

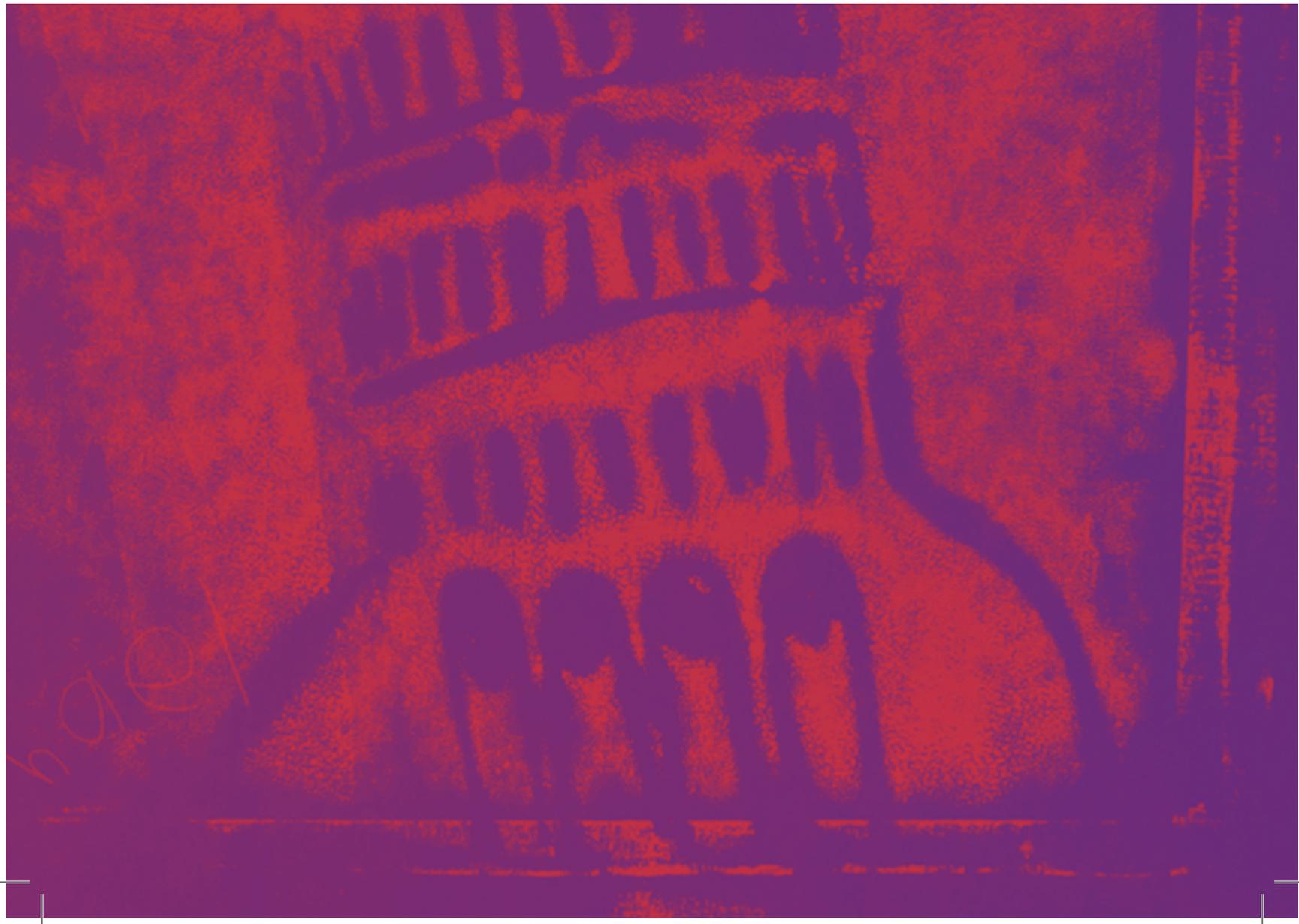


Canadian Autism  
Partnership Project

An Initiative of the Canadian Autism Spectrum Disorders Alliance

# Stakeholder Engagement Analysis of Findings

## Detailed Findings



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# 1. OVERVIEW

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## BACKGROUND

This project was initiated by the Canadian Autism Spectrum Disorders Alliance (CASDA) in partnership with its members, with the submission of a formal request to the federal government for the development of a Canadian Autism Partnership in Canada. This request presented an opportunity to create a mechanism to mobilize 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. Many of these complex issues were identified in the CASDA (2014) Autism in Canada: National Needs Assessment Survey for Families, Individuals with Autism Spectrum Disorder and Professionals.

The Canadian Autism Partnership Project (CAPP) received funding to support the development of a business plan for the implementation of a Canadian Autism Partnership and to solicit support for the partnership concept through a Canada-wide stakeholder engagement process. Consultation with stakeholders (including individuals with ASD; families and caregivers; the federal, provincial and territorial governments; Indigenous Peoples; researchers; service providers; professionals; autism advocates; and the public) took place through an extensive stakeholder engagement process in the spring, 2016.

The primary purpose for engaging with stakeholders was to seek their reaction and input to the draft Canadian Autism Partnership (CAP) model that was developed by the Working Group and the Self-Advocates Advisory Group through the winter and early spring, 2016. The model, called the *CAP Collective Impact Framework* is the proposed approach to addressing complex issues. The Framework is a structured process for driving systemic change in the autism sector in Canada based on the emerging “Collective Impact” 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>1</sup> This model is gaining momentum at community and regional levels; the CAP Framework has been adapted for application on a national scale. It should be noted that the model was refined and strengthened as suggestions and recommendations were brought forward from the community round table discussions.

## OBJECTIVES

The objectives of the stakeholder engagement process were to:

- Determine what added value the Canadian Autism Partnership (CAP) can bring to the autism ‘ecosystem’ that will make a difference to individuals with autism and their families / caregivers;

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<sup>1</sup> Stanford Social Innovation Review – Winter 2011; Collective Impact; John Kania & Mark Kramer; page 36

- Involve stakeholders in developing the CAP model through various discussion and feedback methods described below;
- Learn about system enablers and barriers to achieving improved outcomes for families and individuals living with autism and enhanced capacity for services and support within the community; and
- Achieve stakeholder feedback and support for CAP.

## **2. METHODOLOGY**

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### **In-person Interviews**

In-person interviews were conducted with federal, provincial and territorial governments, representatives of indigenous communities, and other key informants to gather their input on the proposed model, as well as key issues impacting people living with autism in their community/province.

### **Online Survey**

An online survey was promoted through the Community Round Table (CRT) sessions by CASDA member organizations, the National ASD Working Group, the Self-Advocates Group, Professional Associations and through social media. The survey was initially launched during the first Community Round Table session in Yellowknife, on May 2, 2016, with the issuance of a news release. Respondents connected to the survey through the CAPP website.

### **Written Submissions**

Fillable PDFs were created with specific questions for each of the two respondent groups – Autistic Self-Advocates and Professional Associations. Invitations to prepare written submissions were distributed by email to each of these groups.

### **Community Round Tables**

Community sessions were planned for all ten provinces and two of the three territories. (Nunavut declined the invitation to host a CRT as their communities are too widely distributed for this approach to be effective). Focus groups were organized by a local CASDA member organizations (where they existed) that were responsible for inviting up to 25 individuals selected to be representative of all groups – autistic self-advocates, families/caregivers, service providers, professionals, and researchers.

## 3. SUMMARY OF FINDINGS

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### ENGAGING WITH CANADIANS

#### Governments

Meetings were held with 100 elected and non-elected government representatives in ten provinces and three territories. In some cases, multiple meetings were held for a total of 21 sessions which included:

- Ministers of Health, Social Services, Education
- Deputy Ministers of Health, Social Services, Education, Human Services
- Senior Directors
- Program Directors

#### Community Round Tables

A total of 494 individuals participated in 17 community round table sessions held in 14 communities across the country. Participants were organized into 92 table discussion groups to promote sharing of knowledge about innovations in their communities and perspectives on the proposed CAP model. A scribe at each table captured the discussion on a worksheet that was subsequently analysed.

The first Community Round Table (CRT) session was held at the CASDA Autism Leadership Summit in Ottawa, on April 18<sup>th</sup>, 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 Model that was subsequently used for the community-based roundtable discussion sessions held across the country between May 2<sup>nd</sup> and June 23<sup>rd</sup>, 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 the 16 community-based CRT participants by region.

Table 1: 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	RESEACRHER
ATLANTICA <sup>A</sup>	73 22.5%	7 (26.9%)	17 (25.4%)	10 (14.7%)	35 (23.1%)	4 (36.4%)
CENTRAL <sup>B</sup>	72 22.2%	6 (23.1%)	19 (28.4%)	20 (29.4%)	23 (15.1%)	4 (36.4%)
WEST <sup>C</sup>	143 44.1%	12 (46.2%)	21 (31.3%)	27 (39.7%)	80 (52.6%)	3 (27.2)
NORTH <sup>D</sup>	36 11.1%	1 (3.8%)	10 (14.9%)	11 (16.2%)	14 (9.2%)	0 (0.0%)
TOTAL	324	26	67	68	152	11
% OF TOTAL	100%	8.0%	20.7%	21.0%	46.9%	3.4%

A = New Brunswick, Newfoundland and Labrador, Nova Scotia, and Prince Edward Island

B = Ontario and Québec

C = Alberta, British Columbia, Manitoba, and Saskatchewan

D = Northwest Territories, Nunavut, and Yukon

## Stakeholder Survey

A total of 4,371 respondents participated in the survey, either in full or in part. The vast majority responded in English (3,992), with an additional 379 responding in French. Respondents represented all ten provinces and three territories, and were distributed across the four main respondent types:

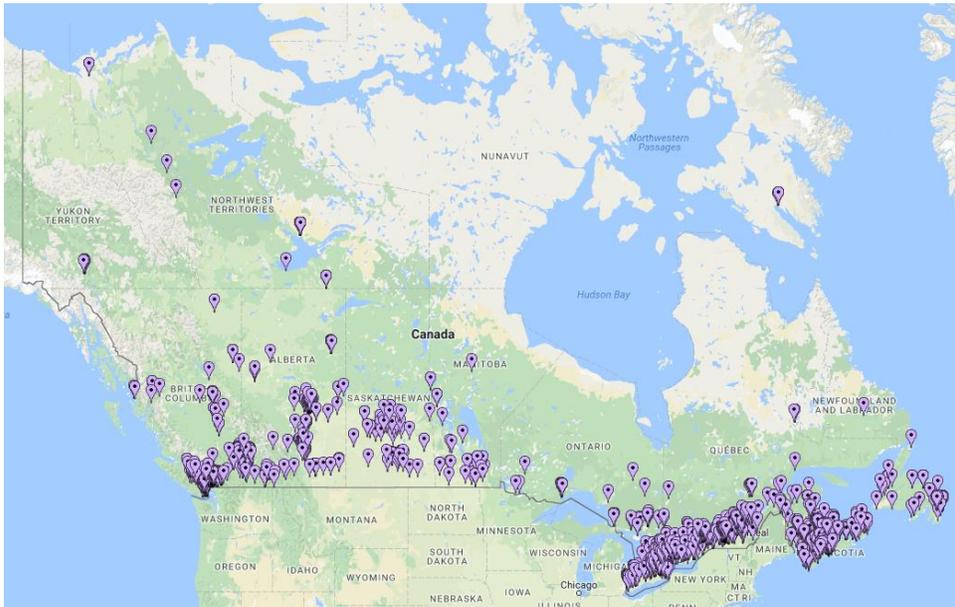
Table 2: Frequency & Percentage of Each Respondent Type by Region

	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	OTHER
ATLANTICA <sup>A</sup>	643 15.0%	26 (11.6%)	349 (13.7%)	170 (20.5%)	49 (12.5%)	49 (16.7%)
CENTRAL <sup>B</sup>	1,994 46.4%	98 (43.8%)	1,233 (48.2%)	352 (42.4%)	170 (43.1%)	141 (48.0%)
WEST <sup>C</sup>	1,599 37.2%	99 (44.2%)	968 (37.9%)	280 (33.7%)	158 (40.1%)	94 (31.9%)
NORTH <sup>D</sup>	60 1.4%	1 (0.4%)	4 (0.2%)	28 (3.3%)	17 (4.3%)	10 (3.4%)
TOTAL	4,296	224	2,554	830	394	294

\* Other includes: individuals that associate with multiple respondent types; friends; interested citizens; researchers; and government representatives.

Using the postal code data submitted by 4,197 respondents, the geographic dispersion of respondents across the country is shown in the map below. Detailed distribution for each province and territory can be found in the Appendices.

*Figure 1: Detailed Map of Respondents by Postal Code*



Respondents were well distributed by community type. Urban (1,848) and Suburban (1,478) respondents made up the majority, but Rural (766) and Remote (99) respondents provided a well-rounded distribution across the country.

*Table 3: Frequency & Percentage of Respondents by Region and Size of Community*

	TOTAL	REMOTE	RURAL	SUBURBAN	URBAN
ATLANTICA <sup>A</sup>	628 15.0%	12 (12.1%)	246 (32.1%)	171 (11.6%)	199 (10.8%)
CENTRAL <sup>B</sup>	1,942 46.3%	19 (19.2%)	273 (35.6%)	810 (54.8%)	840 (45.5%)
WEST <sup>C</sup>	1,562 37.3%	25 (25.3%)	242 (31.6%)	493 (33.3%)	802 (43.4%)
NORTH <sup>D</sup>	59 1.4%	43 (43.4%)	5 (0.7%)	4 (0.3%)	7 (0.4%)
<b>TOTAL</b>	<b>4,191</b>	<b>99</b>	<b>766</b>	<b>1,478</b>	<b>1,848</b>

## Written Submissions

Recognizing that many professional organizations have made significant contributions to the diagnosis and treatment of autism and autism related conditions, 15 professional associations representing medicine, health, social services, mental health, justice and education, were invited to submit a written response to a small set of questions.

The Self-Advocates Advisory Group requested that autistic adults also have access to this method of engagement. As a result, invitations were sent to the members of the Self-Advocates Advisory Group, and adults who identified on the Autism Spectrum that participated in a CRT discussion. The invitation also requested that the written submission form be distributed throughout their networks in an attempt to reach others who might want to use this written approach to provide feedback about the CAP model.

## **ANALYSIS APPROACHES**

**Government meetings** – Notes taken at the government meetings were reviewed and key themes, comments, and suggestions were noted for inclusion in this findings report.

**Community Round Tables** – The written notes from each of the 92 tables at the 17 sessions were transcribed, and professionally translated from French to English where necessary. The notes were then analysed, with each individual comment coded into common themes. The frequency of the themes within the notes from all tables at all sessions were then plotted in bar charts, with the frequency of the theme making up the horizontal axis and the actual number of instances for each theme at the end of the bar in the chart. Additional qualitative analysis of the comments for the top themes from each question was conducted to identify specific areas of common interest or perspective, which are reported below the charts.

**Stakeholder survey** – Quantitative data from the surveys were combined, and plotted into charts to report frequency and/or percentage of responses for each question. Written responses to questions were analysed to identify common themes, frequency of responses, and trends.

**Written Submissions** – Written submissions were reviewed and the responses to each question were summarized.

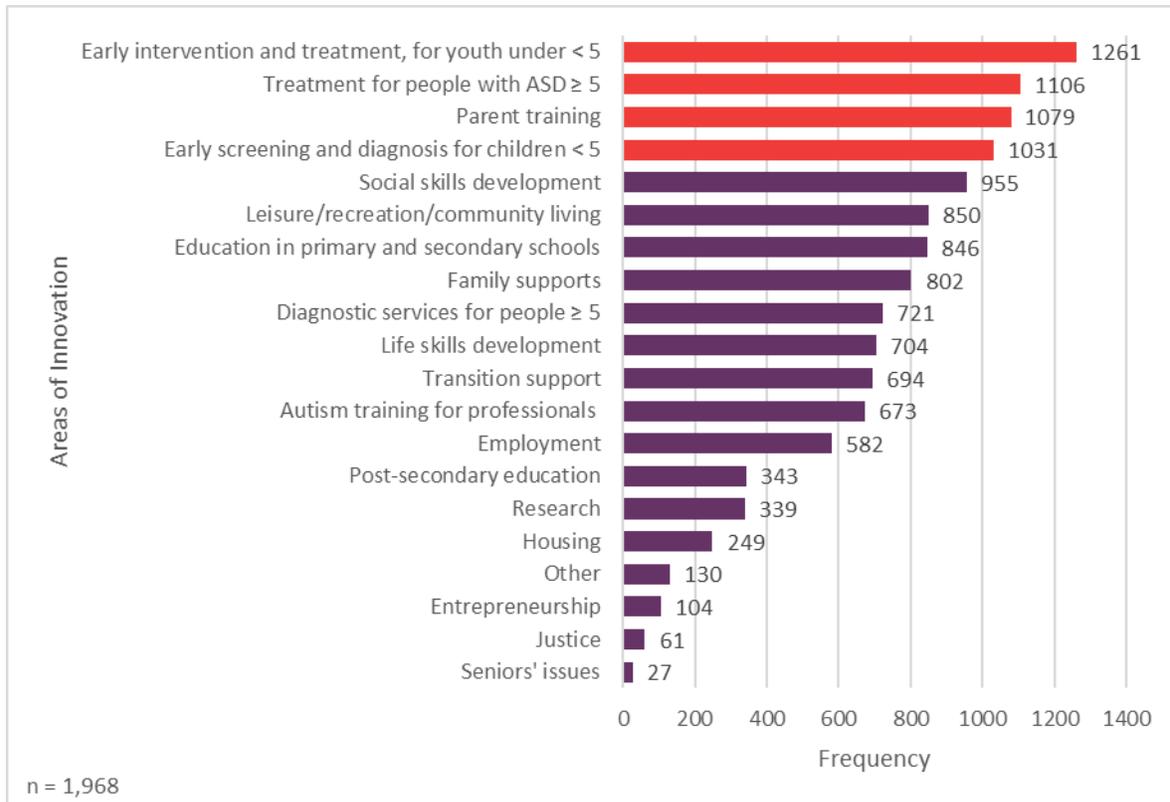
## **RESULTS**

### **Innovations**

The lists of 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. It is important to note that the project team did not narrow the definition of what “Innovations” in each community could be defined as. This allowed for a wide range of responses and an unbiased approach to input and feedback. It also provided a greater understanding of the scope of programs, services and needs in each community.

In the survey, 2,023 respondents indicated that they were aware of innovative practices and services, and 1,968 of them identified areas of innovation as detailed in the following chart:

Figure 2: Frequency of Areas of Innovation



In a follow-up question, respondents provided further details on 4,296 innovative programs and services in their communities. They further described the breadth and depth of programs and services across the country, including:

- Specific service providers and agencies;
- Health care programs and services;
- Grassroots, community based initiatives;
- Knowledge sharing initiatives between organizations;
- Funding and funding models;
- Technology tools, apps, and services;
- University and college programs and research;
- Elementary & secondary school based programs; and
- Employment services and programs, and specific employers

For further community-identified innovations, please refer to *Analysis of Findings – Stakeholder-Identified Innovations*, where responses from the CRTs and the survey have been compiled into a

comprehensive list of innovations by province/territory. The rich innovation-related data collected through the stakeholder engagement process provides opportunities for future analysis.

## Barriers to Service

Respondents reconfirmed the results of CASDA’s 2014 National Needs Assessment, indicating that the top barriers to service are: being on a waiting list (72%), lack of services (66.9%), and not being able to afford service (57.2%). Additionally, 55.4% of respondents identified “being too old to access service” as a significant barrier, and 54.7% identified lack of trained professionals as a barrier.

## CAP Outcomes

The majority of the 3,767 respondents agree that the proposed outcomes would positively impact people with ASD in their communities.

*Table 4: Percentage of Respondents That Agree the Outcome Would Positively Impact People with ASD*

OUTCOMES	% OF RESPONDENTS
Better access to information for families/caregivers and people living with ASD.	74.3%
Providing coordinated outreach and expertise to help address critical issues of concern to the ASD community.	72.3%
Increased collaboration and sharing of information across organizations, within your community/province.	69.2%
Identification of innovative ASD approaches nationally and internationally	62.7%
Bringing together a broad spectrum of federal, provincial and territorial representatives for greater collective impact.	59.2%
Promotion of evidence-based decision making	54.2%
None of the above	9.2%

## Communications with Stakeholders

Respondents generally agree that the best ways to share information with stakeholders across the country are: electronic newsletter, email, social media and through an ASD network. Additional ways of sharing information are to use schools, service providers, traditional media, and conference & symposiums. The best ways to receive input from stakeholders are: email, social media, online forums, and through an ASD network. Additional ways of gathering input are through surveys, by phone, and in face-to-face meetings.

## Areas of focus for the Canadian Autism Partnership

CRT participants and survey respondents were presented with the following proposed areas of focus for CAP:

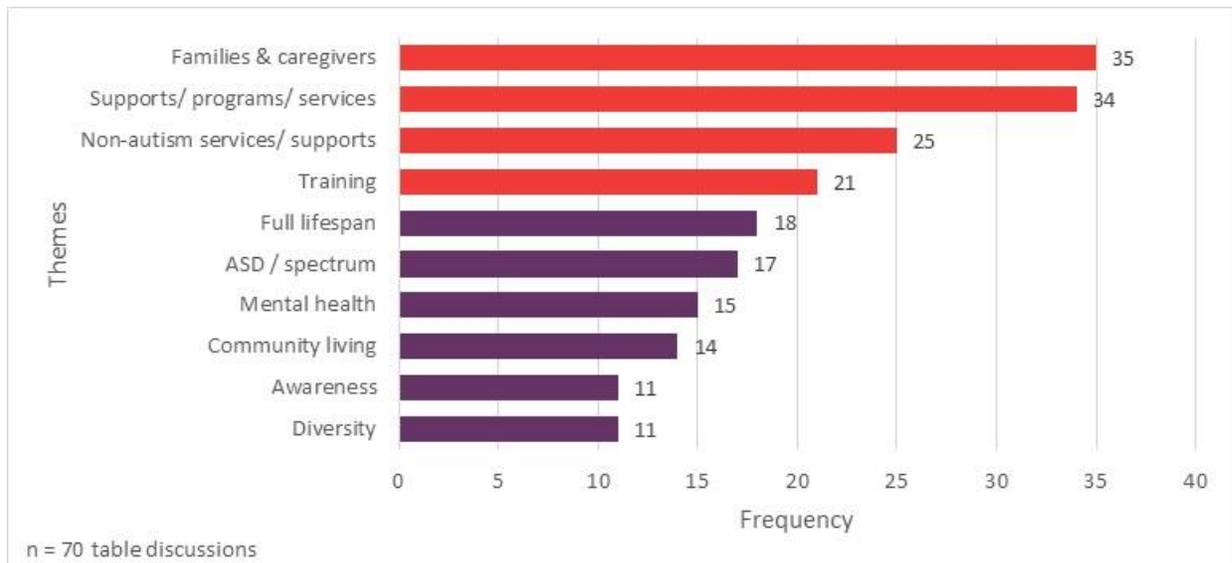
- Early detection and diagnosis

- Treatment and support across the lifespan
- Education, training and awareness
- Attachment to the labour force
- Community living (includes recreation, leisure and housing)
- Impact on caregivers (includes health, mental health, respite, and senior issues)
- Research

All community round table sessions were asked if additional priority areas of focus should be added. As well, of the 3,527 survey respondents to this question, 2,617 (74.2%) felt that the proposed areas of focus were appropriate. The remaining 910 respondents identified 832 items that either added clarity to the proposed areas of focus, or presented new areas of focus. Written responses also provided input on the biggest issues that need to be addressed.

The following chart depicts the frequency of areas of focus themes identified during the community-based CRT sessions.

*Figure 3: Frequency of Areas of Focus Themes*



Overall, the areas that received the highest level of response were:

- Health, mental health, and co-occurring conditions
- Families & caregivers, specifically the inclusion of siblings, and the need for financial support
- Supports, programs & services, with emphasis on schools, housing, and respite
- Training for parents and professionals
- Care and support across the lifespan, the spectrum, and the diverse community
- Awareness of ASD in the general community

- Community living, particularly housing and transportation

## **Vision, mandate, and foundational statements**

Survey respondents were asked to indicate their level of agreement with the proposed vision, mandate, and foundational statements for CAP, with the following results.

- **VISION** – All Canadians living with autism have the opportunity to lead fulfilling and rewarding lives. This means that they are able to access the necessary supports and services in a welcoming and understanding society.
  - 80.3% of respondents agree or strongly agree with this vision.
- **MANDATE** – To mobilize partners across sectors on a national level to accelerate innovation and action to address complex issues affecting Canadians living with Autism.
  - 81.4% of respondents agree or strongly agree with this mandate.
- **FOUNDATIONAL STATEMENTS** – 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.
  - 87.1% of survey respondents agree with these foundational statements

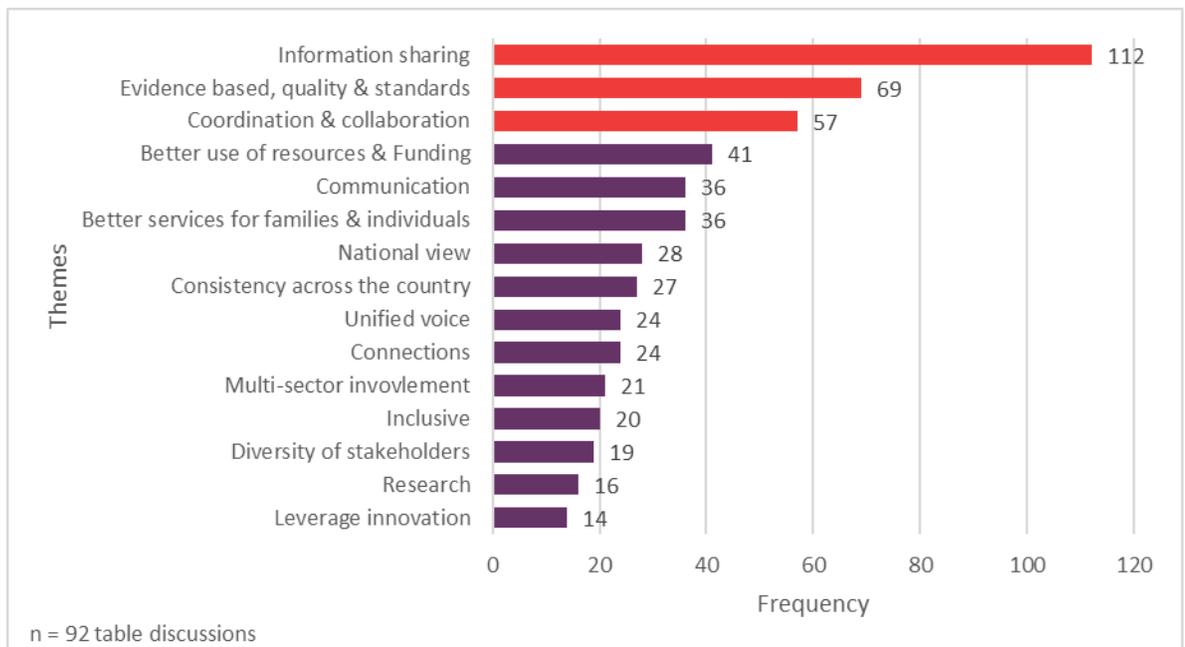
## **Viability and added value**

The CRT participants were asked to consider the viability of the CAP model as it was presented, and to identify ways the model could be strengthened, barriers to its success, and gaps in the current model.

- **POINTS TO STRENGTHEN THE MODEL** – The three main areas that were identified as needing to be strengthened were: providing more details on the strategic and implementation plans; detailing approaches to communication and stakeholder engagement; and using clear terminology and definitions to ensure information has the same meaning to all stakeholders. (This question was asked only at the CASDA Autism Leadership Summit.)
- **BARRIERS TO CAP'S SUCCESS** – Participants at the CASDA Autism Leadership Summit identified a variety of barriers to the success of the CAP model, with the following themes receiving the most input: funding, culture / language / diversity, and national vs. provincial / territorial mandates.
- **GAPS IN THE MODEL** – Many of the identified gaps focused on the structure of the model diagram and made many suggestions about how its presentation could be improved. Suggested changes were made to the mandate, vision, goals and objectives as they were presented, and better clarity was recommended around the organizational model diagram. There were additional comments about ensuring that the organization is inclusive in its membership and work, that ongoing engagement ensures all voices are being heard (specifically those of families and people with ASD), and that changes are needed to existing programs, services and supports across the system.

- VIABILITY** – CRT participants were overall supportive of the proposed model and feel it is viable. Many tables moved directly into the sub-questions, which we have interpreted as implied acceptance of CAP’s viability. We did not receive any comments indicating any group felt the model was not viable. As well, the feedback received during meetings with government representatives strongly supported the model, with many indicating they would be willing to provide their support in writing. There was genuine enthusiasm for a system that would allow governments to learn from others across the country, and collaborate and coordinate when possible.
- ADDING VALUE** – Every community identified “information sharing” as the most significant 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, the ability to coordinate activities, collaborate with others in service delivery or knowledge sharing, and reduce duplication of effort were identified in many communities. Written submissions supported the perspectives from the communities, and added bringing together the entire Canadian autistic community as a value added by CAP.

Figure 4: Frequency of Values Added by CAP Themes



## CONCLUSION

With input from 4,967 Canadians representing all ten provinces and three territories, we are able to conclude 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

acknowledged 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 following chapters provide details of what we heard from each of the stakeholder engagement approaches. The data gathered during the stakeholder engagement process provided the necessary input into the business plan that will enable CASDA to implement the CAP model and achieve the proposed outcomes.

## 4. GOVERNMENT MEETINGS

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Face-to-face meetings, with either individuals or small groups, were held with elected and non-elected government representatives in ten provinces and three territories (in some cases multiple meetings were held) for a total of 21 sessions:

- British Columbia
- Alberta (3)
- Saskatchewan
- Manitoba
- Ontario (3)
- Northwest Territories
- Nunavut (2)
- Yukon (2)
- Québec (2)
- Newfoundland & Labrador
- New Brunswick (2)
- Nova Scotia
- Prince Edward Island

One hundred (100) participants attended the meetings, which included:

- Ministers of Health, Social Services, Education
- Deputy Ministers of Health, Social Services, Education, Human Services
- Senior Directors
- Program Directors

There was a strong positive response to the proposed Collective Impact Framework, and to the development of a Canadian Autism Partnership. The government representatives were able to identify many ways in which the proposed model would add value for them:

- They expressed genuine 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 part of the “value add”.
- 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 network was identified as a positive step to supporting their enhanced collaboration.
- First Nations’ representatives also identified the value of having a network 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 FASD Network model as a having a similar network component which they considered effective.

## 5. COMMUNITY ROUND TABLES

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### METHODOLOGY

#### CASDA Autism Leadership Summit Round Tables

The first Community Round Table (CRT) session was held at the CASDA Autism Leadership Summit in Ottawa, on April 18<sup>th</sup>, 2016.

The two-hour session began with a presentation from the project Co-Directors, which provided background on the CASDA 2014 National Needs Assessment Survey results and key findings and how that led to the development of the Canadian Autism Partnership Project. The proposed CAP model was presented in detail, providing participants with an overview of the structure, process, and anticipated outcomes. Participants were then asked to consider two questions during a moderated discussion at each table. The discussions were scribed and reported back at the end of the session.

- Question 1 – Recognizing that the CAP model will continue to evolve through the stakeholder engagement process, in your view, is the CAP concept a viable working model?
  - Are there any aspects that you think could be strengthened?
  - What barriers exist that might impede its success? How might we address these barriers?
- Question 2 – How could CAP add value to your organization or community?

The outcome from the Ottawa session allowed the team to refine the questions and the CAP model that were subsequently used for the community-based roundtable discussions held across the country.

#### Community Round Tables

Similar to the Ottawa session, each three-hour community-based CRT session began with a presentation by the project Co-Directors to outline the results and key findings from the National Needs Assessment Survey and how that led to the development of the Canadian Autism Partnership Project. The CAP model was presented in detail, providing participants with an overview of the structure, process, and anticipated outcomes. Participants were then asked to consider two questions in a moderated discussion at their table. The discussion was scribed and results were reported back at the end of the session.

- Question 1 – We would like to learn more about areas of innovation for individuals with ASD across Canada. Are you aware of any research, program and/or service innovation(s) in your community or province? Please describe them, tell us why they are innovative, and who led them.
- Question 2 – Recognizing that the CAP model will continue to evolve through the stakeholder engagement process, in your view, is the CAP concept a viable working model?

- How could CAP add value to you and your family, your organization and/or community?
- Is anything missing or are there changes that would make it stronger?
- Are there any additional areas of focus that CAP should address?

## **PARTICIPANTS**

The CASDA Autism Leadership Summit session was attended by 170 registered Summit attendees; there were 22 tables of participants in the session, including a wide range of leaders and experts with an interest in autism, including: directors of service organizations, government representatives, researchers, and professionals who work with individuals with an ASD and their families. The attendees reflected the membership of CASDA, with representatives from across the country and across a wide variety of leadership organizations.

Participants in the community-based sessions were invited by the local host, who was for the most part a CASDA member, and represented a broad range of stakeholders in each community, including:

- |                     |                                |
|---------------------|--------------------------------|
| • Self-Advocates    | • Occupational Therapists      |
| • Families          | • Physiotherapists             |
| • Caregivers        | • Speech Language Pathologists |
| • Researchers       | • Psychologists                |
| • Service providers | • Police officer               |
| • Social workers    | • Educators                    |
| • Physicians        | • Government officials         |
| • Nurses            |                                |

Sixteen round-table sessions were held in 14 communities across Canada between May 2<sup>nd</sup> and June 23<sup>rd</sup>, 2016 (by order of occurrence):

- |                     |                     |
|---------------------|---------------------|
| • Yellowknife, NWT  | • Whitehorse, YT    |
| • Edmonton, AB      | • Prince George, BC |
| • Calgary, AB       | • Québec City, QC   |
| • Regina, SK        | • Montréal, QC      |
| • Winnipeg, MB      | • St. John's, NL    |
| • Toronto, ON (2)   | • Fredericton, NB   |
| • Vancouver, BC (2) | • Halifax, NS       |

The goal was to have 25 participants at each session, arranged in tables of 5-6 to encourage active discussion of the questions. The outcome was that some sessions were smaller, while others were

quite large resulting in a total of 324 participants, who were organized into a total of 70 tables, with between 4 and 8 individuals at each table.

The following table details 16 community-based CRT participants by type and region.

Table 5: 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
ATLANTICA	73 22.5%	7 (26.9%)	17 (25.4%)	10 (14.7%)	35 (23.1%)	4 (36.4%)
CENTRALB	72 22.2%	6 (23.1%)	19 (28.4%)	20 (29.4%)	23 (15.1%)	4 (36.4%)
WESTC	143 44.1%	12 (46.2%)	21 (31.3%)	27 (39.7%)	80 (52.6%)	3 (27.2)
NORTHD	36 11.1%	1 (3.8%)	10 (14.9%)	11 (16.2%)	14 (9.2%)	0 (0.0%)
TOTAL	324	26	67	68	152	11
% OF TOTAL	100%	8.0%	20.7%	21.0%	46.9%	3.4%

## ANALYSIS APPROACH

The notes from each of the 92 tables were analysed, with comments coded into common themes. Lengthier comments were coded into multiple themes. The frequency of the themes within the notes from all tables at the sessions were then plotted in bar charts as shown in the following pages, with the common theme on the Vertical axis and the frequency of the themes plotted on the horizontal axis in the bar chart.

Additional qualitative analysis of the comments for the top themes from each question was conducted to identify specific areas of common interest or perspective, which are reported below in the charts in the following pages. The “n” for each chart depicts the number of table discussions that responded to the specific question.

## RESULTS

*Question: We would like to learn more about areas of innovation for individuals with ASD across Canada. Are you aware of any research, program and/or service innovation(s) in your community or province? Please describe them, tell us why they are innovative, and who led them. (Asked at the 16 community based sessions)*

The lists of 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.

The table below provides a sample of the community identified innovations, which is the same list that was made public on the CAPproject.ca website. Locations are shown in the order of occurrence of the CRTs.

Table 6: Sample Community Identified Innovations

LOCATION	INNOVATIONS
Yellowknife	<p><b>Learning retention program</b> extends the school year so children with autism are better able to retain what they learned from one year to the next.</p> <p><b>Program of mindfulness training</b> was developed and is delivered in the classroom.</p> <p>A rehab <b>team</b> at the hospital offers skill building ‘camps’ for autistic children (i.e. speech camp, bike riding camp).</p>
Edmonton	<p><b>The Adult Autism Diagnostic Clinic at the Glenrose Rehabilitation Hospital’s Lifespan Clinic</b> provides assessment, diagnosis, and education for the client and family; information about community resources; and makes referrals as needed.</p> <p><b>The I Can Pretend, Drama for Children with Autism</b> program at the Citadel Theatre, Foote Theatre School is for children aged 5-12. It aims to help children learn to play imaginatively and co-operatively with other children, achieve a positive sense of self-awareness and self-esteem, and gain a basic understanding of perspective taking (understanding of the perspectives of others). <a href="http://www.citadeltheatre.com/academy/foote-theatre-school/">http://www.citadeltheatre.com/academy/foote-theatre-school/</a></p> <p>The <b>Kids Uncomplicated TELEROO™ app</b> allows parents to upload media quickly and securely to their Kids Uncomplicated team, which brings individuals, families and clinicians together in online chats for information sharing and knowledge transfer. - <a href="http://www.theuncomplicatedfamily.com/#section-teleroo">http://www.theuncomplicatedfamily.com/#section-teleroo</a></p> <p><b>Gateway Association’s “We Belong” program</b> matches individuals' skills to jobs, and follows the full employment history of individuals through their careers.</p>
Calgary	<p><b>Alberta Health</b> funds Asperger's screening for adults</p> <p><b>The Child Development Centre (CDC)</b> aims to create a collaborative environment that promotes optimal outcomes for children and their families across the developmental continuum by integrating world-class research, training, services and policy. <a href="http://www.ucalgary.ca/facilities/buildings/child_development_centre">http://www.ucalgary.ca/facilities/buildings/child_development_centre</a></p>

LOCATION	INNOVATIONS
	<p><b>Arnika Centre for Developmental Disabilities Mental Health</b>, offers assessment by a psychiatrist for people 16 years and older with below average intelligence and a mental health condition, as well as consultation and working with caregivers and community agencies.</p> <p><b>The Calgary Police Service</b> has created a database where people with physical, mental or medical conditions can register to alert first responders in the event of an emergency.</p>
Winnipeg	<p>Asperger's <b>Manitoba Inc.</b> can train and accredit Lego social skills facilitators</p> <p><b>A focus on supporting rural and remote communities</b> is achieved in part through telehealth and includes (among other things), support for families, diagnostic clinics, knowledge exchange and participation in working groups</p> <p><b>Specialized Services for Children and Youth (SSCY)</b> is an initiative focused on the integration and, where possible, co-location, of services for Manitoba children and youth with disabilities and special needs. <a href="http://sscy.ca/">http://sscy.ca/</a></p>
Regina	<p><b>Big Sky Centre for Learning and Being Astonished Inc.</b>, addresses barriers facing young adults with complex physical disAbilities by creating opportunities for teaching and learning, social, recreational and cultural engagement, and for employment and housing. - <a href="http://www.beingastonished.com/">http://www.beingastonished.com/</a></p> <p><b>Globe Theatre</b> has a program for individuals with autism that helps to improve their social skills.</p>
Toronto	<p><b>Researchers at Holland Bloorview Kids Rehabilitation Hospital</b> have developed a new, wearable device that detects states of anxiety in children with ASD, and helps these children manage their symptoms.</p> <p><b>MacART - McMaster Autism Research Team</b> is a partnership between McMaster Children's Hospital, Hamilton Health Sciences, and McMaster University aiming to bridge the research-to-practice gap in autism. <a href="http://www.macautism.ca/">http://www.macautism.ca/</a></p> <p>The <b>Toronto Catholic District School Board</b> created <b>The Transition to Secondary Service</b> for students with Autism to support their transition from elementary to secondary school.</p> <p><b>MyHealth Passport</b>, a project of the SickKids Good 2 Go Transition Program, is a customized, wallet-sized card that gives users instant access to their medical information when they go to a new doctor or visit an emergency room.</p>
Vancouver	<p><b>Pacific Autism Family Centre</b> will bring together service providers, professional services, and researchers in a hub and spoke model that will use state-of-the-art</p>

LOCATION	INNOVATIONS
	<p>technology to support individuals and families living with autism throughout BC. - <a href="http://pacificautismfamily.com/">http://pacificautismfamily.com/</a></p> <p><b>Provincial Outreach Program for Autism and Related Disorders (POPARD)</b> provides consultation, training and support services to all public and independent schools across the province of BC with a primary focus on increasing the capacity of school district staff to support students with an ASD. - <a href="http://www.autismoutreach.ca/">http://www.autismoutreach.ca/</a></p> <p><b>ASBC Talent Bank</b> is an online tool designed to help parents and behavioural interventionists find each other. - <a href="https://www.autismbc.ca/asbc-talent-bank/">https://www.autismbc.ca/asbc-talent-bank/</a></p> <p><b>Douglas College's Behaviour Intervention Certificate Program</b> prepares students to work in a family setting or centre with young children diagnosed with an ASD. - <a href="http://www.douglascollege.ca/programs-courses/catalogue/programs/CNBHVI">http://www.douglascollege.ca/programs-courses/catalogue/programs/CNBHVI</a></p> <p><b>University of Victoria's Authors with Autism</b> group brings persons with autism together to share autism culture through the power of writing.</p>
Whitehorse	<p><b>NGOs and government organizations</b> coordinate travel to rural communities to provide more comprehensive services</p> <p><b>Family Services Child Development</b> recently merged with Adult services creating a more seamless transition to from youth to adulthood.</p>
Prince George	<p><b>Northern Health Assessment network</b> has two paediatricians who travel throughout the north to provide assessment for children and youth up to the age of 19.</p> <p><b>Adult Autism Initiative</b> is looking at expanding services to individuals up to 24 years of age.</p> <p><b>Adult social group</b> where adults with autism get together to have fun – playing pool &amp; cosmic bowling, making friends &amp; improving social skills.</p>
Quebec City	<p><b>School-to-Independent Living Transition (TÉVA)</b> is a planned and coordinated approach which integrates with the student's Individual Education Plan (IEP), and Individualized, Intersectoral Services Plan (IISP); the measures included in TÉVA aim to support the student during transition from school to other life activities (work and social aspects of employment, continuing education, post-secondary education, recreation, transportation, housing, etc.) <a href="http://www.rophcq.com/TEVA/sections/_index.html">www.rophcq.com/TEVA/sections/_index.html</a> (in French)</p> <p><b>Réseau national d'expertise en trouble du spectre de l'autisme (RNETSA)</b>. Jointly sponsored by the Quebec Ministry of Health and Social Services, and Ministry of Education, Higher Education and Research, the RNETSA brings together people</p>

LOCATION	INNOVATIONS
	<p>who have developed expertise in the field of ASD and who wish to share this expertise. <a href="http://www.rnetsa.ca">www.rnetsa.ca</a></p>
Montreal	<p><b>Aspie Québec</b> - Meetups, socialisation and activity groups organized by autistic people, fosters belonging and socialisation without prejudice. An essential human need is met – interacting with peers in an environment of respect and free of judgment.</p> <p><b>Salon de l'autisme TSA du Québec</b> - A three-day fair with a mission to give all Quebec residents access to information about autism, and help find services and resources to not only increase understanding of autism, but especially, improve support for people with ASD. <a href="http://www.salondelautismetsa.com">www.salondelautismetsa.com</a> (in French)</p> <p><b>Jooay</b> - An interactive, user-friendly app that displays information about nearby physical activities, music classes and art classes tailored to a child's special needs. Parents can browse through activities by category, keyword, or disability type. <a href="http://www.jooay.com">www.jooay.com</a></p>
St. John's	<p><b>First responder training</b> – Autism Society, Newfoundland and Labrador is providing training to help first-responders learn about autism and how knowledge of it can help in emergency situations.</p> <p><b>Feeding Futures</b> provides families with tools, easy to follow recipes, food exposure strategies and a no-nonsense approach to special needs nutrition. Though years of research and practice they have created a hands on, family focused, child-directed and highly motivational approach to food therapy. <a href="http://www.feastfeedingfutures.wordpress.com">www.feastfeedingfutures.wordpress.com</a></p>
Fredericton	<p><b>NBASSE/ASSENB Employment Project</b> – The goal is to develop, test and evaluate a change process and a service delivery model for ADAPT agencies. As a key component, it will include features that will lead to greater community employment outcomes for real wages for adults served by agencies, including adults with an intellectual disability. <a href="http://www.nbasse.ca/employment_project.html">www.nbasse.ca/employment_project.html</a></p> <p><b>Open Sky Co-operative</b> provides home, vocational assistance and a caring community for adults who require supports to improve their quality of life. We are a charitable co-operative social enterprise, made up of many different people and organizations. <a href="http://www.openskyco-op.ca">www.openskyco-op.ca</a>.</p>
Halifax	<p><b>Social Learning In Drama Education (SLIDE)</b> is a non-committal drama class in HRM aimed toward those on the autistic spectrum who want to meet new people</p>

LOCATION	INNOVATIONS
	<p>and work on social interaction skills in a fun, supportive way, free of imposing structure.</p> <p><b>IDEAS for Autism</b> is a volunteer-driven group of parents and professionals dedicated to providing Information, Direction, Education, Advocacy and Support for the Halifax Regional Municipality Autism Community and beyond. www.Ideasforautism.ca</p>

The above list is merely a small snapshot of the innovations identified across the country. For further community-identified innovations, please refer to *Analysis of Findings – Stakeholder-Identified Innovations*, where the responses from the CRTs and the survey have been researched and compiled into a comprehensive list of innovations by province/territory. The rich data that was collected in this question will provide CAP and CASDA many opportunities for future analysis.

*Question: Recognizing that the CAP model will continue to evolve through the stakeholder engagement process, in your view, is the CAP concept a viable working model? (Asked at the CASDA Autism Leadership Summit session and at the 16 community-based sessions)*

Participants in the CASDA Autism Leadership Summit session actively discussed the viability of the model and generally felt that the model was viable. Similarly, many participants in the community-based sessions made positive comments about the viability of the model. Many tables, particularly in the community-based sessions moved directly into the three sub-questions, which we have interpreted as implied acceptance of CAP's viability.

Overall there were no specific comments that indicated any table of participants felt the model was not viable. There were, however, questions raised around CAP's long-term viability, such as:

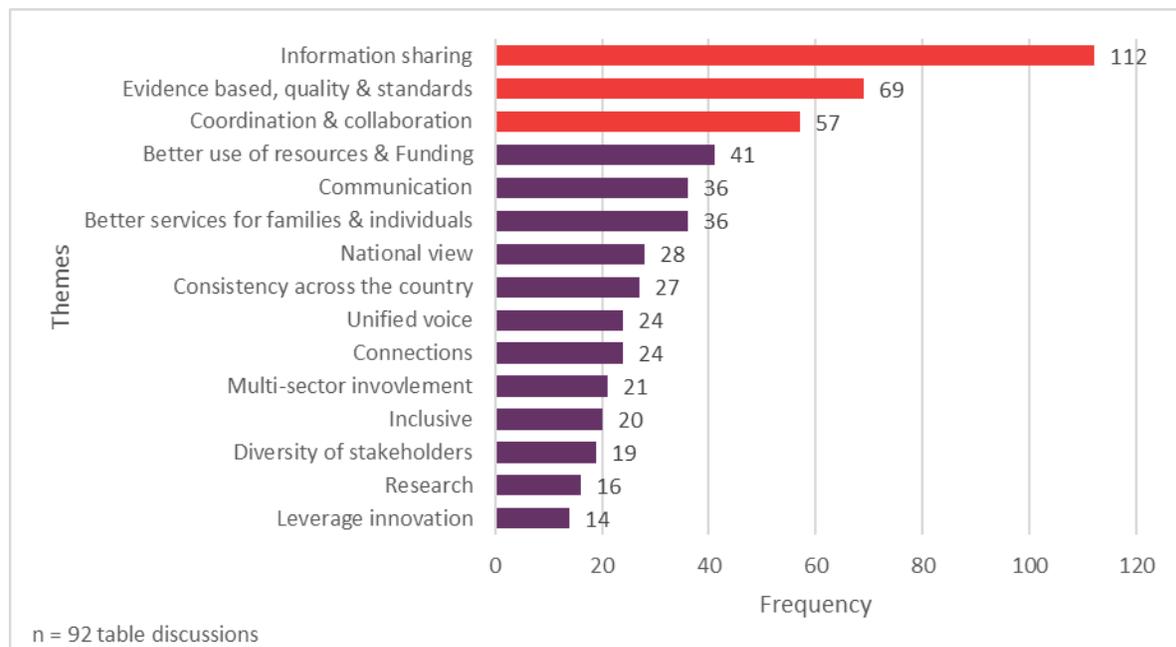
- Is the concept too broad / heterogeneous; will it lose focus?
- How will the federal government collaborate with provincial/ territorial governments?
- How does one account for political differences, despite presentation of the best evidence?
- How will different sources of input be balanced?

*Sub-question: How could CAP add value to you and your family, your organization, and/or community? (Asked at the CASDA Autism Leadership Summit session and at the 16 community-based sessions)*

CRT participants identified many ways in which the proposed CAP framework could add value to their communities and individuals living with autism. 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.

Figure 5: Frequency of Values Added by CAP Themes



Within the theme of information sharing, the following specific values were identified:

- Increased currency of information;
- Clearinghouse – one place to go –easy referral for health care professionals;
- Share successes and failures, resources, research;
- Reduced duplication of effort;
- Increased speed of access to current practices; and
- Consistency of information across the country.

Within the theme of evidence-based, quality and standards the following specific values were identified:

- Increased local capacity;
- Increased inter-provincial connection and information sharing;
- More seamless integration of supports;
- More accurate and effective referrals;
- Preventing duplication of: services, research, practice development;

- Break down silos; and
- Create strength in numbers (single voice).

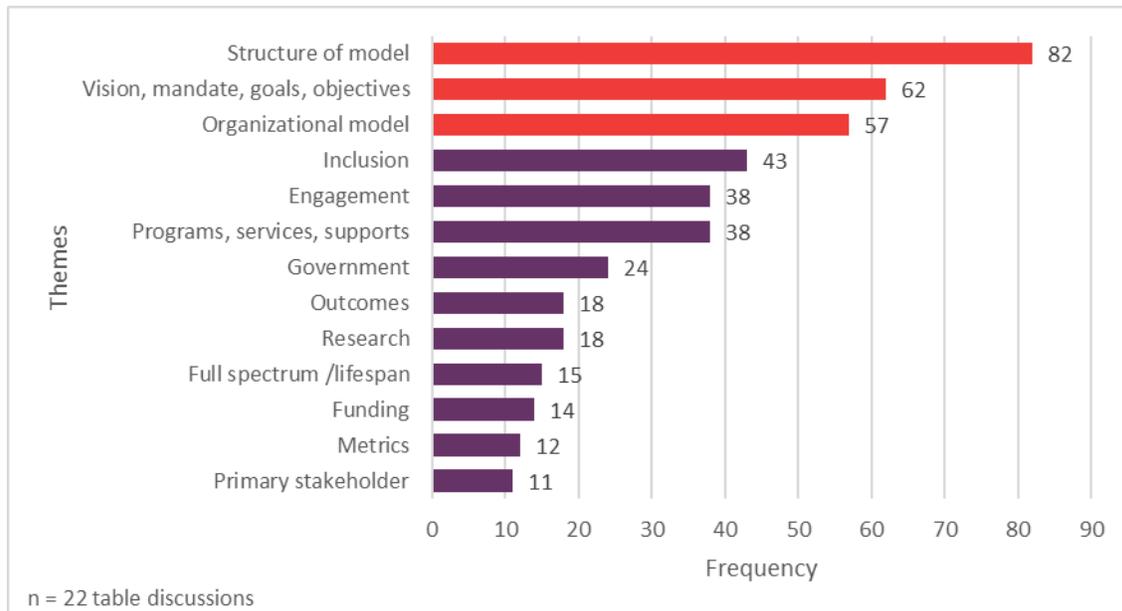
Within the theme of coordination and collaboration the following specific values were identified:

- Supports and promotes nationwide study;
- Increases dependability and consistency across the country;
- Allows for identification of deficiencies;
- Helps families access the right services; and
- Leads to identification of best practices.

*Sub-question: Are there any aspects that you think could be strengthened? (Asked at the CASDA Autism Leadership Summit session)*

Participants in the CASDA Autism Leadership Summit session were the first to see the CAP model, and provided input that was helpful in creating a better description of the model for the community-based sessions which followed. The three main areas that were identified as needing to be strengthened were: strategic plan /implementation, communication & engagement, and terminology and clarity.

Figure 6: Frequency of Areas to Strengthen Themes



Within the theme of strategic plan/ implementation, the following suggestions were identified and questions raised:

- The need for a description of long-term goals and benefits
- How will the processes be operationalized?
- How will CAP bridge between identified solutions on a broad level and implementation at a local or regional level?
- What is the long-term goal of consultation?

Within the theme of communication and engagement, the following were identified:

- Two-way communication between CAP and stakeholders.
- The need for government involvement.
- Ensuring that all relevant voices are heard, including those from small and remote communities.
- Using multiple forms of data collection to ensure broad participation.
- The need to include a communications plan.

Within the theme of terminology and clarity, the following items were identified:

- There are differing definitions for “evidence” and “best practice” between researchers and policy makers.
- Specific examples of how the model will work for each audience would be helpful.
- “Self-advocate” may not be the correct terminology, and could be clarified.
- Clarification of the participants – professional, agency, family?
- Use of plain language in the model so it is easily understood
- Varying opinions around using circles or rectangular boxes.

***Sub-question: What barriers exist that might impede its success? How might we address these barriers? (Asked at the CASDA Autism Leadership Summit session)***

Participants at the CASDA Autism Leadership Summit identified a variety of barriers to the success of the CAP model, with the themes of Funding, Culture / language / diversity, and National vs. provincial / territorial receiving the most comment.

Figure 7: Frequency of Barriers to Success Themes



Within the theme of funding, the following items were identified:

- Concern around the national application of the model when funding practices vary across the country.
- Challenges with time and money are barriers to shared practice.
- Families and service providers need stable funding to ensure consistency of intervention across the lifespan.

Within the theme of culture / language / diversity, the following items were identified:

- The model needs to reflect Canadian society in its entirety including multiculturalism, rural, Indigenous, gender, LGBTQ+, etc.
- Sub-committees may be needed to represent local populations, culturally diverse populations, and families and individuals across the ASD spectrum.
- Geography, language, and cultural differences are all potential barriers.

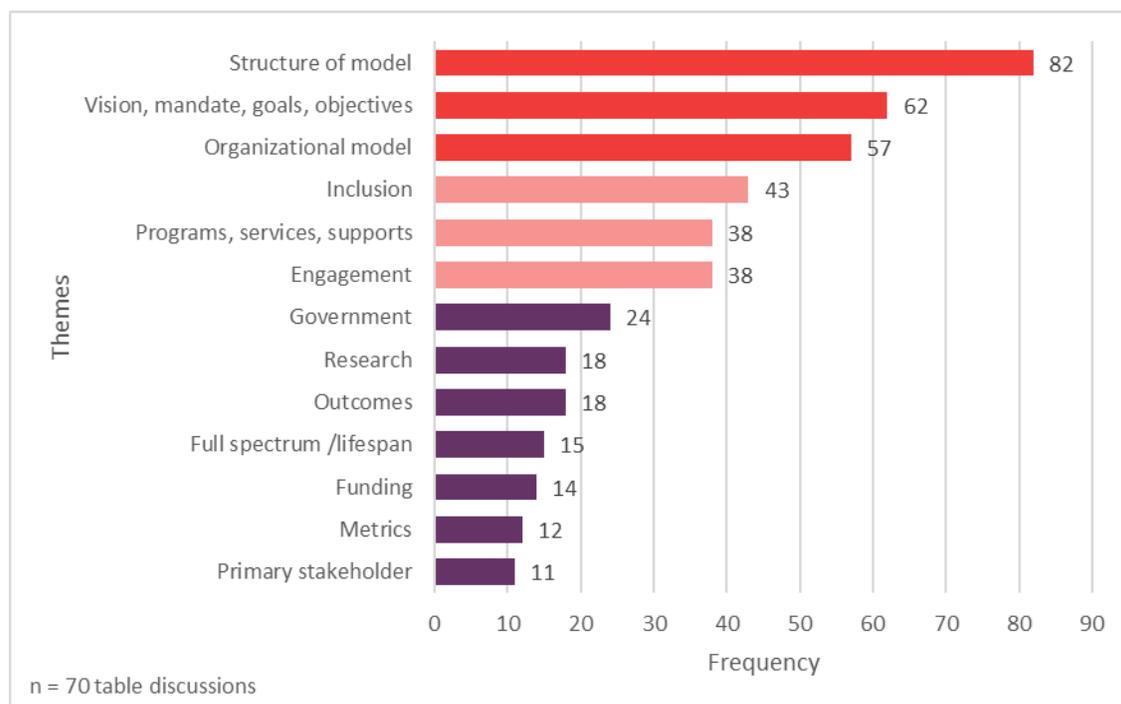
Within the theme of national versus provincial/ territorial, the following items were identified:

- The military should be included in the discussion. DND is a national organization, and frequently moves people from one province to another.
- Affirmation that the creation of a “Central hub” would help cross-provincial navigation through the system.
- Implementation will differ within each province/territory.

*Sub-question: Is anything missing or are there changes that would make it stronger? (Asked at the 16 community based sessions)*

When asked to identify gaps in the proposed model, 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. The second type of responses identified the need for more focus on ensuring that CAP is inclusive in its membership and work, that ongoing engagement ensures all voices continue to be heard, and the need for improvements in programs, services and supports across the system. And the third group identified a variety of gaps including the need for: government involvement, outcomes based planning, additional research, addressing issues across the spectrum and lifespan, funding, metrics and identification of primary stakeholders.

Figure 8: Frequency of CAP Model Gaps Themes



Specific changes to the structure of the model that were suggested include:

- The model should be circular and iterative, with feedback loops;
- The presentation needs to be clearer, with a real example;
- Clear definitions for each step and element should be included;
- The need to clearly describe how people are engaged including entry and exit points;
- The need to clearly define the metrics including what is being measured and monitored; and
- Additional steps or elements needed in the diagram:

- Knowledge sharing;
- Proof of concept;
- Implementation phase;
- Linkages to existing organizations; and
- Who identifies the issues.

CRT participation identified that efforts should be put into developing clear definitions for some key terms used in the model, including “innovative practices” and “evidence-based”. As well, the model needs to provide specific information about CAP’s mandate, objectives, leadership, and scope, a process for selecting and prioritizing issues, goals, funding, focus, deliverables, and policy role, among others. There is also a need to clarify the connections between research and practice; collaboration and engagement; and the difference between best versus innovative practices.

The CAP organizational model will need to clearly define the following:

- Jurisdiction, governance and accountability;
- Who the members will be, how to become a member and member engagement;
- Connection to other organizations;
- The process – the how;
- What constitutes partnership;
- The overall scope of the model; and
- Comprehensive communications.

The CAP model needs to be inclusive of, and engage with, the following:

- Self-advocates and full spectrum of individuals with an ASD;
- Pan-disability communities;
- Provinces and territories;
- Health care, education, justice, community services, etc.;
- Indigenous communities;
- Immigrant communities;
- LGBTQ+;
- Women;
- Private sector;
- Full lifespan;
- Low-income families; and
- Low technology users,
- Families with low income, education/communication barriers, low interest, or in crisis/disruptive situations;

- Health care, education, policing, and judicial systems;
- Professional networks;
- Non-English and/or non-French speakers (location dependent);
- Researchers; and
- Isolated communities.

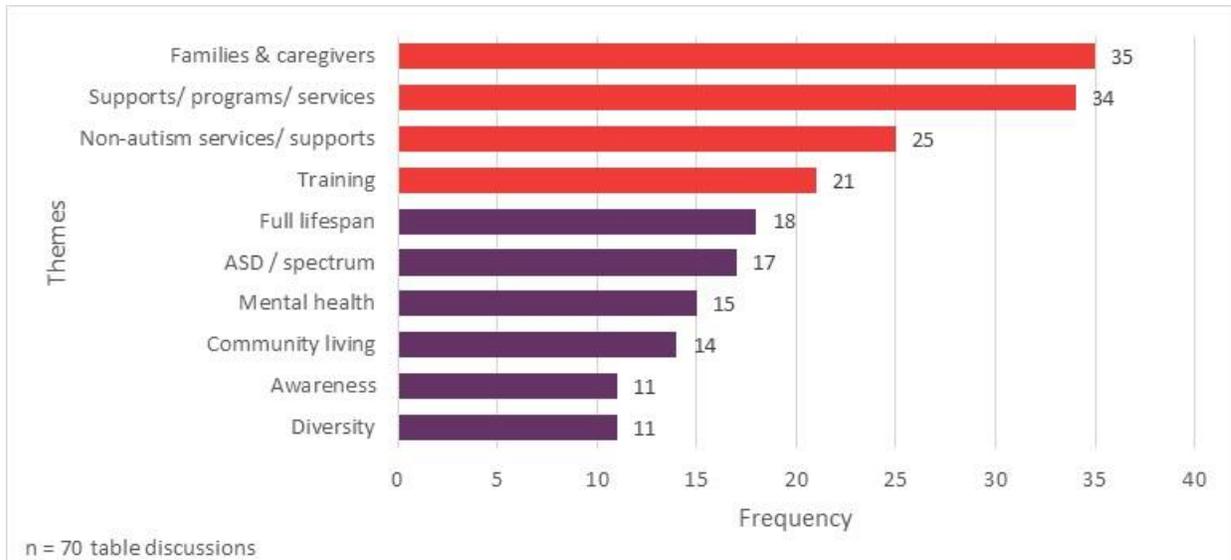
Many of the identified gaps were in relation to programs, services and supports at the community level:

- Programs, services and diagnosis focused specifically at girls;
- Models/guidelines/templates that can be adapted across communities;
- Differences between urban and non-urban communities in service delivery;
- Communication tools – website, apps, one-pagers, etc. - for families and health care practitioners;
- Community education and general awareness within a community as a whole;
- Community policing and first responders as stakeholders;
- Community programs for adolescents; and
- Collaboration between service providers within and between communities.

*Sub-question: Are there any additional areas of focus that CAP should address? (Asked at the 16 community based sessions)*

The areas of focus that were presented to the community round table participants were generally seen to be appropriate; however, 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.

Figure 9: Frequency of Areas of Focus Themes



The top four areas shown in the chart above are detailed below.

The proposed area of focus that was labelled “caregivers” should be expanded to clearly include families, as in “families and caregivers”, and it should explicitly include siblings. Some specific sub-areas of focus for families and caregivers are:

- Knowledge sharing with and among families;
- Continued engagement and consultation with families; and
- Ageing families and the impact on care throughout the lifespan.

Participants identified a great demand for increased supports, programs and services, particularly in the following areas:

- Socialization programs;
- Early and appropriate intervention;
- Timing and availability of diagnostic services –;
- Integration of research into programs;
- Access to services for undiagnosed adults;
- Support for caregivers; and
- Supports for the ageing individuals on the spectrum after their family can no longer provide care?

The interaction between non-autism specific services and supports and those specific to ASD are seen as a key area of focus, specifically:

- General health and mental health, and how they intersect with ASD;
- Physical activity and impact on social skills;
- Substance abuse and addictions;
- Justice;
- Sexual education and awareness;
- Learning from other groups such as Alzheimer's, FASD and others.; and
- Income benefits, CPP, and OAS, and how they apply to adults with an ASD.

Training and awareness building are seen as something that can benefit individuals, their families, and the whole community. Specific areas identified where training is required include:

- General community;
- Public sector/health care workers including doctors, paramedics, police, nurses, etc.;
- School staff;
- Recreational program staff; and
- Managers and front line service delivery workers.

## 6. STAKEHOLDER SURVEY

### METHODOLOGY

The stakeholder survey was launched in Yellowknife, NWT, via the CAPP website on May 2, 2016, and publicized in a news release distributed to media across the country. Invitations to participate and requests to forward the invitation were distributed to the CASDA membership. There was a slow up-take on the initial survey, with only 272 responses. The feedback received was that the survey instrument was long and in some places difficult to navigate.

A revised version of the survey was released on June 4, 2016, with fewer questions and less complexity. Invitations to participate (and several reminders) were sent to the following groups requesting them to engage their members, networks and associates: CASDA members; Self-Advocates Advisory Group, National ASD Working Group; National Needs Assessment respondents; professional associations; and CRT participants.

This promotion effort was successful, and an additional 4,092 responses were received. Not all respondents provided responses to all questions, and not all surveys were completed; however, all input received through the survey has been included in the following analysis.

### RESPONDENTS

A total of 4,371 respondents participated in the survey, either in full or in part. The vast majority responded in English (3,992), with an additional 379 responding in French.

Table 7: Frequency & Percentage of Each Respondent Type by Language

	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	OTHER*
ENGLISH	3,992 91.3%	196 (85.9%)	2,407 (92.3%)	738 (88.4%)	378 (94.3%)	273 (91.3%)
FRENCH	379 8.7%	32 (14.1%)	201 (7.7%)	97 (11.6%)	23 (5.7%)	26 (8.7%)
TOTAL	4,371	228	2,608	835	401	299
% OF TOTAL	100%	5.2%	59.7%	19.1%	9.2%	6.8%

\* Other includes: individuals that associate with multiple respondent types; friends; interested citizens; researchers; and government representatives.

Respondents that identified as Parent/Family Caregiver of a person with an ASD were asked how many people with ASD they provide care or support for, with the following results:

Table 8: Frequency & Percentage of # of People with an ASD Cared for by Family/Caregiver Respondents

# OF PEOPLE WITH AN ASD CARED FOR	1	2	3	4	>5
# of respondents	2,175	308	47	10	4
% of total	85.5%	12.1%	1.8%	0.4%	0.2%

The geographic distribution of respondents is somewhat different from the distribution of the total population, with higher than expected response rates from Atlantic and Northern regions. Atlantic Canadians made up 15% of respondents, compared to only 6.6% of the total population; Central Canadian made up 46.4% of respondents compared to 61.5% of total population; Western Canadians made up 37.2% of respondents compared to 31.6% of the total population; and Northern Canadian made up 1.4% of respondents compared to 0.3% of the total population.

Table 9: Frequency & Percentage of Each Respondent Type by 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	OTHER
ATLANTIC <sup>A</sup>	643 15.0%	26 (11.6%)	349 (13.7%)	170 (20.5%)	49 (12.5%)	49 (16.7%)
CENTRAL <sup>B</sup>	1,994 46.4%	98 (43.8%)	1,233 (48.2%)	352 (42.4%)	170 (43.1%)	141 (48.0%)
WEST <sup>C</sup>	1,599 37.2%	99 (44.2%)	968 (37.9%)	280 (33.7%)	158 (40.1%)	94 (31.9%)
NORTH <sup>D</sup>	60 1.4%	1 (0.4%)	4 (0.2%)	28 (3.3%)	17 (4.3%)	10 (3.4%)
TOTAL	4,296	224	2,554	830	394	294

A = New Brunswick, Newfoundland and Labrador, Nova Scotia, and Prince Edward Island

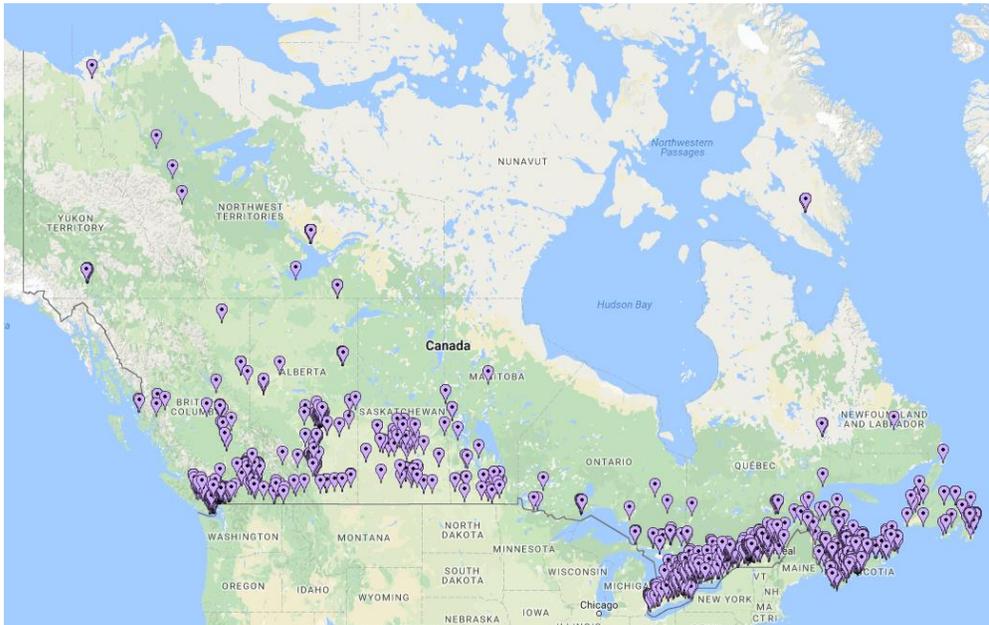
B = Ontario and Québec

C = Alberta, British Columbia, Manitoba, and Saskatchewan

D = Northwest Territories, Nunavut, and Yukon

Using the postal code data submitted by 4,189 respondents, the map below shows the geographic dispersion of respondents across the country. Detailed distribution for each province and territory can be found in the *Analysis of Findings – Survey Responses by Province/Territory*.

*Figure 10: Detailed Map of Respondents by Postal Code*



Respondents were well distributed by community type. Urban (1,848) and Suburban (1,478) respondents made up the majority, but Rural (766) and Remote (99) respondents provided a well-rounded distribution of community types across the country.

*Table 10: Frequency & Percentage of Each Respondent Type by Region and Size of Community*

	TOTAL	REMOTE	RURAL	SUBURBAN	URBAN
<b>ATLANTIC<sup>A</sup></b>	628 15%	12 (12.1%)	246 (32.1%)	171 (11.6%)	199 (10.8%)
<b>CENTRAL<sup>B</sup></b>	1,942 46.3%	19 (19.2%)	273 (35.6%)	810 (54.8%)	840 (45.5%)
<b>WEST<sup>C</sup></b>	1,562 37.3%	25 (25.3%)	242 (31.6%)	493 (33.3%)	802 (43.4%)
<b>NORTH<sup>D</sup></b>	59 1.4%	43 (43.4%)	5 (0.7%)	4 (0.3%)	7 (0.4%)
<b>TOTAL</b>	<b>4,191</b>	<b>99</b>	<b>766</b>	<b>1,478</b>	<b>1,848</b>

A = New Brunswick, Newfoundland and Labrador, Nova Scotia, and Prince Edward Island

B = Ontario and Québec

C = Alberta, British Columbia, Manitoba, and Saskatchewan

D = Northwest Territories, Nunavut, and Yukon

## RESULTS

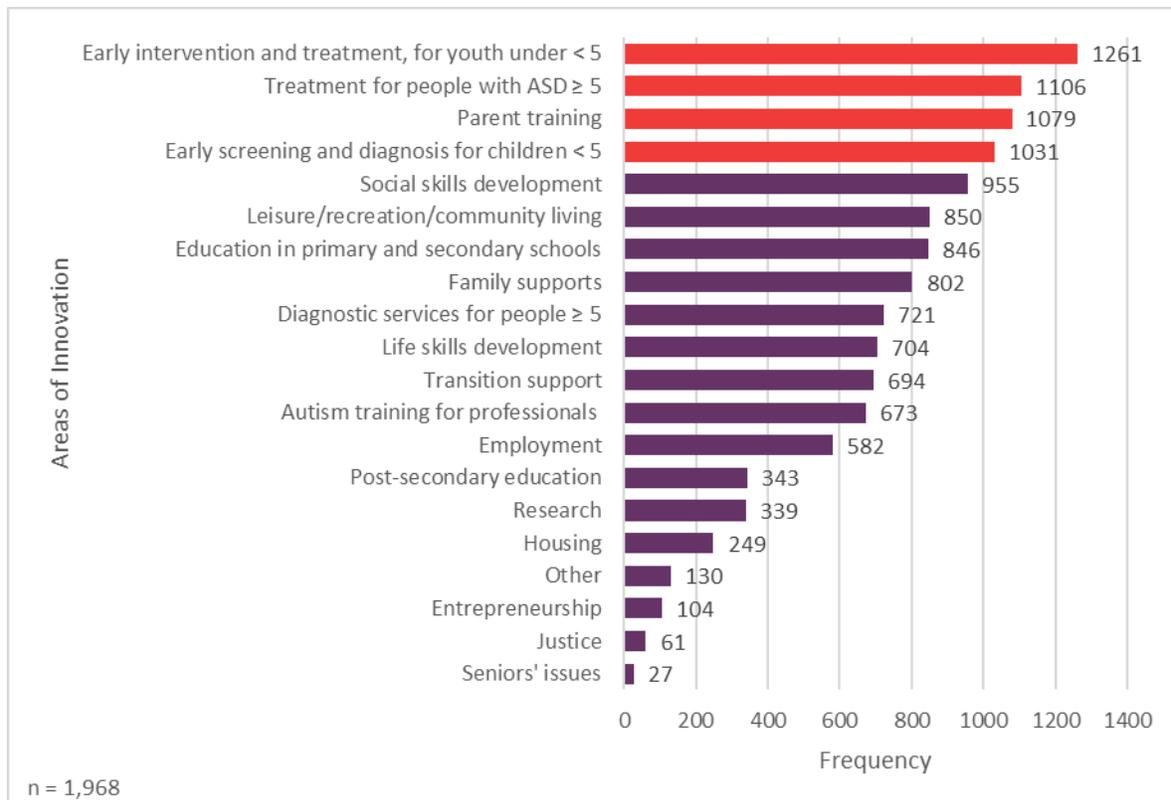
### Innovations

*Question: As part of the CAP project, we are building an inventory of innovative programs and services that have had a positive impact on families and individuals living with ASD. Are you aware of any such programs or services in your community?*

Of the 4,121 respondents to this question, 2,098 chose no, and did not provide any further information on innovative programs or services in their communities, and skipped the next two questions. However, 2,023 respondents indicated that yes, they were aware of innovative practices and services, and proceeded to the next question.

*Question: Please indicate in which area(s) the innovative programs and services are happening.*

Figure 11: Frequency of Area of Innovation with Innovative Programs and Services



In a follow on question, respondents provided further details on 4,296 innovative programs and services in their communities that represent the breadth and depth of programs and services across the country, including:

Table 11: Frequency of Area of Innovation with Details Provided

AREA OF INNOVATION	# OF PROGRAMS DETAILED
Early intervention and treatment, for youth under five years of age, including addressing difficulties with behaviour, social functioning, communication, other skills often associated with ASD.	458
Parent training	428
Treatment for people with ASD five years of age or older (IBI, ABA, etc.), including difficulties with behaviour, social functioning, communication, skill building often associated with ASD.	384
Early screening and diagnosis for children under five years of age.	350
Leisure/recreation/community living	320
Education in primary and secondary schools	285
Family supports	269
Entrepreneurship	268
Autism training for professionals who work with people on the Autism Spectrum	243
Social skills development	236
Diagnostic services for people at least five years of age	233
Transition support	219
Research	133
Post-secondary education	110
Employment	97
Housing	92
Other, please specify:	77
Life skills development	68
Justice	21
Seniors' issues	5

Within each category of innovation there were many instances where the same program was listed multiple times, either within a category by multiple respondents, or in multiple categories by multiple respondents. Details provided range from a single person/organization name to a full, multi-paragraph description of the initiative and its outcomes.

The innovations detailed represent the breadth and depth of programs and services across the country, including:

- Specific service providers and agencies;
- Health care programs and services;
- Grassroots, community based initiatives;
- Knowledge sharing initiatives between organizations;

- Funding and funding models;
- Technology tools, apps, and services;
- University and college programs and research;
- Elementary and secondary school based programs; and
- Employment services and programs, and specific employers.

For further community-identified innovations, please refer to *Analysis of Findings – Stakeholder-Identified Innovations*, where responses from the CRTs and the survey have been researched and compiled into a comprehensive list of innovations by province/territory. The rich data that was collected in this question, and the Community Round Tables, will provide many opportunities for future analysis.

### **Barriers to Receiving Service**

*Question: The National Needs Assessment Survey conducted by CASDA in 2014 identified a number of barriers to receiving service for individuals with ASD and their families/caregivers. We would like to understand if these barriers apply to you and your community. Please check all the potential barriers that currently impact the ability of people with ASD in your community to access the services they need.*

- *Lack of services*
- *Being on a waiting list*
- *Being too old to access service*
- *Being too young to access service*
- *Not being able to afford service*
- *Lack of trained professionals*
- *Negative experiences with professionals*
- *Language difficulties*
- *Other, please specify:*
- *None apply*

Responses were fairly consistent across the country, with “Being on a waiting list” and “Lack of services” being the top barriers in each region. The following chart and table show the detailed distribution of responses by region.

Figure 12: Frequency of Type of Barrier to Service by Region

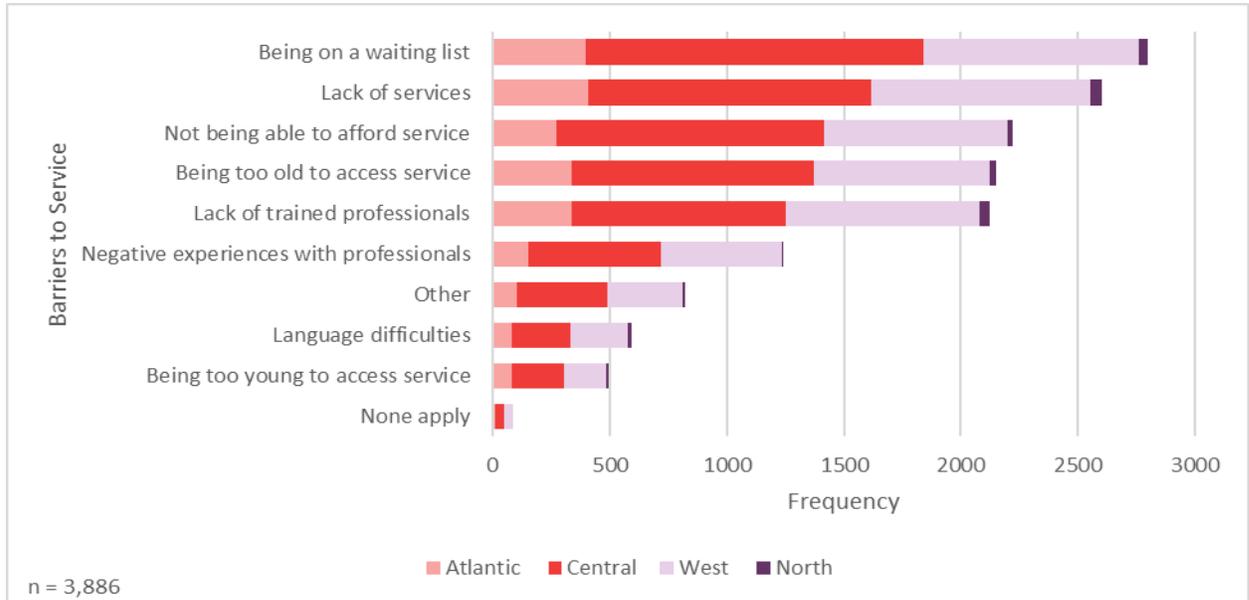


Table 12: Frequency & Percentage of Total of Type of Barrier by Region

	TOTAL	ATLANTIC	CENTRAL	WEST	NORTH
Being on a waiting list	2,797 (72%)	398 (68.2%)	1,441 (79.9%)	923 (63.8%)	35 (66.0%)
Lack of services	2,601 (66.9%)	407 (69.7%)	1,212 (67.2%)	933 (64.5%)	49 (92.5%)
Not being able to afford service	2,221 (57.2%)	274 (46.9%)	1,143 (63.4%)	784 (54.2%)	20 (37.7%)
Being too old to access service	2,152 (55.4%)	339 (58%)	1,035 (57.4%)	751 (51.9%)	27 (50.9%)
Lack of trained professionals	2,124 (54.7%)	340 (58.2%)	912 (44.5%)	828 (57.3%)	44 (83.0%)
Negative experiences with professionals	1,241 (31.9%)	151 (25.9%)	569 (31.6%)	514 (35.5%)	7 (13.2%)
Other	821 (21.1%)	106 (18.2%)	385 (21.4%)	320 (22.1%)	10 (18.9%)
Language difficulties	592 (15.2%)	83 (14.2%)	250 (13.9%)	246 (17%)	13 (24.5%)
Being too young to access service	494 (12.7%)	83 (14.2%)	223 (12.4%)	180 (12.4%)	8 (15.1%)
None apply	88 (2.3%)	13 (2.2%)	35 (1.9%)	40 (2.8%)	0 (0.0%)
Total	3,886	584	1803	1446	53

The responses to this question reconfirm the responses received from the CASDA 2014 National Needs Assessment. Respondents provided 820 additional comments for Barriers “other” than those listed. Many of the “other” responses were clarifications or expansions on the barriers presented. Some of the additional barriers can be categorized as:

- Geographic access to services, lack of transportation;
- Being too high-functioning to qualify for services;
- No access to flexible, diverse, innovative, or appropriate services to meet needs;
- Gender or gender and age specific issues (i.e., girls or adolescent boys);
- Cultural differences;
- Multiple diagnoses, co-occurring conditions, and behaviour issues;
- Changes in funding;
- Lack of awareness of service options and complexity of the system; and
- Uncomfortable accessing services/ anxiety.

Additional analysis of the other barriers provided should be undertaken at a later date, as it may provide additional areas of focus for CAP.

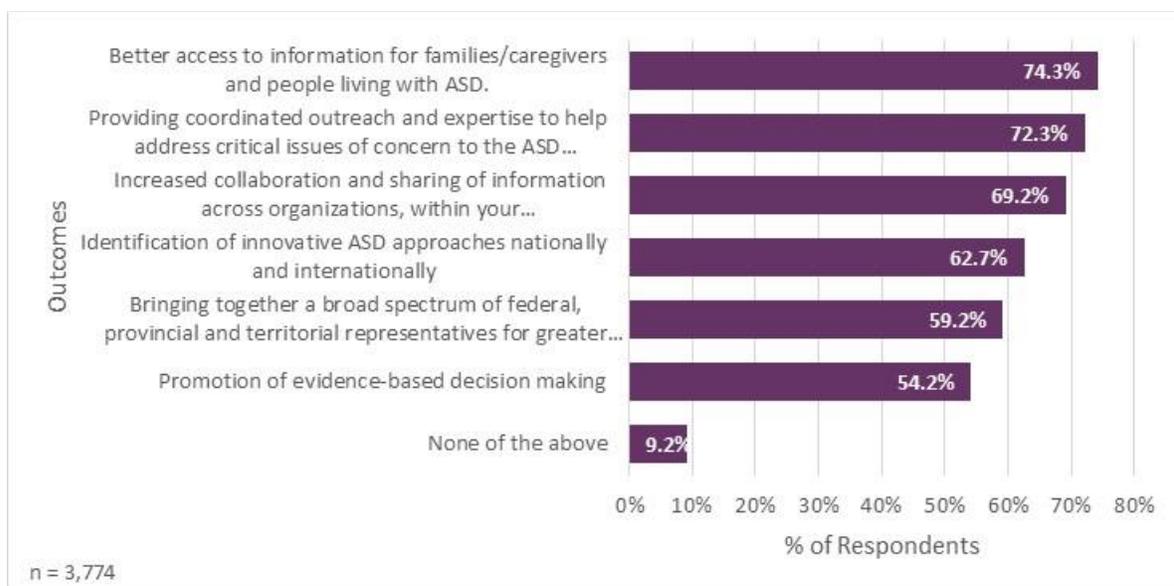
## CAP Outcomes

*Preamble to the following question: The Canadian Autism Partnership will be a pan-Canadian partnership dedicated to accelerating and improving the use of research, effective practices, and technology by establishing and supporting collaborative networks for change. It will be an authoritative source of new information that works to solve complex issues facing Canadians living with ASD.*

*Question: Below is a list of outcomes that have been identified as a critical part of the Canadian Autism Partnership model. Please check the outcomes that you think would positively impact people with ASD in your community.*

- *Providing coordinated outreach and expertise to help address critical issues of concern to the ASD community.*
- *Bringing together a broad spectrum of federal, provincial and territorial representatives for greater collective impact.*
- *Promotion of evidence-based decision making*
- *Identification of innovative ASD approaches nationally and internationally*
- *Better access to information for families/caregivers and people living with ASD.*
- *Increased collaboration and sharing of information across organizations, within your community/province.*
- *None of the above. Please describe what kind of outcomes would be helpful*

Figure 13: Percentage of Respondents That Agree the Outcome Would Positively Impact People with ASD



Respondents were, for the most part, in agreement with the proposed outcomes. However, there were 346 additional outcomes provided by respondents who felt 'none of the above' applied. Many of the responses were clarifications or expansions on the outcomes that were presented. Others identified new outcomes that could be achieved, including:

- Access to appropriate services across disabilities, diagnoses, functioning levels, age, gender, geographies, cultures, etc.;
- Public awareness and acceptance of autism as part of human diversity;
- Bringing the voices of autistic adults to the table, as well as parents and caregivers;
- Better accountability;
- Increased and targeted funding, leading to increased capacity to offer service;
- Increased focus on employers and employment; and
- Better understanding of cause, and prevention.

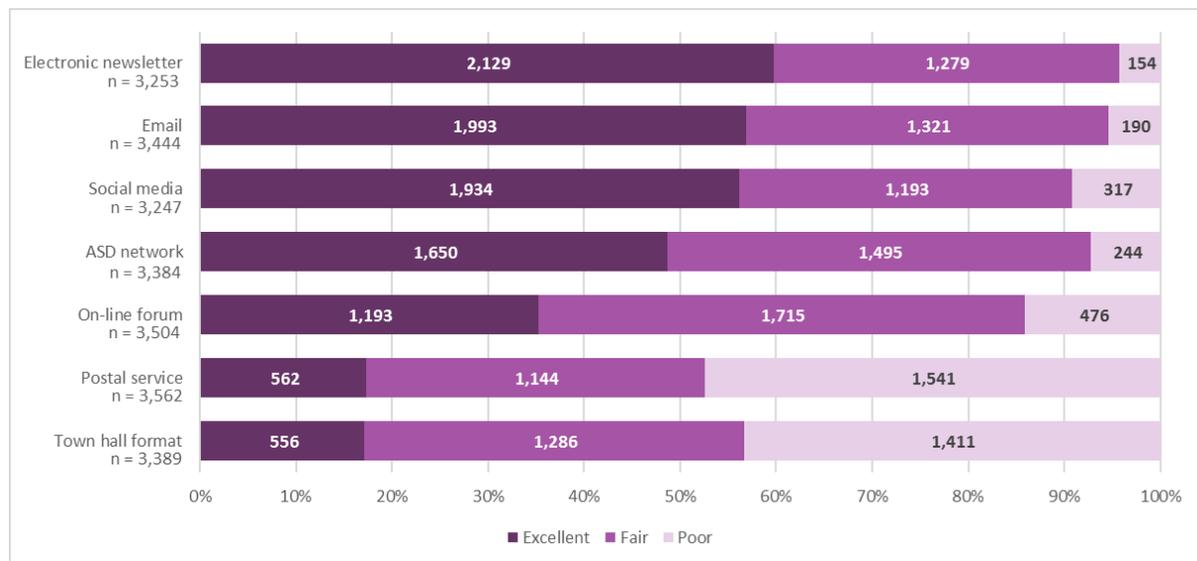
Respondents also identified 1,954 additional outcomes that would be beneficial. The outcomes listed were similar to those included under "none of the above", with the addition of the following:

- Better coordinated approach between government and service providers;
- Addressing inconsistency of services across the country;
- Access to appropriate services in rural areas; and
- Better planning and access to services in adulthood, particularly related to housing.

## Communication with Stakeholders

*Question: How could the Canadian Autism Partnership best communicate and share information across the country?*

Figure 14: Effectiveness of Communication Methods for Sharing Information with Stakeholders



Electronic communication methods, including electronic newsletter, email, and social media were seen as the best means of communicating with stakeholders. Use of the postal service or town hall formats were seen as less effective. Responses to this question were essentially the same regardless of the region or size of community of the respondent.

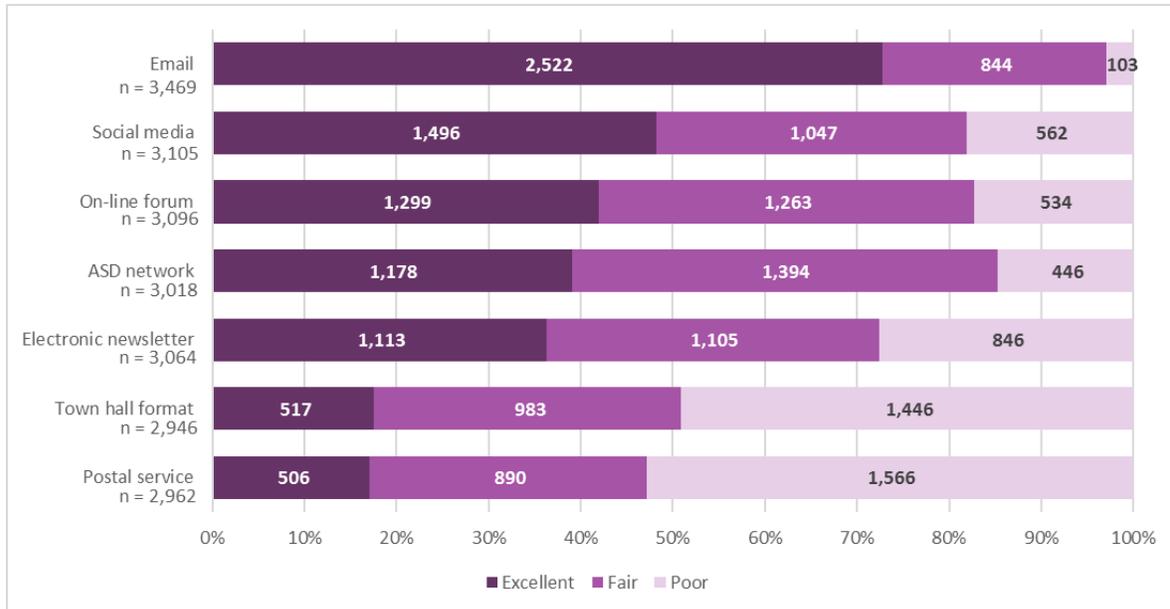
Survey respondents also provided 1,074 responses when asked for additional methods that could be effective in sharing information with stakeholders, including the following (number indicates frequency):

- Service providers (124), associations (14), organizations (64), agencies (50), partners (33), and societies (8);
- Schools (162), churches (12), and libraries (9);
- Television (69), radio (69), news media (94), and traditional media (7), journal (4);
- Conferences (54), symposiums (6), events (33), speakers (5), webinars (18), and workshops (26) in-person (5);
- Social media (43), Facebook (17), and websites (52);
- Professionals (41), medical associations (2), medical schools (1);
- Advertising (33), specifically Facebook, print, and radio (10);
- Professional development session (26), and training (10);

- Phone (15), and hotline (3); and
- Employers (10).

**Question: What are the best ways for the Canadian Autism Partnership to receive input from you?**

Figure 15: Effectiveness of Communication Methods for Receiving Input from Stakeholders



Email was seen as the most effective method of receiving input from stakeholders, followed by social media and an online forum. Postal service and town hall format events were seen as the least effective means of gathering input. There was no difference in response distribution based on the region of the respondent, or the type of community in which they live.

Survey respondents also provided 561 additional responses providing communication methods that could be effective for gathering input from stakeholders, including the following (number indicates frequency):

- Phone (129), Skype (5), and video conferencing (3);
- Surveys and questionnaires (131);
- Face-to-face (28), direct contact with individuals (21);
- Focus groups (48);
- Email (41);
- Conferences and events (11), webinars (10), and forums (13);
- Facebook (8), text messaging (14), social media (5), and website (7);
- Schools (23);

- Organizations/ service providers (19) and professionals (17); and
- Visits to centres, communities, etc. (9)

## Vision, Mandate and Foundational Statements

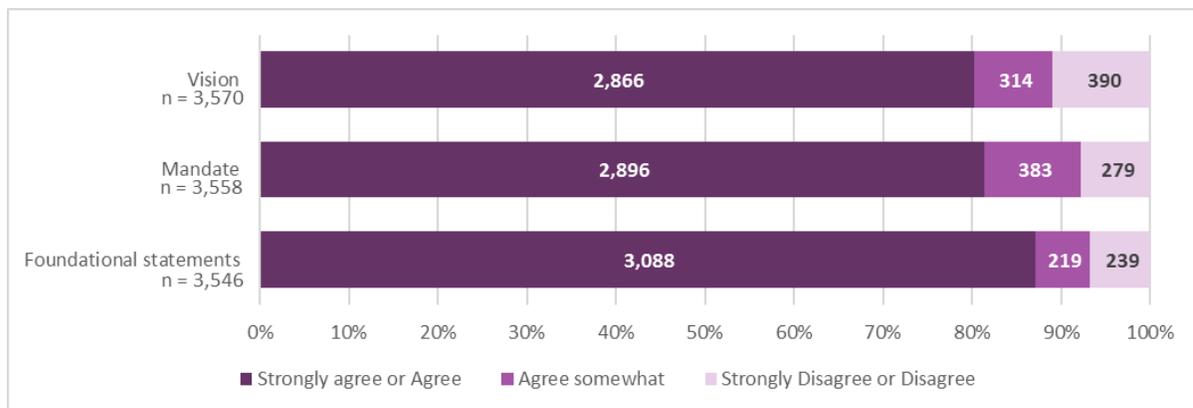
*Question: The proposed vision of the Canadian Autism Partnership is: All Canadians living with autism have the opportunity to lead fulfilling and rewarding lives. This means that they are able to access the necessary supports and services in a welcoming and understanding society.*

*Question: The proposed mandate of the Canadian Autism Partnership is: To mobilize partners across sectors on a national level to accelerate innovation and action to address complex issues affecting Canadians living with Autism.*

*Question: The proposed foundational statement for the Canadian Autism Partnership is: 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.*

Respondents were asked to indicate if they agreed or disagreed with these statements, with five options for response: Strongly agree, Agree, Agree somewhat, Disagree, Disagree strongly. For the purposes of analysis, the responses to Strongly Agree and Agree, and Disagree and Strongly Disagree have been combined to show three categories of responses in the following chart.

Figure 16: Frequency of Level of Agreement with Vision, Mandate and Foundational Statements



The responses clearly indicate that the majority of survey respondents agreed, or strongly agreed, with the proposed vision, mandate, and foundational statements. In all cases, fewer than 11% of respondents disagreed or disagreed strongly with the proposed statements.

## Areas of Focus

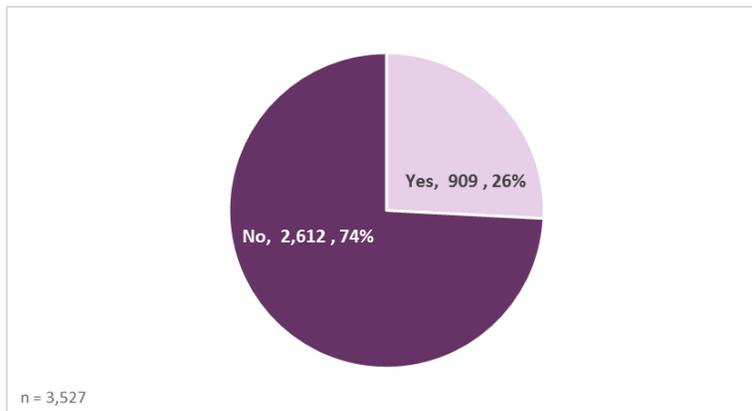
*Question: The national ASD Working Group has identified the following areas of focus for the Canadian Autism Partnership:*

- *Early detection and diagnosis*
- *Treatment and support across the lifespan*
- *Education, training and awareness*
- *Attachment to the labour force*
- *Community living (includes recreation, leisure and housing)*
- *Impact on caregivers (includes health, mental health, respite, and senior issues)*
- *Research*

*Are there any additional priority areas of focus related to ASD across the lifespan that should be considered in the development of the Canadian Autism Partnership model?*

Of the 3,527 respondents, 2,617 (74.2%) felt that the areas of focus that were presented in the model were appropriate and no additional areas needed to be added. However, the remaining 910 (25.8%) respondents felt that the areas of focus should be expanded.

*Figure 17: Frequency & Percentage of Frequency of Agreement with Proposed Areas of Focus*



Many of the additional areas of focus below are sub-categories of the seven proposed areas. In some instances, respondents felt the area was so important it deserved to be listed as a separate area of focus, while other areas were listed for clarity or specification to ensure they were included.

The areas of focus below, selected from 832 responses, were mentioned many times; the number in parentheses indicates frequency.

- School (165) – system, programs, boards, inclusion, etc.
- Adults (152)

- Health (112) – mental health (72), holistic health, access to health care
- Access (113)
- Training (93)
- Funding (92) and financial (63) – support for families, provision of services, schools, government
- Siblings (19) and family (72) – should be included under caregivers
- Respect (17), inclusion (29) versus prejudice (5), bullying (6), and abuse (8)
- Employers (14), employment (36) and employability (2)
- Age (36)
- Housing (23)
- Advocacy (22)
- Prevention (14)
- Respite (11) – should be included as part of Impact on caregivers
- Safety (9)
- Transportation (7) – should be included under Community Living
- Women (7), girls (4), and females (3)
- Sexuality (5)

## 7. WRITTEN SUBMISSIONS

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### METHODOLOGY

Professional associations and autistic self-advocates were given the opportunity to provide their input through a fillable PDF with specific questions targeted towards the needs and interests of the group. Fifteen professional associations with national membership were invited to complete the PDF:

- Canadian Medical Association
- Canadian Physiotherapy Association
- Canadian Association of Occupational Therapists
- Canadian Association of Social Workers
- Canadian Association of Speech Language Pathologies and Audiologists
- Canadian Psychological Association
- Canadian Public Health Association
- Health Action Lobby
- Canadian Nurses Association
- Canadian Mental Health Association
- Canadian Bar Association
- Canadian Psychiatric Association
- Canadian Police Association
- Paramedic Association of Canada
- Canadian Educators Association

Unfortunately, no professional associations responded within the given timeframe. Note: The deadline for responses was extended until the end of September, and any responses received will be analysed and integrated into the final version of this report.

The questions asked of Professional associations were:

- 1. What role(s) could your association play in this cross-sectoral model?*
- 2. If you are involved in or aware of any examples of cross-sectoral collaborations that have allowed your organization or your members to address complex problems for families (not necessarily related to autism), please describe them.*
- 3. Please describe any innovative services, programs and/or practices related to autism (or other disorders that could be adapted for individuals with autism) that you suggest we explore further.*
- 4. If you are aware of any ground-breaking research either directly or indirectly related to autism, please describe it and provide sufficient information so that we can investigate further.*
- 5. Please provide any other input relevant to creating a Canadian Autism Partnership.*

## RESULTS

Two members of the Self-Advocates Advisory Group provided their comments via the fillable PDF, summarized below.

### *1. As a person on the spectrum, what are the major issues that you believe need to be addressed?*

- Education of the facts about autism – countering the myths
- Individuals with autism are the real experts on the topic
- Raise understanding of the need for supports
- Life and social skills
- Employment
- Housing
- Personal finances

### *2. As we design the CAP model, what suggestions do you have for creating a strong national partnership?*

- Continued discussion with self-advocates
- Connecting organizations (public and private) in business, health and education, with the goal of learning about best practices and putting them to work for the whole community

### *3. How do you think CAP could make a difference to you, your family and your community?*

- Information repository and information exchange between organizations
- Bring together the entire Canadian autistic community
- Help ease communication between researchers, service professionals, organizations and autistics.
- Focus on the real needs of people on the spectrum
- Implement best practices policy, based on peer reviewed methods.

### *4. If you are aware of other collaborative models you think we should explore, please tell us about them.*

- No response



**Canadian Autism  
Partnership Project**

An initiative of the Canadian Autism Spectrum Disorders Alliance

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

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