

KNOWLEDGE-SHARING WORKSHOP



The CONTiNuity of carE and serviCes for autistiC adulTs (CONNECT Project)

Reported Findings

November 17, 2017 Shediac Multipurpose Centre

Organized by:

Funding agencies:



WORD FROM CONNECT CO-LEADERS

Dear stakeholder,

Thank you so much for attending the inaugural the knowledge-sharing workshop, held November 17 at the Multipurpose Centre in Shédiac, New Brunswick. The workshop was an exceptional opportunity for knowledge-users to give feedback on the preliminary results of the Maritime Needs Assessment Survey. One of the intangible benefits of this workshop, and the CONNECT project, as you mentioned in the evaluation forms, is that the emerging Maritime Autistic community and stakeholders made connections and came together to help define the future path of Autistic adults in our region.

We were thrilled with the results and rich information collected at the session. Your input from the day has been compiled into this report and this will inform further analyses and interpretation of the data collected with an eye towards continuous improvement.

By participating in the Knowledge-Sharing workshop, you played a large role in helping us identify gaps in CONNECT survey design and priority areas for autistic adults research. Our Operation Committee reviewed the report and discussed its immense value to our work moving forward. We will use the feedback to guide our work in reporting health status and service use of adults and their families on the autism spectrum. During the coming year, we will approach you to further refine the types and formats of information you need in order to provide you with the best tool usable for your organization to improve decisions and service provision for the adult autism community.

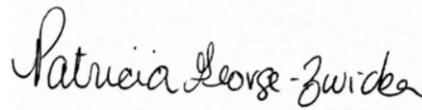
We hope that your participation in the day continues to be of value to you and provides a new frame of thinking as you approach your work or daily-living with autistic people. We also hope you will stay connected to the CONNECT team and Maritime autism research community going forward and seek other opportunities to be involved, whether it is talking to us about potential research questions or keeping research ideas flowing in your organization.

If you have questions or further feedback on the attached report, please contact connect@mssu.ca.

The CONNECT team would like to sincerely thank the many volunteers who made the workshop possible, as well as the funders and partners supporting the CONNECT project. And again, thank you for your commitment to the Autistic community.



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WORKSHOP OVERVIEW

The **CONtiNuity of carE** and support for autisti**C** adul**Ts** (CONNECT) study aims at:

1. Portraying the adult ASD population and its service needs via surveys;
2. Facilitating the development of a Maritime inventory of services and their availability to the public; and
3. Sharing and transferring knowledge resulting from this project and the best practices in autism to health and social service providers, policy-makers and the ASD community through several targeted approaches.

The CONNECT team invited stakeholders to a knowledge-sharing workshop on November 17, 2017 in order to give them a chance to share their input and generate feedback on the preliminary results of the surveys. The aim of the Maritime Needs Assessment Survey is to gather a wide range of data to help better understand the needs and challenges faced by more than 15,000 Autistic adults in the Maritimes. It is the CONNECT teams hope that, with this critical information, we will provide evidence for policy development and decision-making. The questionnaire was launched in July 2017.

When this project is completed, decision-makers will have access to a portfolio of evidence-based tools, created in collaboration with autistic adults, their families and other key knowledge users to improve the continuity of care and support.

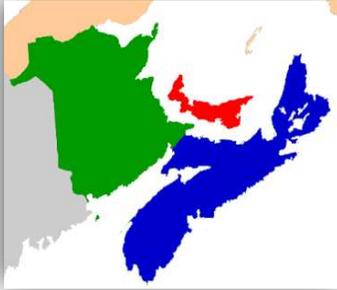
GENERAL STRATEGIC THEMES

Stakeholders and participant from the CONNECT team were asked to discuss the following themes after receiving a presentation of the preliminary results:

- What do you think about the adult and caregiver-reported sample representation?
- What do you think about the similarities and differences in adults- and caregivers-reported comorbidities, and how this relates to the differences in perceived health?
- From your perspective, what do you feel is important to explore in future analyses?

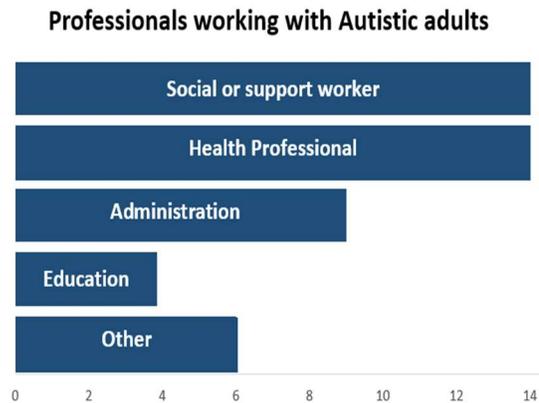
CONNECT SURVEY PRELIMINARY RESULTS SUMMARY

The workshop participants received the following snapshot of the questionnaire results as of November 9th, 2017.



	Number of respondents		
	Adults	Caregivers	Professionals
Nova Scotia	40	24	10
New Brunswick	10	26	25
Prince Edward Island	6	6	11
Total	56	56	46

Adults self-reported		Caregiver reported
94%	White/Caucasian	89%
0	First nations/Aboriginal	4%
43%	18 – 30 years old	89%
43%	31 – 40 years old	7%
14%	+ 41 years old	4%
84%	Formal diagnosis	96%
48%		18%
45%		82%
7%		0



We still need more participation!
Our goal is to reach at least 400 Autistic adults.



The questionnaire is easy to complete in just 20 minutes.
 Just scan the QR code.
 Or to fill out the questionnaire on paper, just contact us at connect@mssu.ca or by phone 1-506-863-2266



GENERAL STRATEGIC THEMES

The primary objective of the workshop was to discuss and share different viewpoints in relation to the preliminary results of the CONNECT questionnaires. Team members and stakeholders that attended the event were presented with a detailed breakdown of the responses to the questionnaire obtained up to that point in time. For both reasons of confidentiality and that, the data collection is still ongoing; the more detailed results will not be released as part of this report. A complete report will be available after completion of the CONNECT project in June, 2018.

The organizing committee of the workshop did however identify three key questions that emerged from the preliminary analysis. Those three questions, the context from which they arose, and the main themes identified during the ensuing group discussions are presented below. Workshop participants enjoyed the preliminary results presentation and were excited to discuss the three themes presented to them.

First question

What do you think about the adult and caregiver-reported sample representation?

Background

As seen in the table provided in the summary of the preliminary results on page 4 of this report, both adult-reported and caregiver reported samples were predominantly white/Caucasian and both lacked representation in the category of adults older than 41 years old. In contrast, the groups differed in that the caregiver-reported sample was younger than the adult-reported sample. There was also an over-representation of males in the caregiver-reported sample. This led us to ponder several questions such as how could these sample distributions impact the results, are these samples similar to what we should expect in the population at large, are they small sample noise, do we need to find strategies to reach the underrepresented segments of the autistic adult population? We decided to keep the question as vague as possible in order to capture as many ideas as possible.

Themes identified by the workshop participants

The workshop participants did not have much to say about the adult and caregiver-reported sample representation. Most participants cited: "caregivers are taking care of men more than women; it could be that males are more on the severely affected/early diagnosis side". Participants were more eager to express their opinion on the second question, but did mention that they thought that women are diagnosed/self-diagnosed more often as adults. The quote that came out the most: "experience is different when you're an adult completing the survey than a caregiver, this could affect the results and we should make sure to be able to match the answers of a caregiver and adult that both answered the survey".

Second question

What do you think about the similarities and differences in co-occurring diagnoses, and how this relates to the differences in perceived health?

Background

Of the most prominent co-occurring mental health / neurodevelopmental / intellectual disability diagnoses, we found the following in both adult and caregiver reported samples: anxiety, learning disabilities, sleep disorder, and obsessive-compulsive disorder. Of the most prominent co-occurring physical health diagnoses, we found the following in both samples: sensory issues, gastrointestinal problems, and vision problems. As for difference between the two samples, the adult-reported group signaled depression, attention-deficit (with or without ADHD) and bone, joint, muscle problems, whereas the caregiver-reported group reported intellectual disability, speech (language disorder) and epilepsy.

As for perceived health, the results showed that caregivers tended to report more positive perceived physical, dental and mental health than the adults did.

Themes identified by the workshop participants

The workshop participants were not surprised of the difference between the two samples, except for perceived health results. They thought that caregivers probably answered more for autistic adults lower on the spectrum and it could explain the differences in the survey results of caregivers and autistic adults. Participants pointed out that salary of autistic adults are low, this could impact their health. Here is a few surprise participants had when discovering some of the survey results:

- Depression reported high by autistic adults but not by caregivers
- Autistic adults reported the desire for more services in mental health but not caregivers
- Housing was only a need for caregivers and not autistic adults, does caregivers think more about the future?
- Results showing what caregivers need versus what autistic adults need

As for perceived health, participants quoted: "Is the perceived health very good more often with caregivers because autistic adults are living in a household rather than living alone"?

Participants also mentioned that we tend to have better health when we live as a couple and poorer if we live alone. Participants also mentioned that caregivers are more positive than autistic adults about the adults health.

Third question

From your perspective, what do you feel is important to explore in future analyses?

Background

With a deliberately wide scope, the questionnaire captures a range of variables touching on employment and housing, autism spectrum diagnosis, health status, life skills and level of autonomy, as well as service use and needs. This question was proposed as a chance for workshop participants to voice their interests as to what they would like to know in relation to the data, and what possible future steps the CONNECT team could take, having now a better sense of the strengths and weakness of the ongoing data collection.

Themes identified by the workshop participants

Workshop participants were excited about the results and think they will be a good resource library to help develop new policies for helping autistic adults and their caregivers. Will be helpful for resource centers.

Following the reveal of some of the results, participants thought it would be great to explore further:

- why mental health was not perceived the same way for caregivers and autistic adults.
- compare the survey results of caregivers and autistic adults that both answered the survey for the same person
- development of resources and services for rural areas (link between the needs and what already exist or could be created)
- autistic adults experiences of using hospitals ER, doctor visits, etc.
- disability support program, gap in what is available and what is used
- availability of service in Maritime Provinces
- what are the best practices
- how to advocate a strong cooperative productive network of stakeholders rather than silos
- acceptance in workplace and schools, accommodations and accessibility

NEXT STEPS

The results from this event are now summarized and will be collated with information from the final survey results so that the CONNECT team can establish priorities for the dissemination plan of the CONNECT survey results. Additionally, these results will be circulated back to the participants, with the goal of establishing new partnerships with interested stakeholders in New Brunswick, Nova Scotia and Prince Edward Island.