To use this data, please cite: Janet McLaughlin and Margaret Schneider, Autism Services in Ontario: Impacts on Family and Child Well-Being, Research Summary, Laurier Autism Research Consortium, June 2019.

The authors gratefully acknowledge the hundreds of parents and caregivers who took time out of their busy lives to complete the survey and/or the interviews

grants through Wilfrid Laurier University.

Autism Ontario provided supplemental support, including knowledge translation funds to allow for the design costs of the report.

Research Assistants and Laurier students Abigail Belleth, Allison Chen, Nicholas Denomey, Rachel Dobbs, Carlos Felipe Centelles García, Alycia Guile, Bridget Livingstone, and Melissa Norley aided with survey building, interviews, transcription, literature review and data analysis. Many groups and individuals assisted us by reviewing early drafts of the survey and distributing it.

We wish to especially thank Autism Ontario, Ontario Autism Coalition, and the KidsAbility Autism Program for distributing the survey.

A number of community stakeholders and clinical experts also contributed their time, expertise and insight to strengthen the development of this project and/

Spoelstra.

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List of Acronyms

– Augmentative and Alternative Communication

– Applied Behaviour Analysis

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

immediate use of participants, policymakers, and

common themes in open-ended responses,

participants and highlights key recommendations
from participants and the researchers.

recommendations to holistically address the needs

an overview of methods and the demographic

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

implications of paying for services for families.
Next, the report highlights areas of challenge

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

men and women.

The key conclusion from examining these various
aspects of caregivers' lives is that autism families
in Ontario, as elsewhere, are struggling to

and other dem05Dhendati1(wh50005D001bo000030050005D0058id othe.36i0030062006800620063005400 5C00100

There may be concerns that eliminating caps will mean the system is unsustainable. This is understandable if we believe that every child was

and/or if intensive therapy programs were never-ending. Importantly, however, most children with

short period of time. It is fair to say, however,

therapeutic interventions including targeted programs, such as social skills or life skills groups, OT, SLP support, or focused ABA, which are

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

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

programs allowed (e.g. many families indicated this former program with two hours a week in

children's goals), this breakdown still provides insight into the likely share of Ontario children

Based on these data, less than one in six Ontario

intensive intervention.

Participants in our research also indicated that the average weekly hours of ABA received (at the maximum level provided, as these hours

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

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 in other environments.

To this end, a child's clinical needs and responsiveness to therapy are two factors that

[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

their needs change but, generally, will diminish over time as skills and core competencies are

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

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.

In short,

. However, until

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

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.

is to invest wisely

respite, therapies

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.

we believe one of the factors

for respite and education. If these other programs received

would likely decline, as children could be more readily and safely integrated across other domains once their therapeutic goals are

responsive to children's diverse and ever-changing needs.

with autism in an evidence and needs-based system within the available budget is

wrap-around meaningful supports in the health and education systems; providing children with the exact amount of therapy

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.

RECOMMENDATIONS

RECOMMENDATIONS

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

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

funding could be provided to government-run treatment centres or grants

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.

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

RECOMMENDATIONS

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

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

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

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

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

The Ministry of Training, Colleges and Universities should expand doctoral level ABA programs where appropriate throughout the province.

Considering the enormous costs that many families incur out-of-pocket for

A survey was developed by Drs. McLaughlin and

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.

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

  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

  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 service4005300030051005B005E0052005A000

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)
-

  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)
-
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- 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

  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
-

  prefer DSO for convenience
-
    - 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
    -

      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

towards issues with the previous system in place.

Nonetheless, we can extrapolate some insight

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

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

Indeed, those receiving services in the OAP were

system and one which allowed for the funding of intensive therapy when needed. Further, while private ABA services are enjoyed by many families,

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

The choice for this service has been removed as an option with the new program.

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

   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

   rural/remote, Francophone, refugee, new immigrant, Indigenous and other marginalized populations.
4. Improve therapies and supports in schools and better coordinate services between schools

   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
6. Expand capacity of ABA training programs and other needed therapies to reduce wait times for service. Work with providers to ensure

   only further reduce capacity.

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

“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.”

“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.”

“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.”

“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.”

Context

Given their varied diagnoses and co-morbidities, families normally access a range of health and support services. While some of these are provided

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

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 that long to get an appointment with
  -

- Improve and expand respite options (71%)
- Provide more education to families on savings

- Education campaigns for other Ontarians to

“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.”

“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.”

“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.”

“[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 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.”

“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.”

[redacted]

text of changing autism policies.

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

  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

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.

- 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

-
- 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. who have complex special needs – legislation to protect from losing employment for taking kids to therapy, etc.
2. compensate for lost time that they need to take children to appointments
3. Back-up caregiving for children who are called

   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. aspirations
7. More funding for respite services and therapies
8. Counsellors trained in challenges of ASD freely available to families
9. 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
12. Shorten wait lists for services, including both respite and therapy so that children

    optimal employment hours and invest in their own retirement

"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 benefts 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 fnancial 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 fnancial 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."

"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

we began this research, Ontario autism

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 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.

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/

gap. Even though our sample was based on many who have higher than average socioeconomic

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,

to support their children in the absence of

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

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.

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

roadmap to achieving these goals.

supports is expensive. Failing to do so is even more costly.

A society is only as strong as the sum of its parts.

both children and families. It would also generate

including savings across other social sectors.

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

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1 This is in accordance with the BACB (2019) guidelines, which state: “Although the Guidelines reference some

derived from research and expert opinion, they state repeatedly that all aspects of ABA interventions must

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

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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.

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