



Canadian Autism  
Partnership Project

An initiative of the Canadian Autism Spectrum Disorders Alliance

# Better Together: The Case for a Canadian Autism Partnership Executive Summary



## CAP's Vision

All Canadians living with Autism have the opportunity to lead fulfilling and rewarding lives, and are able to access the necessary supports and services in a welcoming and understanding society.

## CAP's Mission

Accelerate systemic change at the national level by mobilizing multiple sectors to address complex issues related to Autism, using a shared leadership approach to achieve collective impact.

# Executive Summary

## AUTISM IN CANADA – DEFINING THE NEED

The current state of Autism support services, intervention, and care in Canada requires urgent attention and political action.

Autism Spectrum Disorder (ASD) is the most common neurodevelopmental disorder diagnosed among children in Canada today. According to the Centers for Disease Control (CDC) (2014), ASD affects 1 in 68 children. When one considers the support network surrounding each Canadian with an ASD diagnosis, including parents, grandparents, siblings and caregivers, the number of Canadians in need of guidance and support grows exponentially. This also impacts the demand for qualified and trained professionals knowledgeable in ASD, required to support the lifespan needs of Canadians living with this condition.

The investment by the Government of Canada in July 2015 supported the exploration of a Canadian Autism Partnership (CAP), which included: the development of a National ASD Working Group and Self-Advocates Advisory Group; a comprehensive stakeholder engagement strategy; and the development of a business plan for the implementation of a CAP on the national landscape.

Canadians have spoken. The findings from this extensive engagement process validate previous research highlighting the need and inequities of ASD program and service delivery across the country. These inequities and failure to systematically address the complex needs across the lifespan come at an enormous cost to all levels of government, service providers and most importantly individuals and families.

The development and implementation of CAP represents a comprehensive solution that will address systemic issues and complex needs of individuals on the Autism Spectrum. It will also create the following efficiencies:

- A national platform for multi-sectoral collaboration and innovation to drive systemic change;
- Focussed, robust and readily accessible knowledge translation and exchange, promoting greater efficiency of effort and resources;
- An authoritative access point for reliable data to inform policy development, funding decisions and service delivery;
- Increased collaboration between all segments of the autism sector, promoting broader influence on the research agenda in Canada and acceleration of the time from research to implementation;
- A unique Indigenous Engagement Strategy that reflects the cultural values of Canada's Indigenous communities and addresses the specific needs of their population;
- Increased capacity of northern and remote communities by providing a hub for shared information, policy and research, and collaboration with more well-resourced parts of the country;
- Effective partnerships to enable pooling of resources across multiple sectors and all levels of government; and
- Greater equity across all Provinces and Territories through enhanced capacity to share resources and adapt models of service to reflect the diversity of Canada, its people and its geography.

The CAP approach creates opportunities for many Autistic individuals, along with their families and caregivers, to benefit from the efforts of decision makers to enhance coordinated and timely support by reducing the frustration and isolation that can accompany their search for appropriate and effective intervention and care.

The findings from this extensive engagement process validate previous research highlighting the need and inequities of ASD program and service delivery across the country.

CAP will positively affect universality and accessibility to services, promote innovation in planning and delivery of service, and strengthen processes to support evidence-based decision making.

To date, some significant investments in autism programs and treatment have been made at the provincial/territorial and federal government levels, mostly targeted at early identification and early intervention, pre-employment training and employment support. Although these are significant and important investments, without a coordinated approach that encompasses the lifespan, the long term outcomes and return on investment for these initiatives and others will be limited.

It is for these reasons that CASDA, in partnership with Autism Speaks Canada and Autism Canada, remains committed to proposing the implementation of a Canadian Autism Partnership (CAP) on the Canadian landscape. Stakeholders across the country strongly concur with the following vision, mission, principles and outcomes that would positively impact Canadians with ASD:

#### **CAP's Vision**

All Canadians living with Autism have the opportunity to lead fulfilling and rewarding lives, and are able to access the necessary supports and services in a welcoming and understanding society.

#### **CAP's Mission**

Accelerate systemic change at the national level by mobilizing multiple sectors to address complex issues related to Autism, using a shared leadership approach to achieve collective impact.

#### **Principles**

All Canadians living with Autism have the right to:

- Inclusion, understanding and acceptance
- Respect and dignity
- Full citizenship
- Equitable opportunities and access
- Personal autonomy and decision-making

## COLLECTIVE IMPACT FRAMEWORK

A foundational component to establishing the Canadian Autism Partnership (CAP) is the implementation of the Collective Impact framework that will aid in the selection and tackling of complex issues being addressed. This framework will embrace the emerging Collective Impact approach to social change, originating in the United States, and more recently coming to regions across Canada, to address deeply entrenched and complex social issues. It is an innovative and structured approach to fostering collaboration across government, business, philanthropy, non-profit organizations and citizens to achieve significant and lasting social change.<sup>1</sup>

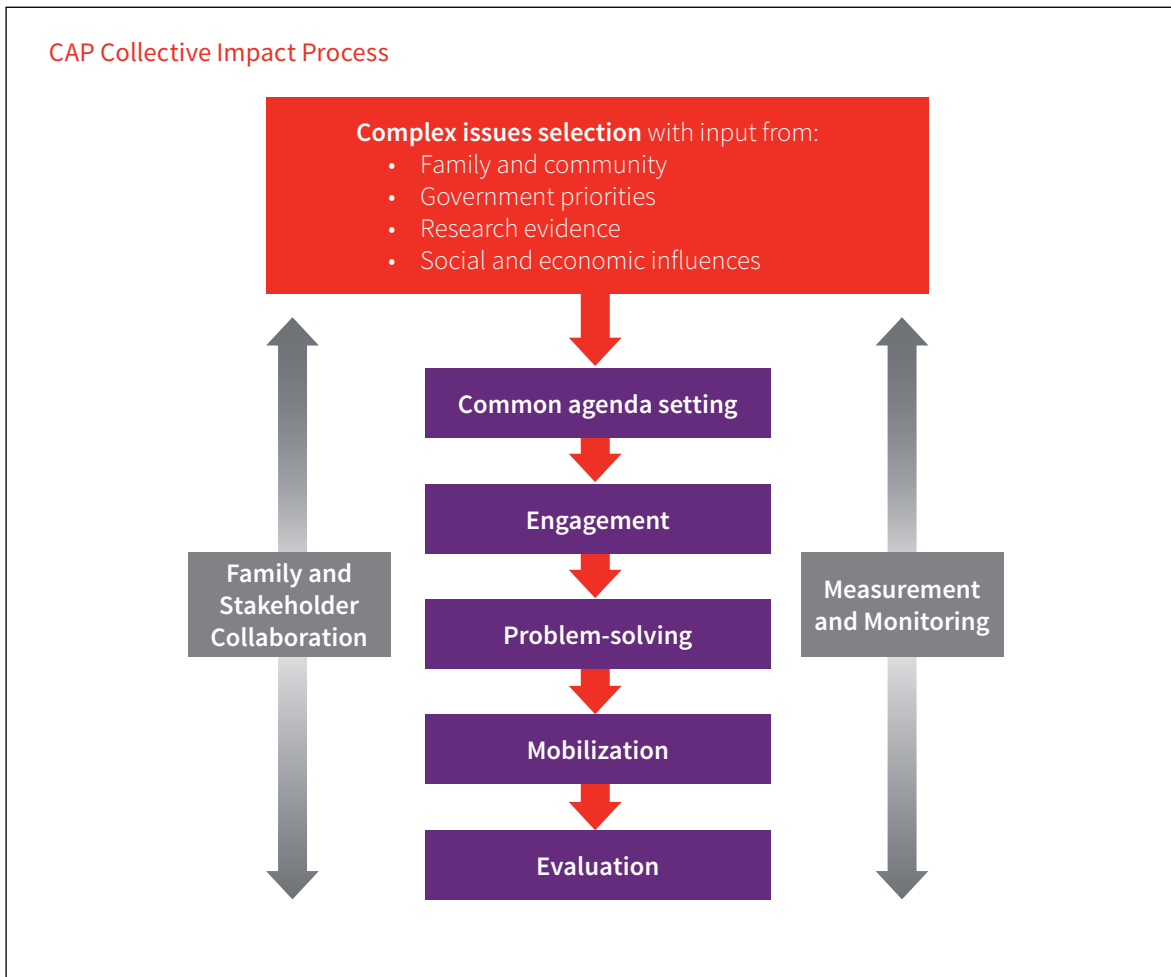
Discussion, debate, customization and refinement of the Collective Impact framework were central elements of the Stakeholder Engagement process undertaken in the Canadian Autism Partnership Project. There was broad consensus among stakeholders across the country that this model presented a new way to do business, built on existing strengths, and introduced processes and supports to enhance collaboration, partnerships and shared ownership of the future of autism in Canada.

The CAP Collective Impact Process, illustrated on the following page, provides a structured methodology for bringing stakeholders together to find solutions to the complex, systemic issues that are barriers to optimal outcomes for Canadians with ASD. CAP will positively affect universality and accessibility to services, promote innovation in planning and delivery of service, and strengthen processes to support evidence-based decision making.

A detailed description of each of the phases of the process is found in Appendix C.

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<sup>1</sup> Stanford Social Innovation Review – Winter 2011; Collective Impact; John Kania & Mark Kramer; page 36. Both the Harvard Business School and the Harvard Business Review have published articles about the advantages of the Collective Impact model in making large scale social change. The articles are: Business Aligning for Students: The Promise of Collective Impact; Allen S. Grossman and Ann B. Lombard; Harvard Business School; <http://www.hbs.edu/competitiveness/Documents/business-aligning-for-students.pdf>; and Collaboration is the New Competition; Ben Hecht, Harvard Business Review; January 10, 2013; <https://hbr.org/2013/01/collaboration-is-the-new-compe>



## PRIORITIES IDENTIFIED BY CANADIANS

The CAP Project heard from nearly 5,000 Canadians using a variety of methods to engage and seek input from stakeholders to the CAP concept and model. The stakeholder engagement process included:

- Twenty-three meetings with 101 government officials representing all 13 provincial and territorial governments;
- Seventeen community roundtable sessions across the country in 15 communities attended by 494 participants; and
- An online stakeholder survey which garnered input from 4,371 respondents from every province and territory, as shown in the map on the following page.

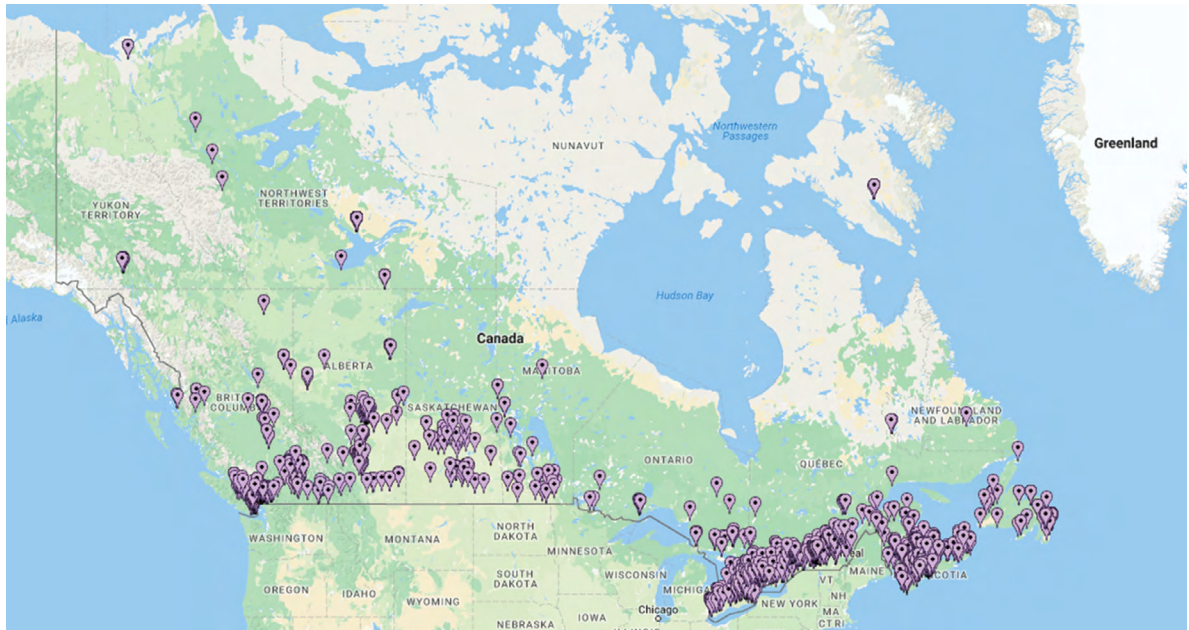
Canadians identified a range of pressing concerns that have been consolidated into the following five broad categories, which reflect the complex, systemic issues facing Canadians with ASD:

- Early identification and early intervention;
- Employment;
- Interventions and services to optimize quality of life at all ages;
- Specialized medical care, including access to dental and mental health services; and
- Education, including transitions to work, post-secondary education and independent life.

A summary of the stakeholder engagement process and the findings can be found in Appendix D.<sup>2</sup>

<sup>2</sup> Analysis of the stakeholder engagement process and findings is detailed in four volumes – Detailed Findings, Survey Responses by Province/Territory, Stakeholder-Identified Innovations by Provinces & Territories, and CAPP Surveys.

Community stakeholders from northern and remote communities, and government representatives alike, identified the need for careful consideration of the unique needs of their communities.



*Detailed Map of Respondents by Postal Code*

Building on the priority areas identified by Canadians in the consultation process, CAP will develop a strategy for bringing Collective Impact activity forward to address specific issues within each priority category. Embedded within each Complex Issues Initiative (CII) is a recognition that addressing lifespan supports and supports for caregivers are essential to successful outcomes. As well, the unique needs of Indigenous communities and remote, rural and under-served communities will be included in the action plan for each CII.

Engagement with Indigenous Peoples across the country must be a priority. An effective means of engagement will require a very different and separate approach informed by Indigenous communities. Stakeholder feedback reflected an openness to partnering with CAP to start this process. In moving forward, a unique Indigenous Engagement Strategy will be developed.

Community stakeholders from northern and remote communities, and government representatives alike, identified the need for careful consideration of the unique needs of their communities. They identified that an important benefit of CAP would be the opportunity to work with other jurisdictions to develop best practices, to receive support and assistance to adapt these practices to the realities of their communities, and to partner with other organizations and jurisdictions to share their expertise.

## CAP ACCOUNTABILITY STRUCTURE

The Collective Impact framework requires an organization to lead and coordinate the activities of collaborating stakeholder organizations and individuals. In the CAP model, the structure extends to include governance and accountability to not only the funders, but to the autism community as well.

The CAP overall accountability structure consists of:

### **Governance**

**Board of Directors** – the governance and oversight body, including a robust committee structure.

**CAP** – the operational structure that manages the collaborative partnerships, selecting and addressing complex issues, and outcome evaluation, led by a National Director.

### **Community**

**Advisory Council** – consists of expertise and resources to address the complex issues, in part through participation on Action Teams, and disseminate information on the work of CAP.

**Stakeholder Groups** – provide expertise and resources to address the complex issues, in part through participation on Action Teams, and disseminates information on the work of CAP.

In addition to the National Director, CAP resources will include a staff team of up to 11 FTE positions, recruited over the first 18-24 months responsible for administration and finance, communications, engagement, including engagement with Indigenous Peoples, and complex initiatives.

With input received from

# 4,963

Canadians representing all ten provinces and three territories, it is clear that there is strong, positive support for the CAP model as presented in this business plan.

## FINANCIAL SUMMARY

The financial projections represent a total investment of \$19,000,000 over a five-year period, including start-up, operating and project costs allocated to the complex issue initiatives. Funds are also specifically allocated for targeted outreach and engagement with Indigenous Peoples, and all complex issue initiatives will include funding allocation for rural and northern regions of Canada to support equitable participation in CAP and ultimately, equitable access to its outcomes.

## CONCLUSION

With input received from 4,963 Canadians representing all ten provinces and three territories, it is clear that there is strong, positive support for the CAP model as presented in this business plan. In particular, stakeholders valued the opportunities that CAP would provide for collaboration and knowledge exchange. They saw the potential for achieving efficiencies in programming and service delivery and the benefits of a knowledge repository. Families and self-advocates were enthusiastic about the potential for being able to influence the research agenda, and recognized that although the proposed CAP may not necessarily address their immediate issues, its focus on addressing complex issues and systemic barriers was an essential part of moving towards improved outcomes for families and individuals and enhancing capacity in communities.

The development of a Canadian Autism Partnership provides a unique opportunity to harness the collective investment, innovation, knowledge and capacity of a nation to get behind one of the most pressing issues of our time by enabling governments, researchers and service leaders to work together to address those barriers that prevent Canadians with Autism from participating in the full experience of our Canadian society.

## ACKNOWLEDGEMENTS

CASDA would like to acknowledge and thank the Public Health Agency of Canada (PHAC) for its financial support to this project.

The following individuals were instrumental in the development of this business plan. Together they provided the leadership needed to move this ground breaking initiative from the idea stage to a concept that has been enthusiastically endorsed by nearly 5,000 Canadians, to this business plan which provides a roadmap for moving forward.

### ***With thanks we recognize:***

**Senator Jim Munson**, for starting the political conversation about the needs of Canadians facing the challenges associated with Autism Spectrum Disorder and for keeping that conversation alive.

**Mike Lake, MP**, for his tireless championing on behalf of parents of children with ASD and his pursuit of collaboration among all stakeholders with a role to play in the autism agenda in Canada.

**Members of the Working Group** who together represent some of the best expertise in autism in Canada and who provided knowledgeable guidance, direction, and perspectives to the engagement of Canadians across the country and development of the plan.

**Members of the Self-Advocates Advisory Group** from across Canada who embraced this project with passion and wisdom, and whose insights and lived experiences brought credibility to the idea and helped move it to a tangible concept.

**The over 100 Provincial and Territorial Government officials** from all 13 jurisdictions who shared with us the barriers their provinces/territories encounter in delivering autism services and programs, the successes and innovations they have achieved, and their uniform support for this concept.

**Our Community Round Table hosts** without whom the face-to-face engagement of nearly 500 Canadians would not have been possible. Their organization, recruitment of participants and enthusiasm for the project was invaluable. Special thanks to:

- Autism Calgary
- Autism Edmonton
- Autisme Québec
- Autism Nova Scotia
- Autism Resource Centre, Regina
- Autism Society of British Columbia, Prince George Chapter
- Autism Society New Brunswick/Autism Resource Centre, Fredericton
- Autism Society of Newfoundland and Labrador
- Autism Society NWT
- Autism Yukon
- Geneva Centre for Autism, Toronto
- Gold Learning Centre, Montréal
- Government of Manitoba
- Holland Bloorview Rehabilitation Centre, Toronto
- Pacific Autism Family Centre, Vancouver

**Our Participants** – Most important of all, we extend our deepest gratitude to the almost 5,000 parents, family members, individuals with ASD, researchers and professionals in the ASD sector who completed the survey, participated in the community round table sessions, and provided comments in writing, for sharing their insights, input, knowledge and their experience. They have enriched the development of this business plan.

This report was prepared for the Minister of Health by the CASDA Board of Directors with thoughtful, knowledgeable and essential input by members of the National ASD Working Group and the Self-Advocates Advisory Group.

## **CASDA Board of Directors**

### **Cynthia Carroll – Chair**

Executive Director, Autism Nova Scotia

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of Autism

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Executive Director, Autism Yukon

### **Margaret Whelan**

CASDA Member

## **CAPP Secretariat Group**

### **Margaret Whelan**

Co-lead

### **Cynthia Carroll**

Co-lead

### **Chris Hornberger**

Project Manager

### **Ruth Blades**

Engagement Coordinator

### **Andy Cutten**

Financial Lead

### **Lin Zhang**

Website Development

### **Carol Cox**

Administrative Lead

### **Allison Garber**

Communications Lead

### **donalee Moulton**

Communications Coordinator

## National ASD Working Group Members

### **Cynthia Carroll, Chair**

Chair, CASDA  
Executive Director, Autism Nova Scotia  
Co-Director, Canadian Autism Partnership Project

### **Margaret Clarke**

Senior Vice President, The Sinneave Family Foundation

### **Sergio Cocchia**

Board Chair and Co-Founder, Pacific Autism Family Centre

### **Kim Elmslie**

Assistant Deputy Minister, Public Health Agency of Canada

### **Jill Farber**

Executive Director, Autism Speaks Canada

### **Stelios Georgiades**

Co-Director, McMaster Autism Research Team, McMaster University

### **Warren Greenstone**

President and CEO, Miriam Foundation

### **Laurie Mawlam**

Executive Director, Autism Canada

### **Stephen Scherer**

Director, The Centre for Applied Genomics  
The Hospital for Sick Children

### **Robert Strang**

Chief Public Health Officer, Nova Scotia Department of Health and Wellness

### **Jonathan Weiss**

Research Chair, Autism Spectrum Disorders Treatment and Care Research, York University

### **Margaret Whelan**

Co-Director, Canadian Autism Partnership Project

### **Lonnie Zwaigenbaum**

Co-Director, Autism Research Centre, Glenrose Rehabilitation Hospital

## Self-Advocates Advisory Group Members

### **Patricia George-Zwicker**

Nova Scotia  
Artist, Writer, Photographer & Poet

### **Trudy Goad**

Newfoundland & Labrador  
Author

### **Kristian Hooker**

Manitoba

### **Georges Huard**

Québec

### **Jackie McMillan**

Ontario  
BES, Asperger's, ThriveWithAutism.ca

### **Jessica Pigeau**

Alberta

### **Corey Walker**

British Columbia  
Northern Regional Coordinator for the Autism Society of BC





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**Canadian Autism Spectrum Disorders Alliance (CASDA)**  
Business Address: 23 Evanshen Crescent, Kanata, ON K2K 2Z6  
Mailing address: 5945 Spring Garden Road, Halifax, NS B3H 1Y4  
[info@casda.ca](mailto:info@casda.ca)