



Canadian Autism  
Partnership Project

An initiative of the Canadian Autism Spectrum Disorders Alliance

# Better Together: The Case for a Canadian Autism Partnership



## 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.

Dear Minister Philpott:

In February of 2015, the three national autism organizations; Canadian Autism Spectrum Disorders Alliance, Autism Canada and Autism Speaks Canada, came together to present a funding proposal to the Government of Canada for a Canadian Autism Partnership.

Close to two years later, not only do our organizations remain united in our call to action, we've gained the support of thousands of Canadians along the way. We want to thank the Government of Canada for funding this project and supporting the development of this critical resource on the national landscape.

Great credit should be given to the members of the Canadian Autism Partnership Project's Working Group – comprised of some of Canada's leading Autism experts representing various organizations and sectors. Their tireless leadership and adherence to presenting a comprehensive and compelling case for change is evident in this report.

Immense gratitude also needs to be given to our Self-Advocate Committee – a group of some of the most passionate, dedicated and committed people with whom we've had the honour to work. We were privileged to have these self-advocates share their personal experiences, and the insights that came with them.

From coast to coast to coast we met with Canadians and shared our framework for a national partnership model that would provide better access to information for Autistic Canadians and their families and caregivers. We talked about a model that could facilitate and coordinate outreach and expertise to more effectively address complex issues pertaining to Autism. We shared samples of innovative programming that are being executed across the country, and how a Canadian Autism Partnership could identify these creative initiatives and support provinces and territories to translate them to accommodate their region's unique needs.

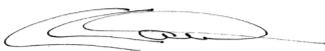
It has been ten years since the release of the Senate Report, "Pay Now or Pay Later". While we are getting precariously close to that proverbial "later" – this business plan outlines a profound opportunity for Canada to not only orchestrate a better landscape for Canadians living with Autism, but also to assert ourselves as a leader on the global stage.

Developing this comprehensive strategy was a rewarding task – one that was accomplished due to the significant investment given by a vast number of people.

Lastly, we want to recognize the thousands of Canadians who came forward to contribute to this business plan. Nothing could have prepared us for the overwhelming response we received, which is indicative of the need for a consolidated approach to addressing Autism in Canada. Over 4,900 people provided input on this business plan through various consultation initiatives – proof positive that the Government of Canada would have significant encouragement to move forward in establishing a Canadian Autism Partnership and changing the narrative for Canadians with Autism Spectrum Disorder.

The case for a Canadian Autism Partnership is there: solidified support, amplified momentum and a profound urgency. If in 2007, the 'Pay Now or Pay Later' Report issued a call to action; then in 2016, it's time to sound the alarm.

Sincerely,



Cynthia Carroll, Chair  
CASDA



Jill Farber, CEO  
Autism Speaks Canada



Don Blane, President  
Autism Canada

Developing this comprehensive strategy was a rewarding task – one that was accomplished due to the significant investment given by a vast number of people.



# National ASD Working Group's Foreword

On behalf of the National ASD Working Group, I wish to convey our appreciation for the opportunity to provide leadership to the national discussion about making change for Canadians on the Autism Spectrum.

In our last formal working group meeting on October 31, 2016, the group reached consensus on the CAP process model, performance indicators, governance structure and funding request which has informed the development of “Better Together: The Case for a Canadian Autism Partnership”.

Throughout this process, we have been continually impressed with the high levels of participation from government representatives and community leaders across Canada. Their feedback to us indicates that they are encouraged with the idea that a Canadian Autism Partnership could facilitate greater collaboration – bringing the diverse sectors and jurisdictions together to collectively address common issues that impact Canadians with Autism.

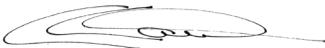
With internationally acclaimed researchers, first-class medical clinicians and a robust health care delivery model – Canada is well positioned to be a global leader when it comes to addressing Autism. One thing that was made exceptionally clear throughout this project's consultation process was that our country does not lack for innovation and creativity – evidence of this was clearly provided as we visited the provinces and territories across Canada. Rather, our deficit is exposed in our inability to translate that innovation to other regions in Canada, to share expertise and best practices, and adapt them to accommodate each jurisdiction's unique needs.

Canada is at its greatest when we come together. While this statement at face-value may seem trite, it truly is an apt description of the values we hold close: pulling together our diverse skill sets and expertise, along with our shared passion and drive, in order to secure the most optimal outcome for every single Canadian.

That's who we are, and that's what we must achieve.

It has been a privilege and an honour to serve as members of the working group and work alongside the Self-Advocates Advisory Committee to present a strong case for a Canadian Autism Partnership.

Sincerely,



Cynthia Carroll,  
Chair, National ASD Working Group

Throughout this process, we have been continually impressed with the high levels of participation from government representatives and community leaders across Canada.



# Self-advocates Advisory Group's Foreword

Being able to participate and directly contribute to the development of a business plan to support a Canadian Autism Partnership model has been nothing short of a dream come true.

This experience has not been typical of our collective advocacy work. It is unfortunately far more common than not for us to have our voices silenced on the issues that impact us, and the people most like us. This means our unique experiences and insights as Autistic adults are often ignored in the face of misinformation, defamation of character, prejudice, and devaluation.

This is why, when we were asked to describe what our participation has been like in the Canadian Autism Partnership Project, we were crying tears of relief and joy, trying to find words to describe what this process has meant to us. To be blunt, if we could have created a "Truth and Reconciliation" process for people with autism, this CAP adventure would be it. This national project is a first step, a coming together of allistics and autistics, a recognition of past short-comings and a good faith plan to build a better future.

At our very core, we are advocates; dedicated to our work, passionate about the changes needed, and committed to creating a better future for the Autistic children following in our path.

Most of all, we believe a better Canada can exist – and that a Canadian Autism Partnership is an integral part of that ideal – but that building and sustaining such an infrastructure needs the involvement of the people whom it will affect the most: Autistic Canadians. A common refrain from the disability community is, "nothing about us, without us" – a Canadian Autism Partnership must respect and incorporate that mantra.

Our Committee has been thoughtful in our contributions and methodical in our review of this business plan. We are confident that the information presented within this report is research-based, and perhaps most importantly, reflects the unique perspectives, challenges and opportunities raised by the thousands of Canadians we consulted with across the country.

We are honoured and grateful to have been a part of this incredibly important project which we hope will shape a ground-breaking national initiative to better the lives of Autistic Canadians.

We are confident that the information presented within this report is research-based, and perhaps most importantly, reflects the unique perspectives, challenges and opportunities raised by the thousands of Canadians we consulted with across the country.

Patricia George-Zwicker

Trudy Goold

Kristian Hooker

Georges Huard

Jackie McMillan

Jessica Pigeau

Corey Walker

# 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

### **Jill Farber**

Executive Director – Autism Speaks

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### **Corey Walker**

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# Terminology

## **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 report.<sup>1</sup>

**Allistic** – a person who is not autistic.<sup>2</sup>

**Collective Impact** – is a model to facilitate large scale social change through broad sector coordination that requires the commitment of a group of key individuals from different sectors to a common agenda and a plan of action for solving a specific social problem. It also involves collecting data, and measuring and evaluating results across all participating sectors to ensure accountability, alignment of efforts, and providing a mechanism to learn from each other's experiences.<sup>3</sup>

**CAP Collective Impact Process** – is a structured process for driving systemic change in the autism sector in Canada based on the Collective Impact model and adapted for application on a national scale. This adaptation is an innovative approach to embracing a commitment to a national problem solving and collaboration effort to effect large scale system change.

**CAP Phase I and Phase II** – Phase I refers to the Canadian Autism Partnership Project funded by the federal government, undertaken in 2015 and 2016, resulting in this business plan. Phase II refers to the launch and subsequent five years of the Partnership to commence following acceptance of this business plan and confirmation of funding.

**Complex Issues** – are those autism-related issues that require a national, multi-sectoral approach to breaking down systemic barriers to allow for the mobilization of large scale change.

**Decision-makers** – refers to political, government, advocacy and program and service delivery leaders who have the power and authority to effect changes in policy and funding, as well as, implement strategic and operational changes.

**Functioning forms of autism** – reference to “high or low” functioning forms of autism are not intended to describe the experience or capabilities of individuals on the spectrum, and are used only where they are being cited in work done by others that reference the use of that terminology.

**Innovation(s)** – for the purposes of the stakeholder consultations, innovation was not defined, to allow stakeholders to share what they viewed as valuable research, programs, and services in their communities without bias or being confined to a standardized definition for this term.

## **National Needs Assessment Survey (NNAS)**

– refers to the survey conducted in 2014 by the Canadian ASD Alliance (CASDA) titled, *Autism in Canada: National Needs Assessment Survey for Families, Individuals with Autism Spectrum Disorder and Professionals*. This survey was developed by Dr. Jonathan Weiss and Cynthia Carroll, with input from the CASDA Leadership Committee and select member partners.

**Stakeholder Groups** – refer to the communities of interest/practice across multiple sectors that will be drawn upon to address complex issues within the partnership model. An initial list of these communities includes: individuals with ASD, families, Indigenous Peoples, northern/remote communities, researchers, inter-governmental leaders, non-government organizations (NGOs) and service providers. This list will evolve as CAP starts up its operations and begins to build the organization.

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1 Collaborative Language and Communication in the Autism Field, Autism Canada – [http://autismcanada.org/wp-content/uploads/2015/04/AC\\_LanguageDocument-2016-1.pdf](http://autismcanada.org/wp-content/uploads/2015/04/AC_LanguageDocument-2016-1.pdf)

2 Urban Dictionary: <http://www.urbandictionary.com/define.php?term=allistic>

3 Stanford Social Innovation Review – Winter 2011; Collective Impact; John Kania & Mark Kramer; p. 36 & 40.



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# 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>4</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.

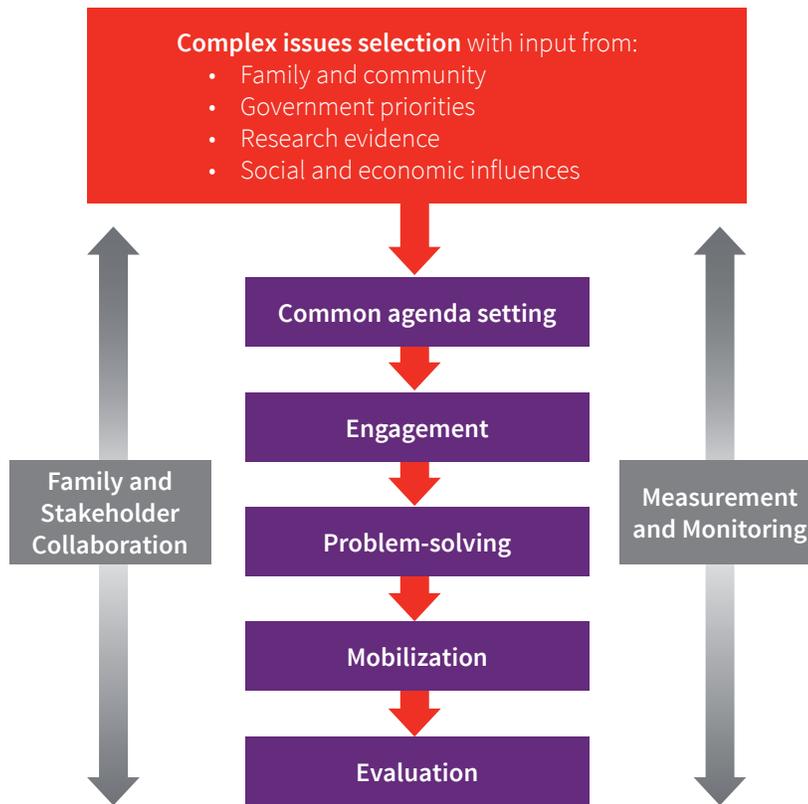
The CAP Collective Impact Process, illustrated on the following page, provides a structured methodology for bringing stakeholders together to find solutions to the complex, systemic issues that are barriers to optimal outcomes for Canadians with ASD. CAP will positively affect universality and accessibility 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>4</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>

## CAP Collective Impact Process



## 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>5</sup>

<sup>5</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.



## 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.

# Canadian Autism Partnership Model

## AUTISM IN CANADA – DEFINING THE NEED

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. Canadian prevalence data have not been released to date by the Public Health Agency of Canada; however, based on the CDC prevalence rates, a conservative estimate of 1.5% of the population or 520,000 individuals in Canada are living on the Autism Spectrum.

This percentage becomes more significant when you take into account the support network surrounding each Canadian with an Autism diagnosis. Parents, grandparents, siblings and caregivers – even with a conservative estimate of 2.9 people per household,<sup>6</sup> approximately 1.5 million Canadians are impacted by Autism. This represents a considerable, growing community in our society that is in need of guidance and service support across the country.

Despite the diagnostic criteria used to determine a formal diagnosis for ASD, the spectrum is complex, ever evolving and diverse. Programs and services have not kept pace with the increase in diagnosis, creating a fragmented and disjointed approach to support and intervention in every province and territory. These inequities across the country, 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 cost associated with supporting individuals with ASD is substantial. Studies from both the USA and from Ontario estimate that the cost of supporting a single generation/cohort of people with ASD in Canada could range from \$1.4 to \$1.8 billion CDN.<sup>7</sup> Another UK study identified out of pocket expenses for the cost of individual care at \$1,325 CDN per week, or \$68,900 CDN per year,<sup>8</sup> depending upon the complexity of need. These costs are generally being downloaded onto families and individuals. And, these costs do not even begin to address the hidden costs that come from reliance on disability supports which many autistic individuals may require, such as basic life, social or employment skills training, but are unable to find in their communities. Further adding to the complexity of ASD support and intervention are the unique considerations faced by northern regions of the country, culturally diverse populations and respectful engagement with Indigenous Communities.

The CASDA National Needs Assessment Survey (NNAS) in 2014 identified and validated top priority needs and gaps in ASD supports and services across the lifespan. The national data collected from this 2014 survey, combined with the data derived from the extensive stakeholder engagement process in the spring of 2016 for the Canadian Autism Partnership project (CAPP), now provide the most comprehensive understanding of the autism landscape in Canada today. Many of the gaps identified in the 2014 survey were found to be still very much evident and considerable through the 2016 engagement process.

One could infer from the data comparison that minimal progress has been made for individuals and families over the last two years. However, evidence and understanding of ASD is growing. Many research, program and service innovations

6 This estimate is based on the population of Canada in 2015 and an incidence rate of 1:68. Centers for Disease Control and Prevention, *Autism Spectrum Disorder (ASD): Data and Statistics*, accessed February 16, 2016. <http://www.cdc.gov/ncbddd/autism/data.html>; <http://www.statcan.gc.ca/tables-tableaux/sum-som/l01/cst01/demo02a-eng.htm>, accessed on February 16, 2016.

7 M. L. Ganz, “The lifetime distribution of the incremental societal costs of autism,” *Archives of Pediatrics and Adolescent.*, 161 (2007):343-349.

8 K. Jarbrink, E. Fombonne and M. Knapp, “Measuring the parent, service and cost impacts of children with autistic spectrum disorder: A pilot study,” *Journal of Autism and Developmental Disorders* 33, 4 (2003).

are emerging in communities across the country.<sup>9</sup> Government funding has enabled a growing number of researchers<sup>10</sup>, professionals, service organizations, families and autistic adults to connect via loosely configured networks at the local, regional, provincial and national levels to address the complexities of ASD. The critical challenge is that most of these networks operate in silos, rarely aware of the existence of others.

Some significant investments in autism programs and treatment have been made at the provincial/territorial and federal government levels. To date, these investments have mostly targeted 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.

The autism community has an opportunity to create efficiencies by increasing coordination and collaboration between program and service delivery partners, reducing duplication of services in the sector, creating greater equities, and improved use of limited resources. The CAP approach also creates opportunities for many individuals, along with their families and caregivers, to benefit from the efforts of decision makers to enhance coordinated and timely support, thereby reducing the frustration and isolation that can accompany their search for appropriate and effective intervention. See Appendix A for further details on Autism in Canada, 2016.

It is for these reasons that, under the leadership of CASDA, the autism community has united to propose the Canadian Autism Partnership (CAP). Stakeholders across the country concur with the following vision, mission and principles:

### **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

It is for these reasons that, under the leadership of CASDA, the autism community has united to propose the Canadian Autism Partnership (CAP).

## **ESTABLISHING THE CANADIAN AUTISM PARTNERSHIP USING THE COLLECTIVE IMPACT FRAMEWORK**

A foundational component to establishing the Canadian Autism Partnership (CAP) is the implementation of the Collective Impact Framework. This platform will embrace a new and emerging Collective Impact approach to social change. Collective Impact is a framework used to tackle deeply entrenched and complex social problems. 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>11</sup>

9 During the stakeholder engagement process, stakeholders across the country identified innovative and emerging practices in their communities. These have been detailed and can be found in a companion document – *Stakeholder Engagement, Analysis of Findings, Stakeholder-Identified Innovations by Provinces & Territories*

10 Asset Map of Resources for Autism Spectrum Disorders (ASD) Research In Canada; Judy Bray, Cynthia Carroll and Margaret Whelan; October, 2016 (prepared for CASDA)

11 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>

The five key elements of the Collective Impact Framework are:

1. All participants have a common agenda for change including a shared understanding of the problem and a joint approach to solving it through agreed upon actions.
2. Collecting data and measuring results consistently across all the participants ensures shared measurement for alignment and accountability.
3. A plan of action that outlines and coordinates mutually reinforcing activities for each participant.
4. Open and continuous communication across the many players to build trust, assure mutual objectives, and create common motivation.
5. A backbone organization with staff and specific set of skills to serve the entire initiative and coordinate participating organizations and agencies.

See Appendix B for further information about Collective Impact.

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. In fact, the CAP Project itself became an example of Collective Impact at work and is described below.

## CAP COLLECTIVE IMPACT PROCESS

The CAP Collective Impact Process 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. CAP activities follow the process validated by input and feedback from the stakeholder engagement process. The chart and descriptions on the following page illustrate how the Collective Impact model has been adapted to build a made in Canada process for selecting and addressing complex issues facing Canadians living with ASD.

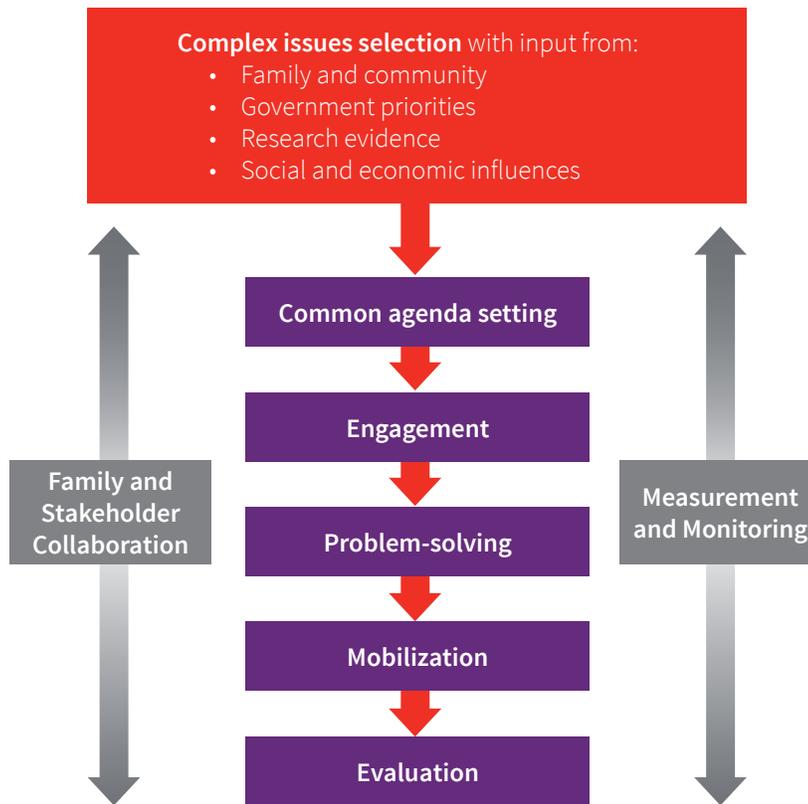
The CAP Collective Impact Process starts with an assessment of pressures and priorities identified by community stakeholders, research evidence, and government priorities. A review of the individual, family, societal and economic impacts of the issue being considered will be completed by CAP and supported by the Advisory Council who will make recommendations regarding the selection of a Complex Issue to be addressed by CAP. The subsequent activity to achieving Collective Impact follows four phases – common agenda setting, engagement, problem-solving and mobilization. These phases are driven by collaboration and partnerships, ultimately leading to systemic change and better outcomes for individuals and families.

The final phase in the process is the evaluation phase, to determine the collective impact for autistic individuals, families, governments, service providers, and communities. The grey arrows on either side of the process diagram show the two activities that are ongoing throughout the process – collaboration with families and stakeholders, and planned measurement and monitoring. Evaluation activity will be evident at every phase of the CAP Collective Impact process.

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

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.

## CAP Collective Impact Process



### The CAP Project as an Example of Collective Impact at Work

The CAP Project, earlier identified as Phase I of CAP, introduced the Collective Impact social change model and methodology to stakeholders. Through the extensive stakeholder engagement process, the Collective Impact model was adapted and refined to reflect the aspirations and objectives of a fully operational Canadian Autism Partnership. As Phase I of CAP draws to a close, it is apparent that the CAP Project itself proved to be an effective example of Collective Impact. The CAP Project activity followed the flow of activity as outlined above.

The **Complex Issue Identification** phase began in February, 2015. CASDA, its members and a group of political leaders met to identify barriers to advancing the opportunities for greater collaboration across the country, to reducing the isolation of families, professionals and governments as they strive to enhance the outcomes for individuals with ASD and

to addressing the systemic challenges which continue to undermine full participation of Canadians with ASD in our society. The result of these conversations and consultations was the proposal for a Canadian Autism Partnership. With the announcement of funding through the Department of Health, the issue was refined, resulting in the plan for the CAP Project.

Having identified the complex issue, work began on the development of a **Common Agenda**. This phase included a draft outline of what the CAP Project could do, followed by an interactive presentation at the CASDA Autism Leadership Summit in April 2016 with 170 leaders from the Autism community and meetings with relevant Ministers whose portfolios had direct impact on the lives of Canadians with ASD. Based on these sources, further refinement of the objectives and performance indicators of the CAP Project were made, forming the basis for the development of the Stakeholder Engagement plan. The contract negotiations with

Public Health Agency of Canada (PHAC) set the goals and outcome measures into the contract between CASDA and PHAC.

The **Engagement** Phase began following the Leadership Summit. Meetings with all 13 provincial and territorial governments, through their representatives (elected leaders and/or bureaucrats) with responsibility for ASD, community round table consultations sessions with community leaders from all provinces and territories and an on-line survey resulted in the participation of 4,963 Canadians in the discussion of a model for a Canadian Autism Partnership.

The **Problem Solving** phase included feedback from stakeholders in all three modes of engagement. Refinements to the process flow model, improvements to the language used in the documents and overall support for the vision, mission and principles for a CAP continued throughout the stakeholder engagement process, with each session adding onto the work of the previous session. The end result was a systemic change model that resonated with stakeholders and a commitment to a business plan for CAP built on consensus.

The **Mobilization** Phase for the CAP Project developed in an organic manner. Within stakeholder meetings and round table consultations, attendees began to identify ways in which they could begin to use the principles of Collective Impact immediately, within their communities and organizations. Similarly, the Project Co-Directors were able to facilitate partnerships and collaboration between service providers and other stakeholders based on problem identification discussions. As an unplanned outcome of the CAP Project, two northern communities were able to connect with new partners and set out new ways of addressing specific issues related to identification and support services. As well, the Directors were able to provide information and linkages to government representatives of initiatives occurring in other jurisdictions which could enhance their own work on specific ASD related issues.

The feedback loop built into the CAP Project supported the mobilization by stakeholders across the country, resulting in a strong expectation that the CAP business plan would move forward and

would result in approval for a Canadian Autism Partnership. The Working Group, Self-Advocates' Advisory Group and CASDA Board provided on-going review, feedback and input into the final version of the business plan for submission to the Minister of Health.

## 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 below.

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

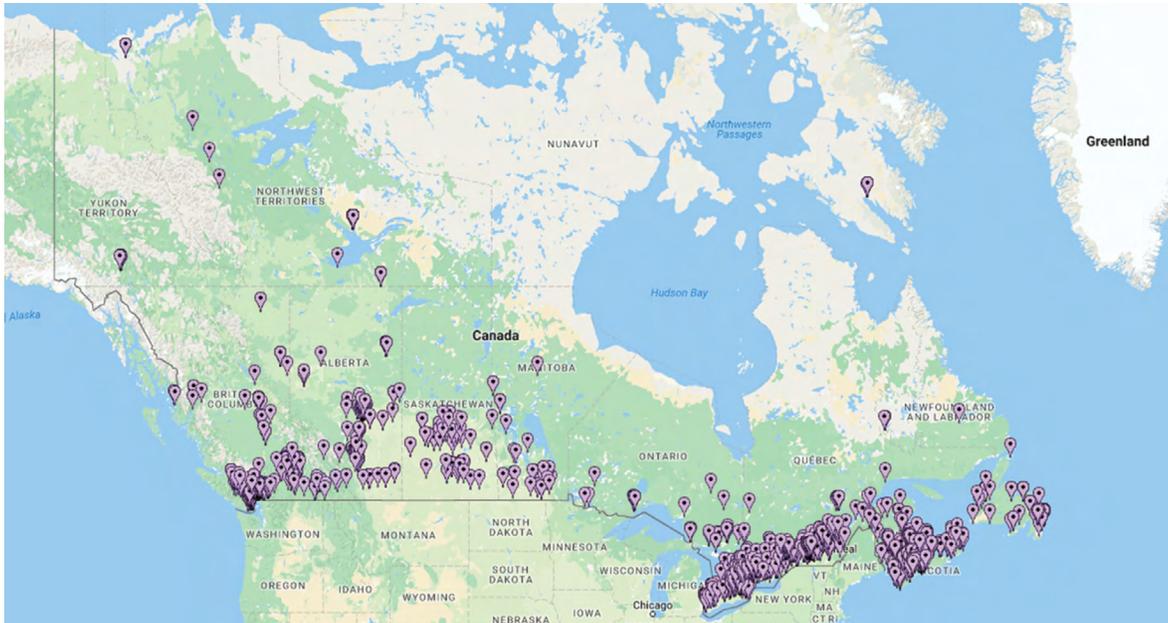
- Early identification and early intervention;
- Employment;
- Interventions and services to optimize quality of life at all ages;
- Specialized medical care, including access to dental and mental health services; and
- Education, including transitions to work, post-secondary education and independent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

A summary of the stakeholder engagement process and the findings can be found in Appendix D.<sup>12</sup>

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<sup>12</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.

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.



Detailed Map of Respondents by Postal Code

## Complex Issues Initiatives (CII)

Building on the priority areas identified by Canadians in the consultation process, the selection of the five complex issues below were influenced by:

- Frequency of identification by stakeholders;
- Current priority areas of focus and investment by varying levels of government;
- Current state of research and evidence on the issue; and
- Current best practices and innovations that could be leveraged to provide more equitable access to support, intervention and care.

Embedded within each CII is 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.

Below is a description of the why and how CAP proposes to take action in the first five (5) years of its operation, on issues within each of the broad priority areas identified above. The first two CIIs present immediate opportunities to move forward quickly given the work already underway in both early identification of ASD and employment. The

latter three will be reviewed and validated once CAP is functional with initiation anticipated during the second year of operation.

### ***CII#1 – Enhancing Practice Related to Early Identification of ASD***

By building on work done to date within the Public Health Agency of Canada, this Early Identification Complex Issue Initiative can be launched quickly. Harnessing the current momentum, further activity to address this complex issue and creating standardized ASD screening and identification guidelines will allow for improved access to intervention and support at the earliest possible time in a child’s developmental track, opening up the potential for earlier intervention and positive impact on the developmental trajectory for children identified with ASD. This activity also introduces opportunities for new Canada-wide and non-traditional partnerships, and significantly broadening the scope for collaboration, resulting in greater collective impact.

### ***CII#2 – Enhancing Employment Opportunities***

A variety of employment issues were identified among stakeholders, including: inhibitors to employment among autistic people; transition to employment from high school; the implications of unemployment and underemployment; and impacts in senior years. Seeking solutions to labour force issues is among the highest priorities for every

provincial and territorial government, as well as for the federal government. Further, a number of P/T government representatives identified employment initiatives in the planning or early implementation stages. There are already two national autism-related programs underway that relate to employment, providing opportunities for ready partnerships. Because of its prevalence, the many issues related to employment, and the opportunities for partnerships, this was designated as the second priority issues for CAP to tackle in detail during the first years of CAP.

### ***CII#3 – Housing Options***

The unique needs of Canadians with ASD and accommodations which are necessary to facilitate optimal success over their lifetime were identified as broad systemic challenges. Options for appropriate housing, access to and support for participation in recreational and leisure activities, as well as social and life skill supports were recognized as central elements for achieving the quality of life enjoyed by most Canadians, but which remain beyond the reach of many Canadians with ASD.

Safe and affordable housing is clearly a basic need for all Canadians. Individuals on the autism spectrum have specific needs, unique to their autism symptoms, making successful housing options illusive at best and disabling at worst. This complex issue also aligns with current government priorities, at all levels of government across the country. The Collective Impact process related to this diverse priority area will begin with comprehensive activity at the Common Agenda phase.

### ***CII#4 – Access to Specialized Mental Health Supports***

The National Needs Assessment Survey (NNAS) reported that “across all age groups the presence of mental health issues was significant, with anxiety and depression reported at levels that are high enough to be of real concern when planning for services and looking at what further role the health sector has to play in the ASD service network”<sup>13</sup>. Similarly, the community stakeholder consultation sessions identified the interaction between mental health and ASD as one of the top priority areas of focus for CAP. The recently formed Canadian Mental Health Commission (CMHC) is well positioned to partner with CAP to initiate activity in this important area.

As a Complex Issue Initiative, access to and the range of mental health intervention options will be the focus of comprehensive activity during the Issues Selection and Common Agenda phases.

### ***CII#5 – Education***

The educational challenges faced by Canadians with ASD are profound. At each educational milestone, autistic children and adults face barriers to maximizing their educational experiences and successes. As this is a very broad and wide-ranging issue, during the first five years of CAP, education will be identified as a Complex Issue Initiative requiring extensive collaboration and partnering to select the specific issues with which to start, and will require comprehensive Issue Selection and Common Agenda activity.

## **Conclusion**

The identification of these top priorities closely reflects the priorities identified in the 2014 National Needs Assessment Survey. They remain the top priorities today for Canadians living with ASD or working in the ASD sector. Getting this confirmation through feedback from 5,000 Canadians during the 2016 CAP consultation process provides a strong message about the importance of taking action to address these systemic issues now. Effectively addressing these issues will have enormous positive social and economic impacts for individuals with ASD, families, and Canadian society as a whole, while improving long-term outcomes for individuals with ASD and their families.

## **How Collective Impact will be put to Work by CAP**

For purposes of this proposal, two of the identified priority complex issues, CII#1 and CII#2, were selected to demonstrate how the framework for Collective Impact will be applied and how activity and resources will be organized to lead to action on problem-solving and systemic change. Detailed descriptions of Enhancing Practice Related to Early Identification of ASD and Enhancing Employment Opportunities in ASD are found in Appendix E.

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13 NNAS, page 037

Effectively addressing these issues will have enormous positive social and economic impacts for individuals with ASD, families, and Canadian society as a whole, while improving long-term outcomes for individuals with ASD and their families.

## ENGAGEMENT WITH INDIGENOUS PEOPLES

In 2014, the National Needs Assessment Survey identified a significant gap in services for Indigenous Peoples across the country, in both remote and urban areas. During the first phase of the CAP project, ways of engaging with various Indigenous Communities have been explored and some progress has been made. It is clear that the need is great and resources are scarce or, more often, non-existent. For example, representatives from government in Iqaluit and the Nishnawbe Aski Nation (NAN) in Thunder Bay, Ontario identified the practical barriers they face associated with having a very large number of fly-in communities where access to professionals is extremely difficult. Across northern, remote and Indigenous communities, barriers exist due to social inequities. This is especially evident in the identification and diagnosis experiences.

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. To move forward, a unique Indigenous Engagement Strategy will be developed that will include:

1. Development and implementation of a separate and distinct engagement strategy, informed by representatives of Indigenous communities. Lead by guidance and input from Indigenous leaders, activity will be initiated in a manner that reflects the cultural values of the Indigenous communities.
2. Specific outreach and engagement with, and inclusion of, Indigenous Peoples in all of the Complex Issue Initiatives identified above, and any other priorities that CAP addresses. A parallel process will be developed if required or requested.

## ENGAGEMENT WITH NORTHERN AND REMOTE COMMUNITIES

Community stakeholders from northern and remote communities, and government representatives alike, identified the need for careful consideration of the unique needs of these communities. Widely dispersed populations, scarce resources and challenging access to existing services all conspire to create systemic barriers to inclusion and access to necessary services and supports. All governments with northern/remote ministerial portfolios identified the need to be more effectively connected so they can coordinate their efforts. They also identified that a unique benefit of CAP would be the opportunity to work with other jurisdictions to develop best practices, and then get support and assistance to adapt these practices to the realities of their communities. As well, the capacity to partner with other organizations and jurisdictions to share their expertise was seen as a strength of the CAP partnership approach.

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.

# 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 Working Group (WG) recommended that the Canadian Autism Partnership be established as an independent federally incorporated entity. The CAP overall accountability structure consists of:

### Governance

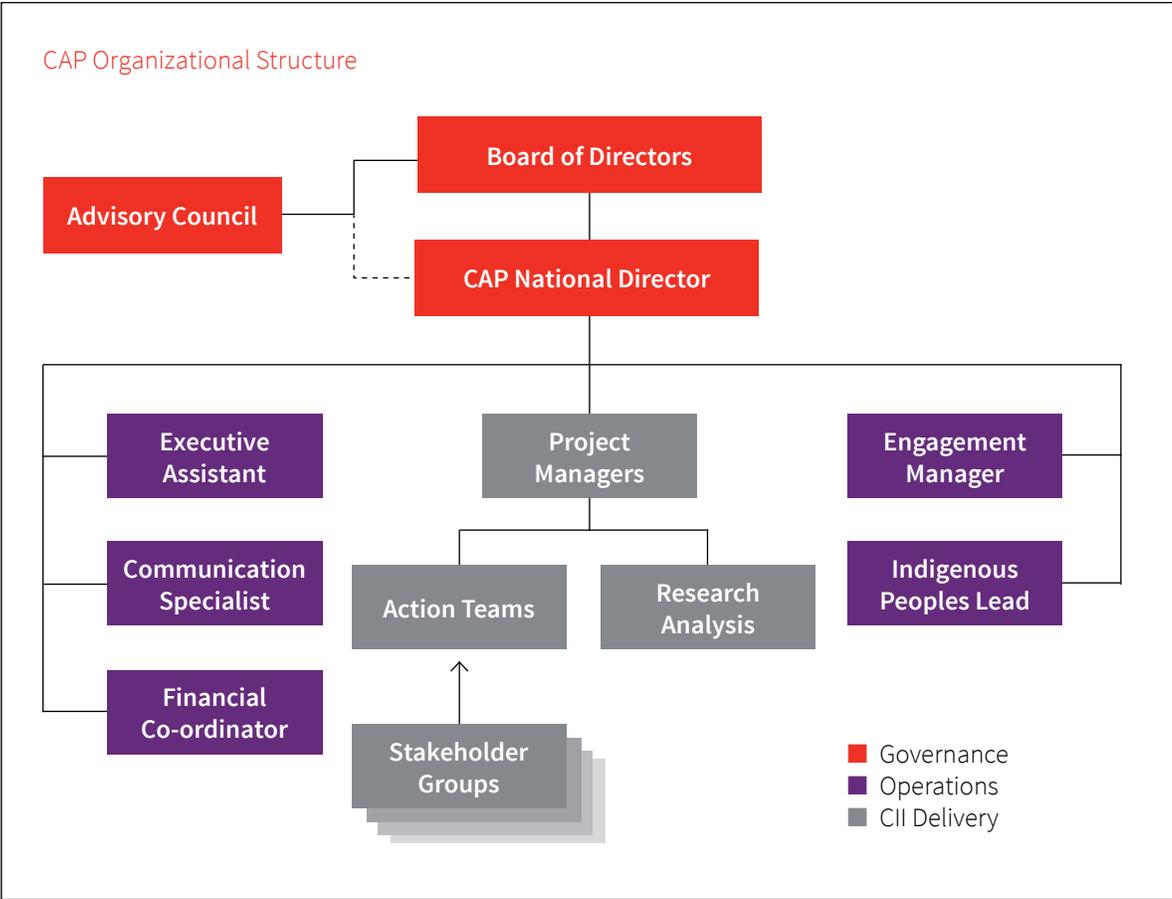
**Board of Directors** – the governance and oversight body, including a robust committee structure.

**CAP** – the operational structure that selects and addresses complex issues and conducts outcome evaluations, led by a National Director.

### Community

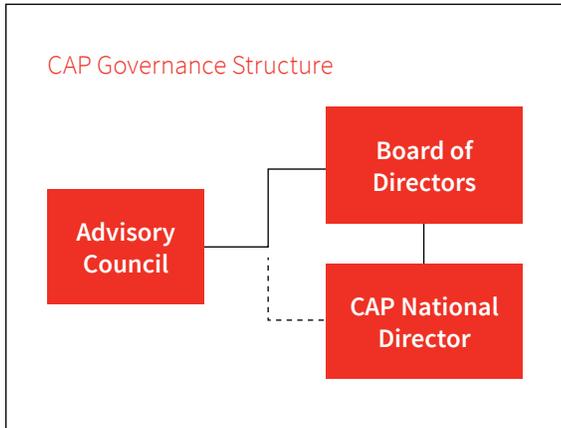
**Advisory Council** – consists of leaders from within the autism community to provide input and advice to CAP.

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



## GOVERNANCE

The graphic below provides an overview of the CAP governance structure.



### Board of Directors (BOD)

During the start-up period while the CAP Board is being recruited and oriented, and for approximately 18 months, or as required, the CASDA Board will assume fiduciary and implementation accountability for CAP. It will engage a governance expert and a recruitment firm to assist with:

- Drafting the Board's terms of reference and bylaws;
- Developing the structure and composition of the Board to reflect a diverse and broad spectrum of relevant expertise, geographic representation, and gender and cultural balance, and ensuring that the collective skills of the group bring sufficient breadth to the Board to allow it to provide necessary direction and guidance to the CAP National Director;
- Designing a robust committee structure that includes operations, finance and audit, nominations, governance, and other appropriate committees; and
- Conducting a transparent and unbiased Board recruitment process.

Once the CAP Board is fully functional, it will be directly accountable to CAP funders and will function as the governance and oversight body of the Canadian Autism Partnership. It will be comprised of 10 to 15 individuals, which will include three

permanent seats for representatives from CASDA, Autism Speaks Canada and Autism Canada, and up to 12 other members.

The CAP Board's accountability may include recruiting and hiring the National Director, depending on the amount of time it takes to recruit the Board. This responsibility will more likely fall to the CASDA Board with support from the interim National Director, discussed below.

The CAP Board will, however, provide ongoing oversight and monitor the National Director's performance. The Board will also be accountable for ensuring performance and progress of the Collective Impact Initiatives, and evaluating impact in the field through defined performance indicators and outcome measurements described later in this plan. Monitoring, measurement and impact evaluation will be carried out throughout all phases of CAP activity on an ongoing basis. A third party evaluation will occur at the end of the first five years of operation.

### CAP National Director

The National Director will be the face and the voice of CAP. They will be accountable for bringing together experts from across the country to provide guidance and input to CAP's initiatives and to mobilize the solutions through the Stakeholder Groups and Action Teams. The National Director will build the CAP staff team, processes and tools to move the initiatives forward. This individual should be well regarded in the autism community, have previous similar organizational start-up experience, and the capability and capacity to build relationships, motivate teams and achieve successful outcomes.

An Interim National Director will be engaged for the start-up phase and until the permanent National Director has been hired and on-boarded, as described in detail in Chapter 4 – Implementation. The Interim National Director will support the CASDA Board with recruitment of the CAP Board of Directors and the National Director and other start-up activities. This will ensure the momentum gained in Phase I of the CAP project continues seamlessly into Phase II.

## Advisory Council

The CAP Advisory Council will consist of a minimum of 8 and a maximum of 12 individuals comprised of leaders and experts from across the country, ensuring diversity and balanced representation of areas of expertise, as well as the voices of individuals on the autism spectrum and caregivers. Advisory Council members will be recruited through a well-defined, transparent nomination and selection process. Their activities will be guided by the Terms of Reference.

This group is critical to the success of CAP and the Complex Issues Initiatives. Its contribution will be through its deep roots in the autism and related communities, knowledge and expertise, and the relationships the individual members bring to the CAP table.

The Advisory Group's role will include:

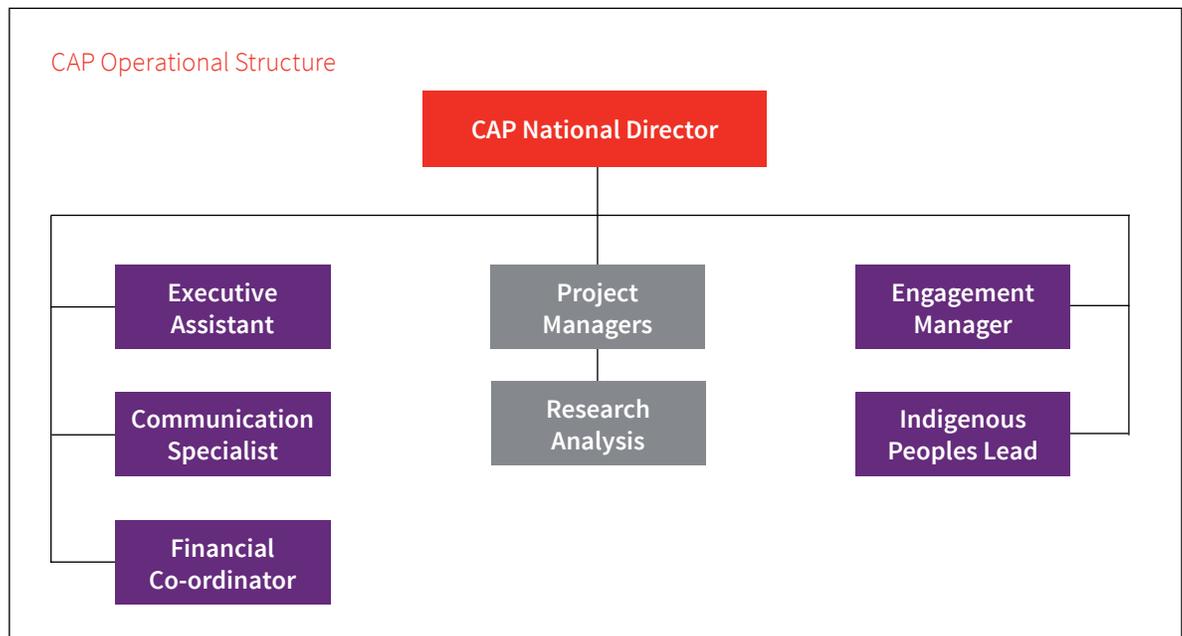
- Making strategic recommendations related to the Complex Issues Initiatives, in partnership with the National Director;
- Providing input and guidance, informing, trouble shooting and advising the Action Teams charged with addressing the Complex Issues Initiatives (CIIs); and
- Identifying and assisting with securing private and/or public funding.

## CAP OPERATIONS

The graphic below provides an overview of the CAP operations. Role descriptions can be found in Appendix G.

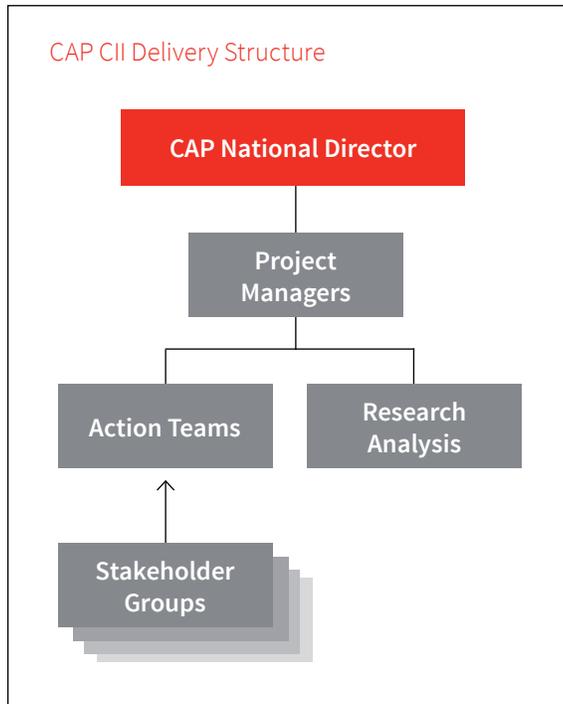
In addition to the National Director, CAP resources will include a staff team that is responsible for administration; communications; engagement, including engagement with Indigenous Peoples; complex issues initiatives; and evaluation.

Once CAP is fully operational and the CIIs are underway, it is anticipated that in addition to the National Director, there could be up to 11 FTE positions, recruited over the first 18-24 months. The Project Managers' and Research Analysts' time will be committed to working within the Complex Issue Initiatives; they will be recruited and hired as these initiatives are launched and determined by the volume of work.



## Collective Impact Initiatives (CII) Delivery Structure

The graphic below provides an overview of the CII Delivery Structure within the operations of CAP.



Every Complex Issue Initiative will be managed within a delivery structure that is overseen by the CAP National Director, managed by a Project Manager and resourced with a Research Analyst and an Action Team of subject matter experts drawn from the CAP Stakeholder Groups.

### Stakeholder Groups and Action Teams

Stakeholders, through affiliation with a Stakeholder Group, will provide the direct connection to the communities needed to participate in the CIIs. An initial list of these communities includes: individuals with ASD; families; Indigenous Peoples; researchers; inter-governmental leaders; and service providers. This list will evolve as CAP starts up its operations and begins to build the organization.

The role of the Stakeholder Groups includes:

- Identification of individuals within each respective group and subject matter experts to participate on the CII Action Teams;
- Sharing innovative and emerging practices from within their communities;
- Disseminating solutions into their respective communities; and
- Acting as a peer-to-peer communication and collaboration platform.

Action Teams will be primarily recruited from within the Stakeholder Groups, but could include other expertise, depending on the issue being addressed. Individuals recruited to the Action Teams will bring subject matter expertise to address the given complex issue. They will be actively engaged in working to find optimum solutions to the complex issues and to develop mobilization and implementation plans. Action Teams will work closely with the staff Project Managers and Research Analysts.

### CASDA'S COMMITMENT

As described previously, CASDA will be accountable for the start-up phase of CAP. It will assign a start-up team that will report to the Board. This team will work closely with the interim National Director, the recruitment firm and the governance expert to ensure the governance of the new organization is built on a solid foundation before transitioning accountability to the new CAP Board at an appropriate time.

CASDA is fully committed to ensuring that CAP will be successful and for that reason, if the proposed governance structure is not a viable option, the CASDA Board and the autism community will work with the Government of Canada to ensure the successful development and implementation of CAP within a governance structure that meets the goals and objectives of CAP as laid out in this document, and that provides the Government of Canada with the assurances necessary for responsible governance and accountability.

CASDA is fully committed to ensuring that CAP will be successful.

# Implementation

## TOOLS & TECHNOLOGY

CAP will require a variety of tools and technologies, some of them internal to CAP and others required to facilitate collaboration, therefore needing to be accessible to partners and stakeholders. Some of these include:

- A fully accessible website/portal;
- A knowledge repository/database that captures data related to the CIIs and other key information;
- Standardized project management tools, technology and approaches;
- Meeting protocols and adoption of a collaboration platform (e.g., WebEx, GoToMeeting, or others on the market);
- An overall communications strategy for CAP and individual communications plans for each CII;
- A guide for standardizing and facilitating recruitment and engagement of groups and individuals, establishing communications and meeting protocols, and providing a template for terms of reference; and
- Standardized practices for national and international collaborations (where they do not exist today) to develop, maintain and grow partnerships and relationships.

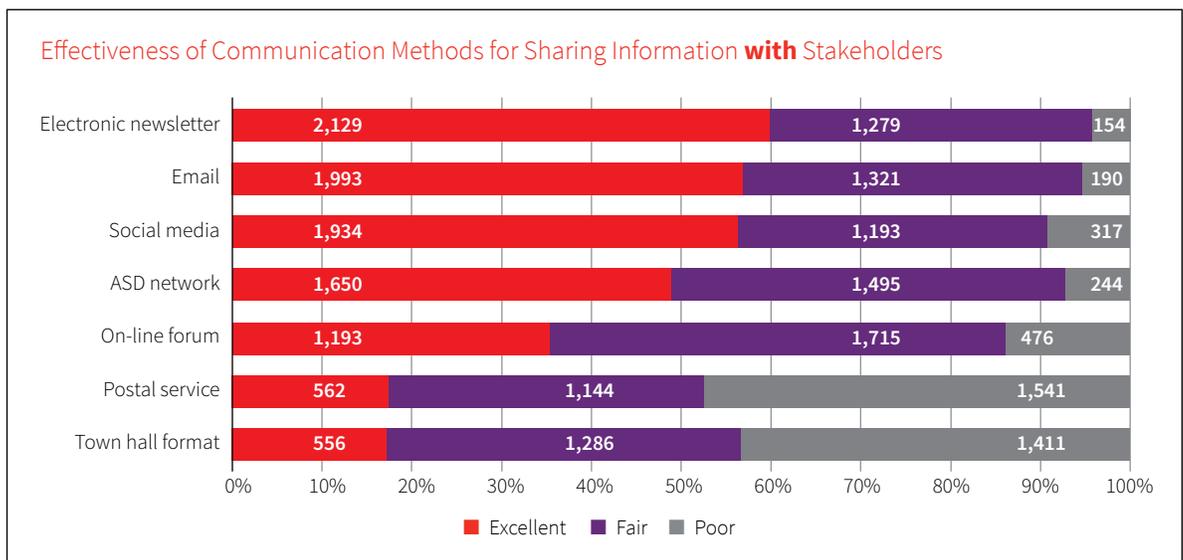
As part of its engagement strategy, CAP will make research, information, and data it gathers and synthesizes readily available to a wide and diverse audience.

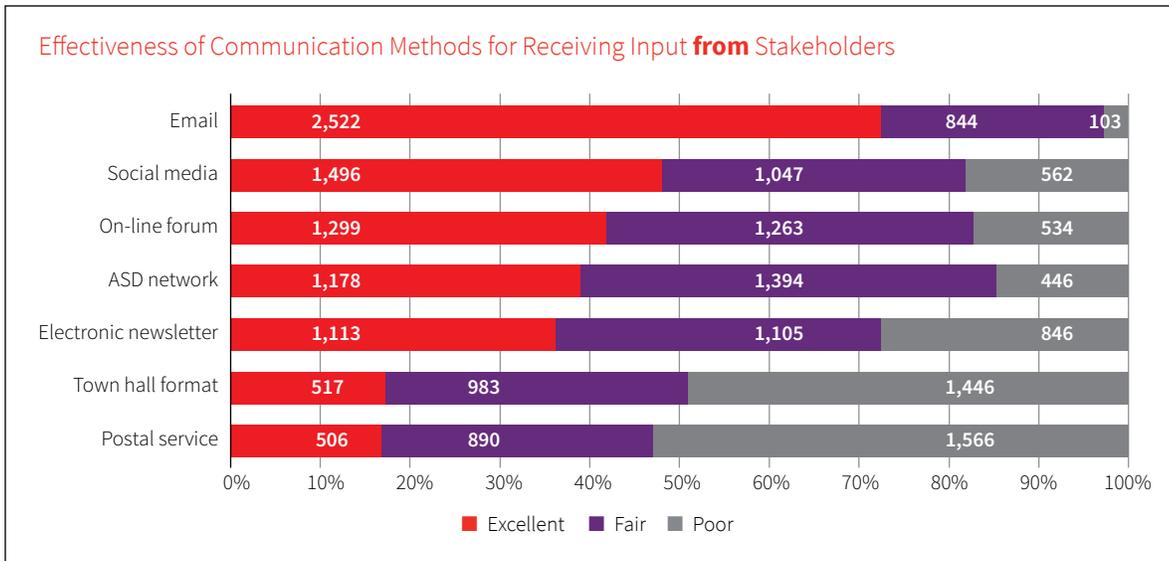
## COMMUNICATIONS & ENGAGEMENT STRATEGY

Communications and engagement are key to the success of the Canadian Autism Partnership (CAP) and the Complex Issue Initiatives (CII). CAP will need to communicate and engage with a diverse group of stakeholders across a variety of platforms, requiring a sophisticated communications and engagement strategy.

As part of its engagement strategy, CAP will make research, information, and data it gathers and synthesizes readily available to a wide and diverse audience. As it consults and engages with stakeholders across the country, it will develop cost effective communication mechanisms to do so. These will include some face-to-face interaction, electronic (e-mail, social media, and collaboration) tools, and paper/mail. Communications and engagement also will include development of the stakeholder groups, relationship building with all levels of government and public relations.

The CAP online survey solicited respondents' preferences around receiving communication and providing input into the organization's work and have driven the planning related to the communications modalities. Results are ranked in the two charts below.





## FACILITIES

While no specific location for CAP has been determined, being centrally located in Toronto or Ottawa provides certain advantages including ready access to federal decision-makers, and easy access for partners and stakeholders. Ideally, CAP will find a venue where it can co-locate with a synergistic organization (whose mandate aligns with that of CAP) to share common space and resources, with the provision that there is a clear distinction between the operations of the two organizations and the autonomy of CAP is not compromised. However, space in an executive office centre may be a more efficient and flexible option.

## PRELIMINARY IMPLEMENTATION PLAN

### Start-Up Activities

CASDA will engage an interim National Director as soon as the commitment for funding is received. This individual should have leadership experience in organization start-ups or managing large projects. This interim role is time limited to support the CASDA Board in recruiting, hiring and on-boarding a permanent National Director. Ideally this position would not exceed nine months.

During this period, the interim National Director will move forward quickly with launching CAP. Activities during the start-up period include the following:

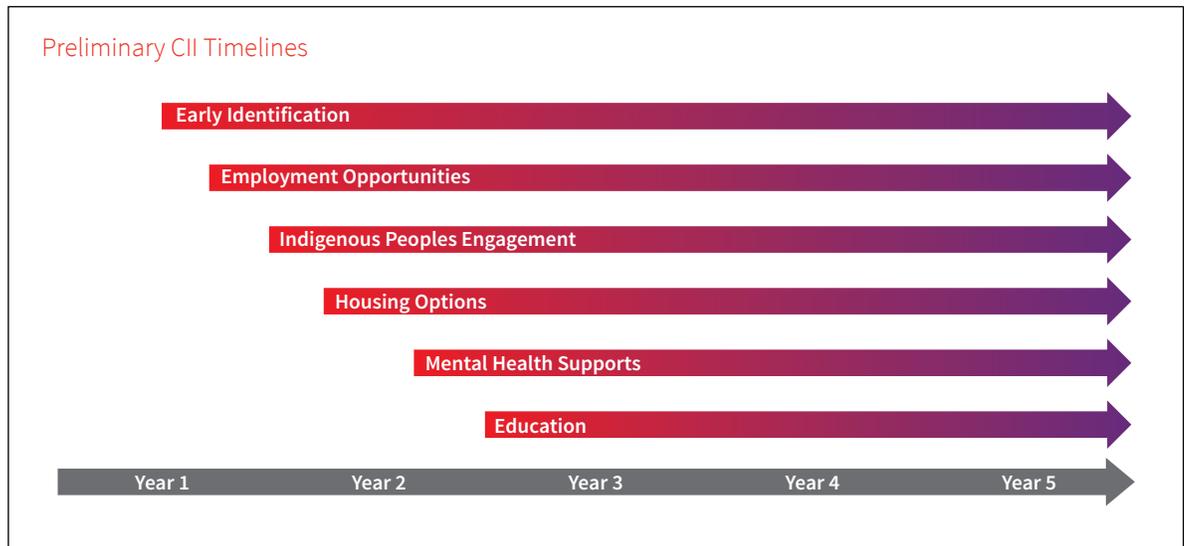
- Supporting CASDA with development of the CAP governance structure and recruitment of the CAP Board of Directors and National Director;
- Recruiting and hiring a core group of resources to carry out administrative, communications, and project management activities;
- Further developing the CAP Collective Impact Process;
- Initiating development of detail related to outcome measures;
- Initiating development of the stakeholder groups;
- Launching the first two Complex Issues Initiatives;
- Initiating the development of the Indigenous Engagement Strategy;
- Defining and developing the website and data repository;
- Developing a draft operational plan and budget for the first five-year period; and
- Initiating development of the communications and engagement strategy.

While this is a comprehensive list of activities, there is a sense of urgency. The effort required to tackle the complex issues, and to engage with and to fully understand the needs of Indigenous communities is significant. As a result, initially CAP operations may be supplemented with contract/consulting resources to allow the team to move forward quickly and efficiently within the time lines allotted in the proposed funding cycle.

## Preliminary CII Timelines

Over the course of the first five-year period, the Canadian Autism Partnership will address five complex issues to varying degrees, and develop and initiate an Indigenous Peoples engagement strategy. Two of the complex issues will be initiated within the first year and will run the full course of the process from the common agenda phase to the evaluation phase. Similarly, engagement with Indigenous Peoples will commence in the first year. The remaining three complex issues will be validated and initiated throughout year two and early in year three. They include housing, mental health supports and education.

The timeline chart below provides a visual overview of the phased approach to addressing these complex issues.



# Performance Indicators & Outcome Measures

## CAP PERFORMANCE INDICATORS

CAP's performance will be defined, monitored and measured against a set of performance indicators that will be developed for CAP, as the backbone organization, in the start-up phase of CAP and will be defined for each CII in the Common Agenda phase, as they are undertaken. The key performance indicators have been organized into three domains under which all CAP responsibilities fall:

- Guide vision and strategy;
- Support and align activities; and
- Measure and monitor process & evaluate impact.

Each of these domains has been categorized into specific sub-domains based primarily on the CAP Collective Impact model.<sup>14</sup>

## GUIDE VISION AND STRATEGY

### *Vision & Strategy*

- CAP's vision, mission and strategy is clearly articulated, communicated and understood within the autism sectors.
- Key leaders and decision-makers increasingly look to CAP for initiative support, strategic guidance and leadership.
- CAP's strategy continues to move forward reflecting priorities identified by stakeholders in the autism sectors.

## *Complex Issues Selection*

- Partners identify potential issues to determine priorities for action, based on community and government priorities and analysis of potential impact.
- Parameters for complex issues are clearly defined.
- Partners agree that selected issues are priorities to be activated under the CAP Collective Impact process.

## SUPPORT AND ALIGN ACTIVITIES

### *Common Agenda*

- Environmental scan is undertaken and informs articulation of the common agenda.
- Partners can accurately describe the common agenda.
- Partners publicly discuss/advocate for common agenda goals and objectives.
- Expected outcomes for the Complex Issue are defined.

### *Stakeholder/Partner Engagement*

- Relevant stakeholders are recruited and engaged in the initiative.
- The voices of autistic individuals and families are clearly embedded in the initiative.
- Partners can articulate their role in the initiative.
- Partners agree on shared measurement practices.
- Partners commit to action in addressing the identified Complex Issues.
- Shared data system is in development.

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<sup>14</sup> The performance indicators have been adapted from the Collective Impact Framework, specifically FSG and Greater Cincinnati Foundation.

### ***Problem-Solving***

- Action groups are formed, with terms of reference and outcomes identified
- Partners make decisions based on data
- Solutions are articulated/tested
- Evidence of practice is identified
- Process for knowledge translation and dissemination is developed
- Shared leadership for next steps is identified

### ***Mobilization***

- Recommendations for action are implemented
- Shared leadership is leveraged to achieve capacity building
- Process for knowledge translation and dissemination is implemented
- Training needs are identified
- Partners' individual work is increasingly aligned with common agenda
- Target audiences (e.g., influencers and policymakers) are increasingly aware of the initiative and proposed action
- Target audiences advocate for changes to system, aligned with initiative goals
- Community members are increasingly aware of the initiative and recommendations
- Community members express support for the initiative
- Community members feel empowered to engage in the issue(s)
- Community members increasingly take action

## **MEASURE AND MONITOR PROCESS, AND EVALUATE IMPACT**

### ***Measurement & Monitoring***

- Measurements are defined and implemented
- Processes and activities are monitored and reported on regularly
- Appropriate actions are taken to respond to deficits/short falls/missed targets

### ***Impact Evaluation***

- Impact measurements are developed and tested
- Public policy is increasingly aligned with initiative goals
- Partners increase scope/type of collaborative work
- Partners' work (individuals and organizations) is increasingly aligned with common agenda
- Partners improve quality of their work
- Partners improve efficiency of their work
- Partners feel supported and recognized for their work
- Funders are asking non-profits to align to initiative goals
- Funders are redirecting funds to support initiative goals
- New resources from public and private sources are being contributed to partners and initiatives
- Autistic individuals and families are reporting improvements

## OUTCOME MEASURES

Outcome measures will be developed based on the over-riding objectives for all CAP activities as identified in the stakeholder engagement process, namely, supporting and developing **Partnerships, Innovations** and **Efficiencies**. The overall outcomes that can be expected from this national asset include:

- 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.

Measurement of Collective Impact outcomes will be developed for each specific Complex Issue Initiative. At recommended intervals and upon completion of each CII Collective Impact process, the outcomes will be measured using a matrix of the above three over-riding objectives and the impact on:

- Knowledge translation and exchange;
- Service development/change;
- Policy development/change; and
- Economic/financial benefits.

Annually, a consolidated report card on the impact outcome measures for all activities will be completed. See Appendix H for a sample of the outcome measurement template.



The background is an abstract, textured composition. The left side is dominated by vibrant red and orange tones, with some darker, almost black, areas. The right side features deep blue and purple hues, with some lighter, white or yellowish areas. The overall effect is that of a layered, possibly marbled or painted, surface with a grainy, organic texture.

# Appendices

# APPENDIX A – Autism in Canada – Snapshot 2016

*Autism in Canada, 2014*, a national ASD needs assessment commissioned by the Canadian Autism Spectrum Disorder Alliance (CASDA), provided an important snapshot of Canadians living with ASD. A total of 5,608 Canadians responded to the survey. These respondents included 3,273 caregivers, 166 self-advocates and 2,104 ASD professionals. In addition to a thorough analysis of the needs and experiences cited by the respondents, the report identified the top five service needs categorized across the lifespan by pre-schoolers, school age children, adults with ASD and self-advocates. Perhaps not surprisingly, the need for social skills programming was prevalent in all four groups, followed by activity based programming in all but the self-advocates' group. Early intervention and behavioural therapy were at the top of the list for pre-schoolers, and life skills training for school age children and adults. Self-advocates identified mental health treatment, employment services, post-secondary education and housing/residential options as their top needs. The detailed report of the findings can be found on the CASDA website ([www.casda.ca](http://www.casda.ca)).

This survey data, combined with the data derived from nearly 5,000 Canadians who participated in the CAPP stakeholder engagement process undertaken during the spring, 2016, now provide the most comprehensive understanding of autism in Canada today. The nearly 5,000 Canadians who participated in the CAPP process were clear that with prevalence statistics on the rise, there is an urgent need for researchers, government systems and community-based organizations to adapt quickly to support the challenges being faced by this growing segment of Canadian society.

## DEFINING THE NEED

Autism Spectrum Disorder (ASD) is the most common neurodevelopmental condition currently being diagnosed, affecting as many as 1 in 68 Canadians<sup>15</sup>. With a 30 per cent increase in diagnoses since 2006, it is clear that autism has a vast and

significant impact on Canadians in every province and territory, across the country.

Based on these prevalence rates, an estimated 1.5% of the population or about 520,000 individuals in Canada are affected by autism or identify as autistic. In addition, immediate families, grandparents and caregivers are also affected; at the most conservative level 1 million to 1.5 million Canadians live with autism, or are impacted by autism every day, representing a large and growing community in need of guidance and service support across the country. These numbers are based on an average of 2.9 people per Canadian family in 2011<sup>16</sup>.

Autism Spectrum Disorder includes a broad range of presentations, from those who are mildly symptomatic to those who are quite severely affected. Accordingly, there is no single solution to addressing the complex issues facing autism today. To complicate the matter further, autistic individuals often experience other health and psychiatric conditions which frequently mask the ASD condition, requiring highly specialized expertise to render an accurate diagnosis.

## IMPACT ON FAMILIES AND CAREGIVERS

The challenges and stresses encountered by families and caregivers are many but their impact on the family unit is perhaps the most significant issue to consider. A diagnosis of autism within a family, and the resulting lack of necessary supports, can cause stress and lead to burnout. Significant, and often, negative impact on the health and wellness of the entire family unit has been well documented. This is especially so among siblings whose needs can become secondary to their ASD family member. Siblings often face the additional pressures of caring for their family member as parents and caregivers age. This can be particularly burdensome in parts of the country where there are few support services in the community.

<sup>15</sup> <http://www.cdc.gov/ncbddd/autism/data.html>

<sup>16</sup> Statistics Canada – [https://www12.statcan.gc.ca/census-recensement/2011/as-sa/98-312-x/98-312-x2011003\\_1-eng.cfm](https://www12.statcan.gc.ca/census-recensement/2011/as-sa/98-312-x/98-312-x2011003_1-eng.cfm); accessed June 11, 2016

Financial pressures can be caused by both increased costs related to treatment and support, and the loss of income when one family member gives up their career to become the primary care provider. It is not uncommon to hear that families have re-mortgaged their homes or drawn down on their retirement savings to pay for necessary supports and interventions.

In addition, with limited coordination within the system across multiple government departments, and a variety of health care and other service providers, families are left to navigate a complicated system themselves with little support for informed decision-making.

ASD is an expensive condition where many of the costs become the responsibility of the family. In 2014, The School of Public Policy from the University of Calgary noted that the lifespan value of caregiver time can be up to \$5.5 million above the costs of raising a child without ASD. Only 27% of respondents in the CASDA survey indicated that the financial support they had received from their province/territory was sufficient to access the services they required.<sup>17</sup> In other words, 73%, or nearly three quarters of the respondents did not receive sufficient financial support.

Autism Nova Scotia recently undertook a literature review into the costs of care and its findings indicate the following:

- “Failing to address the needs of people with autism has an enormous cost. Using figures from studies in the US and Ontario<sup>18</sup> it is estimated that the cost of support for a single generation of people with ASD in Canada could range from \$1.4 to \$8.4 billion CDN. Costs are largely being downloaded onto families and individuals.”
- “One UK study estimates cost at \$1,325 CDN per week, or \$68,900 CDN per year in out of pocket expenses” for families<sup>19</sup>.

- “Parents are also spending as many as 60 hours a week on care—of which 40 hours would otherwise have been spent on other activities. One study showed that families with children with ASD experienced a 28% decrease in family earnings relative to families of kids with no disabilities.<sup>20</sup>

This area of research is just beginning to develop, but evidence is mounting that the loss in productivity and well-being in jurisdictions with poor supports for people with ASD is substantial.

## THE NEEDS OF ADULTS WITH AN ASD

It is now well acknowledged that “...as the prevalence of ASD in the population increases, so too does the incidence of adult diagnoses. Increased awareness about autism means that many people with Asperger’s Syndrome or other “high-functioning” forms of autism, which are largely invisible disabilities or were previously misdiagnosed, and who slipped through the system without a diagnosis as a child, may be diagnosed as adults.”<sup>21</sup>

In 2009, The Centre for Excellence for Early Childhood Development (CEECD) and the Centre of Excellence for Children and Adolescents with Special Needs (CECASN) hosted an adult autism policy forum. It was recognized during that forum that untreated adults with ASD are at risk for serious mental health concerns (sometimes leading to suicide), isolation, addictions, unemployment, and ongoing dependence on aging families, social services, income support, and mental health programs (Policy Forum, 2009)

The intense public and scientific pressures to invest in early intervention treatment have resulted in focussed research and the increase in evidence related to young children, but has limited investment in services required throughout the life span. With increasing prevalence rates, families are demanding reductions in wait lists and more early intervention

17 CASDA, National Needs Assessment Survey, 2014; pages 6-7

18 Governor in Council Education Act Regulations, NS Reg 74/97, accessed on February 16, 2016, <http://canlii.ca/t/52fq>.

19 K. Jarbrink, E. Fombonne and M. Knapp, “Measuring the parent, service and cost impacts of children with autistic spectrum disorder: A pilot study,” *Journal of Autism and Developmental Disorders* 33, 4 (2003).

20 Xiong, N. et al., “Investigation of raising burden of children with autism, physical disability and mental disability in China,” *Research in Developmental Disabilities* 32 (2011): 306-311.

21 D. V. Bishop. and A. J. Whitehouse, H. J. Watt, E. A. Line, “Autism and diagnostic substitution: evidence from a study of adults with a history of developmental language disorder,” *Dev Med Child Neurol.* March 31 (2008)

services. At the same time, those who were among the first to receive early intervention therapy some 15 years ago are now transitioning from high school to employment, from adolescence to adulthood. The dearth of service options at this time in the lifespan, often referred to as ‘the service cliff’, has become increasingly apparent. Stakeholders across the country in every community indicated that when a young adult leaves the school system, there are essentially no services available in the community, leaving young people with an ASD without a way to navigate the transition from school to work or other adult activities.

However, diagnostic services and interventions for older autistic individuals are also generally lacking or not accessible across the country. In particular, employment supports were identified as being essential. Provincial and territorial employment policies and services vary across the country but regardless of location, families and individuals with ASD reported frustration with the inadequacy of supports. This is not surprising, given that a significant number of respondents to the National Needs Assessment Survey of 2014 and participants in the most recent stakeholder engagement process indicated that they or their family member with ASD are either unemployed or underemployed. This becomes even more problematic as adults transition into their senior years and find themselves with little or no pension benefits or other financial resources because of their poor employment history.

Results from the National Needs Assessment Survey identified troubling questions about increased health care issues for adults with ASD due to lack of early identification of health issues such as seizures. Over 50% of the respondents reported treatable mental health conditions among adults with ASD including anxiety, depression and ADHD, but a concomitant lack of availability of youth and adult based mental health and transition services to address these issues. Coordinated research and evaluation is required to develop standardized treatment guidelines related to these needs.

This all points to a significant and wide-spread lack of life-long planning for Canadians with an ASD. Transitions occur throughout a person’s life from early years to school age, elementary to high school, high school to employment or post-secondary education, and later in life from middle age to senior years. Planning and support for each transition is essential to success. Governments are left to manage these many and often conflicting demands and to make difficult decisions about where to invest their scarce resources, often in the absence of evidence-based data and information.

## SERVICE AND COLLABORATION NEEDS

This dramatic increase in identification of Canadians with ASD has created an unsettling reality, with every jurisdiction across Canada struggling to have their service offerings keep up with the rapid influx of new diagnoses. For the most part, the provinces and territories have found themselves working in silos – independently forming strategies to address autism the best they can with the information and resources they have.

The result is widely varying levels of support and inconsistent responses across the country, creating serious inequities across Canada. Furthermore, services vary within each province; with the availability of professionals diminishing the further one goes from an urban centre. Regardless of location, barriers increase and become more complex when addressing the needs of culturally and linguistically diverse communities.

Further exacerbating the inconsistencies in services is the absence of standardization in the training or qualifications of service providers across the country. The professionals who can diagnose vary by province, and the number and type of qualified professionals is dependent on where you live in the country. For example, behavioural specialists, specifically Board Certified Behaviour Analysts (BCBA), are not recognized in every province, making it difficult to train and retain qualified professionals in some parts of the country. Even within a given province, there is a lack of standardization. In BC, for example, “there are no qualification and experience requirements for Behaviour Interventionists and the qualifications and experience for educational support workers varies from school to school and district to

district”<sup>22</sup> Furthermore, there is a shortage of trained mental health professionals who understand ASD and among those who are available, impending retirements pose even greater challenges for the system as there is a limited number of new professionals coming up the ranks.

Feedback from stakeholders in every province and territory has shown that there is limited collaboration across the provinces and territories (P/T), between levels of governments (Federal/ Provincial/Territorial (F/P/T/)) and sectors. There is no formal structure to support collaboration in any systemic way resulting in many silos not only from a pan-Canadian perspective but also within communities and provinces/territories. Government officials across the country confirmed that there is a renewed appetite for cross-governmental collaboration with the current federal government and among P/T governments, presenting an opportunity to build a new network of collaborative partnerships. All provincial governments have acknowledged that having a greater network of colleagues and professionals, providing greater access to evidence-based information and best practices, would be an efficient and valuable asset to their decision making process. The Federal government is positioned to play a critical role in coordinating this strategy and leading the way for better collaboration.

## RESEARCH, DATA AND INFORMATION ACCESSIBILITY

CASDA’s CAP Project consultations confirmed that families; decision-makers in government, communities and organizations; researchers, and service providers across the country are keenly interested in having ready access to the latest research, data and information. Comprehensive evidence-based autism related data and information regarding complex issues, at present, is not widely disbursed and generally not readily accessible. The need for access to knowledge translation and exchange is essential in a country as diverse and expansive as Canada.

Stakeholders across the country are engaged in developing and using innovative and emerging practices in communities and organizations with little opportunity to share them, resulting in similar initiatives being developed from the ground up rather than being adopted or adapted based on what others have done. For example, during the CAPP community roundtable meetings, the CAPP team learned that four communities in various parts of the country have all independently developed first responder programs and training. Similarly, several provinces indicated that they were about to embark on early intervention demonstration projects and outcome evaluation projects that could benefit from shared planning and collaborative resource allocations.

Autism researchers are found across the country in various academic and clinical institutions. However, they are often removed from those who live with ASD every day. It can take many years for research to be translated into practice that has an apparent impact for families and persons with ASD in their everyday lives. Stakeholders are eager to engage with researchers and are interested in seeing more applied research that is considered to have a greater immediate impact on their needs, is visible, takes less time to be of practical benefit, and is community driven.

During the consultation process, researchers expressed their own frustrations with the time lag between their work and its impact on families and individuals with ASD. They also identified isolation within the research community and a strong interest in a mechanism that could support communication and collaboration with their peers across the country.

Canada is well regarded for its autism research on a global platform. Canada enjoys a leadership role in the international autism community and these relationships should be built upon to enhance collaborative work within the country.

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22 Cross-Ministry Autism Services and Supports: Problem Statement; page 3

## APPENDIX B – Collective Impact References

The following references represent some of the resources available about Collective Impact:

1. “Collective Impact.” John Kania & Mark Kramer. *Stanford Social Innovation Review*. Winter 2011. Available from: [http://www.ssireview.org/articles/entry/collective\\_impact](http://www.ssireview.org/articles/entry/collective_impact)
2. “Embracing Emergence: How Collective Impact Addresses Complexity.” John Kania and Mark Kramer. *Stanford Social Innovation Review*. January 21, 2013. Available from: [https://ssir.org/articles/entry/embracing\\_emergence\\_how\\_collective\\_impact\\_addresses\\_complexity](https://ssir.org/articles/entry/embracing_emergence_how_collective_impact_addresses_complexity)
3. “Channeling Change: Making Collective Impact Work.” Fay Hanleybrown, John Kania, and Mark Kramer. *Stanford Social Innovation Review*. January 26, 2012. Available from: [https://ssir.org/articles/entry/channeling\\_change\\_making\\_collective\\_impact\\_work](https://ssir.org/articles/entry/channeling_change_making_collective_impact_work)
4. “Understanding the Value of Backbone Organizations in Collective Impact: Part 1.” Shiloh Turner, Kathy Merchant, John Kania, and Ellen Martin. *Stanford Social Innovation Review*. July 17, 2012. Available from: [https://ssir.org/articles/entry/understanding\\_the\\_value\\_of\\_backbone\\_organizations\\_in\\_collective\\_impact\\_1](https://ssir.org/articles/entry/understanding_the_value_of_backbone_organizations_in_collective_impact_1)
5. “Understanding the Value of Backbone Organizations in Collective Impact: Part 2.” Shiloh Turner, Kathy Merchant, John Kania, and Ellen Martin. *Stanford Social Innovation Review*. July 18, 2012. Available from [https://ssir.org/articles/entry/understanding\\_the\\_value\\_of\\_backbone\\_organizations\\_in\\_collective\\_impact\\_2](https://ssir.org/articles/entry/understanding_the_value_of_backbone_organizations_in_collective_impact_2)
6. “Collective Impact for Opportunity Youth.” Fay Hanleybrown, Kate Tallant, Adria Steinberg, Mimi Corcoran. FSG. 2012. Available from: <http://www.fsg.org/publications/collective-impact-opportunity-youth>
7. “The Collective Impact Framework.” Collaboration for Impact. Available from: <http://www.collaborationforimpact.com/collective-impact/>
8. “Rethinking Collective Impact.” Emmett D. Carson. *The Huffington Post*. August 31, 2012. Available from: [http://www.huffingtonpost.com/emmett-d-carson/rethinking-collective-imp\\_b\\_1847839.html](http://www.huffingtonpost.com/emmett-d-carson/rethinking-collective-imp_b_1847839.html)
9. “Business Aligning for Students: The Promise of Collective Impact”. Allen S. Grossman and Ann B. Lombard. Harvard Business School Available from: <http://www.hbs.edu/competitiveness/Documents/business-aligning-for-students.pdf>
10. “Collaboration is the New Competition”. Ben Hecht. *Harvard Business Review*, January 10, 2013. Available from: <https://hbr.org/2013/01/collaboration-is-the-new-compe>
11. “Transaction, Transformations, Translations: Metrics that Matter for Building, Scaling, and Funding Social Movements”. Manuel Pastor, Jennifer Ito & Rachel Rosner. October 2011 [http://aspencommunityfoundation.org/wp-content/uploads/transactions\\_transformations\\_translations\\_web.pdf](http://aspencommunityfoundation.org/wp-content/uploads/transactions_transformations_translations_web.pdf)

# APPENDIX C – Detailed Description of CAP Collective Impact Process

## Complex Issue Selection

### Actions

- Assessment of priority issues identified by community stakeholders, government priorities, research findings
- Recommendation by Advisory Council regarding priority issue(s) to address and establish initial parameters of the priority

## Common Agenda Setting

### Actions

- Clearly articulate and scope the issue
- Determine goals and expected outcomes
- Examine from a care and cost perspective to determine whether the return on investment can be justified
- Make go/no go decision
- Undertake an environmental scan to objectively understand the environment surrounding the issue currently, historically and in the future
- Carry out thorough research of best and emerging/innovative practices, services and/or programs; provincial and federal policies; current and emerging research; and where available, qualitative and quantitative data
- Engage network partners and stakeholders to provide input as needed and to participate in sourcing and gathering information as appropriate

## Engagement

### Actions

- Develop a terms of reference for the problem solving and mobilization phases
- Recruit the people best suited to address the complex issue from within the Stakeholder Groups to form an Action Team and supplement the team with other expertise as required
  - For example, employment issues may require expertise that is not found within the Stakeholder Groups or the autism sector.
- Engagement may not be for the full period of the process depending on the knowledge and expertise required. Some people may be consulted for specific issues and others may participate for the duration of the process. This allows for fluid, flexible and transparent engagement.

## Problem Solving

### Actions

- Carry out activities related to developing the best possible option(s) to address the Complex Issue including consultations and seeking input from others both within the autism community and external to it, engage in additional research, and/or conduct problem solving workshops or other activities related to developing and selecting the best possible options.
- Engage in knowledge translation including potentially involving a demonstration project(s)
- Identify the shared leadership model, and groups, individuals or organizations to mobilize the solution
- Scope out and develop the broad steps for the mobilization phase

## Mobilization

### Actions

- Develop detailed mobilization plan to implement recommendations and disseminate knowledge gained through the previous phases
- Implement the shared leadership model by engaging groups, individuals and organizations identified in the problem solving phase
- Work with partners to develop training and determine how best to build capacity and enhanced support

## Evaluation

### Actions

- Develop and implement a monitoring, measurement and evaluation framework for measuring impact on families, individuals, organizations and communities
- Identify innovations and best practices for dissemination

**Family and Stakeholder Collaboration** will be achieved through:

- The development of stakeholder groups that will provide input into the common agenda and identification of priority areas of focus
- Utilization of these stakeholder groups provides a dissemination pathway for information sharing purposes

**Measurement and Monitoring** will:

- Measure and monitor the process
- Refine the process
- Identify and disseminate lessons learned
- Ensure goals and outcomes are being achieved for each complex issue

Essential processes that are critical to the success of the Collective Impact Framework include, but are not limited to, the following:

- Developing action teams and engaging other stakeholders through the stakeholder groups;
- Collecting and disseminating knowledge during the problem-solving and mobilization phases;
- Developing agreement and consensus building approaches;
- Building capacity and capabilities in the sector;
- Measuring, monitoring and evaluating progress and impact; and
- Developing communication protocols with stakeholders, government, media and the public.

# APPENDIX D – Stakeholder Engagement and Input

The mandate of the extensive stakeholder engagement process was to reach out to provincial and territorial governments; to engage with Indigenous communities; and to deliver to the Minister of Health, a business plan for the Canadian Autism Partnership (CAP) incorporating the input received through the consultation process.

Below is a summary presentation of the Stakeholder Engagement process and findings. A full reporting of the data and analysis of the data from the stakeholder engagement can be found in the accompanying four volume document entitled *Stakeholder Engagement, Analysis of Findings – Detailed Findings, Survey Responses by Province/Territory, Stakeholder-Identified Innovations by Provinces & Territories, and CAPP Surveys*.

In total, the Canadian Autism Partnership Project heard from 4,963 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;
- Community roundtable sessions that included the first session at the Autism Leadership Summit in Ottawa in April attended by 170 delegates, followed by 16 sessions in 14 communities across the country involving 324 participants;
- An online stakeholder survey which garnered input from 4,371 respondents from every province and territory; and
- Written submissions solicited from professional associations and self-advocates resulting in two responses.

Prior to initiating the stakeholder engagement process, the Canadian Autism Partnership Project developed the CAP Collective Impact Process, the approach which CAP would use to address Complex Issues. The process is based on the “Collective Impact Framework” a model of shared leadership and “a structured process that leads to a common agenda, shared measurement, continuous communication and mutually reinforcing activities among all participants”.<sup>23</sup> The CAP Collective Impact Process has been modified and adapted for application on a national scale in Canada, bringing an innovative new approach to facilitate collaboration and knowledge sharing among partners in government and communities, and bringing the lived experience of families and individuals with ASD/autistic people to the table. Please see the Terminology section for further description.

The objectives of the stakeholder engagement process were to:

- Determine the benefit of the Canadian Autism Partnership (CAP) in the autism ‘ecosystem’ that will make a difference to individuals with an ASD and their families/caregivers;
- Involve stakeholders in evolving the Collective Impact Process;
- Learn about system enablers and barriers to achieving improved outcomes for families and individuals with an ASD and enhanced capacity for services and support within the community; and
- Achieve stakeholder feedback, and support for CAP.

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23 Stanford Social Innovation Review – Winter 2011; Collective Impact; John Kania & Mark Kramer; page 36

## GOVERNMENT MEETINGS

Government officials in attendance at the meetings included ministers, deputy ministers, senior directors and program directors representing departments of health, social services, human services, and education. The agenda for the meetings included a presentation and discussion of the Collective Impact Process, and discussion around innovations in autism in their own provinces and territories.

General response to the proposed CAP Process was genuinely enthusiastic. Government representatives were able to identify a number of ways in which the partnership would add value to their jurisdictions, including: ability to interact and collaborate with peers from across the country to exchange and share knowledge, and access to credible information that would allow them to build on the experiences of others using evidence-based data, research and information. They recognized that this access and shared knowledge would translate into improved efficiencies, better solutions and greater impact for autistic individuals and families in their communities.

Government officials shared innovative practices, research, programs and services occurring in their province/territory, and all indicated a willingness to share knowledge and lessons learned with other jurisdictions. They were also encouraged by CAP's interest in understanding and addressing the unique needs of Indigenous and remote communities, particularly in the northern regions of the country.

There was a favourable response to the proposed Collective Impact Process and the development of a Canadian Autism Partnership. The government representatives identified many ways in which the proposed model would add value for them:

- They expressed enthusiasm for a structure to enable them to come to the table and learn from others across the country, and collaborate and coordinate when possible.
- They identified knowledge collection, translation and dissemination as the most tangible and immediate “value add” of the model.
- There was feedback that the Collective Impact concepts of collaboration, shared leadership and shared problem-solving could provide a means to enhance the effectiveness of their efforts at the policy development and implementation levels.
- They were encouraged that the unique needs of remote communities would be taken into consideration, such as focussing on individualized needs and intervention strategies rather than diagnosis to initiate intervention.
- A designated Northern/Remote Communities stakeholder group was identified as a positive step to supporting their enhanced collaboration.
- First Nations' representatives also identified the value of having a stakeholder group specifically for them to coordinate the conversation and planning for service responses.
- All government representatives engaged in conversation about the importance of planning for adequate employment options and supports within their jurisdictions, particularly across the multiple ministries that figured into the employment sector.
- Most are willing to put their support in writing.
- Many in the western provinces referred to the Fetal Alcohol Syndrome Disorder (FASD) Network model as having a similar network component, which they considered effective.

## COMMUNITY ROUND TABLES

### Overview

Similar to the government meetings, the community round table (CRT) sessions involved a presentation and discussion of the CAP Collective Impact Process – how it could add value to their families, communities and organizations; how it could be strengthened; and what additional areas of focus (complex issues) it should pursue. (Note: the suggested areas of focus that CAP would pursue were shown in the presentation as: attachment to the labour force, community living, early detection and diagnosis, intervention and support across the lifespan, education, training and awareness, caregivers, and research). Participants were also asked to identify areas of innovation in their communities.

The first Community Round Table (CRT) session was held at the CASDA Autism Leadership Summit in Ottawa, on April 18th, 2016. This session was attended by 170 registered Summit attendees organized into 22 tables for discussion during the session. The attendees reflected the membership of CASDA, with representatives from across the country and across a wide variety of leadership organizations.

The outcome from the Ottawa session resulted in a modification of the questions and the Collective Impact Process that was subsequently used for the community-based round table discussion sessions, held across the country between May 2nd and June 23rd, 2016. During that time, 16 CRTs, with 324 participants arranged into 70 table discussion groups were held in 14 communities across Canada.

The following table provides a breakdown of participants by region.

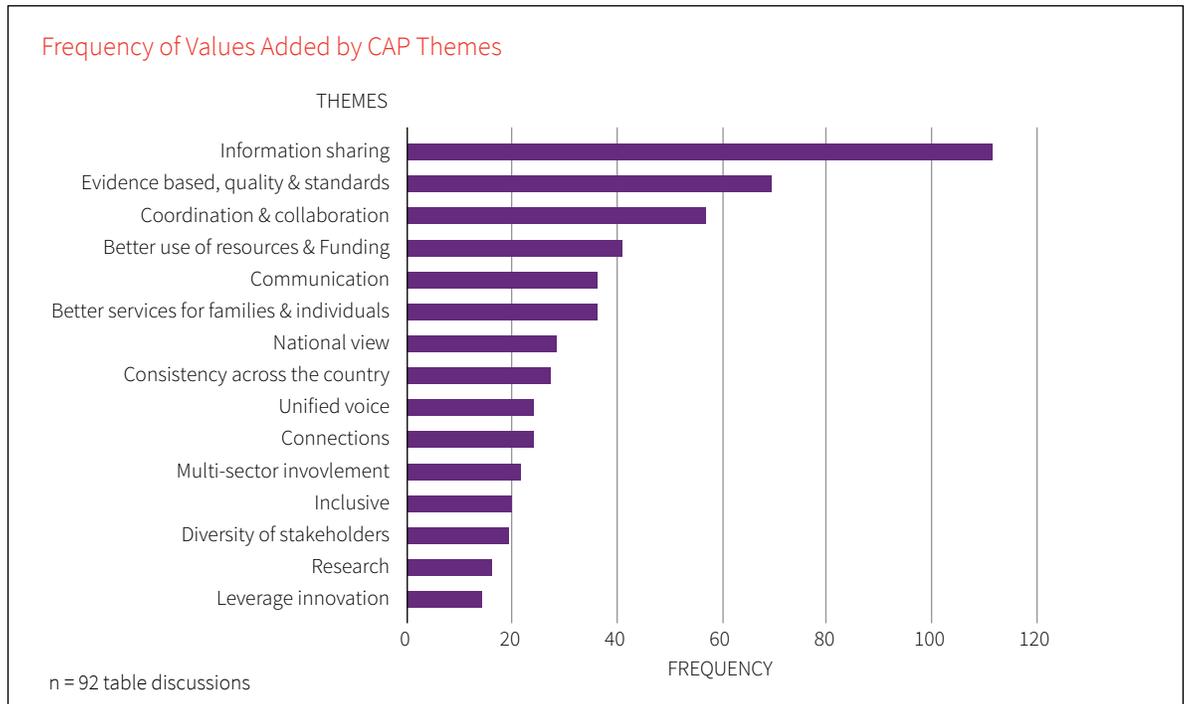
*Frequency & Percentage of Community-based CRT Participants by Type of Participant, and Region*

	Total	Adult with an autism spectrum disorder	Parent/family caregiver of a person with an ASD	Professional working with persons with an ASD	Organization providing support/ services to persons with an ASD	Researcher
<b>Atlantic</b> New Brunswick, Newfoundland and Labrador, Nova Scotia, and Prince Edward Island	73 22.5%	7 (26.9%)	17 (25.4%)	10 (14.7%)	35 (23.1%)	4 (36.4%)
<b>Central</b> Ontario and Québec	72 22.2%	6 (23.1%)	19 (28.4%)	20 (29.4%)	23 (15.1%)	4 (36.4%)
<b>West</b> Alberta, British Columbia, Manitoba, and Saskatchewan	143 44.1%	12 (46.2%)	21 (31.3%)	27 (39.7%)	80 (52.6%)	3 (27.2)
<b>North</b> Northwest Territories, Nunavut, and Yukon	36 11.1%	1 (3.8%)	10 (14.9%)	11 (16.2%)	14 (9.2%)	0 (0.0%)
<b>TOTAL</b>	<b>324</b>	<b>26</b>	<b>67</b>	<b>68</b>	<b>152</b>	<b>11</b>
<b>% OF TOTAL</b>	<b>100%</b>	<b>8.0%</b>	<b>20.7%</b>	<b>21.0%</b>	<b>46.9%</b>	<b>3.4%</b>

## Ways in which CAP can add value

CRT participants identified many ways in which the proposed CAP model could add value to their communities, families and autistic individuals. Every community identified “information sharing” as a key value that would bring benefits to many in their community. Participants also identified access to

evidence-based information, quality, and standards for service delivery across the country as a key value of CAP. Similarly, many communities identified the ability to coordinate activities, collaborate with others in service delivery or knowledge sharing, and reduce duplication of effort. The following table shows the value that CAP would add by the frequency with which it was mentioned.



n - indicates the number of instances or responses

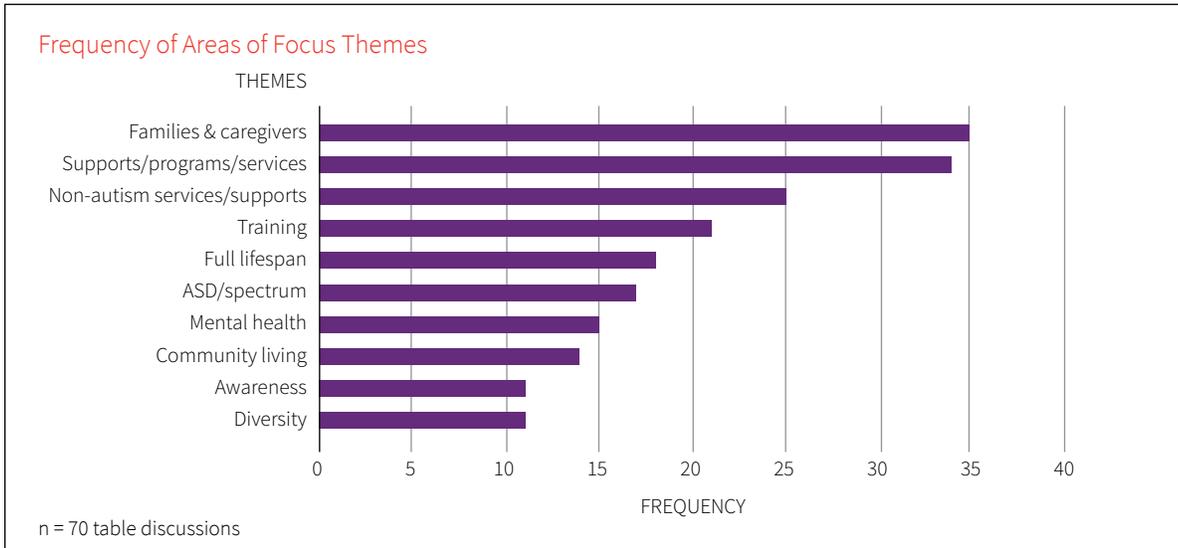
## Ways in which the CAP model could be strengthened

When asked how the proposed model could be strengthened, three categories of responses emerged. Some groups focused on the structural and organizational elements of the model including the diagram and how it could be better presented; on changes to the mandate, vision, goals and objectives; and better clarity around the organizational model. The second cluster of comments identified the need for more focus on ensuring that CAP is inclusive in its membership and work, that ongoing engagement ensures all voices are being heard, and the need for changes to programs, services and supports across the system. And the third cluster identified a variety of way in which to strengthen CAP including: government involvement, outcomes based planning, additional research, addressing

issues across the spectrum and lifespan, funding, metrics and identification of primary stakeholders. All of these recommendations were addressed in the development of this business plan.

## Areas Of Focus

The areas of focus that were presented to the community round table participants were generally seen to be appropriate; however, various refinements and additions were suggested. Many of the additional areas discussed could be considered to be subsets or clarifications of the areas of focus that were presented. The additional areas of focus have been grouped into themes and are shown in the following chart by the number of times each was mentioned.



## Innovations

The innovations identified in each community were extensive and wide ranging. They included programs offered by public sector organizations, public and private service agencies, education programs and services, social groups organized by volunteers, technology developments, research projects at universities and colleges, and grassroots initiatives developed at the community level. A full list of the innovations identified by participants is available in an accompanying document entitled *Stakeholder Engagement, Analysis of Findings – Stakeholder-Identified Innovations by Province & Territory*.

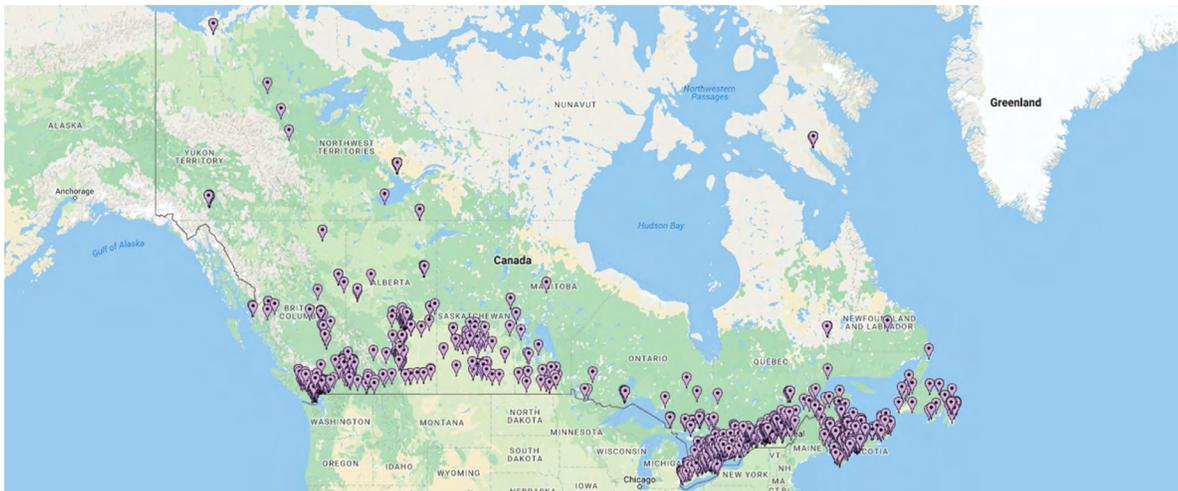
## ONLINE STAKEHOLDER SURVEY

### Overview

The online survey asked stakeholders about areas of innovation in their communities; barriers to service; expected outcomes of CAP; methods of communication to push information out and pull information and innovations into CAP; the proposed vision, mission and foundational statements; and the proposed areas of focus. Responses were received from every province and territory.

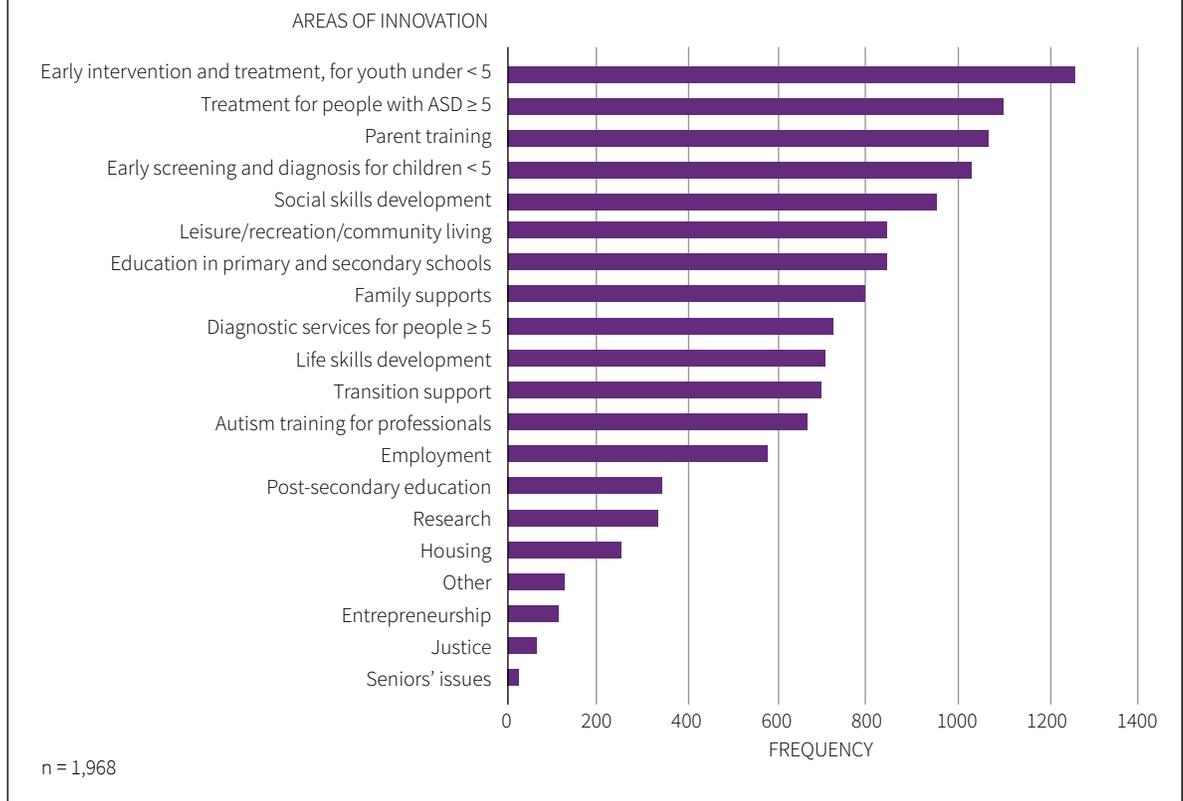
Using the postal code data submitted by 4,197 respondents, the geographic dispersion of respondents across the country is shown in the map below.

Some of the highlights from the survey follow.



Detailed Map of Respondents by Postal Code

## Frequency of Area of Innovation with Innovative Programs and Services

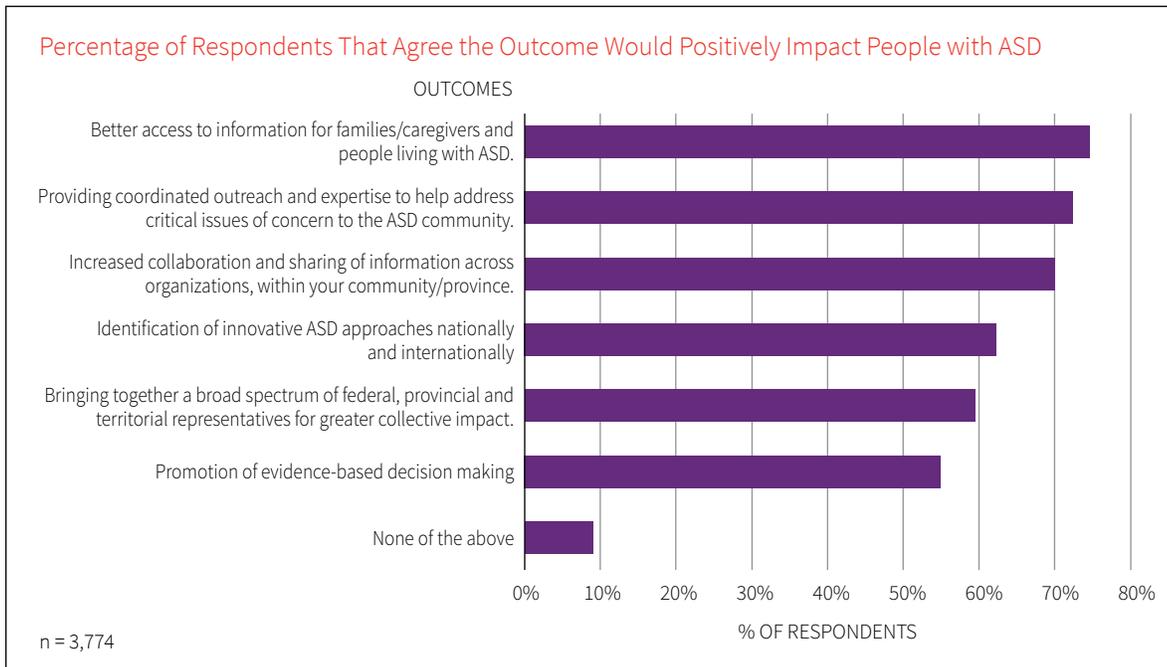


### Innovations

Of the 2,023 respondents who indicated an awareness of areas in which innovations are happening in their communities, the chart above shows the number of responses to each area. The top five all pertain to young children, followed by others that are focused across the lifespan.

### Cap outcomes that would positively impact people with ASD

Respondents were asked to check the CAP outcomes that they thought would positively impact people with ASD in their community. Results shown in the chart, on the following page, support the input received from government representatives and stakeholders at the community round table sessions.



### Proposed vision, mission & foundational statements/areas of focus

More than 80% of respondents agreed with the proposed vision, mission and foundational statements (found in Chapter 2), and there was strong agreement with the proposed areas of focus. Respondents were given the opportunity to identify additional areas of focus and 832 provided responses that were categorized into themes. The top four additional theme areas identified were school (system, programs, boards and inclusion); adults; health and mental health; and access.

#### Written Submissions

Two submissions were received in writing, both from self-advocates. They were asked to comment on the major issues that need to be addressed; suggestions for creating a strong national partnership; and how CAP could make a difference to them, their families and their communities.

Major issues that were identified as needing to be addressed included education about the facts of autism to counter the myths; raising understanding of supports; life and social skills; employment; housing; and personal finances. They suggested that continued discussion with self-advocates, and educating and implementing best practices among organizations in business, health and education would create a strong national partnership. Similar to other stakeholders, the self-advocates identified

access to information and information sharing, bringing together the Canadian autistic community, communication, focussing on the real needs of people on the spectrum, and implementing best practices based on evidence, as the ways in which CAP could make a difference.

#### 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 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 consistency of the identification of the priority issues across both the 2014 Needs Assessment Survey and the CAP project, and across the country, speaks to the urgency of taking action now, and to the expectation of Canadians that CAP will be a leader in moving these initiatives forward.

# APPENDIX E – Sample Descriptions of How Two Priority Complex Issues will be Addressed

## PRIORITY ISSUE #1 – ENHANCING PRACTICE RELATED TO EARLY IDENTIFICATION OF ASD

### Determining a Common Agenda

- Complex issue is defined, goals and outcomes established, justification confirmed.
- What is being done elsewhere?
- Assessment of the current situation in Canada

### **Discussion:**

The average age of diagnosis of ASD in Canada remains approximately age 4 years, often >2 years after parents first identify concerns, and despite advances in knowledge about early behavioural signs. Delays in diagnosis contribute to parental stress and prevent timely access to interventions that can improve long-term outcomes.

### **Actions:**

- Develop best practice guidelines for early identification of ASD that can be applicable to the range of community contexts across Canada;
- Develop stakeholder partnerships among autistic families, clinicians, and policy makers to optimize uptake of these guidelines and reduce the average age of ASD diagnosis across Canada.
- Optimize opportunities for earlier access to services which will decrease the level of support required at a later age.

### **Considerations:**

CAP could play an important role in facilitating additional stakeholder engagement, including policy discussions with provincial policy makers to ensure a national approach to this important and complex issue.

In the US currently, there is mixed messaging regarding the importance of early screening, with the American Academy of Pediatrics recommending universal ASD screening, and the US Task Force for Preventative Health Care (USTFPHC) concluding, based on a recent systematic review, that there is insufficient evidence to warrant universal ASD screening, with no recommendations regarding surveillance and screening in other contexts.

Canada does not currently have practice guidelines regarding early identification and diagnosis of ASD that have been endorsed by national professional societies, nor provincial policy makers.

### **Actions:**

- Establish a task force, comprised of the membership of the current PHAC committee and potentially others
- Develop best practice guidelines and dissemination/training strategies

### **Considerations:**

CAPP working group member Lonnie Zwaigenbaum currently co-chairs a multi-disciplinary committee, formed by the Public Health Agency of Canada (PHAC), to develop a systematic review and synthesis of current evidence for approaches aimed at early detection of ASD, including screening. The committee includes representation from several professional societies (pediatrics, psychiatry, family practice) as well as CASDA. The evidence synthesis has been completed (in partnership with an external consultant contracted by PHAC), and now further partnerships are being sought to achieve the goals listed above.

## Engagement

- Bringing the right people to the table to ensure broad engagement in resolving this complex issue

### **Discussion:**

Further stakeholder consultation regarding:

- Current barriers to early detection and diagnosis of ASD across Canada;
- What would constitute desired outcomes related to early detection (e.g., from the perspective of policy makers, would earlier age of diagnosis suffice, or would they insist on evidence of improved longer term outcomes, as per the USTFPHC);
- What is the current capacity and range of early detection/screening strategies already in practice across Canada;
- What other professionals/professional organizations could contribute to the defining of standards and implementation practices;
- Which government departments need to be part of this process, and;
- What would be the optimal mechanism for providing feedback on draft guidelines, and providing input into the mobilization plans.

## Problem-Solving

- Develop options to solve this issue.
- Examine current guidelines and review need for amendments, accommodations and/or enhancement.
- Develop knowledge transfer and exchange (KTE) strategies.
- Identify next steps.

### **Discussion:**

Once broader stakeholder engagement is achieved, special issues, contingencies and mitigation strategies can be addressed.

### **Actions:**

- Review the representation on the guidelines task force;
- Facilitate the development of detailed practice guidelines on early identification, screening and diagnosis of ASD, informed by current evidence;
- Identify current practice and community capacity (strengths and gaps) across Canada, including regional barriers and opportunities for shared resources/ strategies to increase capacity to meet proposed standards;
- Vet the proposed guidelines with key stakeholders;
- Draft communications materials and training opportunities to ensure knowledge translation and exchange; and
- Concurrent development of dissemination strategies.

## Mobilization

- Develop recommendations.
- Identify training required for successful implementation.
- Identify strategies to enhance capacity in under-resourced areas.
- Identify champions – leaders.

### **Discussion:**

Upon development of relevant guidelines and strategies, review and ratification are required, as are broad-based sharing of information for optimal impact.

### **Actions:**

Once the guidelines are developed and vetted with key stakeholder groups:

- Broad KT/dissemination to stakeholders, including families, individuals with autism/Autistic individuals, clinicians and policy makers;
- Distribution of materials based on the guidelines that would be informative to each group (practical resources for families to help recognize early signs, training materials for physicians and other relevant professional groups, policy briefs etc.);
- Development of partnerships to support professional training and uptake into public policy;
- Identification of implementation strategy; and
- Identification of monitoring and evaluation process.

## Collective Impact

- Monitor outcomes.
- Evaluate impact

### **Discussion:**

Impact evaluation will require a detailed evaluation plan with buy-in from key stakeholders, especially provincial policy makers, regional health services, and others. It should include:

- Evaluation of fidelity of implementation within and across provinces;
- Changes in age of initial referral;
- Age of diagnosis;
- Age of access to intervention, and;
- Other areas of evaluation to be determined.

## PRIORITY ISSUE #2 – ENHANCING EMPLOYMENT OPPORTUNITIES IN AUTISM SPECTRUM DISORDER

### Common Agenda

- Complex issue is defined, goals and outcomes established, justification confirmed
- What is being done elsewhere?
- Assessment of the current situation in Canada

### Discussion:

A disproportionately low number of adults with ASD are in post-secondary education or employment. Disparities in employment access and retention are noted, with negative impacts on income security, quality of life and community engagement.

### Action:

- Develop sector (type of employment/vocational activity and/or nature of industry) guidelines
- Develop mental health (relative to employment) guidelines
- Develop employer (engagement, capacity building) guidelines
- Develop policy guidelines
- Develop stakeholder (self-advocate, family, service provider, employer, policy maker) partnerships to ensure uptake of guidelines and optimize sustained employment across Canada

### Considerations:

This issue is multi-layered. Its varying components need to be defined and outcomes (viable variables/impacts and respective metrics) need to be established and justified.

CAP would play a critical role in facilitating additional stakeholder education and engagement, including policy development with federal and provincial policy makers to ensure a pervasive and impactful approach to this important and complex issue

Multiple data sources indicate deleterious outcomes related to employment for adults with ASD. Ongoing barriers to employment are noted in multiple international studies including Canadian research.

Canada currently does not have guidelines addressing the inclusion of individuals with ASD in employment. Limited traction has been achieved in considering and achieving best practices related to employer awareness and capacity, self-advocate job readiness skills development, family role, and community capacity in supporting employment optimization.

Multiple important efforts are underway in the Canadian ASD community including national programs such as 'Worktopia' and 'Ready, Willing and Able' as well as multiple regional programs across Canada. Multi-level evaluation designs are being developed and implemented in the aim of producing data that can guide practice and policy.

There is increased commitment to building capacity including involvement of key national organizations such as CASDA, Autism Speaks Canada and the Sinneave Family Foundation, as well as a Collective Impact initiative in building promising practices in employment opportunities in ASD.

### Action:

- Identify the roles and experiences of stakeholders that are needed to advance outcomes.
- Outreach to professional associations and relevant bodies (e.g., Chambers of Commerce, unions, etc.).
- Compile and critically review evidence informed initiatives
- Determine relevant metrics for evaluation (and gaps) for program and initiative advancement

**Considerations:**

- What is being done across Canada and elsewhere? Who needs to be a part of this discussion that is not already at the table? Assessment of the employment situation in ASD in Canada is required.
- Consider cross-disability sectors and levels/means of engagement, and build on strengths? How does this fit/not fit relative to ASD?
- Consider policy contexts relative to capacity
- Consider employment/vocational engagement across the diversity of ASD expression, range of supports needed and context.
- Consider international exemplars

**Engagement**

- Bringing the right people to the table to ensure broad engagement in resolving this complex issue

**Discussion:**

Stakeholder consultation is needed regarding:

- Barriers in communities regarding employment access and retention
- Current capacity and strategies across Canada
- Diversities relative to ASD that should be incorporated
- Professional, community or other organizations that could contribute to standards development and implementation
- Consideration of what government departments (and how departments) need to be involved
- Assessment of contextual ecosystems and need for accommodations for sustained change

**Action:**

- Examine investments with respect to employment access and development both within and beyond Canada
- Optimize partnerships and mutual learning in the aim of innovation that can be regionally applied and tailored to diverse communities and contexts
- Build a promising practice network in employment in ASD which offers approaches
- Develop repository of measures for evaluation of employment programming
- Develop support initiatives.
- Survey what is being done in Canada to invite shared resources/strategies across industries and community contexts.

**Considerations:**

- Bringing the right people to the table to ensure broad engagement in identifying key issues and solutions, implementing measures for constructive change
- For sustained change, need to critically consider contextual ecosystems and needs for accommodation in approach (e.g., program design may require accommodation relative to regional population, politics, culture, language, geographic, industry vertical, regional economy and funding systems)

## Problem-Solving

- Develop options to solve this issue
- Examine current guidelines and review need for amendments, accommodations and/or enhancement
- Develop KTE strategies
- Identify next steps

### **Discussion:**

Once broader stakeholder engagement is achieved, special issues, contingencies and mitigation strategies can be addressed.

### **Action:**

- Facilitate guidelines on employment access, support and retention
- Identify current practices and community capacity (and barriers), with a focus on small, medium and large communities, regional barriers, and opportunities for shared learning strategies and resources to increase capacity to meet proposed standards
- Consider mediating issues (e.g., age, social determinants [e.g., linguistic barriers, new Canadians, remote communities, etc.]) which may require mitigation and/or additional resources/planning
- Invite proposed guidelines with stakeholders
- Draft communication, training and capacity building materials to ensure collective impact
- Concurrently develop knowledge and capacity impact across the wide range of employment sectors

### **Considerations:**

- Develop opportunities for learning across the range of employment contexts and stakeholder groups (e.g., employees, employers, employment support personnel, families, policy makers, various sectors, etc.)
- Develop collective impact strategies for sustained change and continuous quality improvement across disciplines/areas of community, jurisdictions, policy/practice, and regions
- Identify next steps (e.g., post-secondary education access, other adult issues [e.g., aging in place, retirement and senior citizenship in ASD])
- Identify barriers to goal achievement (e.g., social determinants of health-related barriers) that need to be addressed to mitigate risk to optimal outcomes

## Mobilization

- Develop recommendations.
- Identify training required for successful implementation.
- Identify strategies to enhance capacity in under-resourced areas.
- Identify champions – leaders.

### **Discussion:**

Upon development of relevant guidelines and strategies, review and ratification are required, as are broad-based sharing of information for optimal impact.

### **Actions:**

- Broad KT/dissemination to stakeholders, including self-advocates, families, policy makers, employers, service providers, sectors, etc.
- Distribute materials based on guidelines, along with evaluation tools (e.g., repository of metrics used in evaluation), training materials (e.g., educational resources for job coaches, employers, etc.) and policy documents (e.g., policy briefs)

- Invite and nurture partnerships to support training and informational uptake across relevant sectors
- Facilitate policy impact strategy and implementation plan
- Share metrics for evaluation
- Implement and monitor evaluation and continual quality improvement

**Considerations:**

- Develop key recommendations and interventional strategies at practice, education, professional development and policy levels
- Identify training priorities and design components
- Identify leaders and key ambassadors in moving this agenda forward

## Collective and Sustained Impact

- Monitor outcomes.
- Evaluate impact

**Discussion:**

Regional application and scalability of initiatives across provinces and territories are required toward the optimization of sustained impact.

**Actions:**

- Determine resource requirements for collective impact strategy
- Identify and engage key stakeholders including policy makers, employer sector leaders, advocacy and community champions
- Determine anticipated targets and desired outcomes

**Considerations:**

- Collective impact to be realized through the intentional distribution of key information and the implementation of strategies for regional and collective gain
- Targets need to be developed (e.g., employment expectations, standards, shared resources, ongoing supports to regions)
- Key metrics for regional, provincial and national collective impact need to be identified and applied in targeting and measuring impact achievement

# APPENDIX F – Canadian Autism Spectrum Disorders Alliance (CASDA)

In 2007, the Canadian Autism Spectrum Disorder Alliance (CASDA), a national coalition of autism related professionals and community partners, was formed. Following the release of the Standing Senate Committee on Social Affairs, Science and Technology report entitled, *Pay Now or Pay Later: Autism Families in Canada* a number of leaders from ASD-specific organizations from across Canada initiated an alliance to ensure the momentum created by the report's release continued.

The members of CASDA identified a single focus for their work: to work with the federal government and its departments to develop a national ASD strategy. By reaching out to leaders in the ASD sector from across Canada, CASDA undertook the process of developing a unified voice for autism in Canada and a strong national body with which our government could work. Through CASDA, the autism community has come together to provide that strong national voice to advance the collective messages of our sector. Together, CASDA and its members have worked to promote the federal government's commitment to the development of a National Autism Strategy.

Since 2007, membership has grown and the alliance formally incorporated in 2015, further developing its national profile. Since inception, CASDA has engaged in significant project-based initiatives and events that align with its mandate. As with the intended governance and accountability for CAP, each CASDA project or partnership has been guided by a sub-committee of CASDA with authority and accountabilities delegated by the CASDA Board of Directors. These initiatives include:

1. National Needs Assessment Survey – 2014
2. Ready, Willing and Able (in partnership with Canadian Association for Community Living) – 2014 to present
3. (Annual) Autism Leadership Summit – 2015 to present
4. Canadian Autism Partnership Project – 2015 to 2016
5. National Accessibility Legislation (in partnership with others) – 2016

The graphic below provides a visual of these initiatives.



Today, CASDA has over 150 members and values its vital relationship with the Public Health Agency of Canada (PHAC). In 2014, with financial support from PHAC, CASDA conducted an historical national needs assessment survey, canvassing over 5,600 Canadians affected by ASD, to better understand the current state of supports, gaps and needs of autism in Canada. This survey resulted in quantitative and qualitative data that identified priority areas of focus, strengths and gaps in the service delivery system across the lifespan. Since its release, advocates, researchers, professionals, service organizations and governments, when considering the needs of Canadians living with an ASD and their families, have cited this report.

Priorities arising from the analysis of the extensive data gathered in this study included:

- Increased early and timely access to diagnosis and evidence-based early interventions;
- Social skills, behavioural, and adaptive behaviour supports across the life span, including comprehensive planning for and transition to adulthood;
- The development of accessible mental health services for youth and adults; and
- Targeted outreach to Self-advocates, Canada's northern communities, and linguistically and culturally diverse communities.<sup>24</sup>

In 2015, key leaders from the autism sector came together to discuss the development of a Canadian Autism Partnership. Building on the strong foundation from the national needs assessment, CASDA was asked to take the lead on this initiative and submitted a proposal to the Government of Canada, in partnership with Autism Speaks Canada, Autism Canada, and its members. The proposed Canadian Autism Partnership presented an opportunity to accelerate systemic change at the national level by mobilizing multiple sectors, and by utilizing a shared leadership approach to address complex issues related to ASD across the lifespan. The CAP would create a mechanism to rally stakeholders across disciplines and sectors on a national level to accelerate innovation and action to address the most complex issues affecting Canadians living with autism. This request also presented an opportunity for Canada to become a global leader in autism.

In the 2015 federal budget, the Government of Canada accepted the Canadian Autism Partnership proposal and announced a \$2M investment to develop a comprehensive business plan for the model. This included the development of a National ASD Working Group and Self-Advocates Advisory Group, as well as, a comprehensive stakeholder engagement process across the country, under the direction of the Minister of Health.

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24 CASDA National Needs Assessment Survey, 2014; page 006

## APPENDIX G – Role Descriptions

**Executive Assistant** – provides executive level administrative support to the CEO, the staff and the CII, and liaises with the CASDA administrative staff.

**Communications Specialist** – will include accountability for developing and managing the CAP communications plan; managing all external communications to government, stakeholders, and the public; media, government and public relations; and overseeing all CII communications. This role is essential in the knowledge dissemination mandate of the Partnership model and ensuring a seamless stakeholder feedback loop that will inform priorities related to the CII.

**Financial Co-ordinator** – overall fiduciary responsibility including budget preparation and financial coordination between CAP and the Federal Government, with specific responsibility for financial reporting; cash management; accounting/general ledger and all supporting activities including financial policies and procedures; payroll and benefits (which may be outsourced); all tax filings including HST returns; and audit processes and interfaces with external auditors.

**CII Project Manager** – includes engagement and problem solving with tasks that involve project planning and management, convening and fostering discussions at meetings, applying qualitative and quantitative methods, and ensuring projects progress as planned. Specific skill sets include project management, qualitative methods, relationship building and management of collaborative processes. Each CII will be managed by a project manager.

**Research Analyst** – responsible for developing the common agenda document: issues, goals, outcomes and cost justification; working with stakeholders on the environmental scan; providing research, writing, quantitative research methods support; and communications and engagement support to the initiative. Similar to the Project Manager, each CII will require a research analyst.

**Engagement Manager** – involves identifying and recruiting key individuals to the stakeholder groups and actions groups, building and maintaining relationships, working with the stakeholder groups to identify resources for the Action Teams, and supporting communications within and between the stakeholder groups. Given the close proximity to the autism community envisioned in the role, it would also include an active role in identifying new priority issues within the national autism landscape for consideration by the Advisory Council.

**Indigenous Peoples Lead** – a unique engagement strategy requires development by, and with representatives of the Indigenous communities. This staff resource will be selected from within and by Indigenous leaders and be responsible for collaborating closely with the National Director, Engagement Manager and Project Managers in leading engagements in Indigenous communities and development of the Indigenous Peoples strategy.

CAP's hiring policies and practices will include reaching into the autism community across the country to encourage and support autistic individuals to apply for posted positions for this initiative.

# APPENDIX H – Sample Template for Tracking Outcomes

MEASURES	Early ID	Employment	Lifespan supports	Mental Health	Education	Indigenous Peoples Engagement
<b>PARTNERSHIPS</b>						
Knowledge						
Service						
Policy						
Economic/Financial						
<b>INNOVATIONS</b>						
Knowledge						
Service						
Policy						
Economic/Financial						
<b>EFFICIENCIES</b>						
Knowledge						
Service						
Policy						
Economic/Financial						

Rating: A = Achieved  
 U = Underway  
 N = Not achieved





**Canadian Autism  
Partnership Project**

An initiative of the Canadian Autism Spectrum Disorders Alliance

**Canadian Autism Spectrum Disorders Alliance (CASDA)**  
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