

Blueprint for a National Autism Spectrum Disorder Strategy

How the federal government can lead

A Policy Brief from the Canadian ASD Alliance

March 2019



CASDA-ACTSA

Executive summary

Autism spectrum disorder (ASD) is the most common and fastest-growing neurodevelopmental disorder in Canada, affecting 1 in 66 Canadians aged 5-17 and an estimated 500,000 people nationwide and their families.

Without appropriate supports that fit their needs, people with ASD and their families see drastically worse health, education, employment and quality of life outcomes. These effects ripple throughout their communities. We need to do better.

ASD is not just a provincial responsibility or a federal responsibility. It is a Canadian responsibility. That's why the Canadian ASD Alliance is calling for federal leadership on a National ASD Strategy.

Our vision: to make sure 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.

This Policy Brief provides a blueprint for how to move forward with federal leadership to improve the lives of Autistic people and their families. The blueprint has three main components:

1. **Federal leadership** to facilitate cooperation and coordination across the country.
2. **Immediate federal action** in areas of direct federal responsibility on:
 - a. **Affordability and access**
 - b. **Information**
 - c. **Employment**
 - d. **Housing; and**
 - e. **Research**
3. **A cross-government approach to ASD** to ensure a consistent response from all parts of government that touch the lives of people on the spectrum.

The time to act is now. In 2019, we can begin a National ASD Strategy that finally answers the needs of Canadians with ASD, their families, and their communities.

It's time for a National ASD Strategy

Autism Spectrum Disorder (ASD) is the most common and fastest-growing neurodevelopmental disorder in Canada. ASD affects the well-being of Canadians and their families in a variety of ways throughout their lifespan. An estimated 1 in 66 Canadians aged 5-17 have been diagnosed with ASD, equivalent to approximately 500,000 Canadians of all ages.ⁱ An ASD diagnosis is 2.5 times more common than it was less than 20 years ago.ⁱⁱ This is in part because we are coming to better understand and diagnose ASD. But there are likely hundreds of thousands more Canadians who are on the spectrum but have not been diagnosed. Without a diagnosis, Canadians will not get the support they need, missing the opportunity for crucial early interventions.

Despite the number of individuals and families touched by ASD in Canada, their needs remain mostly unrecognized by public policy and programs. As a spectrum disorder, people with ASD have a range of needs that vary throughout their lives. For many families, support is out of reach: unaffordable, unavailable in their community, or tied to eligibility requirements that don't fit the needs of Autistic Canadians.

Canadians with ASD and their families should have access to support where and when they need it to lead fulfilling lives and reach their full potential. Without a continuum of supports to respond to complex needs, we are leaving Canadians with ASD and their families out of our social contract, hurting health, education, and economic outcomes for families and communities.

WHAT IS AUTISM SPECTRUM DISORDER?

Autism Spectrum Disorder (ASD) is a lifelong neurodevelopmental disorder with a range of characteristics. People living with autism will experience challenges with communication and social interactions and will display restrictive and repetitive behaviour. There are many degrees of autism, making each individual unique. All people living with autism respond to effective intervention.

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

Children with ASD are four times as likely to suffer gastrointestinal problems and more than twice as likely to have a psychiatric diagnosis than the general population.

Note on Terminology: Autistic people, Canadians/individuals living with autism/ASD/an ASD, Canadians/individuals on the Spectrum/Autism Spectrum– in previous 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 report.

The time to act is now

12 years ago, the Senate of Canada produced *Pay Now, or Pay Later: Autism Families in Crisis*, an urgent warning on the need for a comprehensive National ASD Strategy.ⁱⁱⁱ The ASD community responded by forming the Canadian ASD Alliance to work with the federal government to craft and implement a strategy. While there have been important investments since, the Senate committee's recommendations remain as urgent as ever.

We can't afford to wait. Without appropriate supports that fit their needs, people with ASD and their families see drastically worse health, education, employment and quality of life outcomes. The average lifespan for people with ASD is half that of the general population.^{iv} People with ASD have higher rates of suicidality (ideation, attempts, and deaths by suicide).^v Four of five adults with ASD are out of the labour force entirely, and Autistic people are far more likely to have police interactions that escalate unnecessarily.^{vi}

It's not just people with ASD who are impacted. Families are being pushed past breaking points to access life-saving and life-improving support. Evidence-based therapies can cost upwards of \$60,000-\$80,000 per year. Some people with ASD require 24-hour care, which means their family would need an annual income of \$200,000 a year before paying for shelter, food or clothing.^{vii} For those in rural, northern and remote areas of Canada, accessing care can be even more costly — if it is available in their region at all. A University of Calgary study found that the lifetime care associated with a high needs ASD diagnosis can amount to \$5.5 million above and beyond the average care costs for the general population.^{viii} With evidence-based supports, early intervention, and proper support for transition to adulthood, Autistic Canadians can see significant improvements in their quality of life. Unlike other health conditions, families are expected to bear many of these costs themselves, often pulling parents from the labour market when they cannot find or afford supports.

The cost for families isn't just financial. Lack of support for people with ASD puts incredible strain on parents, siblings, and extended family, and can be damaging to their emotional well-being.

Canada has leading ASD researchers, and world class health and education systems. We have the groundwork to be world leaders on supporting people with ASD. But instead we are failing them and their families. **We need to do better.**

ASD is not just a provincial responsibility or a federal responsibility. It is a Canadian responsibility. In 2019, the federal government should launch a National ASD Strategy, in

partnership with provincial and territorial governments, Autistic Canadians and their families, and the experts serving and supporting the community.

This is an opportunity to change the lives of people with ASD and their families.

Vision for a National ASD Strategy

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

Blueprint for a National ASD Strategy

As the Senators urged a decade ago and political leaders from all parties have urged since, Canadians need leadership from their federal government. While many of the health, education and social services that support people with ASD fall under provincial jurisdiction, the federal government holds some important levers. **The federal government has an obligation to lead and a key role to play.**

Federal leadership doesn't mean testing the boundaries of federal and provincial roles. The federal government can leverage our current system with better coordination and learning across Canada, to ensure that Canadians from coast-to-coast-to-coast can access a continuum of quality supports throughout their lives. Provincial and territorial government officials have clearly voiced a need for more opportunities to collaborate nationally, sharing information and best practices.^{ix}

We also recognize that federal leadership is not about asking the federal government to act alone. Along with federal, provincial and territorial governments, a National Strategy depends on contributions from researchers and academics, service providers, experts, employers, and most importantly, Austistic people and their families. A National ASD Strategy should put the needs of people with ASD at the centre.

Principles to guide a National Strategy

The Federal government should undertake all its work — consultation, design, and implementation — in accordance with five key principles that will ensure the Strategy reflects the varied lives and needs of people with ASD across their lives. The Strategy should be:

- Person-centred, reflecting needs across 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.

Components of a National Strategy

This Policy Brief recommends three ways that the federal government can provide leadership for a National ASD Strategy:

- **Federal leadership** to facilitate collective impact by governments in partnership with the ASD community.
- **Immediate federal action** in five areas of federal jurisdiction.
- **Cross-government collaboration** to ensure consistent, co-ordinated approaches from all areas of government that touch the lives of people with ASD.

Federal leadership

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

Canadians on the spectrum have vastly different access to services and supports depending on where in Canada they live, both within and across provinces. Some families move across Canada to access the supports they need. While some provincial variation is to be expected, families, researchers, frontline caregivers and provincial and territorial governments themselves have consistently called for better exchange of knowledge, working models, and practices.

The federal government should lead **by facilitating better cooperation and coordination across provinces and territories**. The federal government should create a platform to allow clinicians, researchers, service providers, ASD self-advocates and provinces and territories to develop and disseminate learning for the best approach to a continuum of care for people with ASD. This work should focus on creating a network and knowledge base that can joint efforts on areas like early diagnosis and transitions to adulthood which will improve outcomes for people by creating a strong shared evidence base and support system for all Canadians.

Intergovernmental cooperation will be essential to an effective strategy. Because ASD does not fit neatly into any single department, the federal government should launch the strategy by convening **a multi-ministry intergovernmental meeting on ASD**, bringing together ministers of health, social services, and other appropriate provincial ministers, just as finance and health ministers met together to design the recent landmark federal-provincial-territorial health funding agreement.

Immediate federal action

In addition to coordinating across Canada, the federal government can lead a National ASD Strategy through discrete actions that fall within federal jurisdiction. In this blueprint, **we propose first steps across 5 action areas to form the foundation of a National ASD Strategy:**

1. Access and Affordability
2. Employment
3. Housing
4. Information
5. Research

We have selected these areas based on where our research has shown that federal public policy can most improve outcomes for Autistic Canadians. For each of these areas, we propose practical steps that the federal government can take to lead.

Action area: Affordability and access

End state: An ASD diagnosis does not carry major financial burden to access the supports people need where and when they need them.

An ASD diagnosis comes with a massive price tag for people with ASD and their families. At \$60,000-\$80,000 per year per child, the annual cost of evidence-based supports such as Applied Behaviour Analysis can easily exceed a family's entire income. The cost of therapies and supports is compounded by the challenge of balancing caregiving and work for family members and the low earning levels for many adults with ASD. Only 27% of respondents in the 2014 National Needs Assessment Survey for Families, Individuals with Autism Spectrum Disorder and Professionals reported that the financial support they received was enough to manage costs.^x

Even where financial resources are not a concern, it can be very challenging for people with ASD to access the right supports because of the complexity of their needs. As a spectrum disorder with a variety of co-occurring conditions, all people with ASD have unique needs, making it hard to find appropriate professional services. This is particularly acute outside of urban centres, especially in Northern and remote regions of Canada. Access is especially challenging for LGBTQ+ Canadians,

military families, seniors and other communities that require specialized approaches to support and service delivery. A National ASD Strategy should address both affordability and accessibility barriers faced by Autistic people and their families.

Opportunities for federal action:

- **Reform the Disability Tax Credit:** The purpose of the Disability Tax Credit (DTC) is to help people offset some of the added costs that come with a disability. People with ASD face a high rate of rejection for their claims under the existing requirements. This creates additional affordability challenges because eligibility for the DTC is also the gateway for approval for Registered Disability Savings Plans, Child Disability Benefits, and the Canada Workers' Benefit Disability Supplement. DTC eligibility screening should be reformed to recognize the legitimate claims of people with ASD. The DTC should also be made a refundable tax credit to ensure it provides a full benefit to the many Autistic adults with low incomes.^{xi}
- **Build leading ASD support into federal health systems:** The federal government has direct responsibilities for healthcare related to First Nations people living on-reserve, Inuit, Canadian Forces members and veterans, and some refugees and incarcerated people. The federal government should ensure that those health systems provide adequate and evidence-based diagnosis and support for people with ASD, including mental health.
- **Training the next generation of ASD professionals:** Through the Autism Research Training program, the Canadian Institute for Health Research (CIHR) invested in training a cross-disciplinary group of health professionals to understand, research, and provide support for Canadians with ASD. While funding for this program was discontinued, a shortage of professionals remains a major barrier to access. In order to increase access to vital services, the federal government should invest in a new research and training institute — like those within CIHR for other health conditions like arthritis and diabetes — to support current professionals and train future ones to work with Canadians with ASD in a variety of settings. This should include a range of researchers and practitioners to allow for essential interdisciplinary collaboration.
- **Ensure consistent recognition of ASD costs for the Medical Expense Tax Credit:** This tax credit provides some relief for the high out-of-pocket costs often associated with ASD support and associated medical issues. However, families of people with ASD have experienced inconsistent treatment of their claims, often seeing their expenses rejected because they did not fit an approved list of medical providers. The Canada Revenue Agency should simplify these rules, include the full breadth of providers of evidence-based ASD supports, and update operational policies to ensure consistent treatment for families.

- **Enhance the Child Care Expense Deduction:** The costs of childcare and educational support are much higher for children with special needs, including those with ASD. The Child Care Expense Deduction is currently limited to \$8,000 for children under 6, or \$5,000 for children aged 6-15. The amount increases to \$11,000 for children eligible for the DTC. This is far below the real costs of childcare, especially for parents of children with ASD that may require additional supports. The CCED should be enhanced to recognize these real costs.

While these federal actions can improve affordability and access in the near-term, for deeper impact Canadians need deeper cooperation between federal and provincial governments. Long-term transformation could include federal-provincial cooperation to create a simplified, user-centred model like Australia's National Disability Insurance Scheme to help people access the supports they need regardless of their circumstance.

Action area: Information

End state: Decision-makers, professionals, individuals and families have access to comprehensive and credible information about ASD to inform their decisions, and community services, employers and businesses are informed to create inclusive environments.

A National Strategy should invest in research and knowledge exchange on promising practices. This is not about standardizing provincial approaches or the work of medical practitioners but rather about providing a much-needed evidence base and consensus to support work across the country.

The Canadian Autism Partnership Program consultations made it clear that best practices and information sharing are priority areas for provincial governments, service providers, and experts. There is a particular need for sharing knowledge about ASD and people who belong to vulnerable populations, such as LGBTQ+ Canadians and seniors.

There is also a need for far greater understanding of ASD throughout Canada, across different sectors. A better-informed public is a critical safety issue for people with ASD, given risks of wandering for children and frequent unnecessary and dangerous negative interactions with police and in hospitals and emergency rooms.^{xii}

Public awareness, especially when targeted at particular segments of society, can lead to better outcomes. For example, shopping can be a very stressful experience for those with sensory sensitivities, but well-informed retailers have started creating sensory-friendly shopping experiences to reduce these stresses.^{xiii}

Opportunities for federal action:

- **Build a learning network for practitioners and policymakers to build evidence and consensus on promising practices:** Building on the work of the Public Health Agency of Canada, the federal government is uniquely positioned to facilitate the sharing of evidence and best practices between practitioners and jurisdictions on priorities like early diagnosis and transitions to adulthood. For example, guidelines to help ensure the consistent implementation of best practices can help support the many practitioners that interact with people with ASD and their families but do not have specialized training. Current federal funding is supporting work by the Canadian Paediatric Society to develop ASD guidelines.
- **Create awareness strategies to promote inclusion for Autistic Canadians:** Misunderstanding and discrimination against people with ASD is an unfortunate reality in Canada. Just as the National Housing Strategy includes a public engagement campaign to reduce stigma and discrimination, the federal government should partner with the ASD community to promote better understanding and acceptance of people with ASD. This work can equip those delivering services to the public and employers to provide ASD-welcoming environments. In the US, a partnership with the Ad Council has produced successful campaigns that have improved understanding and inclusion of people with ASD.^{xiv} Public education campaigns should include messages for targeted audiences and campaigns targeted at all those who may interact regularly with people with ASD.

Action area: Employment

End state: Adults with ASD are employed at rates near the Canadian average, supported with the resources they need to succeed, and welcomed into inclusive workplaces.

Only about 1 in 5 adults with ASD are in the labour force, and those that work report average earnings well below the poverty line.^{xv} Autistic adults have lower rates of employment than other Canadians with disabilities. The Canadian ASD Alliance National Needs Assessment showed employment supports as one of the top-ranked needs among service providers and ASD self-advocates.^{xvi}

When Autistic people are not able to meet their full employment potential, the economy suffers. People with ASD have valuable contributions to make in the workforce. In some cases, barriers to employment reflect discrimination and a lack of effort by employers on creating inclusive workplaces. In other cases, policy design means that people with ASD could lose access to essential benefits if they take employment with even very modest earnings. There is also a shortage of specialized employment readiness and training programs tailored to the needs of people with ASD.

While provinces and territories deliver most employment and training supports, there are clear roles for the federal government to lead on improving employment outcomes through funding, federal programming, and support for research and innovation around skills and employment.

Opportunities for federal action:

- **Invest in Labour Market Information about people with ASD:** The first step to designing better policies and programs is to have a clear picture of where we stand. The Minister of Employment, Workforce Development and Labour should task the Labour Market Information Council with gaining a better picture of labour market outcomes for adults with ASD, and with providing individuals and employers with information that will promote greater matching between skills and opportunities.
- **Support the creation of inclusive workplaces:** The proven Ready, Willing and Able program and other initiatives break down barriers to employment by educating employers, matching them with talent and supporting on-boarding. These programs need sustainable funding to engage employers and promote best practices.
- **Re-invest in pre-employment programs for people with ASD:** Through the Worktopia program, ASD service providers developed innovative programs to build pathways for young people with ASD to the labour force and achieved increased labour market participation. There is a continued gap in pre-employment programming tailored to the needs of Canadians with ASD. Pre-employment programming is an essential part of the employment support ecosystem for Canadians with ASD, providing support with work-relevant social communication skills and exposure to potential career opportunities.
- **Ensure federal training programs respond to the needs of people with ASD.** The federal government should ensure that federally-funded training programs (e.g. the Aboriginal Skills and Employment Training Strategy, Youth Employment Strategy) include training and employment supports that are responsive to the needs of Autistic people. Federal labour market training agreements with provinces and territories should also be designed to be responsive to ASD needs, including flexibility to support people regardless of their eligibility for EI.

- **Break down barriers in benefit design:** Work with provinces and territories to coordinate the design of income supports and benefit programs to reduce the “welfare wall” penalties that create adverse incentives for people with ASD who want paid employment.

A future integrated approach should see young people with ASD receive employment skill-building opportunities throughout their youth, post-secondary education options that meet their learning needs, and supported pathways to the labour market in which they are hired by inclusive employers in accommodating workplaces.

Progress Since Pay now or pay later

While the core diagnosis of *Pay now or pay later* remains true 12 years later, it is important to acknowledge that since that time successive federal governments have taken important measures that can help form the foundation of a National ASD Strategy.

These include:

- Public Health Agency of Canada’s critical work in leading the National ASD Surveillance System, providing essential Canadian data to inform our understanding of ASD.
- Investment alongside the Canadian ASD Alliance and other ASD organizations in the creation of the first research chair in ASD at York University.
- Funding for the Canadian ASD Alliance’s National Needs Assessment which provided the first national data on needs, gaps and services used by people with ASD across their lifespans.
- Support for Ready, Willing and Able, Worktopia and other innovative programs that connect Canadians with ASD with employment opportunities and build inclusive workplaces.
- Funding for the initial work of the Canadian Autism Partnership Project and the creation of the Autism-Intellectual Disability National Resource and Exchange Network (part of a \$20 million commitment in Budget 2018).

Action area: Housing

End State: Autistic Canadians and their families have a variety of housing options available to them that are affordable and meet their needs, ranging from supportive housing to independent living in non-profit and market housing.

Beyond the challenges of housing affordability faced by many Canadians, many people with ASD also need appropriate housing that is responsive to their circumstances. Unaffordability is compounded by high rates of poverty and the financial pressure of paying for supports. Housing was a top priority for people with ASD and caregivers in the Canadian ASD Alliance National Needs Assessment.^{xvii}

Many people with ASD who need supportive housing face long waitlists in their home communities. Some find themselves ineligible for supportive housing. The Ontario Ombudsman has pointed to the consequences of these gaps — high-needs people with ASD ending up in unacceptable situations, including psychiatric hospitals, nursing homes, homeless shelters and jails.^{xviii}

The federal government has launched a National Housing Strategy with a vision that all Canadians should have housing that meets their needs and that they can afford. To meet that vision, we need to respond to the housing needs of Canadians with ASD.

Opportunities for federal action:

- **Invest in the creation of more housing options suitable for the needs of adults with ASD:** The National Housing Strategy includes a focus on the needs of people with disabilities. The commitment to a minimum of 2400 new units for people with developmental disabilities is welcome, but not enough, and it is not clear that a general approach to developmental disabilities will be responsive to the varied and distinct needs of people with ASD. For example, people with ASD may benefit from environments that provide social support and are designed for people with sensory sensitivities.
- **Prioritize innovation in housing options that provide independence and support for people with ASD:** The Innovation and Research stream of initiatives in the National Housing Strategy provides an opportunity to support new approaches to housing that can meet the range of needs for people with ASD. The Canada Mortgage and Housing Corporation should make housing options for Canadians with ASD a priority for this funding stream, in particular for the National Housing Strategy Demonstrations Initiative and Solutions Labs. People with

ASD often need different service modalities that reflect the complexity and continuum of their needs throughout life.

Action area: Research

End state: Professionals and policymakers have access to ASD research that informs their practice including a thorough understanding of ASD prevalence and the diversity of ASD experiences throughout all regions. Canada has world-leading research on ASD that is mobilized to improve the lives of Canadians with ASD.

Canada is home to some of the world's leading researchers on ASD from a variety of disciplines. However, the level of research and the connection of that research to practice remains low relative to the complexity of ASD experiences and ASD's status as the most common and fastest-growing neurodevelopmental disorder in Canada. The federal government has the opportunity to lead in supporting ASD research.

Opportunities for federal action:

- **Complete the National ASD Surveillance System:** Until last year, we had no national statistics on ASD prevalence in Canada. The creation of the National ASD Surveillance System is an example of federal leadership that has allowed us to finally have a conversation about ASD using Canadian statistics. However, this picture remains incomplete, representing only seven provinces and territories covering only 40% of the population, and only for children aged 5-17. We need data on ASD prevalence across Canada and all age groups to design and deliver services, and we need to continue to monitor prevalence and progress over time.
- **Invest in world-leading ASD research:** Through CIHR and other granting organizations, the federal government plays a critical role in supporting scientific advancement. The Chair in Autism Cognitive Neuroscience at Université du Montréal and creation of the Chair in ASD at York University have produced valuable improvements in our scientific understanding of ASD — something that should be replicated. A CIHR Institute on ASD could promote research and learning across disciplines to improve understanding and treatment for Canadians.

Indigenous ASD Strategy

Alongside the National ASD Strategy, the federal government should develop a distinct Indigenous ASD Strategy in partnership with Indigenous communities, respecting government-to-government relationships, the need for culturally-appropriate services, and responsive to the distinctive needs of Indigenous communities.

While needs and access to services vary across Indigenous communities, with important differences between urban experiences and those in remote First Nations, Indigenous communities have distinct needs. The experiences of Indigenous people with ASD intersect with other factors such as the high prevalence of youth-in-care and legacies of residential schools. There is evidence that Indigenous children are systematically under-diagnosed.

An Indigenous ASD strategy should embed Jordan's principle, to ensure that jurisdictional questions are never an obstacle to children accessing care and support.

The existence of a distinct Indigenous strategy does not mean Indigenous people should feel unsafe or unserved by mainstream services, which should be equipped to provide culturally safe supports.

Cross-government approach

A cross-government approach ensures federal action is coordinated and integrated across all policies that affect Autistic Canadians.

To be successful, a National ASD Strategy needs to look beyond "autism policies" to make sure that a full range of public policies and services are responsive to the needs of people with ASD throughout their lives. If the Youth Employment Strategy, Poverty Reduction Strategy, and Seniors strategy don't take account of the needs of Autistic Canadians, then we will not succeed in achieving the vision of a National ASD Strategy.

The needs of Canadians with ASD — and the recommendations in this blueprint — touch on many areas of government. Just as the federal government should support coordination across Canada, a National ASD Strategy should establish leadership, accountability and coordination mechanisms within the federal government.

Opportunities for federal action

- **Establish leadership and accountability for the strategy within the federal government:** The Prime Minister should designate a lead minister for the strategy and ensure appropriate accountability in the mandate letters of other ministers with key responsibilities, including the Ministers of Health, Finance, Employment and Social Development, Indigenous Services and the Minister for Sport and Persons with Disabilities. The Lead Minister should be supported by a coordinating table of ADMs from relevant ministries.
- **Engage with the ASD community on accessibility standards:** The federal government should ensure that the development of accessibility standards under the proposed *Accessible Canada Act* includes recognition of the needs of people with ASD and participation from people with ASD and professionals to inform those standards.
- **Deep, broad consultation on the National ASD Strategy:** This document presents a blueprint for a National ASD Strategy. It will be imperative for the government to have a deep, meaningful conversation with the ASD community, including people with ASD, their families, experts and service providers from across the country in order to validate and help design the final strategy that government will implement.

Summary for policymakers

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



Affordability & Access

First steps:

- Reform the Disability Tax Credit
- Build leading ASD support into federal health systems
- Train the next generation of ASD professionals, including with a new CIHR institute
- Consistent recognition of ASD for the Medical Expense Tax Credit
- Enhance the Child Care Expense Deduction



Information

First steps:

- Build a learning network for practitioners and policymakers
- Create awareness of strategies to promote inclusion for Canadians with ASD



Employment

First steps:

- Better labour market information
- Access to pre-employment programming
- Ensure federal training programs are responsive to ASD
- Break down barriers in benefit design



Housing

First steps:

- Invest in the creation of more housing options suitable for the needs of adults with ASD, including supportive housing
- Prioritize innovation in housing options that provide independence and support for people with ASD



Research

First steps:

- Complete the National ASD Surveillance System
- Invest in world-leading ASD research

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.

Notes

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- ^{xvi} Weiss et. al, 2014
- ^{xvii} Weiss et. al, 2014
- ^{xviii} Ombudsman Ontario. "Province must act immediately to support people with developmental disabilities." August 2016. [https://www.ombudsman.on.ca/resources/news/in-the-news/2016/province-must-act-immediately-to-support-people-with-developmental-disabilities-editorial-\(toronto](https://www.ombudsman.on.ca/resources/news/in-the-news/2016/province-must-act-immediately-to-support-people-with-developmental-disabilities-editorial-(toronto)