

## It Takes a Village to Support Adults with Autism Spectrum Disorder

New Brunswick has made great gains in providing early intervention programmes for children with autism spectrum disorder (ASD), a neurological disorder, and is currently developing a comprehensive programme to train teachers and teacher assistants within the province to work in an effective manner with our students. To date, no initiatives have addressed the needs of adults. Once a student reaches the age of 21 years, there are no services, no supports, and the entire burden of support and care falls upon parents and family.

It is therefore imperative that New Brunswick establish an Autism Treatment and Residential Centre. The centre should be situated in Fredericton so that it is physically close to regional autism expertise at the UNB-CEL autism program and the Stan Cassidy Centre. The Centre would provide treatment for all autistic adults who are too old for treatment at the Stan Cassidy program and permanent residential care for the most severely autistic some of whom have been sent to the Spurwink Facility in the State of Maine and to the Restigouche Regional Psychiatric Hospital in Campbellton. Autism specific group homes around the province are required with autism trained staff and oversight from the Centre. In this sense, the model proposed could be characterized as a “satellite” model in which the centre in Fredericton would be linked directly to a number of satellite homes around the province. Medical issues commonly associated with autism disorders including epilepsy and depression would also be treated in the context of persons suffering from autism and the extra challenges it presents to treating those common co-morbid conditions.

The scope of the problem can be appreciated when one considers the fact that autism spectrum disorder is the single largest disability across Canada. Current estimates of the number of individuals diagnosed with autism spectrum disorder range from the recent estimate by the *Center for Disease Control* in the USA of 1 per 68 persons<sup>1</sup> to slightly more conservative estimates around 1/160<sup>2</sup>. This means that the incidence of autism spectrum disorders ranges from 4700 to 11,100 individuals in New Brunswick. It also means that services are needed for roughly 3,300 to 7900 are in the age range between 22 years and 75 years.

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1 CDC, Prevalence of Autism Spectrum Disorder Among Children Aged 8 Years — United States, 2010, March 28, 2014 / 63;1-21

2 Elsabbagh M, Divan G, Yun-Joo Koh YJ *et al.*. Global prevalence of autism and other pervasive developmental disorders. *Autism Res.* 2012;5(3):160–79

One can also understand the scope of this problem by looking at the following list of challenges that are faced by parents of an adult son or daughter with autism spectrum disorder. Because the range of disability within ASD is so broad, we present a wide range of very typical challenges that families face.

- *Cessation of Educational Opportunities* – Once a student leaves the school environment in which they have supported learning opportunities, there are few if any places a student can go to advance their learning. Most of these students could not avail themselves of post secondary learning opportunities as they require a significant amount of scaffolding to enable them to succeed. At age 21 most typical students have a variety of skills and are reasonably literate. Even they need ongoing training and many even most do some form of additional education or job training. This is not possible for the majority of the young people with ASD.

- *Unemployment* – The rate of unemployment among all levels of persons on the spectrum is close to 100%. Some do manage to find limited employment opportunities through the services of centres such as Fredericton's Jobs Unlimited. However, the majority of persons on the spectrum are not successful. It is believed that people with Asperger's (the most functional of persons on the spectrum) have a 75-85 percent unemployment rate. Autism Speaks estimated that 85 percent of adults with autism in the United States are currently unemployed or underemployed. Among young adults between 21 and 26 years old, only 50 percent have ever had a paid job outside of their households. This means that parents may have to support their son or daughter for most of their lives. There are some government supports such as the disability tax credit and the disability retirement savings plan but we know that not all persons with a diagnosed condition will qualify for support and even if they did, the support is minimal in comparison to a living wage. The 40% to 50% of persons with ASD who also have intellectual limitations are most likely to remain totally unemployed although a few may find very limited opportunities through non profit community agencies. The half of the ASD population with relatively higher intellectual skills will also have very limited employment usually because of social challenges.

- *Regression of skills* – All professionals who work with persons with ASD have seen the loss of skills that results from a lack of stimulation that comes from learning in functional social contexts. In fact, several years ago, UCLA Psychologist, Ivar Lovaas, did a study in which individuals who had increased their IQ scores in a three-year treatment programme, lost almost all of the

functional skills (e.g., language skills, self-help skills, and cognitive skills) they had learned after three more years of no educational programming. We experience these kinds of regression frequently when an individual passes from a relatively stimulating learning environment to living at the family home without a planned curriculum. Early intervention is the best way to provide long lasting learning but not all individuals will succeed sufficiently to be immune to regression of skills once formal training stops.

- *Lack of respite Care* – There are very few services available to provide respite to parents or guardians of individuals on the spectrum. In addition, even fewer services exist (if any) that have staff that are appropriately trained. This is a crucial service needed by almost all families affected. Parents with adults on the spectrum can be in very desperate need for respite care. In some cases, the individual with ASD will require care 24 hours a day and 7 days a week. Depending on a family's circumstances, this may mean that either a father or a mother will need to be at home with the child at all times. In other circumstances, the needs may be different. An individual may not require as intense care but may present with many challenging behaviours and the parents may need short-term breaks.
- *Lack of opportunity for recreation* – Recreation has been shown to be an effective treatment for many of the challenging behaviors we encounter with individuals on the spectrum. In addition, there is research to show that individuals with developmental disabilities tend to be less fit in general and tend to have more illnesses. In large measure this situation arises from lack of suitable recreational and vocational services and far too much unstructured, idle, time.
- *Restricted Social Lives* – Individuals with a diagnosis are by definition less interested in social interactions and more likely to seek solitary pursuits. The major disability in autism spectrum disorder is a social disability. Left on their own this pattern of behaviour intensifies and we know that increasing isolation from healthy social interactions can lead to major challenges. With supports in employment and in other kinds of social interactions, persons with ASD can enjoy and benefit from social contacts.
- *Mental Illness* – The research is clear. Individuals with ASD are more likely to be affected with co-morbid forms of mental illness such as depression. The factors that contribute to the high percentage of mental illness are social isolation, lack of social supports in meaningful activities, lack of education, and lack of meaningful work and recreational activity.

- *Behavioural Challenges* – We need to point out that access to regular society (employment, residential living, recreation, etc) requires a minimum of compliance and an absence of aggressive behaviours. Many individuals with more severe forms of ASD have some level of behavioural challenge. These behaviours are almost always caused by poor communication skills and inadvertent reinforcement of problem behaviours by caretakers who do not have sufficient training to handle these kinds of behaviours.

*Summary of the Problem:* It is clear from the description above that families with an adult child can be faced with overwhelming challenges and stress related to providing the very best services they can to their son or daughter.

*Solutions:* The needs of individuals and families and the scope of the problem described above can be mitigated or overcome by our proposed centre. Our proposed centre would not be a single building as such but rather a satellite network of homes, apartment-styled buildings and other facilities integrated as much as possible within residential neighborhoods. The design is explained in more detail below. Our approach will be innovative and uniquely designed to suit families in the New Brunswick situation. The key principles for this proposed village are that all programmes and services are as much as possible evidenced-based, that the centre be dynamic in the sense of being flexible enough to meet diverse needs. It also needs to have a meaningful connection to the NB community and that includes accessibility of services and easy accessibility for families to maintain a connection to the clients in the centre (or centres).

*Comparative Analysis:* There are some existing facilities that serve adolescents and adults across Canada, in the USA and in Europe. For example, in the Toronto region there is a group called Kerry's Place that offers evidenced based services for adults. New Jersey has some outstanding private facilities and in particular the model developed at Princeton Child Development Centre is called Mountain View. There are no services in New Brunswick that are remotely comparable to these services. Currently, when we have an adult with ASD that is unmanageable in a home or in existing special care homes, they are sent to a facility in Maine called Spurwink. The facility in Maine is a fine service but it costs the taxpayers thousands of dollars and is far away for the client's family.

**THE NEW BRUNSWICK "SATELLITE" MODEL:** We have proposed a "satellite" model that would provide residential and other adult services in several regions around NB but also would have a home base located in

Fredericton. In general, the best way to provide the physical spaces and to find appropriate staff is to make use of existing facilities but offer upgrading and training. There are a number of options available such as providing training and other upgrades to selected group homes in the province. In addition, one can look at working with selected developers to create some residential complexes for both typical individuals and persons with special needs of various kinds. Possibly, an autism centre can be created at UNB or in association with the Stan Cassidy Centre. The details of the physical spaces need to be planned carefully but the guiding principal is to provide dynamic services for all adults involved either as residents or as day users of the facilities. As well, we want facilities that serve the diverse needs of the adult population.

## **SERVICES OFFERED BY THE NEW BRUNSWICK MODEL:**

In a future draft of this proposal we will provide a detailed description of the kinds of services that we envisage. These will include at a minimum residential services, sheltered work and vocational services, ongoing training in life skills and personal care, treatment of behavior problems, recreational skill development, respite care for families, training of families in skills needed to maintain their son or daughter in a home setting, and social skill development. There are clearly levels of support needed and the following is a list of some of the more obvious levels. Over the course of their lives, individuals may move from level to another.

- **Independent living with assistance.** Some adults with ASD are able to live on their own. Others can live in their own home or apartment if they get help dealing with major issues, such as managing personal finances, obtaining necessary health care, and interacting with government or social service agencies. Family members, professional agencies, or other types of providers can offer this assistance.
- **Living at home.** Government funds are needed for families who choose to have their adult child with ASD live at home. These programs include some form of pension, disability tax credits, and support for extra services. However, we know that there is a point at which family may no longer be able to provide support at home and other options need to be available. Training for parents needs to be available.
- **Other home alternatives.** Some families open their homes to provide long-term care to adults with disabilities who are not related to them. A home setting such as this type needs to provide some form of skill development such as teaching self-care and housekeeping skills and arranging and getting involved in leisure activities.

- **Supervised group living.** People with disabilities often live in group homes or apartments staffed by professionals who help with basic needs. These needs often include meal preparation, housekeeping, and personal care. People who are more independent may be able to live in a home or apartment where the staff only visit a few times a week. Such residents generally prepare their own meals, go to work, and conduct other daily activities on their own. Once again however, training of staff is a key to success.

**Long-term care facilities.** This alternative must be available for those with ASD who need intensive, one-on-one constant treatment and supervision. While this group is a minority, they present the biggest challenge for their families who, at present, have no means to provide the services required.

**THE SATELLITE MODEL:** There are good reasons to have the base for our satellite model located in Fredericton. There are already a number of sources of autism expertise in this location. For example, a satellite model based in Fredericton would have a permanent connection to the University (Psychology, Education, Nursing) and the autism team at the Stan Cassidy Centre as well as other local health professionals. The base would also be the home for one of the most important functions of our model and that is the training of staff and setting forward operational procedures and protocols. Since 2003, the University of New Brunswick (especially the College of Extended Learning) has been a key in the development of training for staff for preschool and school-aged children to date. It has also been involved in building capacity for Applied Behavior Analysis in other jurisdictions such as Saskatchewan and has developed new programs for undergraduates at UNB as well as an open access programme. Thus, we envisage a Fredericton based centre that offers training and support and then a series of satellite facilities around the province that follow service protocols developed by the

**THE IMPORTANCE OF EVIDENCE-BASED SERVICES:** The key to success in providing excellent services to adults and adolescents is that the methods employed are grounded in a body of research evidence. The philosophy of the proposed model is one that embraces growth for all of its clients at all times. In no way is the center activities to be construed as a facility for warehousing its clients – quite the opposite. The philosophy is to keep residents and other clients engaged in meaningful social, work, and recreational activities. Keeping all clients learning and actively involved in a range of activities is crucial. All services delivered need to be held up to the rigorous standards of evidence.

**THE IMPORTANCE OF ETHICALLY-BASED SERVICES:** The second key ingredient is that the services must have the highest level of ethics and as a

result we may base our model's ethical treatment on a modification of other relevant ethics codes such as the *BACB Guidelines for Responsible Conduct* or the *Canadian Psychologist Association*. In the CPA code there are four basic tenets or major principles that are fairly typical of most codes. These include:

- 1) Respect for the Dignity of Persons
- 2) Responsible Caring
- 3) Integrity on Relationships
- 4) Responsibility to Society

Ethically-based services will not only meet with public approval, they will be more effective. Clearly, one of the ethical principles is that we offer clients only those interventions that are scientifically demonstrated to work. Thus, interventions are less likely to cause problems and clients are more likely to thrive and develop more skills and adapt more to typical life.

**NEW BRUNSWICK SATELLITE MODEL**  
**FOR**  
**ASD SERVICES FOR ADULTS**