularly relevant in Ontario's context of changing autism policies.

Work and Time

One of the major sources of stress among parents relates to the amount of time they have to sacrifice from other activities due to lack of societal supports. On average, caregivers estimated they spend 14 hours per week facilitating service provision for their children (e.g. researching, navigating, facilitating, transporting, and/or providing services) and 10 hours advocating for their children, for a total of 24 hours per week.

In order to do this, they regularly sacrifice the following activities (in descending order): couple leisure; personal leisure; time with friends or social peer groups; household duties; family leisure; amount of sleep received; time spent at work or profession; and time spent with other children/ family members.

The work implications varied by gender, with men more likely to work extra hours/jobs to pay for therapies, and women more likely to quit jobs, de-professionalize, or work part-time or from home to manage school exclusions, therapy appointments, etc. (See Figure 4.)

Figure 4: Work Implications by Gender

	Women	Men	Difference
Average Hours Worked per Week	23 hrs	39 hrs	16 hrs
% who work LESS than desired (due to time to manage ASD)	45 %	21 %	24 % points
% who work MORE than desired (due to added costs of ASD)	19 %	31%	12 % points

Themes Cited in Open-Ended Responses

- I want to work less to take better care of my child, but I have to work more to pay for their therapies
- I have to work extra jobs in order to pay for therapy costs- resulting stress / well-being implications
- I have to use emergency leave / sick days to take my child to appointments
- I had to leave job and/or work reduced hours and/or work a different, lower paying, more flexible job, in order to take children to therapy appointments, be available when school sends child home, etc.
- Schools unable to handle children, so parents had to leave jobs

Physical Health Impacts

On average, parents/caregivers stated that they felt their physical health was "somewhat to very" affected by managing the stressors associated with autism.

Physical Health Correlations

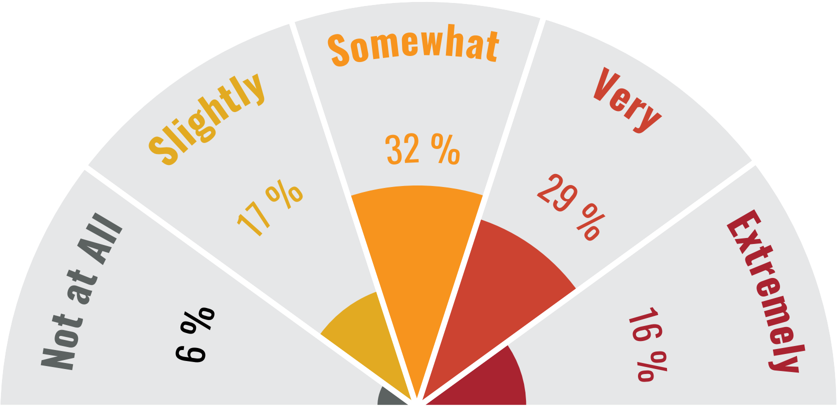
Caregiver physical health ranking was worse when a child had any of the following issues or impairments: speech, intellectual disability, gastrointestinal issues, seizures, sleep disturbances, phobias, food intake, depression, aggression, self-harm, pica, elopement, physical disability, or mental health issues.

Physical health was also associated with caregivers' relationship status; gender; minority group; level of education; income; added mental health issues; added physical health issues; having a partner; and level of education of partner.

Themes Cited in Open-Ended Responses

- High levels of "unimaginable" stress
- Poor health because I can't take care of myself; eat to deal with depression; have no time to cook, eat well, sleep or exercise
- Injuries from child
- Depression and feelings of blame
- Lack of time for other family members (spouses, other children); relationships suffer
- No time to socialize – must stay at home to take care of child; can't go out places

Figure 5: To what extent do you think your physical health has been affected as a result of managing the stressors of autism in your family?



- Fear over child's future weighs heavily
- Daycares/schools can't handle child so parent has to give up everything
- Family/friends/society don't understand and don't give proper support
- Financial strain – have to work long hours

Mental Health Impacts

Most caregivers indicated that their mental/emotional health was fair to poor. Few indicated it was "excellent" (1.8%) or "very good" (14.7%). The majority believed that their mental and emotional health has been very or extremely impacted as a result of the stressors they dealt with as parents/caregivers. (See Figure 6.)

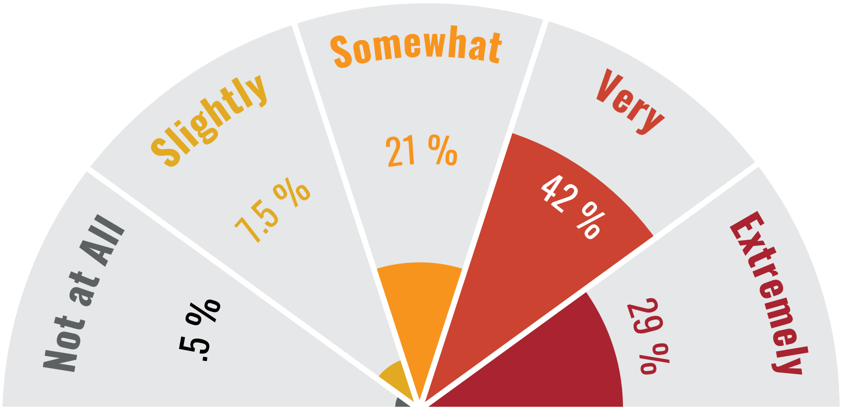
Mental Health Correlations

- There were major mental and physical health correlations with those who work more or less hours than desired to support their children.
- Service access was strongly correlated with mental health outcomes among caregivers.
- Better mental health outcomes were reported with: higher satisfaction with child's school affairs (e.g. safe and supportive education environment, as well as matching learning needs with child); receiving behavioural services (i.e. Ontario Autism Program) – and longer periods of coverage in behavioural services.
- Caregiver mental health was reported as worse when the child had any of the following issues: gastrointestinal issues, hyperactivity, anxiety, depression, self-harm, elopement, or mental health concerns.
- Mental health was associated with caregivers' gender; level of education; income; and added mental or physical health issues.

Themes Cited in Open-Ended Responses

- Added stress due to: need for planning, lack of support/understanding, no break, relationship stress, financial pressures, languishing on wait lists, time needed for advocacy, social isolation
- Depression, sleeplessness, anxiety
- Taking medication to cope
- Dealing with violent outbursts and physical suffering
- Employers don't understand – difficult navigating work or lost job
- Friction with other children in the family and/or partners
- Frustrations dealing with schools, therapists and society

Figure 6: To what extent do you think your mental and/or emotional health has been affected as a result of managing the stressors of autism in your family?



- “Everything revolves around ASD”
- Guilt over not being able to do enough to help child
- Anxiety about the future without proper supports
- Compounded challenges: single parents, families with multiple kids with ASD or special needs, families without extended support, those on waiting lists, parents who have preexisting health issues, parents with aggressive/violent children, parents with young kids

Recommendations for Improving Health Impacts on Parents and Families

1. More flexible employment options for families who have complex special needs – legislation to protect from losing employment for taking kids to therapy, etc.
2. More financial support for families to compensate for lost time that they need to take children to appointments
3. Back-up caregiving for children who are called out of school and better equipped schools to avoid calling parents
4. Therapy schedules that consider parents’ employment needs, assistance with transportation to appointments, or bring therapists to families instead
5. Increased supports and therapies in schools
6. Consider gender equity implications of caregivers, primarily women, sacrificing career aspirations
7. More funding for respite services and therapies
8. Counsellors trained in challenges of ASD freely available to families
9. Increased supports (respite, financial, etc.) especially for single parents, low income families, and others with compounded challenges
10. More programs to assist with families’ social isolation
11. Better supports in schools (including ABA), so parents have reliable care for kids and don’t have to quit jobs or reduce working hours
12. Shorten wait lists for services, including both respite and therapy so that children can benefit, and that parents can return to optimal employment hours and invest in their own retirement

RESPONDENT COMMENTS: HEALTH IMPACTS

WORK AND TIME

“Very hard for working parents! Need to work to provide funds for service but also need time off to bring child to the services that are often provided during regular work hours. Can’t do both at the same time!”

“Prior to being a parent I earned 3x minimum wage, able to work full time, had full benefits and able to invest in my retirement RRSPs. Now I have a constant worry about money and care of my disabled son. I worry about the future. There are no service provisions for before or after school care for 13 year old children without a further financial impact. The stress of the disability led to the breakdown of my marriage. Now I am a single parent, living with minimum wage, cannot work full time.... I have limited healthcare, and cannot put away for retirement. I love my son, however, the financial impact it has had, leads to a second class life in our current society.”

“I’m unable to work due to inadequate care for my special needs child.”

“My spouse is the main breadwinner of the family and has to work more hours because I am forced to work less.”

“My husband is exhausted due to the demands at home but he cannot reduce his hours since we need the money to support our family.”

“I have two children with ASD. I am not able to hold down a job as I have no one to care for my kids. My husband works fulltime and drives UBER after work to provide for our family.”

PHYSICAL HEALTH

“I worked two jobs eating very late and not getting the proper sleep. I have not been able to focus on my physical self at all.”

“Since my son’s diagnosis, I have gained over 50 pounds in stress eating weight. Because of the constrained schedule, there is no time for exercise.”

“We are exhausted having to care for our son. He is becoming more difficult to manage and we are constantly in pain from carrying and often restraining him.”

“I drive four to six hours a day to my child’s therapy centre. I have a very sedentary lifestyle due to the time I spend in the car and the fact that my child cannot venture out.”

MENTAL HEALTH

“Stress has overwhelmed our entire family.... (We—the parents)...are taking medication to help with our own anxiety and depression directly linked to lack of resources for my son.”

“I used to be extremely healthy... My emotional health has declined significantly. I have no benefits, now that I no longer work full time. Sad irony is that this is now when I need it the most. No money for therapy etc. and no benefits. No time for self care. A luxury the demands of raising these children does not allow.”

“I have never experienced this amount of stress in my life...”

“Child tried to kill me. PTSD”

V. CONCLUSION

Supporting Families is an Investment Worth Making

WHEN we began this research, Ontario autism services were in a state of flux and transition. Throughout the course of our data analysis and writing the perceptions of how best to support autism families has gained a new poignancy.

The Ontario Government is again revising its Ontario Autism Program.

Although the recommendations in this report draw on the extensive evidence from our research, the most up-to-date input from families, autistic advocates, clinicians and other stakeholders, as submitted through the Ontario Government consultations, should be at the forefront in devising the new program.

Much is at stake.

It is critical that the Province take stakeholder feedback into account and work diligently to create plans that are informed by the experience and the evidence…

Much is at stake. It is critical that the Province take into account stakeholder feedback and work diligently to create plans that are informed by the experience and the evidence that takes children and families' diverse needs into account.

We hope that our carefully considered findings may be useful to provide input and to inform the important public dialogue around these issues.

Across all services examined — diagnosis, therapies (particularly the OAP), respite, and education — wait times are too long, and/or services are insufficient to provide the comprehensive and effective supports that families need. Consequently, children's outcomes often suffer, and families do their best to fill the gap. Even though our sample was based on many who have higher than average socioeconomic status, it is quite clear that families of children with autism in Ontario, as elsewhere, face heightened levels of stress, physical, mental and emotional health concerns.

Many families are in a situation of acute crisis, having sacrificed their jobs, savings and/or homes to support their children in the absence of sufficient public programming.

In a system with insufficient public supports, families of lower socioeconomic status often have no option but to wait longer for services, likely receive fewer of them and are thereby in a two-tiered system which merely compounds social inequities.

The extensive amount of time, money and emotional energy that families across all income groups spend in advocating for and supporting their children greatly impacts their personal and professional lives. Far too often it undermines their health and well-being in the process.

This, in turn, has ripple effects in the society and economy. Affected families are less able to live productive, healthy lives, and consequently become more dependent on social and health supports.

There is a better way. Improved timely access to evidence-based services, resources and supports for both children and their families, across education, therapy, respite and other services, could mitigate many of these negative impacts and optimize outcomes. The recommendations offered at the beginning of our report provide a roadmap to achieving these goals.

Adequately investing into autism therapies and supports is expensive. Failing to do so is even more costly.

A society is only as strong as the sum of its parts. Investing wisely in effective, evidence-based autism and other disability services would benefit both children and families. It would also generate positive economic, health and social ripple effects, including savings across other social sectors.

Properly supporting these members of our provincial community is an investment worth making.

Now is the time to finally get it right.

> Many families are in a situation of acute crisis, having sacrificed their jobs, savings and/or homes to support their children in the absence of sufficient public programming.

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ENDNOTES

1 This is in accordance with the BACB (2019) guidelines, which state: “Although the Guidelines reference some quantitative treatment parameters that have been derived from research and expert opinion, they state repeatedly that all aspects of ABA interventions must be customized to the strengths, needs, preferences, and environmental circumstances of each individual client and their caregivers, and must be flexible so as to accommodate changes that occur over the course of treatment. Due to the variability and symptom presentation, no two individuals with an ASD diagnosis are the same with respect to how the disorder manifests and its impact on families....individualized treatment is a defining feature and integral component of ABA, which is one reason why it has been so successful in treating this heterogeneous disorder....Treatment may vary [across individuals] in terms of intensity and duration, the complexity and range of treatment goals, and the extent of direct treatment provided” (2019:1).

2 The full report can be found here: https://www.policyschool.ca/wp-content/uploads/2016/03/caregiver-brief.pdf.

3 “An intervention is considered to be an evidence-based practice when there is scientific evidence to support its claims. Evidence-based practices must be selected for implementation based on sound professional judgment, coupled with the careful review of available data, input from individuals and family members, and an honest evaluation of interventionists’ capacity to implement the interventions accurately.” (https://vkc.mc.vanderbilt.edu/assets/files/tipsheets/ebptreatasdtips.pdf).

4 For a succinct summary of the highlights of studies demonstrating the broad financial savings associated with appropriate investments into autism therapy, see: https://create.piktochart.com/output/35892914-invest-in-individuals-with-autism?fbclid=IwAR16-xHKmYD9lWdjBHlFW_M0AbP54nT-ATFOYRJGkYicW535mxaj_-mtQuM.

5 Applied Behaviour Analysis (ABA) “is a scientific approach for discovering environmental variables that reliably influence socially significant behavior and for developing a technology of behavior change that takes practical advantage of those discoveries” (Cooper et al., 2007, as cited in: http://www.hauglandlearningcenter.com/haugland-learning-center-applied-behavior-analysis-programs-aba.html).

6 The following articles summarize some of the evidence on the clinical effectiveness and outcomes of ABA and other evidence-based therapies: https://www.ncbi.nlm.nih.gov/m/pubmed/19437303/; https://www.researchgate.net/publication/26816222_Applied_behavior_analytic_interventions_for_children_with_autism_A_description_and_review_of_treatment_research; https://autismpdc.fpg.unc.edu/sites/autismpdc.fpg.unc.edu/files/2014-EBP-Report.pdf; https://www.nationalautismcenter.org/national-standards-project/phase-2/; http://www.ontaba.org/pdf/ONTABA%20OSETT-ASD%20REPORT%20WEB.pdf; https://www.ncbi.nlm.nih.gov/books/NBK79228/; https://www.ncbi.nlm.nih.gov/books/NBK81385/.

7 See: https://www.huffingtonpost.ca/2019/03/07/ontario-should-look-to-missouri-virginia-for-autism-funding-models-that-work-psychologists_a_23687292/?ncid=fcbklnkcahpmg00000008 for further details.

8 See: https://nationalpost.com/news/politics/over-16000-children-on-ontario-wait-lists-for-autism-services-some-families-are-waiting-years-for-help.

9 See BACB (2014) for more specific practice guidelines.

10 See BACB (2014, 2019).

11 See: http://www.health.gov.on.ca/en/pro/programs/hhrsd/about/regulated_professions.aspx.

12 Various studies have demonstrated that high-intensity treatment produces the largest improvements (Eldevik, Hastings, Hughes, Jahr, Eikeseth, & Cross, 2009, 2010; Klintwall, Eldevik, & Eikeseth, 2015; Virués-Ortega, Rodríguez, & Yu, 2013). At least 36 hours of direct ABA treatment per week for at least two years is associated with clinically significant, reliable changes in cognitive and adaptive skills (Eldevik et al., 2010).

13 Team meetings, consultations, planning, supervision, essential materials, and assessments should all be included in the costs covered by the government.

14 See note 1, above.

15 It is essential that money sent to school boards is specifically earmarked for these services, so they do not become lost among other expenses in overall budgets.

16 For more ideas on integrating evidence-based practices into schools, see: https://www.nationalautismcenter.org/download/5155/.

17 See, for example, http://www.summit-school.com/, https://www.oakbridge.ca/, https://www.therecord.com/news-story/9177262-spectrum-academy-expands-to-provide-specialized-classroom-for-autistic-students/.

18 As Ganz et al. (2017) conclude: “Although the type of display and level of technology is an important factor in AAC interventions, it is likely that the particular strategies used to implement the communication mode are more critical.”

19 See: http://www.autismgrantprogram.on.ca/faq/.

20 See: https://www.casda.ca/wp-content/uploads/2019/03/Blueprint-for-a-National-ASD-Strategy-1.pdf.

21 See: https://www.canada.ca/en/health-canada/corporate/transparency/health-agreements/shared-health-priorities.html.

22 See the 2007 Senate Report, Pay Now or Pay Later, pages 13-14 for further discussion of the need for innovative funding strategies. One suggestion included is based on the proposed Catastrophic Drug Transfer. “The Romanow Commission recommended the establishment of a federal Catastrophic Drug Transfer, which would reimburse 50% of the costs of provincial and territorial drug insurance plans, above a threshold of $1,500 per person per year....The commission also suggested that the Catastrophic Drug Transfer would serve as a precursor to the eventual incorporation of out-of-hospital prescription drugs into the Canada Health Act” (https://lop.parl.ca/sites/PublicWebsite/default/en_CA/ResearchPublications/201610E).

23 Researchers have uncovered a wide array of family impacts associated with raising a child with autism, including numerous psychological effects, including depression (Hartley et al., 2016; Walsh et al., 2013) and anxiety (Hodge et al., 2011); social effects, such as problems with interpersonal relationships and marital distress (Higgins et al., 2005; Petalas et al., 2012); and physical health effects (Allik et al., 2006; Giallo et al., 2011).

In addition to these concerns, studies have reported that parents of children with ASD are more likely to report difficulties associated with access to services, insurance coverage, and care coordination, resulting in adverse family impacts when compared to families of children with other developmental disabilities and/or other mental health conditions (Vohra, et al., 2014). Service professionals who work with children with ASD recognize the importance of the family in the support equation, yet services often ignore family issues and ways in which these families need to be supported to contribute in a meaningful way (Hodgetts, et al., 2015). This discrepancy is even more pronounced when considering immigrant, minority and under-served populations, as their differential needs have been largely ignored despite reports of extreme difficulty while attempting to navigate the service system on the road to adapting to an ASD diagnosis (Weiss et al., 2016; Willis, 2016).