A PROVINCIAL FOCUS ON SERVICES FOR ADULTS WITH AUTISM

Navigating "The Cliff"

"It felt like we fell off a cliff when our son left school."

In Canada, an estimated 50,000 teens with autism become adults – and lose school-based autism services – each year
(2018 National Autism Spectrum Disorder Surveillance System Report)

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Introduction

Autism Connections Fredericton

Autism Connections Fredericton is community-based not-for-profit organization committed to supporting individuals with Autism Spectrum Disorders (ASD), their family, friends, and professionals working with them in the Fredericton area. We provide a variety of accessible supports and services in our community. Our programs are varied including a day camp in the summer, tutoring, and sports-based opportunities. We provide access to referrals, resources, support, education, and outreach services to the members of our community. We also work collaboratively with other community and government organizations to ensure adequate and consistent care for the families with whom we work.

About the Authors

Rick Hutchins is the Executive Director of *Autism Connections Fredericton*. Rick has spent most of his career working as a community development practitioner, facilitator, and adult educator throughout New Brunswick. He has previously worked with many community organizations on a variety of community-based projects, the majority of which have been in the volunteer sector. Rick is also an educator and teaches at the University of New Brunswick's (UNB) Renaissance College.

Dr. Paul McDonnell is a retired clinical psychologist and professor emeritus in the Psychology Department at UNB. His specializations and research were in child psychology, developmental disabilities, and applied behaviour analysis.

For the purpose of this report, "we" refers to Rick Hutchins (or other affiliated *Autism Connections Fredericton* staff) or Dr. Paul McDonnell.

Special Thanks

Autism Connections Fredericton would like to thank everyone who participated in the consultation process. Thank you to all the individuals, families, and service providers who took time out of their day to attend a meeting, complete a telephone interview, or complete a written submission form. Without your input and feedback, we would not have been able to create this report. We would also like to thank the 11 Autism Resource Centers of New Brunswick for organizing or hosting these meetings.

What is Autism?

Autism means many things to many people. The term is often used as shorthand for "Autism Spectrum Disorder" (ASD), the term used in the 5th edition of the Diagnostic and Statistical Manual of Mental Disorders (DSM-5). ASD refers to a neurodevelopmental condition that affects the way a person communicates with and relates to people and the world across the lifespan. ASD is characterized by differences in social communication and social interaction, as well as restrictive and repetitive behaviours. It can impact behaviour, social skills, understanding of non-verbal communication, thought processes in consuming and/or distributing information, self-care skills, and the processing and perception of sensory information.

The use of the word “spectrum” highlights that, while all people with autism will experience certain differences characteristic of the diagnosis, the degree to which each person on the spectrum experiences these differences throughout their lifespan varies in intensity and frequency. Just like all people, each person with autism is different, and has unique strengths and challenges.

A Note About Language

The debate regarding language and autism is ongoing. Individuals differ in their opinions of how best to talk about autism with support for many different approaches including medicalized terminology, person-first language, identify-first language, and normalization of autism through language. There is, as of yet, no consensus on the answer to this question due to the diversity of experiences and perspectives within autism and autistic communities. In writing the report, the authors took into careful consideration the language that the individuals used in their responses and reflected the variety of language used in this report. For this reason, this report uses terms such as “autistic person”, “person with autism”, and “on the spectrum” interchangeably to respect the range of valid and important viewpoints.

What to Expect from this Report

We know that in one report we cannot capture the voice and opinions of all persons with autism living in New Brunswick. We value and respect the individuality that we have already discussed is present among individuals with a diagnosis of ASD. The information in this report is a synthesis of the major themes (discussion topics that were brought up multiple times) that emerged from the discussions we had with the individuals who participated in our focus groups. To identify the major themes, we diligently reviewed the audio recordings and notes taken throughout the sessions and grouped similar statements and opinions together until we were left with a succinct list of themes. We are only able to speak to the information that we heard from the individuals who participated in this tour. It can be difficult to engage individuals with autism in information-gathering-sessions such as this and, consequently, some of the information may represent the thoughts and experiences of some individuals with autism more than others. Our particular difficulty with recruiting self-advocates may lead those individuals to not see themselves in these findings as much as other individuals on the spectrum. For this and many other reasons discussed throughout this report, more research is certainly needed to both support and further what we heard on this tour.

Background on Adult Services Tour

The provision of evidenced-based services for adults on the spectrum is the new frontier, following improvements in services for pre-school children and school-aged children. However, it has not been clear what services are needed and what differences might exist across the province. The

Canadian Autism Spectrum Disorder Association (CASDA) study[1], and similar research developed through the CONNECT project (See Appendix A), both point to service gaps and resulting concerns for adults.

In September 2017, in partnership with UNB's College of Extended Learning and the Department of Social Development (DSD), we hosted a two-day workshop by Dr. Gregory MacDuff of the Princeton Child Development Institute. The workshop was titled, "Adult Life with Autism" and our subsequent report, Adult Life with Autism: A Summary of Major Themes[2], proposed a more extensive consultation on the service needs for adults throughout the province of New Brunswick. Those results prompted the Adult Service Tour in New Brunswick.

We felt it was necessary to hear from service users, family members, and service providers themselves to learn more about what is working well and the areas in which they are facing challenges with regards to services for adults on the spectrum. This conclusion motivated *Autism Connections Fredericton* to conduct a tour of all 11 Autism Resource Centres in New Brunswick from February to April 2019. The tour was comprised of a series of focus groups where we connected with more than 311 individuals (advocates, self-advocates, and service provides). In this report we will be reporting a summary of the major themes.

Methodology

The goal of the New Brunswick Adult Services Tour was to speak with self-advocates, families, and service providers to gain an in-depth understanding of the unique service needs of adults with autism, what is working well with regards to the quality and access to these services, and in what areas they are facing challenges. We felt the best way to engage with and capture information from these individuals was connecting in-person as it allows more comprehensive dialogue with participants compared to a questionnaire-based approach. As such, we tried to arrange in-person meetings as much as possible. We decided to partner with our newly-formed New Brunswick Association of Autism Resource Centres (NBAARC), which consists of 11 autism resource centres strategically placed around New Brunswick. Their existing connections to their communities as well as their geographic locations allowed us to access a strong representative group of individuals from different areas of the province in both official languages.

Each participant signed a form indicating their consent to participation as well as an understanding of what participation entailed, including that the sessions were going to be audio recorded. The form outlined the goal of the Adult Services Tour and what was expected from participants so that they could make an informed decision whether or not they wanted to participate. An excerpt from the letter reads as follows:

> *"At each focus group, participants will be given an opportunity to describe in detail the kinds of needs they have now or expect to have in the future and what kinds of supports they think the Government of New Brunswick should offer… We will then summarize the discussions in a report that we will present to the Government of New Brunswick upon completion of the provincial tour."*

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[1] Available online of the CASDSA web site.

[2] A copy is available on request from the authors.

The Process

We held community dialogue sessions (focus groups) at each participating centre. Rick Hutchins served as a bilingual facilitator for each session along with either Paul McDonnell or an alternate who took notes and recorded the discussions. In addition, an audio-recording was made of each session using a Zoom H4N Pro Handheld Digital Audio Recorder.

This methodology allowed us to meet our goal of engaging these individuals and creating recommendations based on their feedback to inform future supports and services for adults with autism. Autism Connections Fredericton is a community-based organization and this type of community discussion-based-engagement approach to gathering information is in line with approaches used by other not-for-profit organizations when attempting to get input and feedback from their target populations. In line with our previously stated goal, our desire was to engage with individuals, record their feedback, summarize what we heard and the common themes that emerged to create a snapshot of the overall state of services for autistic adults in our province.
There are opportunities for follow up studies, including rigorous academic research studies, to expand on what we heard throughout this tour. This gathering of information was not meant to substitute a more vigorous methodological approach but to hopefully serve as a catalyst for action and a starting place for further research conducted with autistic adults in New Brunswick.

Participation

All stakeholders were welcomed but the individuals who participated in this tour fell into one of three major categories: Advocates (parents, siblings, grandparents, other family members or guardians), Self-Advocates (persons with a diagnosis on the spectrum), and Service Providers (health professionals, community workers, special care home operators, etc.). Whenever possible, we structured our meetings so that they were composed of participants with common interests. Therefore, we often had sessions that were primarily advocates, primarily self-advocates, and primarily service providers. We recognized that many persons on the spectrum may not be comfortable attending a public meeting so we created a written submission form that could be completed by phone. We also made the written submission form available to those who wanted to participate but were unable to attend a focus group session.

We obtained a total of 311 responses gathered from meetings held at 10 different autism resource centres as well as the written submission form completed either over the phone or a submitted submission.

The main question that we asked participants was:

“What can be done to improve services for adults on the autism spectrum in our province?”

Along with presenting this broad question, we also stressed that we wanted participants to tell us what services they needed for their particular situation. Additional questions were sometimes necessary to prompt or stimulate discussion and keep the focus of responses on this question. The facilitator used an appreciative approach, which meant focusing more on what services the respondents need and what would facilitate access to those services, rather than focusing on what participants felt was wrong.

Methodological Details

We hosted a total of 27 focus groups in 10 of the 11 Autism Resource Centres in the NBAARC. The total number of participants in the Adult Services Tour was 311. We had a total of 280 people participate in focus groups. In addition to the focus groups, we received written submissions from 23 individuals and we conducted telephone interviews with eight individuals.

In addition, consultations were held with two key provincial community partner agencies and organizations that work with adults with autism (New Brunswick Association of Community Living (NBACL) and the Premier's Council on Disabilities (PCD)).

Table 1. This table contains the information on the focus groups that were held at 10 Autism Resource Centres around the province. Information includes the date of the meeting, the number of sessions run, and the number of participants at the sessions are also included.

DATES	**CENTRES**	**NUMBER OF PARTICIPANTS**			**NUMBER OF SESSIONS**
		ADVOCATES	**SELF ADVOCATES**	**SERVICE PROVIDERS**	
02/20/19	Perth-Andover	14	<4	4	<4
02/20/19	Woodstock	21	5	<4	<4
03/11/19	Moncton	20	8	12	5
03/12/19	Miramichi	21	16	10	5
03/13/19	Saint John	8	<4	17	<4
03/14/19	Edmundston	8	<4	6	<4
03/20/19	Bathurst	10	<4	4	<4
03/21/19	Shippagan	11	4	9	<4
03/25/19	Fredericton	26	14	12	5
04/1719	Saint Andrews	7	<4	<4	<4
	Total for 10 Centres	146	58	76	27

Note: We have used <4 for entries of zero to three to insure anonymity for participants. The original data are available upon request.

What We Heard

The following topics were the most frequently cited in the remarks by participants. The authors wrote these descriptions of the major themes based purely on the input and feedback they received from the individuals who participated in the tour. This section has each theme and the description of what points the individuals felt were most important with regards to that theme.

Navigation

Navigation was the most consistent issue that arose in our focus groups. Advocates and self-advocates were frustrated by the difficulty of accessing relevant information to plan for the support they needed. Important information such as where to access funding, assessment services, supports groups, etc., was not commonly known, with no central archive or "go to" resource. We heard that there is even a lack of knowledge within the same government department. Participants explained that if they were to call with the same question three different days, they would be likely to talk to three different people and get three different answers. They furthered their explanation by acknowledging that some government workers are better at gathering the information than others, but there is no system in place that tells them where to go for which resources, or even what resources exist in New Brunswick. Many times in our discussions, participants discovered available services they were unaware of because of what another participant shared. Some participants described having to do all of the "digging" themselves and see themselves as the navigator and the difficulty this presents. We discovered that some people did not even know that the NBAARC, comprised of the 11 Autism Resource Centres, existed. A related concern expressed by participants was the lack of autism-related knowledge and expertise among key resource providers.

Participants gave many suggestions to improve services, including setting up a 1-800 information line using each of the 11 resource centres as a contact venue for advice and counseling on services and an up-to-date online directory of government services. We were also told about *One-Stop-Autism Shop*[3] for adults with autism in Scotland. In each case, there was a distinct reference to "improving" the navigation system and options for adult autism services.

A few of the Autism Resource Centres have already posted a resource guide on their websites and we know that other organizations have similar documents (e.g., NBACL and the PCD). When we asked participants about these guides, most were not familiar with them.

Transition to Adulthood

A common concern in most centres we visited was that respondents commented on the difficulty of the transition from secondary school to college or to a job. Funding through the *Disability Support Program* (DSP) begins only at age 19, two years after many will have graduated from high school. The years between 17 and 19 were described by families as the "*gray zone*" or "*black hole*"; when funding is up in the air and the extensive support of the school system has been withdrawn with no replacement. It is clear that government services and policies were not implemented to accommodate the fact that individuals with autism will continue to require support throughout the adult years. As one service provider commented, *"I work with families that do not know what to do when a student graduates."* The transition is scary for the families of autistic adults, especially if the individual transitioning has complex needs or behaviours. Parents are often unprepared for the transition, and do not know how to prepare themselves.

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[3] The Fife One Stop Shop is based in a central location in Kirkcaldy where they offer autistic individuals, their families and professionals information and advice about autism as well as the kinds of support services that are available locally. https://www.scottishautism.org/services-support/support-families/fife-one-stop-shop

A number of respondents suggested that students who require more time could be allowed to continue under the umbrella of the school system to age 19 or 21, focusing on individualized life skills and employment skills. Although this option currently exists, respondents told us that it is not well known and some said that many requests are refused.

A second *gray zone*, identified by some family members happens at age 64, when DSP funding is withdrawn. It is not clear why these gaps exist and what families are expected to do to provide support for the years in the *gray zones*. The *gray zones* and the service 'cliff' in the transition to adulthood are demonstrated visually in Figure 1.

Many noted that services like those of the Autism Team at the Stan Cassidy Centre for Rehabilitation (SCCR) are only available for school-aged children, while the needs of the individual continue into adulthood. Although the authors were independently informed that the wait for services at the SCCR takes 3 months, participants described long waits for services. Because of the long wait times and the fact that services stop at age 16, some people exceed the maximum age limit before they are able to receive the services they need. Many respondents stated that we need services for adults on the spectrum that are similar to those offered at SCCR for children and adolescents on the spectrum. Many families have had the support of a pediatrician throughout childhood and adolescence but once adulthood is reached, that is another source of knowledgeable support that is withdrawn.

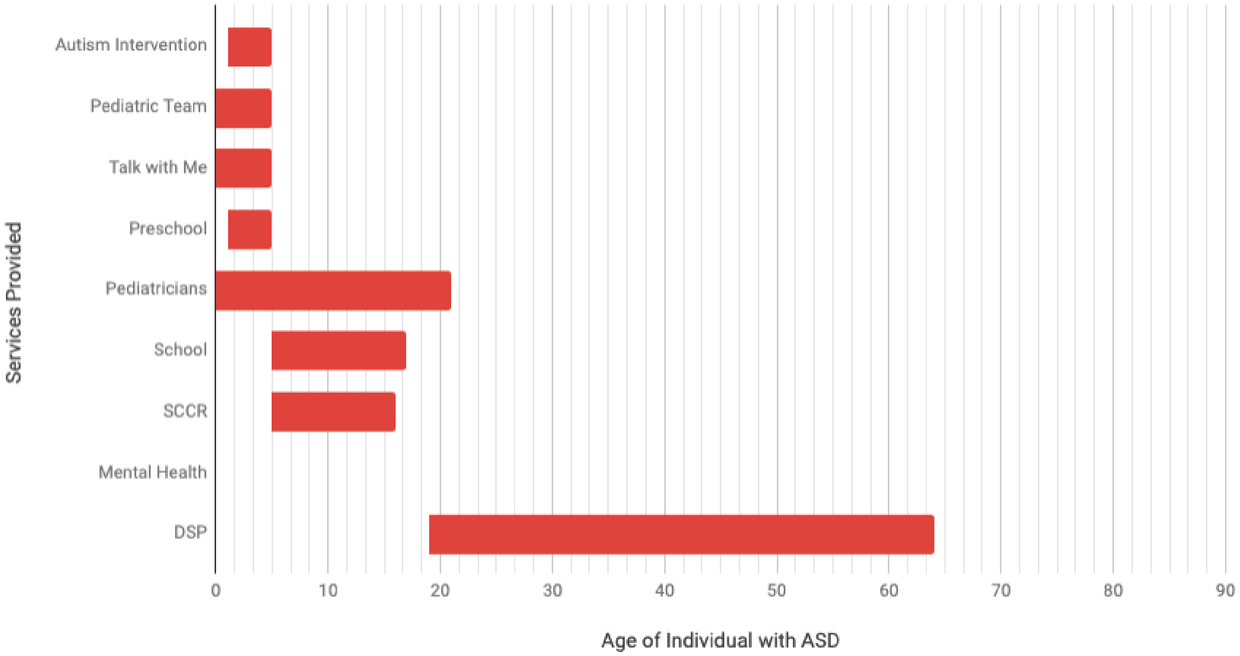

Figure 1. Services and funding provided to individuals on the autism spectrum based on the age of the individual. The Disability Support Program is the only funding service provided to persons on the spectrum until age 64.

Autism Education and Training

It is clear from the participants' responses that training in autism is needed at all levels, including employers, government staff, home support workers, family doctors, and general members of the community. We will break down the feedback participants gave with regards to autism education and training.

Support Workers and Professionals

During the sessions, almost all parents referred to behavioural challenges that needed attention. In some cases, the concern came from a lack of understanding of the characteristics of autism by a service provider. In those cases, improved understanding of the needs of the person on the spectrum would have defused many situations before they escalated. It is clear from the feedback from participants that better education and training regarding autism is essential.

The behavioural problems exhibited by individuals with autism are varied and can look very different from each other. Some families reported meltdowns that are long lasting and dangerous to the individual or to others. Some adults with ASD are at risk of impulsively wandering off (e.g. "flight risk") and some act out violently in frustration when they have challenges communicating. These behaviours can be improved or managed by professionals with appropriate training. It was in this context that we heard repeatedly that there was a need for a tertiary adult autism support team, similar to the current child and adolescent team at the SCCR.

Most families and service providers ubiquitously called for access to more professionals who have received autism-specific training. Without training, caregivers are not able to recognize and identify the needs of the individual or appropriately intervene when a crisis arises. Professionals also need to know how to teach new skills to clients on the spectrum. When listening to participants describe their situations, it seemed that in circumstances where autistic adults were experiencing greater challenges related to daily functioning (e.g., distress, difficulty communicating, lack of appropriate work or activity), the impact of not having service providers with appropriate training was even more pronounced. Without access to trained professionals, chronic and damaging situations will continue and the expenses for services will increase with the increase in demands.

Many government services allocate set funds within their programs. Despite the financial assessment done by Social Development, the comments we received suggest that rates of pay for support workers are not proportionate to the needs of the client. Participants described feeling as though there is little flexibility to provide more funding for families of individuals with higher needs. This is of concern as these families require more supports and need to hire more highly qualified (and consequently more expensive) service providers.

Employers

Parents and self-advocates repeatedly commented that most employers do not understand autism and do not make the accommodations needed to ensure the successful adjustment (and continued success) of a new employee with ASD. Additionally, it is very common for a new worker to lack the kind of on-the-job support they need to be successful. Because employers do not understand autism, they fail to provide crucial support when needed and the worker with autism fails and either leaves the job or is fired. One self-advocate was asked *"do you take a pill for that?"* when they spoke with their supervisor about their autism diagnosis. It was suggested by some respondents that the province could begin a campaign to educate employers about the many advantages of hiring persons on the spectrum and provide training to employers as needed. NBACL offers some of these services through the Ready, Willing, and Able program. However, this is only available in Fredericton, Saint John, and Moncton.

Vocational Preparation

Obtaining job training and finding employment is a challenge for anyone but especially for those on the spectrum. A large percentage of adults with autism are unemployed. One parent summarized the current situation by saying, *"In an area where people beg for jobs, why hire a person with ASD?"* Of course, the authors believe that this is a false stereotype that needs to be overcome. We heard that it is not uncommon for an individual on the spectrum to be hired and paid a stipend of $2 per hour, which participants felt devalues the person and their work. This nominal payment unfortunately often continues even after the worker has acquired the skills needed to be an effective employee.

Parents and self-advocates also expressed frustration with the educational system in failing to provide training in life skills needed to succeed in adulthood. One self-advocate said that five out of seven individuals with autism *"would like to live independently."* The concern expressed by parents and self-advocates was that the focus of school-based curriculum has been too heavily based on academics and needs an increased focus on functional skills that will facilitate employment and independent living. Several individuals said that the emphasis needs to be on teaching skills that will be required for a job as well as skills to enable an individual to function well in the community and workplace. NBACL has informed us that they have launched a pilot for older high school students with significant disabilities as they transition out of the school system; *Transition to Community* is currently operating in four high schools (see Appendix C).

Parents also noted that the kind of training provided in the larger job-training centres in Fredericton (Jobs Unlimited), Moncton (Moncton Employment Training Services) and Saint John (Key Industries) are not as readily available in more rural settings. Parents discussed that there are some other examples of successful social enterprises around the province such as the bookstore at the Miramichi Resource Centre and the Open Sky farm model in Sackville. Both of these enterprises employ, and provide training, for adults with autism. Such enterprises are an excellent vehicle for job training in their community.

Existing Job Training

While we heard that respondents recognized the value of agencies that support job training, they also expressed frustration with two things. First, that there is a lack of understanding around ASD specifically. Second, that there are few opportunities for meaningful employment. They also noted that, in many communities, there are no available jobs. The existing job training centres in NB are all privately operated and, for the most part, there is no formal connection among them. We will give a brief overview of the programs that participants shared during the focus groups.

There is an association called the New Brunswick Association for Supported Services and Employment (NBASSE); it is a volunteer association that provides representation to government for the 38 ADAPT member agencies across the province, which are funded by Social Development. The funding at these agencies primarily supports people with an intellectual or developmental disability and is not specific to autism.

The description of the program by Social Development is as follows:

> “ADAPT is a program that provides long-term care clients appropriate opportunities to learn skills in centre or community-based settings. Through a supported environment, ADAPT focuses on the development and provision of valued training and activities and encourages appropriate behaviour, respect of daily schedules, dress, social habits and all other expectations that are placed on an adult individual. ADAPT services are designed to meet the participant's needs on a full-time or part-time basis. Although ADAPT services, for the most part, are developmental in nature and designed to meet the needs of the client, as a result of this service families and guardians of the client receive valuable hours of respite. Individuals who have been assessed as eligible for long-term care services and for whom it has been determined that this type of activity is appropriate can be referred to an ADAPT program. The individual should be willing to participate in personal growth activities based on his or her interests and strengths.”

Dave Richard from *Moncton Employment and Training Services* provided us with data from their programs. The agencies employed approximately 400 staff at locations around the province. There are approximately 1300 participants in the ADAPT program. To read more information see Appendix C. Based on information provided to us, this program seems excellent. However, eligibility for these services would not apply to all persons on the autism spectrum. For example, those with severe autism symptoms and significant intellectual disability would likely be excluded. Also, since these services are designed for persons with a moderate intellectual or developmental disability, this level of support would also exclude individuals on the spectrum who have average or above average intellectual ability. Yet, individuals on the spectrum can have significant social disability, even with average intellectual ability.

There are other opportunities to find support for employers who wish to hire persons on the spectrum. For example, the federal government has a program called the *Youth Employment and Skills Strategy* or YESS program. A brief description and link can be found in Appendix C.

Role of Government

Participants expressed that they felt that different government bodies operate independently and coordination between departments is lacking. This frustration was expressed by family, advocate, and self-advocate participants. From the stakeholders’ perspectives, government services lack connection and expertise amongst staff on autism itself. This has made it more difficult for families to get answers for complex questions or inquiries.

The tour was a tremendous opportunity to gain a better understanding of the dramatic changes adulthood brings to families and individuals. For adults on the spectrum, services that involved Post-Secondary Education, Training and Labour (PETL) and the DSD were most often mentioned. Given our audience, the focus on these two departments is in line with their needs and the services they would be accessing as they shift from receiving most of their services through the education system.

Several respondents noted that services that were managed by government, and in particular by Social Development, were lacking an understanding of autism within the guidelines of service delivery. Some families noted that rules were enforced rigidly and did not take into account the realities of the families struggling with a member on the spectrum. For example, *"All jobs he has looked for require him to be subsidized. He does not qualify as he must be able to work 20 hours per week. Who sets the rules? We need the rules to be flexible for each individual".* Another parent stated, *"I'm treated like a welfare case".* The rules are the same as for a person on social assistance. Some cited that we may need to have a separate Department of Social Assistance for persons with disabilities, which allows for flexibility based on individual needs and abilities.

Many parents expressed frustration with the need to search for services, navigate many different service providers, each with their own complex rules, and deal with staff that did not seem to understand what challenges are faced by a person on the spectrum and their families. One conclusion from the CONNECT project states that the government must improve accessibility to available services.

There are challenges to navigating a multi-faceted system. There are many moving parts that make up the system of care and support that individuals on the spectrum and their families must navigate to acquire the support that they need. The concern highlighted by many participants was the disconnection between these services. In Figure 2, the players in the provincial system are listed but none of the circles are connected to indicate that there is little to no flow of information between these players, making it additionally difficult for anyone to find the support that they need. In one powerful quote, a parent noted the following: ***"We parents burn out - not from our children, but from the system."*** A similar model could be used for the community service providers who are also loosely connected and have no mechanism to collaborate with each other. At the regional/community level, the connectivity between agencies is stronger.

Figure 2. This figure represents the players in the provincial system that individuals on the spectrum and their families must navigate to acquire the support that they need. None of the circles are connected to each other to indicate that there is little or no flow of information between the different supports.

Health and Wellbeing

<u>*Mental Health Issues*</u>

One of the most frequent comments by all stakeholders was that persons with a diagnosis on the autism spectrum are excluded from Mental Health Services. Based on reports from families and self-advocates, it has been their experience that the Department of Health does not provide services to this population because they do not have anyone trained in the field and their perception is that anxiety, depression, and OCD symptoms are merely a part of the syndrome of autism. According to participants, staff from mental health have explained that autism is *"an exclusionary condition."* A few individuals reported that they have obtained services by not disclosing their ASD diagnosis and some have received services despite the exclusion others have experienced. However, most respondents said they could not access the publicly funded mental health services. Responses from the CONNECT project support the finding that access to mental health services is a pressing concern for adults on the spectrum. This was a major issue voiced by self-advocates because they are a minority group excluded from the only available publicly funded mental health services. This group is also at an increased risk of suicide. This discrimination is felt by many self-advocates to be a human rights violation.

Note: We discussed this issue with representatives from NBACL who directed us to their position paper on this issue entitled, "Equal Access to Mental Health Services and Well-Being for Individuals with an Intellectual or Developmental Disability." See Appendix C for more details.

Co-Occurring Conditions

Some persons with autism are diagnosed with multiple co-occurring conditions. Many of these individuals are also affected by a significant intellectual disability. Many families who participated in the consultation process found attending the session to be a significant hardship in itself due to lack of respite care, and described very challenging life circumstances. In some cases, these complex and co-occurring conditions create unique problems for social development, education, and long-term care.

For example, we heard that autism plus Klinefelter Syndrome or Fetal Alcohol Spectrum Disorders (FASD) can result in circumstances in which the parents are concerned about keeping their adult safe and out of jail. To put these concerns into a proper perspective, autism in combination with other diagnoses can result in poor social understanding, poor impulse control, and lack of appreciation of dangerous or risky behavior, making it more likely that they will come into contact with the justice system. This could be either because of criminal behavior or because of a lack of understanding of the individual's behavior that results in escalation of problem behaviors to the point that police become involved.

Those individuals with a significant intellectual disability will require lifelong care and extensive support. For complex cases such as these and others, the status quo is not meeting their needs. This is exactly when and why an individualized treatment response is essential. On the tour, we heard from a single parent whose grown autistic child required significant support with daily living tasks and engaged in *"challenging behaviours".* For example, their adult child smears feces and plays with their spit all day, becoming violent if someone tries to stop them. The adult has done extensive damage to the home. The parent has been offered $150 a week for respite care but has been unable to find anyone willing to take the job. Care workers hired in the past will not come back and the parent had to quit working to care for their child.

In some cases, a diagnostic assessment conducted in early childhood may need to be re-done or may need to be updated because of co-occurring conditions that have developed later in life. Several parents mentioned that getting access to a proper diagnosis can be very challenging because it often requires an expensive assessment (often > $2000.00) done by a psychologist in private practice because there are no provincial diagnostic teams or diagnostic services for adults.

Parents expressed handling the challenges of complex co-occurring diagnoses differently, but they were all determined to keep their son or daughter at home with them while they can. It was clear that they were terrified when thinking of the future prospects for their families. Many parents lead very secluded and restricted lives because of the enormous demands placed on them by the circumstances. Each one realized that there would come a "*breaking point"* when they will no longer be able to care for their adult child. The question they ask themselves is an ever-present fear; *"What will happen then?"* Although the answer to this question is complex, the need to have a dynamic strategy for the future is imperative. There is growing concern that this issue will not be addressed soon enough to help the families and autistic adults that attended our sessions.

Other Health Issues

In addition to the co-occurring disorders such as Oppositional Defiant Disorder (ODD), Attention Deficit/Hyperactivity Disorder (ADHD), and Fetal Alcohol Syndrome (FASD), participants also discussed physical conditions such as seizure disorders, celiac disease, autoimmune disorders, and self-injurious behavior. In some individuals, these physical disorders can be life–threatening. As a result, it is important that each individual has readily accessible medical assistance and that those working with this population are properly educated about health conditions that their clients may have.

Self-advocates commented that their medical experiences were almost exclusively negative. Some feel they are better cared for **when they do not disclose their diagnosis**, as they are not taken seriously and subject to paternalistic attitudes when the diagnosis is known. We heard that accommodations in their medical experiences are limited, since individuals on the spectrum report that they are not given the time or autistic-friendly environment they need to convey their needs.

It was frequently noted that there was no easy access to or funding for *autism diagnosis and assessments* for adults, nor was there post-assessment support after a diagnosis. We often heard a clear need for a tertiary treatment team to create individualized treatment plans that are adult-focused, multidisciplinary (e.g., occupational therapist, psychologist, speech language pathologist, dietitian, and career counselor), collaborative, and patient focused. It is likely that the provision of an appropriate, individualized plan may cost less to the government than a poor quality, uninformed response. One suggestion that came from participants was to base this tertiary adult team at the SCCR, since availability in all regions of the province is essential. Another suggestion given by participants was that New Brunswick universities and colleges might be engaged in facilitating new educational opportunities and connecting the community to current evidenced-based practices.

Some participants said they would like to see local clinics for autism and developmental disabilities. They said we need structured programs during the daytime – *"parents cannot be with an adult child all day."* The adults need to learn basic life skills. This clinic would also provide the opportunity to access preventative mental health programs. Day programs allow parents to work full time. However, it needs to be said that the 38 ADAPT agencies, that serve about 1300 people, currently provide some level of day programming, but are not available to everyone in the province.

Housing and Support

According to the parents participating in the focus groups, housing is a crucial need. As we have noted, parents have characterized the situation as being in the *"social welfare file"* but, given that ASD is a disability, they felt it needs to be treated differently. There need to be living situations where people on the spectrum will be cared for, as if in a home, and where they can be as engaged and independent as possible. As one parent put it: *"It's a seniors' problem, a woman's problem, a disability problem!"* **There was unanimous opinion expressed to us that an institutional setting like Restigouche is *not* an acceptable alternative.**

Parents of autistic adults with severe and complex diagnoses were more focused on the need for **suitable (and long-term) community supported housing** than any other group. Participants expressed that the current lack of housing options for adults in this population is unacceptable and that there must be a variety of housing options for these individuals. It was clear from discussions that housing options must be staffed with well-trained individuals who can provide engaging living conditions at varied support levels. It was striking that different families in our focus groups had markedly different arrangements. For example, one family has developed their own private team of care providers who work out of their home. Through funding from the DSD, another family has employed many support workers so that the number of care hours the family is responsible for is manageable. However, this family also reported that most of their aides had little to no training, and that there was a high turnover of staff. Still another example was a single mother whose grown autistic child has extremely complex behavior problems and she has no professional guidance and only minimal assistance.

Parents spoke about the need for adequate housing that would be located reasonably close to where the families lived to maintain community connections and support. There is a need for multiple housing options and levels of supports due to the wide range of individual needs. The housing should be included in the heart of our communities and the associated programs should be designed to foster as much engagement as possible. Living arrangements should include skill-building opportunities with the goal of increasing independent living skills, since learning should be a lifelong endeavor that continues beyond the traditional school experience. In order for a housing program to succeed, the staff need to be well trained in autism and appropriately paid for the challenging and valuable work they will be doing.

Some advocates speculated on several novel possibilities such as setting up a housing facility through collaboration with Habitat for Humanity to construct one or more buildings and developing an autism consultation service similar to the model provided by the Extra Mural Program. Still a number of families expressed their support for the *Village Proposal* circulated back in 2015. The support for this proposal demonstrates the need for wrap-around services in care for adults with autism. You can read this paper at the following link: http://nebula.wsimg.com/4d4422cdc17638d4e1d2b99341be9805?AccessKeyId=3053CB106567546B7F10&disposition=0&alloworigin=1

Existing Housing Facilities

Adult housing facilities in the province include Nursing Homes and Special Care Homes. Housing models, possible future options, and existing housing in New Brunswick are discussed further in Appendix B. Both options provide housing for seniors and, in some cases, for adults on the spectrum. We assume that most adults on the spectrum are not living in nursing homes, but we heard of individuals living in autism-specific housing in Tracadie. The Line Ferguson Community Residence in Tracadie serves adult men with autism and severe behavioural problems, some of whom were first in a psychiatric institution (see Appendix B).

There are over 400 privately run special care homes around the province funded by DSD (See Appendix B).

At this point, we do not know how many adults on the spectrum are provided housing in New Brunswick. Many facilities are described as providing long-term care for seniors; however, we heard concerns from participants about the need for long-term accommodations for adults with autism **who are not yet seniors**.

The province does have standardized assessment and eligibility criteria that ensure that all adults with long-term needs have the same access to the services they require. A similar assessment could be done to determine the level of care or type of housing supports that are needed for an adult with autism. The DSD defines four levels of care for clients admitted in approved housing facilities from Level 1 (generally mobile but require availability of 24-hour supervision) to Level 4 (require care on a 24-hour basis due to difficulties with cognition and/or behaviour). This is discussed further in Appendix B.

There are many alternative forms of housing support that already exist in the province but are not specifically focused on persons on the autism spectrum (see Appendix B). Levels of staff training and a commitment to providing a life of meaningful engagement for the individuals with autism is a critical consideration for many advocates with whom we spoke. However, we need to look at all forms of housing that work. The few examples above show that there have already been many creative solutions and with determination and necessary resources, our province can come together to create more effective solutions for our families and individuals on the spectrum.

Respite Care, Day Programs, & Mentorship

Respite care is another topic where most parents expressed a desire to have increased opportunity and easier access. We learned from parents that it is almost impossible to get respite care and that there is very limited funding for those that are able to acquire it. We also learned that the staff available to serve in these roles have almost no training in autism and that turnover in staff is very high. While there are always exceptions, this is the picture that applies to most families in our province.

Parents say that it is hard to find a match between respite care professionals and adults who need that service. Respite needs to benefit the individual on the spectrum and not make future care more difficult. For that reason, it is imperative that the workers are well trained and supervised.

Respite care can come in the form of day programs. We often heard a request for day programs even though there are 38 agencies providing such services under the ADAPT program, telling us that not everyone is able to access these services.

- Here is a typical example of parents who have a 38-year-old nonverbal child with high needs. The mother provides all the adult's care. What she would like is to have *qualified* respite care workers. The mother was unable to place her 38-year-old in one of the agencies funded by ADAPT, which would have provided some respite care during the day.
- Another parent of a young teen requesting a day program said; *"When our [child] is 21 our wish would be for a meaningful day program that would allow [our child] to be out of the house, in a social environment, for whole or part days during the week. We will be senior citizens when [our child] is 21, so we likely will not be able to help as much as we do now. We don't have other family members living in NB."*

These examples clearly express the need for accessible day programming and the urgency many parents feel as they see the *breaking point* when day and/or full-time care will no longer be possible.

In rural communities, we heard that there was a need for *mentors* like *Big Brothers Big Sisters* but it is hard to get them in those areas as there is no funding. Mentorship can help young adults develop social and job skills and can provide someone to guide them through everyday life. This topic of mentorship came up in many sessions. One parent said that *"There is a need for support for transitions from one phase of a job to another or one term in school to another."* This parent also reported that *"In Maine, each child or adult is assigned an advocate that helps with whatever resources are needed."* Someone in this type of mentorship role would also improve the ability to navigate the system.

Virtually every parent expressed a need for competent, trained, and affordable respite care services.

Autistic Adults Without an Intellectual Disability

A number of somewhat unique issues were identified by the participants in this group. Adults with autism without an intellectual disability may be excluded from services for autistic individuals, such as ADAPT programs, because of their average or above average intellectual capacity. However, autism is a disability, regardless of cognitive ability. Adults with autism without an intellectual disability may still experience significant social disability. One parent explained that her son needs transitional support when he is introduced to a new job or a new situation. *"He needs work suited to his abilities. He knows he has a diagnosis, but he also knows he can lead a normal life and be relatively independent. He is however very gullible and needs some help at school with learning the social skills that would help him to cope with bullies and increase friendships. In this sense he has needed transitional support all through his teen years but now that he has reached adulthood, there is nothing there in terms of support."*

Another parent explained that the gap between secondary school and college was huge. We referred to this gap as the "*gray zone."* She said that her son struggled to fit into college despite the preparation they had done. He was stressed every day at school and other students were not always kind towards him. He asked for accommodations for his ASD but the college did not have staff trained to implement this. His parents tried to let him do college on his own, but he did not succeed without support.

One self-advocate emphasized that *"universities and colleges should have more awareness about autism,"* while another clarified that they need minor accommodations such as more time provided to complete testing. In another case, we were told that a student did not have a team that prepared the student or worked with the college. This student unfortunately withdrew in the first term as a result of experiencing severe anxiety.

Parents stated that the college system must train staff in the basics of autism so that they can be flexible and make necessary accommodations for students. Each student should have a specific plan to ensure that the necessary supports and accommodations are in place before they arrive on campus to begin their studies including training and orientation for instructors and staff likely to have contact with the student with autism. This type of preparation is known to happen at some colleges and universities, as long as the student is willing to self-disclose.

Another parent said that New Brunswick educational institutions did not give her child the support that was needed, such as access to a note taker. The college informed her that students must self-disclose to their teacher that they have a disability. However, many cannot self-disclose, in part due to their disability. In these cases, where an individual is uncomfortable disclosing their disability, perhaps more focus on functional academics at school may have prevented some of the negative outcomes. These are the kinds of limitations that can result in failure to complete a program in which they otherwise would succeed. As one parent explained, their [adult-aged] child is *"high functioning,"* but that there is not adequate funding and services in place to build on their child's strengths to help them become employable and independent.

If adequate support had been in place, each of these individuals may have been able to succeed at school, at work, and in social endeavors. Support for the transition to college is needed and should be equitable across the province.

Although many of the issues raised regarding services for autistic adults were similar across groups (parents, service provider/professionals, and self-advocates), several topics were raised by self-advocates that were not raised by other groups. Below is a list of important concerns noted by this group:

- Lack of recreational opportunities (e.g., events tailored to autistics such as sensory friendly events suited to adults)
- Legal considerations /current legislative framework (e.g., updating guardianship laws; minimum wage laws; training for police and RCMP officers)
- Physical heath /access to appropriate medical care (e.g., education for hospital staff, eliminating symptom dismissal due to diagnosis of ASD; family physicians responsive to needs of an autistic adult)
- Autism narrative/ stigma (giving autistics a voice in shaping the narrative about autism)
- Autistic leadership/partnership ("Nothing About Us, Without Us" is a slogan that is necessary in disability justice issues; See Appendix C for more information).

More information regarding the unique needs for services expressed by autistic adults in the Maritime Provinces can be found in the CONNECT project (Appendix A).

Participation of Self-Advocates

Participation of self-advocates was not as extensive as we would have liked. Anecdotally, we heard that many self-advocates found it difficult to participate in the focus groups. Although written submissions and one-on-one telephone calls were offered as alternatives, these methods failed to fully engage self-advocates. To engage these individuals more fully in the dialogue about services for autistic adults, we suggest including autistic self-advocates in all phases of future efforts.

Transportation Issues

Transportation was reported to be a challenge for families and self-advocates. We heard this both from families living in rural areas and in suburban communities. Lack of affordable transportation presents a barrier for self-advocates and others on the spectrum to get to activities, including getting to a job. Even to access our own *Autism Connections Fredericton* location on Lincoln Road in Fredericton, there are no buses on weekends or evenings and a taxi ride costs $25 each way from the downtown Fredericton area. That is a cost that most families or autistic adults cannot or would not want to pay for several family members to get to an event. In some rural locations, there are no buses or taxis at all. Staff at most of the provincial resource centres attribute poor event attendance to the difficulty presented by inadequate transportation. They felt that a creative and thoughtful approach is needed to solve this problem.

Estate Planning

Planning ahead is essential for everyone and it is especially crucial for families with a member on the spectrum. Several parents voiced concern about their child's care after they die, expressing to us their fear that they will not be *"around forever."* They see a challenge with estate planning when faced with no clear path for the livelihood of their child. They also feel frightened that the extra costs they have will result in their life savings running out.

There are a number of things that can be done to ensure the financial future of adults with autism and some parents were able to discuss their unique approaches. Most parents, however, acknowledged that they have not planned sufficiently. Many persons on the spectrum may not be able to obtain or keep a job (whether at a full-time or part-time capacity) and some may never work at all. Unemployment rates among persons on the spectrum are extremely high. Therefore, it is unlikely that they would have a pension plan, which would be crucial after parents are deceased. There is a clear need to ensure that families are provided with assistance in developing a comprehensive plan.

One parent described an approach that they consider to be fairly successful. This family has a child in the late twenties diagnosed about 25 years ago. The young adult has support from Social Development through the *Adults in Care* program and has a social worker. Through the ADAPT Program, this young adult lives in subsidized housing. The young adult has no friends the same age except paid caregivers, but all the young adult's needs are met because the parent has been a strong and assiduous advocate. The young adult has federal government RDSP and has more than $50,000 saved already through the parents' efforts. The parents are fortunate to have good jobs and all the young adult's benefits are paid through their programs. Through the Canadian Revenue Agency, they have arranged to give this young adult a permanent disability status. However, most families do not have the knowledge, skills, or means to do what this parent did. With increased navigability in the system, more parents would be able to support and plan for their children's future.

Regional Differences

Participants in the Adult Services Tour did not differ in their deep concern for the need to address deficiencies in service models, improve understanding of autism, and increase access to affordable and person-centered options and supports.

Given the rural and urban mix in New Brunswick it was not surprising to hear some differences in the services available including the consistency of access, availability, and quality throughout the province. The northern part of the province had the largest variance in services available in contrast with the urban centres of southern New Brunswick. This can be explained in part by the distance from the larger urban centres and a smaller population base in the north. Geographic isolation in some regions was also a key consideration in addressing issues such as transportation and employment.

The large variance in population between regions made it difficult to follow trends but the main issues were consistent throughout the tour. A desire for a community-based response to complex needs was the most frequent recommendation we heard across regions. There was recognition that some clinical services were available only in the larger urban centres (Fredericton, Moncton, and Saint John) and that wait times were longer in rural areas.

Some adult support services such as the ADAPT network are in place throughout the province and community support for this service is very strong and broadly appreciated. However, employment opportunities after training are lacking in all communities and even more so in the rural regions of the province. There were also many participants who felt the programs and services being offered lacked an autism focus and that more could be done to educate the program teams and employers to better understand ASD itself.

Adults and families struggle with navigation of complex systems and finding suitable supports for more specific individual needs is often frustrating. Terms such as having a *“go to place”* were used to describe what a better service model would look like. This was a more pressing concern in many of the rural regions of the province where support services are already in scarce supply.

The issue of respite care is one that is relevant in all areas of the province but often more acute in the rural and more geographically isolated regions where transportation and access to trained respite workers are huge challenges. This issue is also compounded when trying to find community-based services such as day programs or activities to get persons out of the home and into the community. Isolation is a major problem for many families, especially in rural areas.

Although each region of our province differs in size and access to clinical services it was clear that most issues were similar in response and consideration.

Role of the Autism Resource Centres

The NBAARC is a network of 11 community Autism Resource Centres. The centres are strategically located in all regions of the province serving both the rural and urban community. In the proposal for the Adult Services Tour, the centres were identified as the points of contact to host each of the regional consultations. The centres were active in recruiting participants, finding adequate meeting space and helping to promote the tour in their regions. As part of the tour, the Executive Directors of each Centre were asked to participate and respond to the same question posed to the other participants. An additional question was asked: ***"Where can the Autism Resource Centres help to support the need for improved, affordable and accessible adult services?"*** This question gathered a range of responses, but the overall sentiment was that there was certainly a role to play in collaboration with other key community stakeholders.

Each autism resource centre receives an annual operational support grant from the Department of Health of $43,150. Each centre receives the same grant amount and the annual amount has not risen in many years. This level of funding support is essential but in most centres it is insufficient to operate the centres. In most cases, the annual operating budgets exceed this base of support many times over. Therefore, it requires substantial time, effort and energy to secure additional resources mostly through fundraising. This is a significant challenge.

One of the Executive Directors commented in writing:

> *"I have been Director of the autism resource centre for (many) years and I can assure you that there is no simple and single answer to the question of addressing the service needs of adults. Autism is such a wide spectrum, which means that needs differ from one individual to the other. If there is one 'key word' to use here, it would be 'individualized' services and support."*
>
> *"At the moment in our province, the task of coordinating the level of support for adults on the spectrum is left to the families and individuals to take charge. Families are researching in silos, desperately looking for services to support their adult child. These families are also getting older, sometimes having health concerns of their own."*

Key Issues for the Autism Resource Centres:

1. **Lack of funding support to deliver improved services and programs.** There is no magic wand or simple solution for this challenge. A majority of the centres are working as efficiently as possible and are still struggling financially to maintain current levels of service while attempting to respond to increased needs for support and navigation. The current funding support model should be reviewed.
2. **Lack of training for staff.** The staff turnover for the centres is generally extremely high (with a few exceptions) and there is no formal training program available to help the Executive Directors perform to the best of their abilities and capacities.
3. **Lack of key knowledge regarding community and government programs, services and options.** Navigation is a huge concern for centres as points of contact for resources and information. Just-in-time information regarding programs, services, eligibility and access are key considerations.
4. **Coordination between centres.** In 2017 the Provincial Autism Centres created an incorporated provincial body that should lead to more collaboration, sharing of resources and communication between the centres.

5. **Donor fatigue.** The not-for-profit sector often suffers from donor fatigue. Fundraising is such an important part of the Executive Directors' jobs that each centre faces. Those in more rural communities face an additional challenge finding businesses, foundations, and service groups to support their efforts.
6. **Transportation and isolation of service.** Although there are 11 centres, they are serving a very large area and that creates a variety of problems for families and individuals to get to and from the centres. Either they use a personal vehicle (many do not have this option), public transit (often with challenging hours and routes), or other means of transport.
7. **Far too few services for adults.** The Adult Services Tour helped to highlight the significant lack of programs, peer support, or other key social services provided to adults at the centres. There was an overwhelming desire to improve in this area but not without additional support - not just financial support but also volunteer and community partner support.
8. **Limited human resources.** Low wages and remuneration with limited or no benefits are key factors in the high turnover of staff at the centres. Working conditions are difficult to improve upon without additional staff support but budgets do not allow for growth. This creates problems in the development of additional programming and supervision.

One of the Executive Directors shared the following comment:

> *"As an individual, I am worried and close to burn out, feeling overwhelmed on a daily basis. The need for individualized service and supports for adults on the spectrum is growing as our population ages and I feel we are not prepared as Centres to respond to the trends that are emerging and new challenges they bring. The community is strong and resilient but at the same time not connected in a way that will be needed going forward. I believe there are steps we can take to improve services and supports but there will have to be new approaches and models in order to be successful. Same approaches- same outcomes just won't work! It is time to bring about meaningful and positive change."*

The capacity of each centre differs. Therefore, there is no *"one size fits all"* solution. Each centre is unique in its capacities and abilities to expand programming and services to the adult population and the funding should reflect that. Currently, there is very little programming coordinated by the centres. The development of a provincial association is an important first step that will help in particular with information and resource sharing. The NBAARC network of Autism Resource Centres has the potential to address some concerns brought up by families and individuals on the tour if provided with the proper resources.

Navigating "The Cliff": Taking Action

In this section of the report we, the authors, have summarized some of the key areas that participants identified as priorities for service improvement. We have developed the following list of recommendations based on the summary of "what we heard" from the participants. The recommendations are not exhaustive but are meant to be a catalyst for service improvements with a focus on the needs of autistic adults. The authors must note that the recommendations require further consultation and input from key stakeholders in order to ensure their voices are part of any proposed service improvements.

Executive Summary

The provincial tour was a tremendous opportunity to have families, service providers, and self-advocates share their concerns and personal experiences about accessing and navigating services for adults with Autism Spectrum Disorder (ASD) in New Brunswick. It is important to learn more about the state of adult services in New Brunswick as there is an identified gap between the services available during childhood and those available for adults with autism. One participant explained that *"it felt like we fell off a cliff when our son left school."*

The self-advocates who participated in the study were clear that they want to be a part of decisions being made that impact their lives and cited many inequities in the present system for adults on the spectrum. It was clear from the participants that there is a need for more focus on services for adults that are based on the distinct needs of each individual.

The transition to adulthood can be complex and requires improved preparation and support from service providers as well as various government departments. Beyond the early years of adulthood, many concerns are centered around what will happen to an autistic adult when their parents are too old to continue to provide care. Although this report was funded by the Department of Social Development, other government departments were identified by participants and are referenced when appropriate. Ideally, future actions based on recommendations from this report will not just cut costs for services but will redirect money to better uses with measurable outcomes.

Measurable changes in the area of adult services (viz., access to various levels of supported housing and improvements in employment opportunities) will require more collaboration and sharing of resources, as well as an increase in expertise in the area of autism. This report is calling on several supporting organizations and government departments to take action in order to address the needs that were expressed on the tour. Key stakeholders will need to work collaboratively in order to develop better services, and to move from a report to an improved level of delivered options. Our experience was that the autism communities across New Brunswick tend to operate on their own. Collaboration and partnership are not as strong as they could be when it comes to promoting and supporting strategies for change and improved services.

Several themes emerged from the information offered by the self-advocates, advocates, family members, and service providers across New Brunswick who participated in this study. The summary below includes a number of concerns, which reflect the current experience of adults with autism (explained in more depth in the What We Heard section of this report). The themes are not listed in order of priority. This is not an exhaustive list but does highlight the major themes that were identified from the focus groups and written submissions from the individuals who participated in the Adult Services Tour:

- Difficulty with system navigation and obtaining information about autism services
- Transition from school to the workforce and community

- Need for appropriate and consistently-available training in autism and the relevant complex issues encountered by all service stakeholders
- A lack of government services to support autistic adults
- Access to mental health services
- Individualized, community-based supports in homes or home-like settings
- Respite services and community-based programs
- Supportive accommodations for adults with autism without an intellectual disability
- Access to affordable and accessible transportation
- Engagement of self-advocates
- Estate planning

Recommended Actions

The following is a summary of the issues discussed in the report (highlighted above) and informed recommendations the authors concluded after gathering all the feedback from participants. As outlined in the consent form, the authors of the report have done their best to summarize the needs for governmental supports that were expressed by participants. Each recommendation for action will require collaboration and in some cases, changes to the policy, funding, and strategies going forward.

<u>Planning:</u> Delivering services to all the individuals on the autism spectrum is a daunting task. With an incidence rate of 1 in 66 (according to the 2018 National Autism Spectrum Disorder Surveillance System (NASS) Report), there is no doubt that thousands of people in New Brunswick require some level of support. The spectrum is wide and diverse. Extensive planning is needed for many aspects of service delivery including developing new services, coordinating existing services, establishing priorities for delivery of services, establishing long-term goals, and establishing standards for delivery of services.

<u>RECOMMENDATION 1</u>: New Brunswick requires a **comprehensive provincial strategy** for adults with autism. We recommend that such a strategy be developed with policy on the issues addressed in this report.

<u>Consulting with Autism Stakeholders</u>: In order for planning to be effective, the planners must be knowledgeable about autism and experienced in the service delivery needs for this group. We need input from persons on the spectrum, parents, government officials, Non-Governmental Organizations involved with autism services, and professionals in various fields (viz., Education, Medicine, Occupational Therapy, Psychology, and Speech Language Pathology).

<u>RECOMMENDATION 2</u>: We recommend the creation of an **advisory committee** that would meet several times a year to oversee and enforce a provincial autism strategy as well as make ongoing recommendations for change. The committee should be made up of autism stakeholders and relevant government departments. A lead government department should be selected and this mechanism put in place as soon as possible.

<u>Navigation</u>: We frequently heard from families or self-advocates who were unaware of services that are currently available or who had significant challenges in getting access to services. Despite the availability of various resource guides and information on government websites and other navigational tools from NBACL, the services were often not identified or accessed. It is clear that changes are needed to enable families and self-advocates to more easily navigate and access the available services. Collaborative, inter-professional, and community-based *Community Support Teams* would also be a valuable resource in providing guidance to families and self-advocates. Indeed, the 11 resource centres should be better used as the first stop for families or individuals after receiving a diagnosis of ASD, especially as adults. With the proper resources and access to expert knowledge, the centres should be able to provide an understanding ear and relevant, extensive, and complete information on options and resources.

RECOMMENDATION 3: Navigation of service options for adults needs to be addressed as a key opportunity for government and service providers to improve overall access to and inclusion of current adult-focused options. For those on the spectrum and their families, their needs to be a **"go to" place with qualified experts to support inquiries and answer complex questions.** Currently, there is no such unified service that is autism focused. With additional resources and training, we think that the Resource Centres could fill this role well given they are already providing some of this help across the entire province.

Transitional and occupational support*:* A large percentage of adults with autism are unemployed and reducing unemployment for those on the spectrum would be a significant achievement for our province. An enhanced strategy is required to provide training and ongoing support to youth with autism, which will enable successful transitions from school to work and adult life. Individuals on the spectrum need increased opportunities to learn vocational and other life skills. Coupled with this initiative is the need to engage and support employers in discovering the benefits of hiring and supporting employees who are on the spectrum.

One of the core conclusions from the CONNECT project (see Appendix A) stated the need for services for adults with autism that are supportive to their employment and independence. NBACL has launched a pilot for older high school students with significant disabilities as they transition out of the school system; *Transition to Community* is currently operating in four high schools.

We also suggest supporting and promoting programs for employers such as Ready, Willing, and Able (a federally funded initiative in partnership with the Canadian Association for Community Living and the Canadian Autism Spectrum Disorder Alliance), that support employers in hiring people with disabilities. We believe that it should be possible for the existing centres funded by Adult Development Activities, Programs, and Training (ADAPT) located throughout the province to provide this training. *Note: There is currently a reform process underway to change the focus of ADAPT agencies to community employment. Access to individualized day-time support should be made available through the Disability Support Program.*

Employers need to work in partnership with the schools to improve training in life skills while in school, with the option of supervised job placement during school hours, so that students on the spectrum and their parents are better prepared. Such job placements allow: 1) for students to learn valuable, practical skills; 2) for students to try out a variety of placements to learn what types of jobs they find interesting; and 3) the opportunity to fail and start over again within a safe environment. These are all important since students with autism often have challenges learning life skills and may not be exposed to the same variety of career choices and experiences as students without autism. In addition, they may have many challenges that make it more likely that they will have difficulty coping with job demands. Thus, the ability to learn and practice these skills in the school environment will increase their chances of success in employment settings once they leave school.

We heard that it is not uncommon for an individual on the spectrum to be hired and paid a stipend of $2 per hour, which participants felt devalues the person and their work. This is not an acceptable solution - *individuals on the spectrum want real work at real wages*. There are numerous examples of companies around the world that are eager to hire persons on the spectrum because the employers realize the benefits they can bring. A few examples include Walgreens Pharmacy, Microsoft, Freddie Mac, Systems, Applications & Products (SAP), Home Depot, and Hewlett Packard in Australia.

RECOMMENDATION 4: The challenges in the transition from school to the workplace can be addressed by building upon existing infrastructures and services. “Pre-employment” programs exist (e.g., the Ready, Willing, and Able program at NBACL and the Neil Squires Society) and can be made more accessible with a focus on the challenges faced by adults on the spectrum. This strategy will require additional training in autism for the staff at the organizations and agencies currently supplying these services.

The Services “Cliff”: We were struck by the fact that our system has an abundance of support services through the childhood years but as the individual ages into adulthood, those services drop out one by one. Even the Disability Support Program (DSP) terminates at age 64 years. We know that autistic adults are experiencing ongoing challenges that will continue to impact their lives and the lives of their families (e.g. communication, self-care, vocational skills, and daily living skills). The current system does not reflect that children with autism become adults with autism.

RECOMMENDATION 5: Access to qualified professionals and properly trained staff needs to be a priority and government has a key role to ensure that adequate levels of care and support are monitored for quality and are satisfactory to the individual and families. Individuals with autism require expert professional services throughout their lifespan. Thus, we suggest that professionals be encouraged to talk with their clients about the transition process. For example, physicians can talk about the process of transferring medical care to the adult system, and what that entails, including whether things like consent and confidentiality will be transferred to the adult with ASD or whether the parent/guardian will need to seek power of attorney over medical care. The schools can ensure that there is a written transition plan for every child with ASD in their schools.

The idea of a ‘tertiary team’ was repeatedly brought up by those who participated in the consultation process. We believe there is a need for a tertiary care adult autism team analogous to the current pediatric autism team at the Stan Cassidy Centre for Rehabilitation (SCCR). This team could consult with local staff and clinicians who work with autistic adults. An investment in professional expertise to support new initiatives is required.

Autism Education for Service Providers*:* Over and over, we heard that parents and self-advocates encountered employees within government, within the health system, and within businesses that did not understand the type of accommodations needed by the individuals they were serving. It is clear that we need to promote a higher level of autism education and training for service providers, employers, as well as more support for successful employment. The reason for this emphasis on training and education programs is the very clear need to have very high standards for staff working in various roles – particularly for those working directly with adults on the spectrum such as in respite care or housing. Because this was a key theme brought up by participants, the authors want to provide some background on existing training opportunities.

With better trained and consistent access to services, the frequency and severity of crisis situations should reduce and the overall expenditure on services would be less as there would be fewer individuals requiring 24/7 care. The DSP pays only $14 per hour for very challenging work and as a result, the turnover is reported to be very high. These short-term financial savings prolong and exacerbate crises. Salaries must be competitive, otherwise well-trained staff will leave for higher paying positions elsewhere. There is clearly a *pay equity problem* in the broader field. For example, trained and experienced personnel working with the preschool intervention services are very likely to move on to a job with the school system that pays much more (e.g. salaries for educational assistants are typically between $22 to $24 per hour but only $15.65 per hour for a pre-school interventionist).

Rather than providing a set dollar amount for every adult served, there should be a mechanism in place so that families and adults are able to obtain the services they need, and the funding envelope should be such that professionals are paid commensurate with their qualifications.

Autism Nova Scotia has created customized and packaged learning for those who work with and support people with ASD. The creation of a similar enterprise like this in New Brunswick would be beneficial and would meet some of the needs for specialized training for those who work with autistic individuals. However, we also think that the universities and colleges can play a role in providing training alongside the resource centres. We know that the universities were involved in the original training provided to the pre-school programs started in 2004 and they could help with training for staff working with adults. It may be possible to engage programs such as the UNB Saint John medical community, the graduate clinical psychology programs at UNB and Université de Moncton, and the continuing education program at UNB to name a few.

RECOMMENDATION 6: An autism-focused education strategy is needed with government employees, health professionals, community agencies, employers and post-secondary institutions. The reason for this recommendation is the very clear need to have very high standards for staff working in various roles – particularly in positions such as respite or housing. The Department of Post-Secondary Training and Labour could help lead this strategy and engage with community partners as well as experts in autism, and autistic advocates, to ensure the training is relevant, evidence-based, up-to-date, and autism focused.

RECOMMENDATION 7: Wages for support staff should be competitive to ensure that the individuals in our province have consistent access to well-trained individuals.

Accessing Autism Services: All participants in the Adults Services Tour expressed frustration with accessing support services from the government and other service providers. Strategies need to be developed that are focused on reducing barriers of affordability and access to government services such as mental health care, trained staff for respite care, fair employment practices, employment, and community-based housing. These strategies should include improving education among service providers.

RECOMMENDATION 8: We support the proposal from the Premier's Council on Disabilities (PCD) to combine all the disability-related services and programs under a specific unit within the Department of Social Development. There would be a new client category known as the *Disability Benefit Program* with flexible policies on matters such as the Health Card Policy, supported living, and employment earnings. Under this program, employees should be trained in autism and the resources available to support individuals with autism.

Accessing Mental Health Services: In virtually every focus group, we heard that there was an urgent need for mental health services for persons with autism, who frequently experience co-occurring conditions such as anxiety, Obsessive Compulsive Disorder, and depression. Currently, autism is treated as an exclusionary condition that prevents most persons on the spectrum from accessing this publicly funded service. There are no other practical options other than private practice professionals, who are beyond the financial reach of many families and self-advocates.

RECOMMENDATION 9: Relevant policies need to be reviewed, enforced, and changes made to ensure that mental health services are not exclusionary. The Department of Health is the lead government agency that oversees these services. Clearly, there is a need for additional training of mental health professionals – both continuing education opportunities as well as encouraging local universities to ensure that medical, nursing, and mental health services students get adequate training in how to provide services to individuals with autism.

Concern for well-being when families cannot provide support*:* Some of the most poignant moments came when talking with parents whose child with autism had other diagnoses including a significant intellectual disability. Many of these parents were very stressed and anxious about the future as they personally age and realize that a time will come when they will no longer be able to care for their autistic adult children in their own home. They want to carry on as long as possible while planning for the future when they can no longer provide the same level of care.

RECOMMENDATION 10: There is a need to explore several models of supported community living and it is clear that different models will be required depending on the needs of the individual. The key will be providing well-trained staff who are supported by competent professionals specialized in adult care. It would be useful to have a list of the numbers and locations of all facilities in which **adults with ASD** may be living as well as a breakdown by **level of care**. Such a list would help government determine current levels of use and need and would facilitate planning and development of any new housing options. The most important question is whether or not the staff and management of these homes are trained well enough to deliver effective support to those clients on the autism spectrum. We have no information on the standards of care with respect to autism. Respondents, rightly so, have high standards, not only for the physical aspects of care, but also for life skills programming that will fully engage individuals who are in care. They want their children to have the best quality of life possible. Housing support resources and models are discussed further in Appendix B.

Transportation Barriers: Very often, opportunities for employment or recreation were missed because of an inability to find reliable and affordable transportation. While this concern is especially true in rural settings, it is also true in larger city centres.

The PCD identified that some communities have started their own public transit specifically for those with disabilities and seniors. These services are often run by volunteers so that they can run cost effectively. However, while volunteers may play a supplemental role regarding transportation needs, transportation is a vital service, and to rely on volunteers for such an important function is neither appropriate, nor sustainable.

The New Brunswick Association for Community Living (NBACL) recommended reviewing The New Brunswick Disability Executives Network's (NBDEN) "Brief on Access to Transportation for People with a Disability" in order to comprehensively understand the challenges that transportation can cause for persons on the spectrum. Relevant Recommendations from the Transportation Report from NBACL:

- *"In partnership with employers and community stakeholders, develop and implement employment transportation strategies and programs to assist people with a disability and others who face transportation barriers to obtain and maintain employment.*
- *Provide sustainable funding and a visible profile for community transportation organizations using volunteer drivers and ensure these services are accessible. Explore the use of ride-share/ride-hail technology and partnerships to expand transportation options for people with a disability and others in need of transportation services."*

RECOMMENDATION 11: Improving access to affordable and accessible community transportation options will require changes in policy and the full participation of community partners. Improvements in transportation access, affordability, and availability can be made but may require some creative solutions unique to each setting.

Autism Resource Centres: The New Brunswick Association of Autism Resource Centres (NBAARC) is a network of 11 Autism Resource Centres in New Brunswick, which have knowledge of their communities and established memberships of individuals with autism that they support. These centres are underutilized at present. We need to enhance the role of the community autism centres to provide navigation supports to adults with autism and their families, to provide day programs, respite care, and to establish collaborative relationships with other local, regional, and national organizations.

RECOMMENDATION 12: The funding model for these autism resource centres must be reviewed and increased resources allocated to ensure that their capacity to support the adult community is made a priority. The centres, if properly supported, can help to improve navigation, access to important resources, programming, and individualized support.

RECOMMENDATION 13: We recommend that the 11 Autism Resource Centres of the NBAARC be eligible for funding according to the scope or range of the services and programs they are offering. This funding would supplement the core grant that the centres already receive.

Next Steps

The process used to create this report was built around the desire to engage and listen to participants, to record their feedback and summarize what we heard into a "snapshot" or picture of the overall state of services for autistic adults in our province. The recommendations presented in this report are built upon what the authors heard from participants and the synthesis into major themes that emerged. Participants were unanimous in the desire for action to be taken, and thus recommendations for change have been included. In attempting to capture consensus views, we recognize that we have not presented all the issues that may be important to each of the stakeholder groups and that further work needs to be done in this area. Most importantly, we hope that this document will serve as a catalyst for change and improvement in the services for autistic adults and their families.

Conclusion

The Adults Services Tour was designed to better understand the issues faced by adults on the autism spectrum as well as their family members, by talking with them and their service providers. The picture that emerged was complex and has highlighted some excellent services that exist in New Brunswick, as well as several serious gaps in services.

Navigation: Access to the limited adult services that do exist is complex and it was clear that navigating the system was a challenge for many families and individuals. As a result, we encountered families who were fairly successful in acquiring support and others who "fell through the cracks". A more equitable and navigable system is needed.

Education & Training: This tour has highlighted the need for a much higher level of training for all persons working with adults on the spectrum. Government officials, service providers, educators, and employers all need quality training on autism. Currently, the staff that work with the most challenging individuals tend to have the least training; they are the lowest paid, and often have inadequate supervision. This ultimately results in poor outcomes, a lower quality of life, and higher costs to the system. We need to change this inverted model of care. At this point in time, New Brunswick does not have the expertise needed to provide solid leadership in developing adult services nor do we have the expertise that may be needed for appropriate clinical services.

Independent and Supervised Living Arrangements: It is not uncommon for individuals with autism to have a co-occurring diagnosis, often an intellectual disability or other conditions. For this group it was clear that appropriate housing arrangements are essential, especially as parents age and can no longer care for their adult children. Parents want to be able to care for their daughter or son in their own home for as long as possible, while planning for the future when they can no longer offer the same care. For these families, "housing" means more than a physical place to live; it means a home or home-like setting with well-trained staff and competent professional supervision that allows the individual to have a fully engaged lifestyle. Ideally, shared living arrangements should stay small-scale with two or three people on the spectrum living in the same home. The standards of the service need to include high standards for the programming available to individuals in care in addition to the physical aspects of care.

Respite Care: For these families, individuals, and many others across the spectrum there was a pressing need for access to respite care, day programs, and mentorship. In some cases, these services are available but are simply not accessible for a variety of reasons.

Employment: We were also told repeatedly about the problems of obtaining and maintaining employment for adults on the spectrum. Participants mentioned that there was a challenging gap between the end of school and the beginning of financial support through DSP. It was also noted that the school system has not provided adequate vocational training and that the Department of Education and PETL should coordinate the transition from school to the workplace. Employers need to be informed of the advantages of hiring persons on the spectrum and need to be informed of the small accommodations necessary to ensure that individuals are successful in a new job.

Mental Health Services: The difficulty in accessing mental health services was discussed in virtually every centre we visited. In many cases, individuals on the spectrum were told that autism was an exclusionary condition and, therefore, were denied access to mental health services. This is a human rights violation that needs to be addressed immediately. The only other practical options for accessing mental health services include fees for private practitioners that many cannot afford. Additionally, other barriers such as access to qualified professionals (due to language and resources) and access to transportation may also affect an autistic adult's ability to obtain mental health services.

Recommendations: The authors of this report made 13 recommendations based on the information participants shared with regards to service access and delivery for adults with autism. They include the following actionable and measurable items:

1. Create a comprehensive provincial strategy for adults with autism.
2. Create an advisory committee to develop, oversee, and enforce the created strategy.
3. Create a system (e.g., Resource Centres) to help autistic adults navigate available services and supports.
4. Provide services to address the challenge of transitioning from childhood supports to adult services.
5. Provide more autism-specific training for everyone who supports adults with autism. This would include creating a tertiary care adult autism team.
6. Create an autism focused education strategy.
7. Provide adequate and competitive wages for support staff to help ensure quality and reduce turnover rates.
8. Combine disability related services and programs under Disability Benefit Program with flexible policies on matters such as the Health Card Policy, supported living, and employment earnings.
9. Review and change policy so that adults with autism are able to access mental health services for co-occurring conditions.
10. Provide support to parents who are concerned about the care of their adult child when they die such as estate planning and adequate supported community living with staff trained specifically in autism.
11. Improve access to affordable and accessible community transportation;

12. Increase resources allocated to the 11 Autism Resource Centres of the NBAARC so they can continue to serve as the community-based accessible support for adults with autism.
13. Provide funding to supplement the core grant the centres receive to cover operational costs and allow them to increase their operational capacity to service more individuals with autism.

These and other concerns outlined in this report point to our need to develop a more comprehensive strategy for addressing the needs of adults living on the autism spectrum. The concerns and recommendations expressed in this report are by no means exhaustive. We know that in one report we cannot capture the voice and opinions of all persons with autism living in New Brunswick. We are only able to speak to the information that we heard from the individuals who participated in this tour. We value and respect the individuality that we have already discussed is present among individuals with a diagnosis of ASD. The information in this report is a synthesis of the major themes (discussion topics that were brought up multiple times) that emerged from the discussions we had with the individuals who participated in our focus groups. It can be difficult to engage individuals with autism in information-gathering-sessions such as this and, consequently, some of the information may represent the thoughts and experiences of some individuals with autism more than others. Our particular difficulty with recruiting self-advocates may lead those individuals to not see themselves in these findings as much as other individuals on the spectrum. For this and many other reasons discussed throughout this report, more research is certainly needed to both support and further what we heard on this tour.

Appendices

Appendix A

<u>*Relevant Literature*</u>

1) The Standing Senate Committee on Social Affairs, Science and Technology (2007).
Final Report on: *The Enquiry on the Funding for the Treatment of Autism. Pay Now or Pay Later: Autism Families in Crisis.* Chair The Honourable Art Eggleton, P.C. Published in the Committee proceedings Issue No. 20, Friday, April 20, 2007 (1st Session, 39th Parliament).

This report is important as it was the first time that the topic of Canadians living with ASD was discussed at a national level. The report had many recommendations to improve the services provided to persons with ASD but one of the most important was the recommendation to establish a national autism strategy. Other key recommendations included innovative funding arrangements for the purpose of financing autism therapy and supports for caregivers, including respite, family training and assistance, assisted living support as well as career and vocational training. In addition, there were recommendations for insuring autism qualifies as a disability under the DTC, improved public awareness campaigns, research, and an autism knowledge exchange centre.

Prevalence rates: One of the outcomes of the work of the standing committee was the establishment of a National Autism Spectrum Disorder Surveillance System or NASS. The latest report dated 2018 estimated that the prevalence rate in Canada, in general, was 1:66 and the prevalence rate for NB was 1:79.

2) Weiss, J. A., Whelan, M., McMorris, C., Carroll, C. and the Canadian Autism Spectrum Disorders Alliance. (2014). *Autism in Canada: National Needs Assessment Survey for Families, Individuals with Autism Spectrum Disorder and Professionals*.

<u>*The CASDA findings for New Brunswick*</u>: There was a total of 257 respondents from New Brunswick and they consisted of 120 Caregivers reporting on 120 individuals with ASD, 129 Professionals, and 8 Self-advocates. Twenty-five percent of New Brunswick respondents completed the French version of the survey.

CASDA Findings: This is an extensive report so we are highlighting just a few of the findings that pertain to the needs identified.

Caregivers and Professionals identified the top 5 current service needs, selecting from a list provided.

Caregivers, across age groups, reported that their top 5 current service needs were:

- Social skills programs (64%),
- Activity-based programs (49%),
- Recreation programs (41%),
- Specialized summer camps (40%),

- Life skills programs (40%).

For school age children, the top 5 current service needs were:

- Social skills programs (69%),
- Activity-based programs (48%),
- Specialized summer camps (47%),
- Life skills programs (44%),
- Recreation programs (37%).

Professionals identified the following top 5 current service needs for individuals with ASD:

- Early IBI (68%),
- Early detection of ASD (67%),
- Social skills programs (48%),
- Behaviour therapy for behaviour management (45%),
- Non-IBI early intervention programs (41%).

3) The CONNECT project (CONtiNuity of carE and support for autistiC adulTs) aims to break down barriers and understand the everyday needs and challenges faced by autistic adults.

From the beginning, CONNECT recognized the need to engage autistic adults in research and is the first Maritime-wide collaborative research initiative co-led by an autistic adult. CONNECT aims to:

1. Assess the needs of autistic adults via a survey; and,
2. Share what we learned and best practices with health and social service providers, policy-makers and the autistic community.

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

Autistic leadership/partnership ("Nothing About Us, Without Us" is a slogan that is necessary in disability justice issues). Learn more at: http://www.spor-maritime-srap.ca/news/new-video-shares-experience-autistic-adults

Appendix B

Alternative Housing Options

We are committed to the view that all housing alternatives would have well-trained staff and there would be competent supervision provided. The following four options below are completely hypothetical but are presented here simply to illustrate a range of housing options. We think a variety of options need to be considered and, in all likelihood, different solutions may be needed for different people.

Option 1 – Mentorship Model - would offer instruction and support to persons who live in their own homes or apartments within the community. The amount of support would vary from a few hours per month up to 12 hours per day of one-to-one support. Clients would pay for their own rent, food, and other personal expenses while DSD would contract with private agencies to provide these services. Mentors would need to have specialized training in autism.

Option 2 – Foster Home Model – this option would provide services and supports in an adult foster care model with one adult per home who is a client of DSD. The services would be offered in a regular family home approved by DSD to ensure the client's health, safety and well-being. DSD would provide access to proper training and support for the foster "parents" and reimburse the providers for the instruction and support services. The client would pay the providers directly for room and board costs.

Option 3 – Licensed Adult Family Home Model - This would be a regular neighborhood home or situated within an apartment complex in which live-in staff assume responsibility for the safety and well-being of an adult. A room, meals, laundry, supervision and varying levels of assistance with care are provided. Such a home can have two to six residents and would be licensed by the Province.

Option 4. This option might include provincially operated living alternatives. This program would be operated by DSD with provincial employees providing instruction and support to clients. One to four persons would live together as roommates and likely share living expenses and staff support.

Possible Future Options

Service providers will need to determine what kinds of supported living services would meet the needs of a population of adults on the autism spectrum who are not living with their family, and who are not able to live independently without supports. There should be a range of options to suit different needs. However, *the most important ingredient is proper training for staff, as well as ongoing supervision and guidance by professionals with expertise in the field of adults with autism*.

Programs exist in Saskatchewan and Alberta that have multi-disciplinary teams who are taught how to advocate for a client with ASD. The individuals, teams, and programs act as *Navigators*. There are professionals available for consultation, and program support is provided by social workers. These programs also have very strong parent support systems. The Family Navigator Program in

Alberta is focused on individuals with new diagnoses (https://www.autismedmonton.org/what-we-do)

Here are some housing options already in existence in NB.

The Line Ferguson Community Residence in Tracadie serves adult men with autism who have severe behavioural problems, some of which were first in a psychiatric institution (see Appendix B for more detail). The URL for les Residences Line Ferguson in Tracadie is: https://residenceslineferguson.ca.

Department of Social Development Special Care Homes - There are over 400 privately run special care homes (link to list of homes: https://www2.gnb.ca/content/gnb/en/departments/social_development/special_care_homes/special_care_homes.html). The DSD defines four levels of care for clients admitted in approved housing facilities:

- *Level 1* – Clients are generally mobile but require the availability of supervision on a 24-hour basis related to their personal care.
- *Level 2* – Clients may require some assistance or supervision with mobility and require more individualized assistance or supervision on a 24-hour basis with personal care and their activities of daily living.
- *Level 3* – Clients have a medically stable physical or mental health condition or functional limitation and require assistance and supervision on a 24-hour basis. These clients need a great deal of assistance with personal care and often require medical attention.
- *Level 4* – Clients have difficulties with cognition and/or behaviour requiring supervision and care on a 24-hour basis. Clients may display aggressive behaviour toward self and/or others. Most often they need maximum assistance with their personal care and activities of daily living. They also often require medical care.

Source: https://www2.gnb.ca/content/dam/gnb/Departments/sd-ds/pdf/Standards/AdultResidential-e.pdf

• Hayward House Recovery Centre in Woodstock – provides persons who live with a mental illness with opportunities that promote recovery.

• Open Sky Cooperative Limited in Sackville – provides skills programs, vocational assistance and community connections for adults who require support to improve their quality of life such as Autism Spectrum Disorder, and/or mental health challenges like depression, anxiety and schizophrenia. Open Sky is a resource for social, functional and life skills assessments and public training for Mental Health First Aid. They are a charitable co-operative social enterprise, made up of many different people and organizations. Open Sky is located on an 11-acre farm in Middle Sackville and is within walking distance of downtown Sackville as well as Mount Allison University.

• Crosswinds Occupational Activity Center Inc – is one of 38 agencies in NB that provides services to individuals with disabilities through the A.D.A.P.T. program. They serve persons with disabilities by providing increased opportunities for developing community connections, improved life skills, access to education, and employment opportunities that result in an improved quality of life.

- L’Arche in Saint John – the home is called McKim House and it houses five adults with intellectual disabilities and three assistants in a home setting. Together they wake up under the same roof, conversing around the supper table, helping each other to learn and to develop as human beings, engaged with, and contributing to, the broader community. *L’Arche Saint John* belongs to an international federation of 149 faith-based communities creating homes and day programs with people with developmental disabilities in 38 different countries.

Appendix C

Relevant Government and Community-Based Programs

Moncton Employment and Training Services

Dave Richard from *Moncton Employment and Training Services* provided us with data from their programs.

- These agencies employ approximately 400 staff. Twenty-two agencies operate year-round while 16 operate based on the school calendar.
- There are approximately 1300 participants in the ADAPT program – some participate part time while the majority participate full time during the weekdays.
- Eighteen (18) agencies offer bilingual services, 13 Anglophone and 7 Francophone.
- Twenty (20) agencies operate some type of business model as part of their ADAPT program.

Based on information provided to us, this program seems excellent. However, eligibility for these services would not apply to all persons on the autism spectrum. For example, those with severe autism symptoms and significant intellectual disability would likely be excluded. Also, since these services are designed for persons with an intellectual or developmental disability, this level of support would also exclude individuals on the spectrum who have average or above average intellectual ability. Yet, individuals on the spectrum can have significant disability, even with average intellectual ability.

A list of all the 38 agencies can be found at the following link:
https://www2.gnb.ca/content/dam/gnb/Departments/pcsdp-cpmcph/pdf/Employment_Emploi/ADAPT.pdf

Youth Employment and Skills Strategy

There are other opportunities to find support for employers who wish to hire persons on the spectrum. For example, the federal government has a program called the *Youth Employment and Skills Strategy* or YESS program. A brief description and link can be found in Appendix C.

The Youth Employment and Skills Strategy (YESS) program provides funding to organizations to deliver a range of activities that help youth overcome barriers to employment and develop a broad range of skills and knowledge in order to participate in the current and future labour market. Support will be tailored to the needs of youth that are facing barriers to employment. Youth who face barriers often include:

- Youth who did not complete high school
- Recent immigrant youth
- Youth from visible minority groups
- Youth living with disabilities
- Single parent youth
- Youth living in low-income households

- Youth experiencing homelessness or precarious housing
- Youth living in rural or remote areas

YESS link: https://www.canada.ca/en/employment-social-development/programs/youth-employment-strategy.html

New Brunswick Association for Community Living (NBACL)

We discussed the issue of persons with autism being excluded from Mental Health Services with representatives from NBACL who directed us to their position paper on this issue entitled, “Equal Access to Mental Health Services and Well-Being for Individuals with an Intellectual or Developmental Disability.” The link to this document is the following: https://nbacl.nb.ca/brief-on-equal-access-to-mental-health-services-and-well-being-for-people-with-an-intellectual-or-developmental-disability/

NBACL’s Social Inclusion program provides coordination and monitoring of supports to individuals who live in a home of their own through their supported living arrangements. The Social Inclusion Program has proven to be highly effective for adults with autism in NB.

Here is a link to download the brochure for the Social Inclusion Program https://nbacl.nb.ca/sip_brochure_english/

For more information on these reports or their programs, we invite you to contact the NBACL office directly or visit their website at nbacl.nb.ca.