



CASDA Q&A Document

June 9, 2020

1. Why is CASDA advocating for a National Autism Strategy over a National Disability Strategy?

There is much more to do in terms of creating a more accessible and inclusive Canada for people with all kinds of disabilities, including Autistic Canadians.

In June of 2019, the federal government introduced *An Act to Ensure a Barrier Free Canada* (the Accessible Canada Act), in order to enhance the “*full and equal participation of all persons, especially persons with disabilities, in society. This is to be realized, within the purview of matters coming within the legislative authority of parliament, of a Canada without barriers, particularly by the identification, removal and prevention of barriers.*”

While we recognize and appreciate that there is significant work ahead to create a more inclusive and accessible Canada to support disabled Canadians, CASDA’s position is that the vast and diverse issues pertaining to Autism require a unique and targeted approach - one which would be lost within a larger cross-disability strategy.

The policy challenges of a comprehensive disability strategy would be exceptionally difficult to action for a number of reasons. For example, what is considered a disability? Would all chronic conditions be included?

There is a risk that tackling these questions would result in an approach that would try to appease the majority of people, without really advancing the needs of any one disability community.

CASDA’s support of a National Autism Strategy comes with the belief that such a Strategy would help to inform and develop approaches to address other disabled communities. In many other instances, initiatives that emerged to support Autistic Canadians have now been translated to support other disability groups.

2. Do you agree that Autistic advocates need to be included broadly and in significant numbers in a national autism process, as agents of change?

Yes. There can be no true National Autism Strategy without the direct support and involvement of a significant representation of the Autistic community in Canada. Effort must be taken to find the most effective way to make sure that the voices and perspectives of autistics with varying levels of support needs are taken into consideration. “Nothing about us without us” must include the full range of autistics or their surrogates.



3. If a National Autism Strategy proceeds with development and plans to execute, how will Autistic Canadians be involved?

The governance model for a National Autism Strategy has not yet been determined, but CASDA will continue to strongly advocate that the Strategy will need to be developed and executed with direct input from a significant and diverse representation of Autistic Canadians.

4. How is CASDA currently engaging first voice and the Autistic community?

We have benefited greatly from the input of Autistic Canadians since establishing CASDA in 2007. That said, we recognize we need to do more in order to increase representation of Autistic Canadians both within CASDA general membership and to add more first-voice experience to CASDA's leadership team.

We sought input from Autistic Canadians during the National Needs Assessment Survey which took place in 2014, and enacted a working group made up of seven Autistic self-advocates to aid in the creation of a business plan for the Canadian Autism Partnership Project in 2015/2016 - a business plan that was developed with input from over 5,000 Canadians through town halls, in-person meetings and another national survey.

While we currently have first-voice representation on our Board of Directors, we are looking to expand our outreach to the Autistic community in order to create an advisory group of self-advocates to provide feedback on a variety of initiatives. We are in the early stages of figuring out how this would best work.

To date, we have worked with provincial and territorial Autism-focused organizations in order to obtain input from Canadians with direct lived experience with a focus on equity, diversity and inclusion. In order to make sure that we have a diverse range of perspectives from Autistic youth and adults across the nation, we need to be more creative, and diligent, in attracting this input, focusing on ways to reach more communities such as Indigenous, Rural, Black, LGBTQ2S+ and New Canadians.



5. There are growing concerns amongst self-advocate led Autistic organizations that some of the therapies being advocated for are negatively impacting Canadians on the Autism Spectrum (i.e. Applied Behavioural Analysis (ABA)). What independent studies are being conducted to make sure that the services being advocated for by CASDA and other Autism organizations are actually beneficial to the Autistic individual themselves, not just the families, educators etc.

It is important to clarify that CASDA is not a research organization, but rather an alliance of member organizations and individuals. Some of these organizations subscribe to the medical model of disability, some subscribe to the social model of disability, and some others identify with a combination of both. CASDA members are expected to rely on evidence-based practices and peer reviewed research. The role of CASDA, as an alliance of 109 members, is to advance the need for a National Autism Strategy. The role of government is to oversee that Strategy and through that work, determine the type of services included.

CASDA does not advocate for any specific therapeutic approach, focusing instead on the broader need for equal access to consistent scientific, evidence-based support and resources no matter where you live in Canada.

6. With attention needed on the current pandemic, the prospect of a second round in the coming fall, and of course the pressures to protect/restart/rebuild our economy, how will we be able to keep the issues of Autistic Canadians and their families and the need for a National Autism Strategy on the radar in Ottawa among policy makers.

We understand and fully appreciate the need for a hyper-focus on addressing the most pressing needs related to COVID-19. These include providing financial support for Canadian businesses and workers impacted by the health crisis, ensuring our health care and long term care facilities have the human resources and protective equipment necessary to do their jobs, and making sure Canadians in each province and territory are receiving access to testing and medical care as the global pandemic continues.

Thousands of the Canadians mentioned above are Autistic, and their unique needs do not go away as we navigate COVID-19,

In many ways, the pandemic has highlighted not only the large gaps in support for Autistic Canadians, but also our previous inability (or unwillingness) to accommodate individuals on the Autism spectrum. There is something to be said about how quickly workplaces, organizations and public service offerings were able to quickly move to remote workplaces, online meetings and seminars and telehealth offerings.

All to say that we will continue to advocate the need for a National Autism Strategy while taking great care to understand the challenges government is facing with managing public health during this global pandemic.

7. How will CASDA address the division between the National Autism Strategy direction and the advocacy of autistic-led organizations?

To start, we think it is important to recognize and acknowledge that a division exists, and that we need to do better at reaching out and finding ways to work together with Autistic-led organizations. There is so much potential possible with increased collaboration of experience, expertise and skill-sets, and we are committed to these efforts in the days ahead.

While the development and execution of a National Autism Strategy would be the responsibility of the federal government, CASDA will continue to advocate for significant and diverse representation of Autistic voices to be involved in the process.

8. Do you feel the National Needs survey sufficiently sought and captured the voices of the autistic community? Less than four per cent of survey participants were autistic people themselves. The survey sample was primarily white, educated, living in urban & suburban areas. We already know that there are inequities in services generally & specifically access to recognition/assessment in services for low-income people, Black, Indigenous, and other radicalized people. How will you make sure the NAS reflects the diversity of the Autistic community – particularly the high rates of LGBTQ2S+ folks?

CASDA recognizes that the National Needs survey, as well as the National Autism Surveillance System conducted by the Public Health Agency of Canada, are in no way representative of the autistic community. Both the 2014 survey and the 2018 surveillance system document were preliminary scans.

It is CASDA's goal that the National Autism Strategy lead to better measures of autism and the needs of Autistic people, their families, caregivers, and communities, and, most importantly, better surveillance and measurement in marginalized and minority groups as well as groups that experience intersectionality.

To further make sure that Autistic, minority, and marginalized voices are included, CASDA is working on a policy brief for the federal government to select an advisory committee on the development of the National Autism Strategy, modelled after the Canadian Accessibility Standards Development Organization (CASDO). CASDO requires that half of its members be people with disabilities.

To find out more about CASDO, see section 17.1 of the accessibility legislation [here](https://www.parl.ca/DocumentViewer/en/42-1/bill/C-81/third-reading):
<https://www.parl.ca/DocumentViewer/en/42-1/bill/C-81/third-reading>

9. How can we better integrate findings in Autism research into federal public policy?

How research topics are determined, then conducted, and then translated into day-to-day life is a common focus and concern amongst Autistic Canadians as well as their families and caregivers. They have a general understanding that significant research is taking place, but don't necessarily see that research is meaningfully impacting day-to-day life.

This doesn't mean that it is not happening at all. Rather, it means that there is a challenge in how this knowledge translation is occurring and what infrastructure can make it sustainable.. In the consultations CASDA has done for both the National Needs Assessment and the Canadian Autism Partnership Project, it was clear that Canadians wanted more input in what types of research they wanted the government to invest in relevant to Autism, and to better understand the process of taking that research from the lab to actually improving the lives of Autistic Canadians.

A National Autism Strategy needs to address this gap.

Questions from Autistic Community:

11. What is the National Autism Strategy going to do to recognize co-occurring conditions related to autism?

An effective National Autism Strategy absolutely must take into account the vast range of co-occurring conditions that are often associated with an Autism diagnosis. These include mental health conditions, other developmental disabilities and chronic health issues.

12. How will the male vs female diagnostic criterium be addressed?

This is a theme that has come up regularly in our consultations with Canadians. Autism presents differently in girls and women - which in many cases has led to misdiagnosis or late diagnosis. This would be an issue that we believe should be addressed by the federal government as they undergo the development and execution of a National Autism Strategy.

13. How is the NAS going to make sure that it involves the voice of autistic people when it is developing its policies?

The responsibility of overseeing the development and execution of a National Autism Strategy will be held by the federal government. CASDA will continue to strongly advocate that this



Strategy requires significant and diverse representation of Autistic Canadians in order to be truly reflective of the needs across the country.

14. How is the National Autism Strategy going to address the needs of marginalized communities?

Throughout the National Needs Assessment and Canadian Autism Partnership Project consultation processes, CASDA repeatedly heard that there were unique and very specific needs in marginalized communities across Canada - including Indigenous, Black, rural/remote and LGBTQ2S+. A National Autism Strategy must take into account these unique challenges and needs with direct input from representatives from these communities, and address them accordingly.

CASDA is committed to continuing its advocacy efforts to ensure that the priorities identified throughout CASDA's information collection processes inform the National Autism Strategy development process.

15. Are members of the CASDA Board financially compensated?

No. These are volunteer positions and there is no financial compensation provided to any members of the Board of Directors.

We do have a small number of paid positions within CASDA, which have been made possible through project funding.