

# STAKEHOLDER REPORT: Actioning an Autism Data Collaborative



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## **Canadian Autism Spectrum Disorder Alliance (CASDA)**

The Canadian Autism Spectrum Disorder Alliance (CASDA) is a not-for-profit coalition of over 300 sector leaders, including Autistic people, caregivers, clinicians, researchers, and representatives from organizations across Canada that have proactively mobilized as one voice to successfully advocate for a National Autism Strategy (NAS). We lead by convening. We have a track record of delivering national initiatives and a demonstrated history of collaboration with the federal government. We hope to continue to lead by being an inclusive and collaborative convener to address pan-Canadian priorities that impact Autistic people in Canada and their families as a collective voice.

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### **Conflict of Interest**

All authors declare that they have no conflicts of interest to report in professional or commercial interests and have final authority about what is included in this stakeholder report.

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# Introduction

On October 5th, 2021, the **Canadian Autism Spectrum Disorder Alliance** (CASDA) hosted the inaugural Autism Data Collaborative meeting bringing together stakeholders from across the country to discuss how to better leverage Canadian data assets to inform Autism policy in Canada.

CASDA's vision is to develop a Pan-Canadian Autism Data Collaborative that facilitates and accelerates multidisciplinary, multi-sector, and multi-jurisdictional data initiatives and health services and policy research for Autism.

Since the inaugural event, we have been synthesizing what we heard so that we can co-create the next actionable steps toward building this collaborative. This report will summarize the ideas expressed by our diverse group of attendees, and provide you with opportunities for leadership, engagement and involvement in this initiative.

# Background

In 2020, CASDA established policy development working groups in partnership with the Kids Brain Health Network (KBHN). These working groups produced over [15 policy briefs](#) with specific recommendations for immediate action in five areas of federal jurisdiction: access and affordability, employment, research and governance, housing, and information that were submitted to the Public Health Agency of Canada (PHAC).

These recommendations embody the ideas and perspectives of stakeholders, which include Autistic people living in Canada, service providers, researchers, and various others who are dedicated to accelerating the momentum for systemic change. One of the key recommendations developed through these working groups was the need to “Invest in sustainable linkages of population-level databases to determine the trends in prevalence and developmental health of Autistic children over time.” Canada is home to many world-class data platforms that collect data (e.g., government administrative data holdings, Canadian Institute of Health Information, clinical data registries), however, organizations that are custodians and/or stewards of this data often operate in disconnected “islands of excellence”. The lack of coordination and information sharing hinders our ability to use data to improve the effectiveness and efficiency of the health system, better service delivery to Autistic people and their families, and inform autism-related policy throughout the country.

In December of 2020, CASDA contributed to the McMaster Health Forum’s [Evidence Brief](#) to inform stakeholders on the current gap between what is being learned in the research community and what actions are being taken to improve patient care and experiences. The McMaster Health Forum disseminated 5 major challenges people with neurodevelopmental disorders face in Canada:

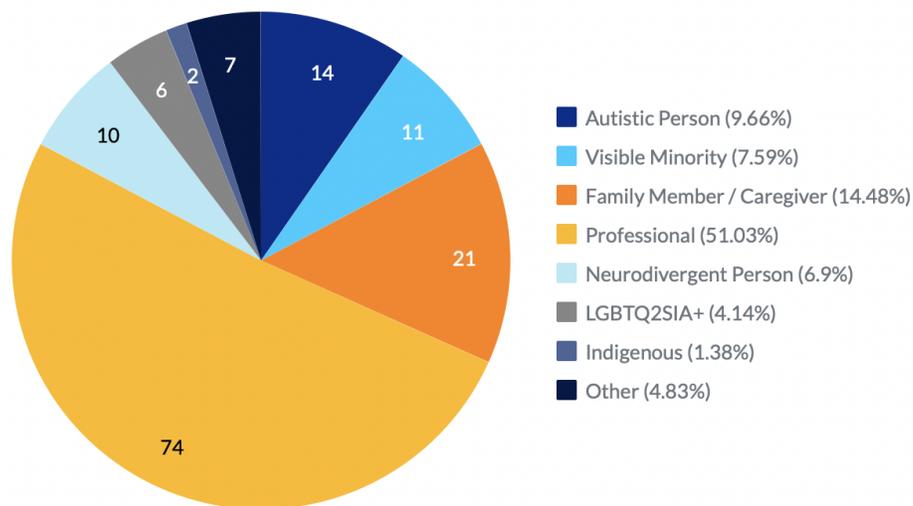
- 1) many Canadians are affected by neurodevelopmental disorders over their lifespan;
- 2) neurodevelopmental disorders are not easy to consider in isolation;
- 3) without appropriate integrated programs and services, neurodevelopmental disorders can place a significant burden on individuals, their families, health systems, and society;
- 4) health-system arrangements are not conducive to optimizing services for neurodevelopmental disorders, and
- 5) health and research systems are not aligned to enable a rapid-learning and improvement approach.

Through a systematic review, one vital component of establishing a rapid-learning health system that arose was the need for the system to be data and evidence-driven. To establish such a system, the community must work together to ensure the digital capture, linkage, and timely sharing of relevant data. This brief further supported the need for a Pan-Canadian Autism Data Collaborative.

# Who Engaged

At the inaugural Autism Data Collaborative meeting, we all participated in building connections across sectors and jurisdictions, while keeping the voice of those with lived experience at the forefront. We engaged in important dialogue around what is needed to drive bottom-up action to better leverage Canadian data assets to inform Autism policy in Canada.

**Figure 1: Description of Participants at the Autism Data Collaborative Meeting**



Upon registration, our attendees indicated how they identify by selecting all that applied to them. We had **103 registrants** and **75 attendees**. Our event brought together people from diverse backgrounds, and across nearly all provinces and territories.

**Please note:** When asked about their role in attending the event, many people selected more than one role, so the sum of responses does not match the total number of registrants.

# Goals of the Event

1. To identify **themes/priority areas** to take collective action
2. To identify **contributions and expectations** from our attendees
3. To **gauge interest**

# What We Did

To achieve our objectives we had participants engage in the following activities:

## 1. Virtual Brainstorming Session

Attendees engaged in a brainstorming activity using breakout rooms and using the online platform Jamboard. Each room tackled topics from the categories that are being used in the current Canadian Academy of Health Sciences (CAHS) autism strategy consultations. Each room also had a facilitator to moderate the discussion. In each breakout room, attendees were asked to list ideas they had about how an Autism Data Collaborative (ADC) could approach the topics in each room and potentially advance these areas, as well as actions that could be taken.

These data were consolidated and the research team at CASDA (led by two doctoral level researchers and two students) conducted qualitative analysis to determine underlying themes that emerged by inductively grouping them into categories. Each member of the research team created thematic categories. These categories were discussed with two additional researchers and another student and a final list of mutually exclusive theme categories were determined by consensus. Results are summarized in [Table 1](#).

## 2. Gives and Gets

To determine the needs of potential members of the collaborative and what members would be willing to contribute, we asked attendees to post in the “Zoom chat” what they could give to the collaborative and what they expected to get out of the initiative. The CASDA research team used the same qualitative inductive analysis outlined above to categorize responses into mutually exclusive theme categories. Results are summarized in the next section of this report, entitled “[What We Heard](#)”.

## 3. Survey

After the event we asked participants to answer the following questions to gauge their future involvement with the Autism Data Collaborative.

1. What stakeholder group do you identify with?
2. On a scale from 1 to 10, how important do you think supporting an Autism Data Collaborative is?
3. How likely are you to continue engaging with us?

Responses are summarized in graphs found on page 12.

## What We Heard

### Values of the collaborative

The following values will guide the mission, goals, and actions of this collaborative. These values were synthesized from dialogue and discussion generated by participants during brainstorming sessions.

**Figure 2: Values**



## Guiding Principles

A significant proportion of participant comments throughout the day reflected beliefs and suggestions that were best captured in a list of guiding principles. These guiding principles emphasize our commitment to Autistic people, their families and people with lived experience. These principles will be used to guide the work that we do together, and the way that we do it.

1. Effective policy should be **evidence- and data-driven**
2. **Co-design**: People with lived experience should be driving research and policy priorities
3. **Multijurisdictional**, with a goal to scale to the national level to help address gaps in policies, services and research inequities across the country
4. Alignment with health sector priorities to ensure **relevance to clinical practice** and the healthcare system
5. Alignment with **community organizations** to ensure relevance to service providers
6. Alignment with **federal policy makers** charged with developing and implementing a National Autism Strategy
7. Alignment with **provincial policy makers** to connect federal and provincial/territorial initiatives
8. Alignment with **national research infrastructure** to reduce duplication, leverage existing resources and interprofessional and multidisciplinary teams

**Table 1: Results of Thematic Analysis**

<b>Thematic Categories</b>	<b>Scope</b>	<b>Identified Priorities</b>
<b>Values</b>	Values that will underpin this collaborative and how we engage with stakeholders and treat each other.	<ul style="list-style-type: none"> <li>● Reciprocity</li> <li>● Inclusivity</li> <li>● Equity</li> <li>● Respect</li> <li>● Diversity</li> </ul>
<b>Community, Patient, and Public Engagement in Data Research</b>	Involving the community in prioritizing, planning, designing, data collection and use of research	<ul style="list-style-type: none"> <li>● Involve patients in setting of research priorities</li> <li>● Inclusion of Autistic voices (and not just those who are verbal), family members, Northern and remote communities, and Indigenous populations</li> </ul>
<b>Awareness</b>	Involving education of and knowledge sharing with the greater public in furtherance of acceptance and countering misinformation	<ul style="list-style-type: none"> <li>● Counter misinformation and enhancing acceptance</li> </ul>
<b>Data Standardization</b>	Concerned with common measures, algorithms, definitions, and datasets	<ul style="list-style-type: none"> <li>● Clear and consistent data definitions and outcome measures</li> <li>● More comprehensive data on education, employment, and housing</li> <li>● National standards for data collection/outcome measures</li> <li>● Learn from existing structures</li> </ul>
<b>Data Governance, Privacy and Ethics</b>	Involving concerns around data security, handling, governance, and how that data it is collected, used, and accessed	<ul style="list-style-type: none"> <li>● Data transparency to all (Autistics, family members, service providers, etc.)</li> <li>● Ensuring data is broadly communicated (including remote and rural communities)</li> <li>● Data ownership and access</li> </ul>
<b>Partnerships</b>	Involves creation of new	<ul style="list-style-type: none"> <li>● Collaborate with national and</li> </ul>

	<p>collaborations, leveraging of existing national networks and infrastructure to advance evidence synthesis and data science in autism</p>	<p>provincial/territories data custodians</p> <ul style="list-style-type: none"> <li>● Partner with existing pan-Canadian initiatives to accelerate data sharing</li> <li>● Leverage existing population-level administrative datasets</li> <li>● Partner with clinician-scientists leading learning health system transformation in NDDs to scale and spread innovative practices</li> </ul>
<b>Data Use</b>	<p>Concerned with potential future uses of data, data utility, and outcomes</p>	<ul style="list-style-type: none"> <li>● Highlight strengths and success stories of Autistics using both qualitative and quantitative data</li> <li>● Data-driven improvements to the navigation of services and supports for Autistics and their families (including rural/remote communities)</li> <li>● Evidence-based practice repository to inform policy</li> <li>● Generate surveillance data to understand the epidemiology of autism across the country</li> <li>● Generate up-to-date diagnostic waitlist information</li> <li>● Collect age-stratified data across the lifespan</li> <li>● Collect data on the impact of current policies and practices, identify gaps and to drive decision-making</li> </ul>
<p><b>Other Salient Priorities</b></p> <ul style="list-style-type: none"> <li>● Training opportunities for all professionals that support Autistics</li> <li>● Standardizing supports across provinces and territories</li> <li>● Increasing inclusion in workplace, school, community, and health settings</li> </ul>		

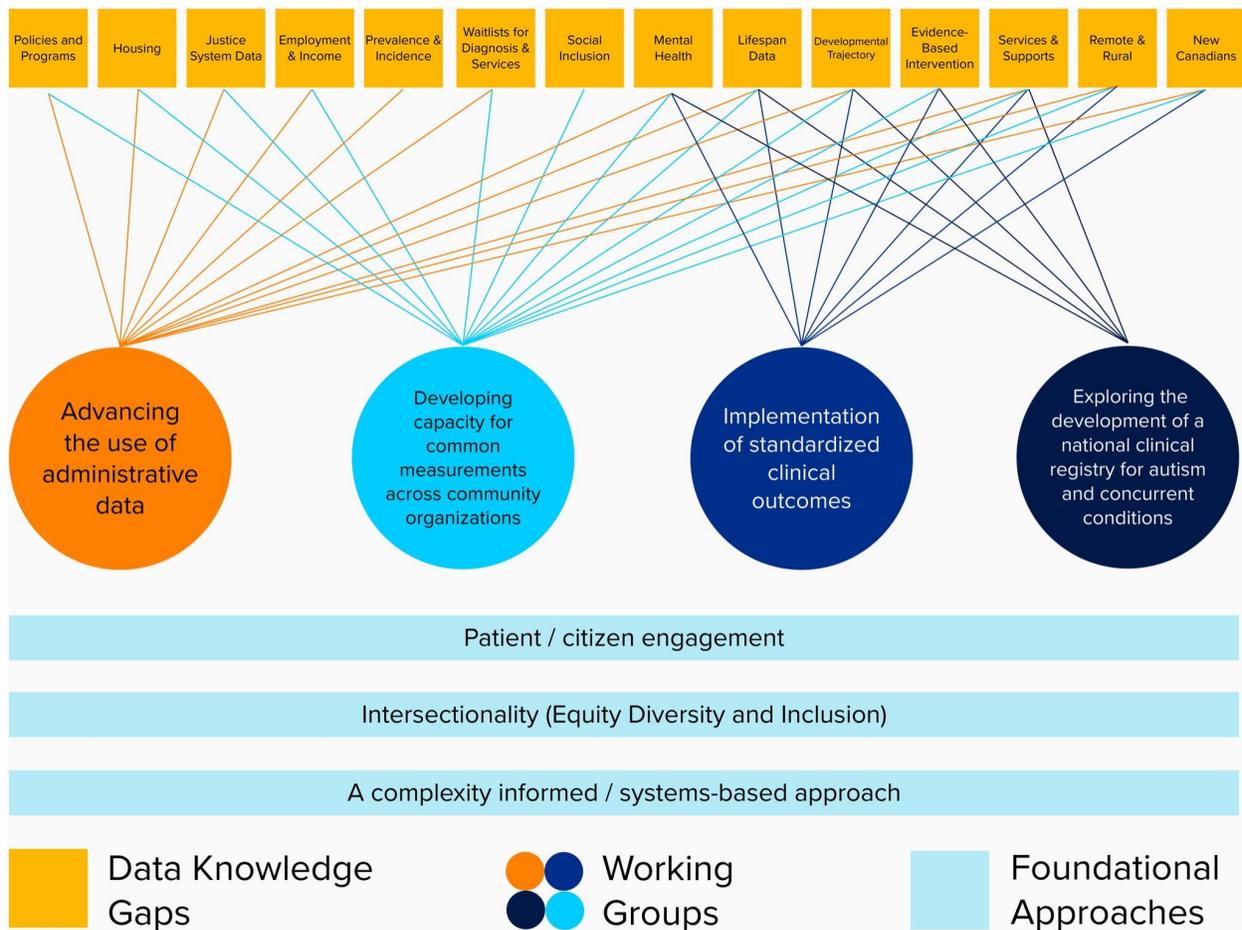
\*See Appendix A (Page 13) for raw data

Through iterative group discussion, fourteen 'Data Knowledge Gaps' were identified from the 'Identified Priorities' compiled in the above table. To address these knowledge gaps, four 'Working Groups' were designated, each informed by several different knowledge gaps.

1. Advancing the use of Canadian administrative data
2. Developing capacity for common measurement across community organizations
3. Implementation of standardized clinical outcomes
4. Exploring the development of a national clinical registry for autism and concurrent conditions.

Values of the collaborative which were teased out from the Jamboard activity informed three 'Foundational Approaches' which will underpin the entire initiative. The figure below depicts this process.

**Figure 3: Summarized Data Gaps and Working Groups**



## Table 2: Synthesized Gives and Gets Data

Attendees indicated that they were willing to ‘give’ the following to the ADC, and interested in ‘getting’ the following from the ADC:

Gives	Gets
<ul style="list-style-type: none"> <li>• Time and leadership</li> <li>• Community voices</li> <li>• Data</li> <li>• Collaboration/Networks</li> </ul>	<ul style="list-style-type: none"> <li>• Networking, teamwork, and collaboration</li> <li>• Making an impact/taking action</li> <li>• Data-informed decisions</li> <li>• Informing best practices</li> <li>• Supporting the autism community</li> </ul>

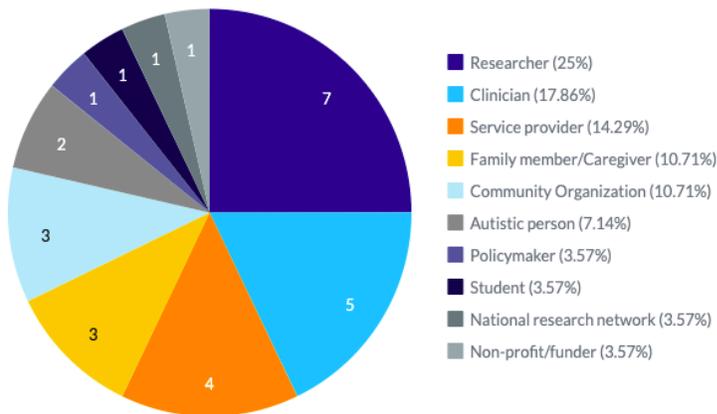
\*See Appendix B (Page 16) for raw data

Individuals’ indications during this exercise will be used to mobilize efforts of the collaborative by providing an understanding of who is willing to contribute, and how we can provide value to those involved.

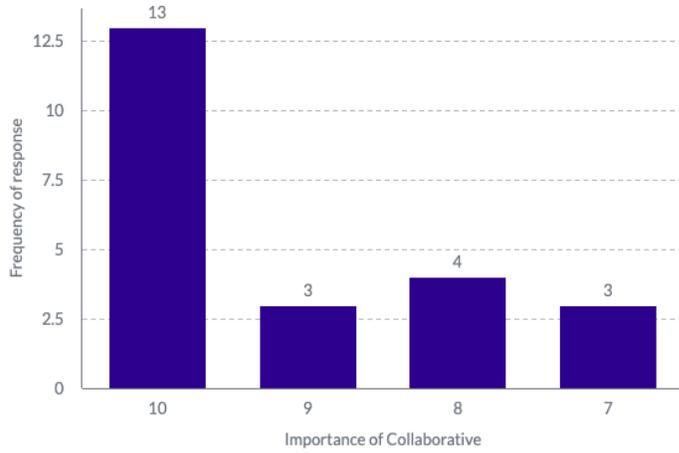
## Attendees’ Commitments

After the event we asked participants to answer a short survey to gauge their future involvement with the ADC. There were 28 responses.

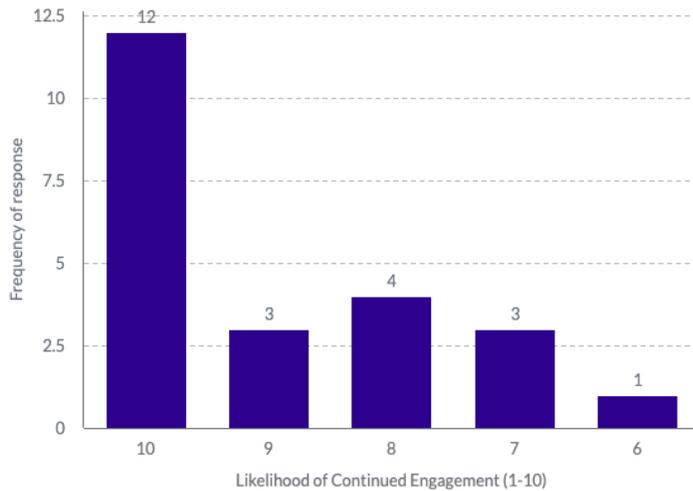
**Figure 4: What stakeholder group do you identify with?**



**Figure 5: How important do you think supporting an Autism Data Collaborative is? (1-10)**



**Figure 6: How likely are you to continue engaging with us? (1-10)**



# CASDA's Next Steps

## Immediate Actions (next 3 months)

- Register participants and potential leads for working groups. From our thematic analysis of the Jamboard data, data knowledge gaps arose, from these gaps, we outlined the above mentioned working groups.
- **If you are interested in participating or leading the working groups, please register here** <https://forms.gle/QhqxKfYA8obeBGeW8>
- Establish governance structure for each working group consisting of a:
  - Systems lead: Policy maker or clinician
  - Research lead: Canadian researcher
  - Lived-experience lead: Autistic self advocate or parent/caregiver
  - Training lead: Postdoctoral fellow
- Develop a terms of reference for each working group
- Identify key champions (leads) and participants for each working group

## Short-Term (3-6 months)

- Working groups begin regular meetings
- Hybrid workshop (in-person and online) for working group members following the Canadian Autism Leadership Summit (April 6th)
- Establish partnership with CHILD-BRIGHT to advance equitable POR approaches in autism citizen engagement strategies
- Partner with SPOR Evidence Alliance to conduct knowledge synthesis projects in key priority areas, eg. community measurements and community-prioritized outcome measures

## Medium-Term (6-12 months)

- Launch of post-doctoral/medical fellowship competition to identify highly training individuals to enable research and actions from the recommendations of working groups (Data2Policy Fellowship)
- Establish partnership/collaboration with Health Data Research Network to explore project opportunities based on identified action from working groups

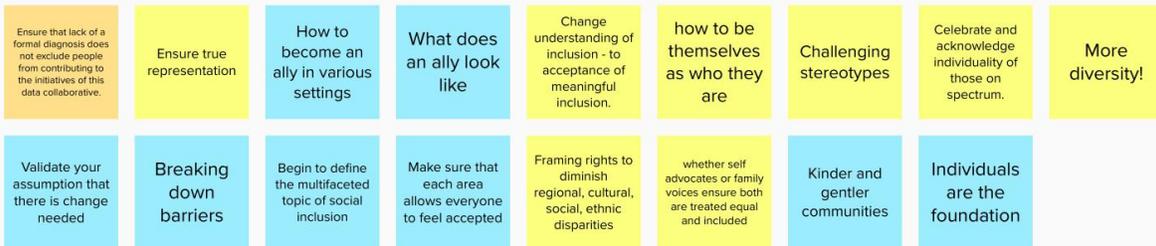
## Long-Term (1 year +)

- Partner with the SPOR-CIHR Data Platform to leverage national infrastructure to advance administrative data science in autism
- Pan-Canadian CIHR team grant emerging from working group action items

# Appendix A



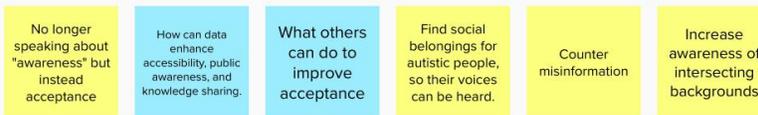
## Values



## Community, Patient, and Public Engagement in Data Research



## Awareness



## Data Standardization

general data collection in housing - what percentage of national housing \$ are going to support autistic adults?

Develop better data collection regarding the needs and status of people with autism re. education, employment and housing

clarify audiences, distinct deliverables, to guide the type of data to be collected

Clear and consistent definitions of what data is capturing

Standardized information categories - we collect same meaningful data nationally.

Need national standards for educational boards that provide educational supports or services to people on the spectrum

Clear and concise language for everything - concrete language vs. abstract language

Develop national standards for educational boards that provide educational supports or services to people on the spectrum; collaboration: Ministries of Education, post-secondary institutions, etc.

Learn from existing reports as a way to start to define common datasets.

Link

Identifying promising and best practices in inclusive employment and education that are contributing to success in education and the workplace. Mobilizing this knowledge / wisdom to stakeholders so they can take action.

work on standardizing language and understanding of ASD - respectful, inclusive

ensure autism (not just disability) is a distinct category within all funding envelopes so that we can see the numbers of people who are accessing programs/services across the country.

standardized outcome measures to guide evidence based practice

Define common outcome measures for program evaluation of publicly funded programs across provinces

define quality of life metrics for aging neurodiverse adults

should we bring up EMR?

Consult on standardizing instruments

Common data collection across service providers to inform our understanding.

Identify common measures that can be used to evaluate/assess outcomes

## Partnerships

Partner with national organizations which already have developed portals to share tools/ resources

here you bring some of the work in ASCE Canada

Greater collaboration between employment organizations, particularly at national level

create a map of available research data where consent is available to share data

Ensure autism is represented on pan-disability projects (e.g. accessibility) example Canada Disability Benefit

great point -- NHS has new ASD strategy

PDF Document

data apart of a learning health system

develop infrastructure for learning health systems

Setting our mind on the fact that data collaboration is one part of the wheel in creating a Learning Health System in Autism. this will enable us to sustain our efforts over time, and inform policy in meaningful ways...

In Quebec, with some centers, we also do collaborative research - including families/start/ managers- in the actual services to propose their needs and select together interventions/support and evaluate them in real life settings to influence decisions on services in specialized services but also from a provincial point of view (excuse me again for my english !!). We observe that it really does have an impact on micro decisions but also in practice changes.

develop methods to combine health education and social sectors data

develop partnerships with national initiative on open science, examples: experts in ethics/legal frameworks for data sharing, experts in large scale data management

In the province of Quebec, the INSPO "travail" the provincial Integrated Chronic Disease Surveillance System (QICDSS) to identify the comorbidities associated with ASD and the profile of health services utilization, and compared the health services obtained by individuals with ASD vs. the general population over a one-year period. This could be a way to start to define common datasets. <https://www.inspq.qc.ca/en/publications/2422>

Gathering local resources

Explore opportunity to leverage existing data sets related to employment and include these assets in a data repository for enhanced utilization (Workshop data, EmploymentWorks data, etc.)

It will help find people in other jurisdiction that are interested in the same data, so the research will be more in line.

NAAS - we need to get all provinces in and need to get deeper into the data already available

Networks! 1) Disciplinary, 2) Cross-disciplinary

Learn from other areas such as FASD national database initiative which gathers standardized data from diagnostic clinics

## Data Governance, Privacy and Ethics

the data needs to be accessible to autistics, families, service providers etc. not just researchers or government

Addressing/unifying privacy rights/ legislation especially as related to data

Why are we using the data, what is the data going to be used for, what does improvement mean? What does social inclusion mean?

data also needs to be broadly communicated to remote and northern communities and their stakeholders -- systems may have some differences

Transparency of data to users/ contributors

It's often up to the parent or individual to advocate when their rights are not being met or respected. This is an unfair burden for the parent/individual. Service providers need to be held accountable.

Hold someone responsible for knowledge transfer of database

## Data Use

Collect and disseminate success stories and data from employment support agencies, employers and advocates about the employment strengths of individuals with autism in employment to combat negative stereotyping.	Post-graduation, universities and colleges collecting data on number of people on spectrum attending; partner with companies to recruit	Recognizing the issue of poverty and how it affects many in our community. Needs to be addressed in order for true inclusion -	<b>Affordable housing</b>	<b>Focus on the stories</b>	Understand the status quo what do things look like on the ground. Then identify goals and objectives for improvement.	information about availability of supports/services in remote/rural areas	include the social determinants of health	what process is needed to define: common data elements
collect and analyze data on caregiver quality of life	Effect of intersectionality on autism presentation	how many autistic adults are able to successfully navigate union or apprenticeship programs (Red Seal or other)	analyze data related to housing initiatives/funding to understand access by autistic adults	Measuring outcomes for social inclusion. How to measure the barriers? Measuring feelings of belonging.	create a repository of evidence based practices that is routinely updated, curated for policy makers to use	Think about the outcome and how we are going to measure the outcome	Better understanding of the needs of job seekers so that service providers can provide targeted supports.	Could this include data across jurisdiction based interventions to support families in making decisions
Is training making a difference - what models are most successful in making a sustained difference?	data for specific ages: preschool, school age, adult, senior	Find a way to measure social inclusion	ability to understand what the gaps in knowledge in the workplace are with the goal of successful integration and employment opportunities in the workplace.	Measure symptomatology & outcomes of evidence-informed supports to inform what works and for whom. Track this across the lifespan and in all populations.	Use the data gathered to create a resource/tool for autistic individuals & their families to understand what is available and how to access it.	use surveillance data to understand capacity issues, training of professionals etc	ensure various types of support are included in the conversation (mental health, OT/SLP, respite care)	
Compare data collected regarding interventions use elsewhere that have positive results	What data do we need to improve social inclusion?	Information about structure, programs, and strategies being used in various provinces with success	Good outcomes include social innovation interventions which are delivered at the community level. Collect data on successful interventions and lessons learned for community organizations	We need to move beyond prevalence data to inform outcome-based policy and service organization that meets the needs of autistic Canadians				

## Other Salient Priorities

National perspective on rights and what constitutes meaningful inclusion.	Community and financial supports	How to feel included in different settings (work, home, school, etc). How to prioritize settings/areas of social inclusion.	What does social exclusion mean and the consequences of this	What does society, in general, need to do to increase inclusion?	National training for first responder, etc. - level and type of training to be standardized or same across country.	Create an educational component for each domain that intersects with autistic individuals so that there is a better understanding of the spectrum. Currently there are medical students so we get enough understanding of autism, so providing more education would better serve the autistic community	Finding the preferences for social inclusion in different areas.	Opportunities for training for all professionals in that support individuals with autism, ie teachers, doctors, dentist, first responders etc
Having education and/or training around inclusion at the system level. Embedded at a high level so everyone has a good foundation	Make sure that this type of social inclusion is important to the individual	Offer on the job training for people seeking employment in a certain field	Better understanding of the needs of job seekers so that service providers can provide targeted supports.	The right for inclusive housing whether supportive or independent	Right to have a medical professional that is trained in understanding autism and the co-morbid conditions	More opportunities to celebrate autism to look at the positives and what they contribute instead of continuing to look at the deficits	In terms of our confederacy work with provincial and territorial governments to "standardize" supports for the ASD community	Mine stories from corporations/ business/private sector round tables re: successes, challenges and solutions being and relating individuals with autism. Learning what accommodations are necessary.

# Appendix B

## Gives

### Knowledge/Expertise

an understanding of what we are measuring	learning health network expertise	Perspectives from clinicians in building a Learning Health System	Personal stories from voices of persons with ASD; information about specific interventions	Insights from my position as a researcher, health information specialist, community org worker	Data-informed policy-making expertise	Evaluation on implementation research and national network	I can give time, perspective, data, ideas
time, data, ideas, critical questions	ensuring representative data						

### Collaboration/Networks

Visibility in Quebec province	collaborative teamwork	Information about the Manitoba context	Evaluation on implementation research and national network	provincial clinical data and networks	perspectives from the north and rural locations
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### Time

personal time and commitment	time, data, ideas, critical questions	I can give time, perspective, data, ideas	Community-based data assets (data sets), in-kind staff time and energy.
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### Community Voices

community representation	community members needs and priorities	voices of all	community awareness and acceptance	Personal stories from voices of persons with ASD; information about specific interventions	My personal drive to make change for the future
Experienced self-advocacy					

### Data

data from research networks	provincial clinical data and networks	time, data, ideas, critical questions	Community-based data assets (data sets), in-kind staff time and energy.	Data from everyday practice	I can give time, perspective, data, ideas
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## Gets

### Networking, Teamwork, and Collaboration

Insight from other provinces on good practices

A national data repository using evidence based/ standardized data

understanding how to access information that creates movement

action to coordinate across P/Ts

a network to learn from and work with

relationships with community

### Making an Impact/Taking Action

To make a difference - I want to be part of the change and see the change happen

get to a point where Cyndi (and others) feel we have actually made progress and the future is bright

Consensus and meaningful action

opportunity to have impact, beyond clinical care

Forward momentum - tangible action

understanding how to access information that creates movement

Feeling like my expertise is somewhat valued.

### Data Informed Decisions

numbers to make informed decisions

information to guide service decisions

data that gives me good info. on how to allocate my time and resources

illumination of gaps and subsequently, seeing resources directed towards filling those gaps

### Supporting Autism Community

research on voice of parents... tool to measure their perception on quality of services trajectories with indicators that are significant for THEM

how to support autistic people around me

A voice in the decision making process

## Best Practices

access to information that we can use as clinicians to support families we work with

Movement from data to knowledge and better understanding of needs

evidence based practice directions

Oversight and feedback on effectiveness in everyday practice

Information on best practices in education pre-kindergarten to young adult; supports for inclusive education

Insight from other provinces on good practices