



Canadian Autism
Partnership Project

An initiative of the Canadian Autism Spectrum Disorders Alliance

Briefing Note

Current Situation

Autism Spectrum Disorder (ASD) is the most common neurodevelopmental condition currently being diagnosed, affecting 1 in 68 Canadians. The rise in Autism diagnoses (30 per cent increase since 2006¹) is a critical health, social and economic issue that requires urgent action. A national partnership is central to ensuring efficient, effective solutions are put in place to address what is being called a crisis in this country.

Following a national ASD needs assessment commissioned by the Canadian Autism Spectrum Disorders Alliance (CASDA) which was summarized in the report, *Autism in Canada 2014*, the Public Health Agency of Canada (PHAC) funded a unique initiative called the Canadian Autism Partnership Project (CAPP) to develop an archetype capable of facilitating information sharing, collaboration and innovation with a view to finding more effective ways to mitigate the complex issues impacting Canadians affected by autism. The Partnership Project has also been tasked with developing a business plan to outline a model for a permanent Canadian Autism Partnership.

Across the country, varying policies and government departments at the provincial and territorial level guide the treatment, intervention and support throughout the lifespan for Canadians on the Autism Spectrum and their families/ caregivers. When comparing services region-by-region, there is a lack of consistency and accessibility of services – meaning that the quality, availability and successful outcomes of programming and resources is largely dependent on where you live in the country. Many government departments are isolated and lack the capacity to truly address the magnitude and complexity of this issue.

Since CAPP launched in July 2015, a National Working Group along with a Self-Advocates Advisory Group, has guided the stakeholder engagement process – including 22 meetings with 101 government representatives in all provinces and territories, 17 consultations in 14 communities with relevant stakeholder groups and 4,371 responses to an online survey hosted by the CAPP website (www.cappproject.ca). Throughout the process, special focus has been placed on the needs of Indigenous people and



One of the Community Roundtable discussions on the Canadian Autism Partnership Project, hosted in Halifax, Nova Scotia.

northern communities to identify their priorities and appropriate methods to examine meaningful responses to their service needs, both on and off reserve.

CAP Proposal

The Canadian Autism Partnership (CAP) will be a pan-Canadian partnership that accelerates systemic change at the national level by mobilizing multiple relevant sectors and federal/provincial/territorial governments to address the vast and diverse issues facing Canadians living with ASD across the lifespan.

CAP's value to the Autism sectors across Canada is that it will provide a platform for innovation, efficiencies and partnerships at a national level. As a collaborative model, it will work in partnership with governments (at all levels), autism and other disability oriented organizations across the country, researchers and post-secondary institutions, and Indigenous Peoples' groups. Its objective over the first five years is to address the complex issues and systemic barriers that impede optimal outcomes for families and individuals with ASD around early identification and early intervention, and employment, as well as begin exploration of additional complex issues, as identified by Canadians.

¹ <http://www.cdc.gov/ncbddd/autism/data.html>

In keeping with the intent of the CAP platform, the following are the key benefits that CAP will offer governments and other key stakeholders:

- Develop a platform for multi-sectoral collaboration to drive systemic change.
- Facilitate opportunities for collective-thinking, collaboration and pooling of resources across multiple sectors and all levels of government creating the potential for more effective solutions than any one organization or government could accomplish independently.
- Ensure the ability to influence the research agenda in Canada and accelerate the time from research to implementation.
- Build capacity and enhanced support in communities through knowledge exchange, education and skills development.
- Increase the capacity of northern and remote communities by providing a hub for shared information, policy, research and partnership with more well-resourced parts of the country.
- Provide access to accurate, evidence-based and timely information to support informed decision-making and policy development around multifaceted issues across the lifespan.
- Allow for potential cost savings and efficiencies.
- Learn from others, across the country and internationally, to avoid “reinventing the wheel”.

Next Steps

The extensive stakeholder information-gathering phase is now complete, and the data has been analyzed. There is overwhelming support for a Canadian Autism Partnership at the provincial/territorial government level, among professionals, service organizations, individuals and families across the country. As per the project mandate, the business plan for the partnership will be complete and will be ready for submission by early November.

Financial Request

Originally, the ASD Working Group was asked to build a comprehensive plan for the original \$50M request submitted to the Government of Canada in 2015. Through the work of the ASD Working Group, Self Advocate Advisory Group and CASDA, it was determined that a phased approach to the partnership was a more viable and appropriate option to ensure measureable and timely outcomes of the work. It is for this reason, reinforced by the stakeholder engagement process, that the funding request for the Canadian Autism Partnership will decrease from \$50M over three years to \$16.5M over five years, approximately \$3.3M annually. CASDA and the ASD Working Group felt strongly that to maximize impact and effectively address priority complex issues, a five-year funding cycle verses a three-year funding cycle was more beneficial. It also allows for greater outcome measurement, which is essential in ensuring long-term sustainability and growth with private and public funders.

Governance Structure

The original funding proposal identified the Canadian Autism Partnership as a new entity at the national level to address the complex issues on the Autism Spectrum. In phase II of the project, it is proposed that CASDA continue to lead the initiative in partnership with Autism Speaks Canada and Autism Canada as key members that will guide the work of the leadership team to tackle the mandate of the partnership. This will ensure ongoing collaboration and alignment of the national agenda as it relates to research, and service delivery development, while ensuring the voice of individuals and families remain at the core of this initiative.

Summary

The business plan delivered in early November will detail the work of the Canadian Autism Partnership; outline the organizational model; identify the priority areas of focus over five years; describe the key performance indicators; and define the method used to measure impact outcomes for the complex issues being addressed.

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