

Roadmap to a National Autism Strategy

March 12, 2020



Introduction

On December 9, 2019, the federal government announced its commitment to developing and implementing a National Autism¹ Strategy (NAS), and has since tasked the Minister of Health, Minister Patty Hajdu and the Minister of Employment, Workforce Development and Disability Inclusion, Minister Carla Qualtrough with leading this vital work.

The Canadian Autism Spectrum Disorders Alliance (CASDA) is encouraged and grateful for this commitment.

CASDA formed after the Senate's seminal 2007 report, *Pay Now or Pay Later: Autism Families in Crisis*, to offer a unified voice for the Autism community, and has been calling for a NAS since that time. In 2018, CASDA developed the *Blueprint for a National Autism Spectrum Disorder Strategy* (the Blueprint) to lay the groundwork for what a NAS could look like for Canada. But the Blueprint is the beginning and not the end of the discussion. It gives suggestions for pillars of focus and some specific actions that government can take, but these are not the whole story of what is required.

To meet the vision of a strategy that delivers real results for Autistic Canadians, we need to continue to identify additional and transformational actions that go beyond the recommendations in the Blueprint. CASDA is ready to work with government and mobilize experts from across the country to develop these solutions.

CASDA is asking the government to develop a NAS that is ambitious and far-reaching in its scope and impact. The NAS needs to reach across government and will require careful coordination and buy-in between departments. Together we can develop a more comprehensive suite of actions to improve the quality of life of people on the Autism Spectrum in Canada, and their families.

¹ A note on language: Autistic people, Canadians/individuals living with Autism/ASD/an ASD, Canadians/ individuals on the Spectrum/Autism Spectrum –in consultations across the country there was recognition that the use of language in the Autism community continues to be an ongoing discussion. As our understanding and acceptance of Autism advances, so does the use and understanding of phrases to describe or reference the condition. In the spirit of being respectful of language preferences, these terms have been used interchangeably throughout the document.

This briefing document provides a roadmap to developing and implementing the NAS.² This includes some recommended early wins where government can demonstrate progress at the outset as well as processes for collaboration, timelines for working together and proposed sequencing of the actions outlined in the Blueprint.

² This briefing document was produced by CASDA with additional support from Autism Speaks Canada (a CASDA member organization).

Who is CASDA?

Canadian Autism Spectrum Disorder Alliance (CASDA) is an alliance of 200 Autism organizations, service organizations, researchers, professionals and Autistic Canadians. We coordinate national conversations about Autism. We are a diverse and inclusive alliance making a difference.

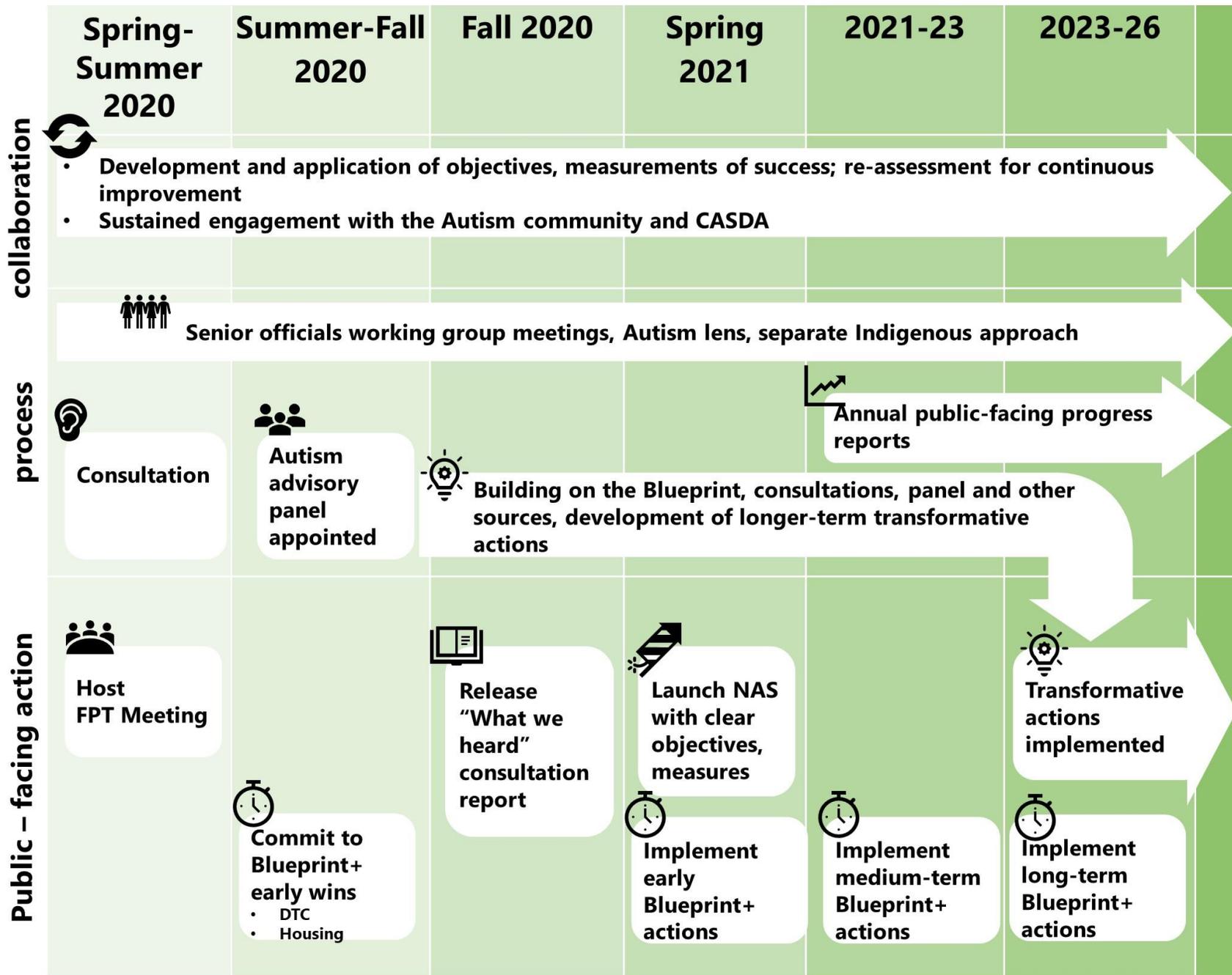
CASDA was formed July 2007 shortly after the Senate Committee Report “Pay Now or Pay Later: Autism Families in Crisis”. During this time the federal government sent a clear message to the Autism community: Work together with a unified voice. The Autism community responded by forming CASDA.

What is the Blueprint?

CASDA developed the Blueprint in order to share a collective vision of a National Autism Strategy. The Blueprint has gained support from the Autism community from coast-to-coast-to-coast. This includes 200 CASDA members, and endorsements from across political party lines. The actions it recommends are only some of what will be necessary for the NAS to meet the vision of the Blueprint and truly improve the lives of people with ASD and their families.

For more detail on the Blueprint, see Appendix A.

A roadmap to develop and implement the NAS



This graphic refers to the **Blueprint+** because actions taken at these stages should include, but not be limited to, those outlined in the Blueprint

A roadmap to develop and implement the NAS

Building on progress

The work of developing and implementing the National Autism Strategy does not start from scratch. Since the Senate's 2007 report *Pay Now or Pay Later: Autism Families in Crisis*, CASDA and the Autism community have not only been calling for an Autism strategy, but have also been working to develop priorities and best practices to inform such a strategy. This work has included key reports and milestones:

2007 - The Senate publishes its report *Pay Now or Pay Later: Autism Families in Crisis* recommends the development of a National Autism Strategy

2014 - CASDA completes its National Autism Needs Assessment Survey, highlighting most pressing areas for people with ASD and their families

2014 - McKinsey and Co publish the *See Things My Way* report which proposes a continuum of care across a lifespan for people with ASD

2015-2016 - The Canadian Autism Partnership Project, with funding from PHAC, holds extensive consultations and identifies top priorities for people with ASD and their families

2018 - CASDA develops the Blueprint for a National Autism Strategy that focuses on federal leadership and actions to deliver progress on key priorities

This work, some of which was funded and supported by the federal government, means that the development and implementation of the NAS can build on a solid foundation of research. With this work in hand, the NAS can be developed and implemented on an expedited basis, so that Autistic Canadians and their communities can start to see changes in their lives as soon as possible.

The end point: an impactful, measurable, sustainable NAS

CASDA is eager to work with the government to develop and implement a robust NAS. This NAS should have a clear and meaningful vision considering the whole lifespan and spectrum of

needs of Canadians on the Autism Spectrum, with special considerations for vulnerable Autistic Canadians.

The government's commitment to a NAS has given the Autism community hope, but the lack of detail to date also raised some concern that the strategy might not be robust, or could be just an enhancement of existing programs and approaches. CASDA and the whole Autism community are ready to work with government to find innovative, transformational approaches to ensure the NAS is more than a collection of new or slightly enhanced program funding.

A cross-government approach

The NAS should be developed to include a full suite of concrete actions that will directly impact the lives of people with Autism and their families. It should also reach across other government activities and strategies to ensure that Autistic Canadians and their families are taken into consideration even when they are not the primary population being served by a program or policy.

To achieve this, the Blueprint proposes a strong cross-government approach to Autism. CASDA is very encouraged to see that a lead Minister has been assigned to direct the NAS, and that the NAS is embedded in mandate letters. In order to maintain cross-government momentum, the Blueprint calls for a **cross-government senior civil servant table meeting at regular intervals to coordinate the development and implementation of the strategy.**

In addition to this, to ensure Autistic Canadians and their needs are considered in all government work, and not just in the NAS, CASDA asks the government to develop an Autism lens to apply to policy proposals. To support this work, including implementing the Autism lens, and to provide a resource to government's policy and program development within the NAS and outside it, CASDA also asks the government to **develop an Autism Advisory Panel made of up self-advocates, family members and experts in the field.**

Setting objectives and taking measurements of success

The NAS cannot succeed if it doesn't measure its progress. In order to do this, CASDA asks the government to collaborate with CASDA and the Autism community to set a series of objectives and success measures, focusing on clear outcomes, to track the progress of the NAS. This will not only maintain momentum and accountability; it will also allow government to take an evidence-informed approach to re-assessing and revitalizing the NAS over time. The NAS

should be sustainable, efficient and provide real outcomes for Autistic Canadians and their families. To do this, we ask the government to **develop a body of evidence on what is working, to aim for continuous improvement, and to have annual, public-facing report backs on progress.**

Timeline

What follows is a proposed timeline for working together with the Autism community to develop and implement a robust NAS.

○ Spring-Summer 2020

Process: Meaningful consultation that builds on what we already know

In order to develop and implement the NAS, the government will need to hear directly from people with Autism and their communities. Consultation is vitally important, but the government should not proceed as if it were starting from zero. We urge the government to be targeted and efficient in its approach. Many of the foundational questions have been posed and answered in previous processes, including the Canadian Autism Partnership Project process and the 2014 CASDA National Needs Assessment, and Autistic Canadians are eager to see government action.

CASDA is eager to explore ways in which it can be helpful to the government in convening productive conversations with self-advocates, their families, and other experts. Given the limits of COVID-19 related to in-person gatherings, CASDA can work with government to identify consultation opportunities that allow for virtual gatherings but remain inclusive.

Process: Strike a cross-government senior civil servant working group to ensure coordination and maintain momentum and develop an Autism lens to apply to work outside the NAS

As described above, CASDA asks the government to assign senior civil servants to a working group that will meet regularly to support the lead Minister and to ensure the NAS is progressing quickly and thoughtfully.

CASDA also asks government to **develop and apply an Autism lens. This means that Canadians on the Autism Spectrum and their distinct needs are incorporated in a**

systematic way into government policy development to ensure strategies, policies, and investments are inclusive. This is imperative because the government's impact on Autistic Canadians goes far beyond programs and policies that specifically target them. Any government program or policy can have a different impact on an Autistic Canadian relative to another Canadian. Autism is a truly intersectional issue that requires a subtle, cross-government approach.

This work of developing the lens can should start as soon as possible, and can be presented to the Autism advisory panel (see below) who can refine the lens as one of their first tasks.

Process: Begin work with Indigenous partners on a separate, distinctions-based approach

It is vital for the government to work with Indigenous partners to ensure that Indigenous-specific strategies are in place to provide the most appropriate responses to Indigenous people with Autism. Using the National Housing Strategy as a model, government should co-develop separate, distinctions-based approaches for Indigenous Autistic Canadians. In addition to this, care should be taken to ensure that all Autism programs, and not just those designed specifically for Indigenous people, are culturally safe and appropriate for Indigenous people, and for vulnerable populations.

Action: Host an initial FPT meeting to learn from and support PTs

While the community recognizes the distinction between federal and provincial or territorial jurisdiction in this space, Autistic Canadians and their families expect their leaders to work together to have coordinated and collaborative responses so that all Canadians can access the support they need regardless of where in the country they live.

CASDA asks the government to open a dialogue about Autism between itself and the provinces and territories through a Ministerial FPT meeting. The goals of this meeting could include sharing best practices and similar challenges, and to set an agenda for continuing meetings and collective work going forward.

Process: Appoint an Autism Advisory Panel to support and collaborate with government on design and implementation of the NAS

CASDA asks the government to convene an Autism Advisory Panel with diverse representation with a mandate to:

- Advise on the development of the strategy
- Assist in developing and implementing the Autism lens that can be used to ensure policies and programs are responsive to the needs and circumstances of Canadians with Autism.
- Play an ongoing role after the strategy is launched to identify opportunities and areas in need of improvement.

Process: Start developing longer-term transformational actions that extend beyond the suggestions in the Blueprint

CASDA's Blueprint for a National Autism Strategy outlines some key actions that government can take to improve the lives of Autistic Canadians. But these are not enough on their own. In order for the NAS to fulfill its potential to radically change the quality of life for people with Autism and their families, the government must work with the Autism community to identify areas for truly transformational action.

Government should begin developing the transformational actions as early as possible in the policy development and implementation process.

Action: Announce early wins

CASDA has developed a slate of suggested "early wins" to help the government show clear leadership and commitment right away. These draw from the Blueprint, and would help people with Autism and their families immediately. Although the details of implementation will take some time to finalize, government could show progress by announcing its commitment to these early wins right away.

These early wins are:

Committing to reforming the Disability Tax Credit.

Reform to the Disability Tax Credit can reduce the high rate of rejection for people with Autism and to make it refundable. Because the DTC is a "gateway" assessment for other disability programs, it could deliver immediate financial relief for Autistic Canadians and their families. This is especially important to ensure that families of

children with Autism benefit from the planned doubling of the Child Disability Benefit. As a tax initiative, this would be appropriate for the government to announce in the fall 2020 Fall Economic Update.

Prioritizing research, innovation, and investment in housing options that provide independence and support for people with Autism.

The Canada Mortgage and Housing Corporation (CMHC) does annual calls for proposals for its research and innovation initiatives. CMHC could make this an early win by identifying initiatives focused on housing options for Autistic Canadians as a priority for the call for the 2021 fiscal year and by working with CASDA to do outreach to promote proposals from the service and research community. In some cases, this may need to focus on calls launched in 2021 for activities that take place in 2022 (e.g. the call for CMHC Solutions Lab proposals for the next year closes on March 20, 2020).

○ Fall 2020

Action: Release “What we Heard” consultation report

In order to show progress and report-back to the Autism community, government can release a “What we Heard” consultation report. This can include early signals about the direction government is pursuing in developing and planning to implement the NAS, so that the Autism community can continue to collaborate and partner with government to course-correct, if necessary.

○ Spring 2021

Action: Launch the NAS, including clear objectives, success measures and timelines for implementation as well as implementation of “first steps” from the Blueprint

CASDA asks government to aim to launch the NAS in Spring 2021. Although this is an ambitious timeline, it is achievable, especially in light of the strong foundation that comes from earlier investments like the Canadian Autism Partnership Project, CASDA’s National Autism Needs Assessment Survey and recommendations in the Blueprint and *Pay Now or Pay Later*.

The launch of the strategy should include clear objectives and measurements of success, as well as a timeline for public-facing reporting on progress.

The work of implementing, and even continuing to develop and redevelop the NAS will not stop when the strategy is launched. As described above, there should be regular reporting, monitoring, assessment and corresponding repositioning of the strategy to ensure results and sustainability, and medium-and longer-term actions should continue to be implemented and improved over time.

○ 2021-2023

Process: Government publishes its first progress report to track success and engage with Autism community

As a part of designing objectives for the NAS and measurements of success, CASDA asks government to set timelines for publishing public-facing reports on progress. This could begin with a one-year report in spring 2022.

Action: Medium-term actions, including those outlined in the Blueprint, are implemented

In the months following the launch of the strategy, government will be ready to implement actions recommended in the Blueprint that CASDA is proposing as “medium-term” actions. For full details see “Proposed sequencing of Blueprint Actions” below.

○ 2023 - 2026

Process: Government publishes progress reports on an annual basis to track success and show continuous improvement

In order to help build the body of evidence for continuous improvement, CASDA asks for public-facing progress reports to be made regularly.

Action: Government implements more transformational changes, developed in collaboration with Autism community to push towards NAS objectives

Having started the collaborative process of developing a slate of transformative actions in 2020, more transformative policy and investments should be ready to begin implementation by 2023.

Action: Longer-term actions from the Blueprint are implemented

As the NAS becomes mature, government will be ready to implement actions recommended in the Blueprint that CASDA is proposing as “longer-term” actions. For full details see “Proposed sequencing of Blueprint Actions” below.

○ Ongoing

The NAS should not be simply a three or five-year commitment. It should be a transformational effort that will continue to be refined to improve the lives of people with Autism and their communities well into the future. With this approach Canada becomes a world leader in providing full and equitable access to Autistic Canadians across their lifespans.

Proposed sequencing of Blueprint Actions

A staged approach to policy development

CASDA's Blueprint for a National Autism Strategy lays out 22 actions that should form a part of the NAS. Some of these actions can be implemented relatively swiftly. Others will take longer-term development before they can be in place. What follows is a proposed sequencing of the 22 actions described in the Blueprint.

It is essential to understand that these actions should form a part of a robust NAS, but that they must be supplemented with broader, more transformational actions, and with specific targeted actions identified through consultation and collaboration with the Autism community.

Proposed sequencing of Blueprint Actions

	First-steps	Medium-term	Longer-term
Strategy and leadership	<ul style="list-style-type: none"> • Launch focused consultations to reach a broad range of Canadians • Begin processes for distinctions based Indigenous Autism Strategies • Convene an FPT ministerial meeting • Announce early win federal leadership commitments 	<ul style="list-style-type: none"> • FPT governments create a platform for collaboration and coordination • Launch the National Autism Strategy • Engage the Autism community on <i>Accessible Canada Act</i> standards 	<ul style="list-style-type: none"> • Facilitate better cooperation among provinces and among researchers • Ensure regular reporting and renewal of the National Autism Strategy with additional initiatives to respond to the needs of Autistic Canadians.
Affordability and access	<ul style="list-style-type: none"> • Reform the Disability Tax Credit • Ensure consistency for ASD costs for the medical expense tax credit • Fund the development of more Autism research that will be of assistance to professionals via CIHR 	<ul style="list-style-type: none"> • Enhance the Child Care Expense Deduction 	<ul style="list-style-type: none"> • Build leading Autism support into federal health systems (e.g. First Nations, military families) • Develop CIHR training for professionals to learn about Autism • Explore a user-centred model like Australia’s National Disability Insurance Scheme
Information	<ul style="list-style-type: none"> • Launch an awareness campaign/public education campaign to promote better understanding and inclusion of Autistic Canadians 	<ul style="list-style-type: none"> • Build strategies to engage institutions and employers to promote best practices for inclusion 	<ul style="list-style-type: none"> • Build a learning network for practitioners and policymakers to build evidence and consensus on promising practices and policy reform

Employment	<ul style="list-style-type: none"> • Invest in Labour Market Information about people with Autism through LMIC. • Support the creation of inclusive workplaces through initiatives like Ready, Willing and Able 	<ul style="list-style-type: none"> • Ensure federal training programs respond to the needs of people with Autism (e.g. youth employment and skills strategy, Labour Market Transfer Agreements) • Re-invest in pre-employment programs for people with ASD 	<ul style="list-style-type: none"> • Break down barriers in benefit design (e.g. claw back rates from income support) in collaboration with provinces and territories • Identify barriers to workplace inclusion and develop program and, legislative policy responses
Housing	<ul style="list-style-type: none"> • Prioritize research, innovation and investment in Autism housing options in NHS programs 	<ul style="list-style-type: none"> • Next phase of NHS programming includes investment streams and programs responsive to ASD 	<ul style="list-style-type: none"> • Invest in the creation of more housing options suitable to need of adults with Autism
Research	<ul style="list-style-type: none"> • Engage PT governments to renew the National Autism Surveillance System 	<ul style="list-style-type: none"> • Map research gaps with provinces and Autism community to inform research priorities 	<ul style="list-style-type: none"> • Invest in world-leading research, including through CIHR, which is co-designed with people with Autism and takes a health equity perspective • Complete and expand the National Autism surveillance system

What is Autism/Autism Spectrum Disorder?

Autism/ Autism Spectrum Disorder is a lifelong neurodevelopmental condition with a range of characteristics. There are many degrees of autism, making each individual unique; however, all people living with Autism can benefit from the appropriate resources and supports.

Autistic individuals often experience challenges with communication and social interactions and can display restrictive and repetitive behaviour.

An Autism diagnosis is often associated with co-occurring sensory, physical, and mental health conditions.

As an example, children with Autism are four times as likely to suffer gastrointestinal problems and more than twice as likely to have a psychiatric diagnosis than the general population.

Appendix A: Summary of Blueprint for a National Autism Spectrum Disorder Strategy

Vision:

All Canadians with ASD and their families have full and equitable access to the resources they need across a lifespan where and when they need them.

Deep, broad consultation with the ASD community on design and implementation of a National ASD Strategy

Principles:

Person centred, reflecting needs over a spectrum and lifespan

Inclusive of pan-Canadian stakeholders

Co-designed with first-person perspectives: *nothing about us without us*

Include a separate co-designed Indigenous approach

Culturally responsive and appropriate, especially for vulnerable Canadians

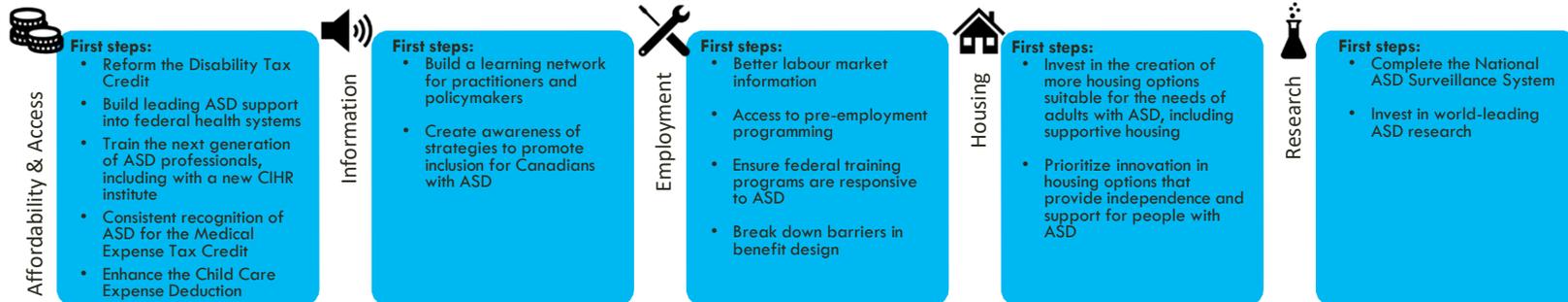
Reflective of different regional needs, especially northern, rural and remote communities

AREA 1: Federal leadership

Federal leadership facilitates pan-Canadian coordinated impact through knowledge exchange and dissemination.

Assemble a multi-ministry federal, provincial and territorial meeting, and commit to a platform to learn, collect, disseminate and gather standards and consensus for a positive impact on the Canadian ASD community.

AREA 2: Immediate Federal Action



AREA 3: Cross Government Approach to ASD

A cross-government approach ensures federal action is coordinated and integrated across all policies that affect people with ASD.

Assigning a lead minister, assembling cross-government tables, and mandating all relevant ministers to collaborate.