

AUTISM SPECTRUM DISORDER (ASD) DEVELOPMENTAL DISABILITIES WITH DISTINCT SUPPORT NEEDS

Glenn M. Rampton, C.D., Ph.D., C.Psych.

The Developmental Services sector is only now coming to understand that persons with Autism Spectrum Disorder (ASD) generally require different kinds of supports than other persons with a Developmental Disability – different supports, not necessarily more expensive ones. Unfortunately, this lack of understanding has contributed to the fact that many of the supports provided to individuals with ASD and their families over the years have often been insensitive, inappropriate, and inadequate.

The most commonly accepted criteria for the diagnosis of psychiatric illnesses and conditions in North America are defined in the Diagnostic and Statistical Manual of Mental Disorders–Fourth Edition (DSM-IV) published by the American Psychiatric Association in 1994. In the DSM-IV, Autism Spectrum Disorder or, as otherwise known as Pervasive **Developmental** Disorders, includes: Autistic Disorder, Rett’s Disorder, Childhood Disintegrative Disorder, Asperger’s Disorder, and Pervasive Developmental Disorder-Not Otherwise Specified. All of these conditions are “characterized by severe and pervasive impairment in several areas of development: reciprocal social interaction skills, communication skills, or the presence of stereotypical behaviour, interests, or activities.” ...”These disorders are usually evident in the first years of life and are often associated with some degree of Mental Retardation ...”

An individual can have a diagnosis of one or more variations of ASD, along with a diagnosis of “Mental Retardation”, and a psychiatric condition. Although individuals with ASD have a higher probability of also having a formal diagnosis of Mental Retardation (hereinafter called Intellectual Challenge) and Mental Illness than people in the general population, ASD, Intellectual Challenge, and Mental Illness are each separate conditions. This is shown heuristically in Figure 1.

Both ASD and intellectual disabilities are, by definition, developmental disabilities. Persons having a diagnosis falling under each, or both, can also have a psychiatric condition, and therefore a dual diagnosis. A person with ASD may also have an intellectual Challenge, but this is not necessarily the case.

It can take quite different understandings and skills to support someone successfully with ASD than it does to support persons with an intellectual disability who does not also on the autism spectrum. This is, in part, because of the special social and sensory issues involved in the former, which are not as likely to be as involved in the latter, at least to the same extent. The requirements to support a person successfully with a mental illness are generally quite different again. The requirements to support someone successfully with various combinations of conditions depicted across the three conditions in Figure 1, render the situation even more complicated because the conditions tend to interact, having greater impact on a person’s behaviour, and specific interventions may be required to deal with these separate interactions.

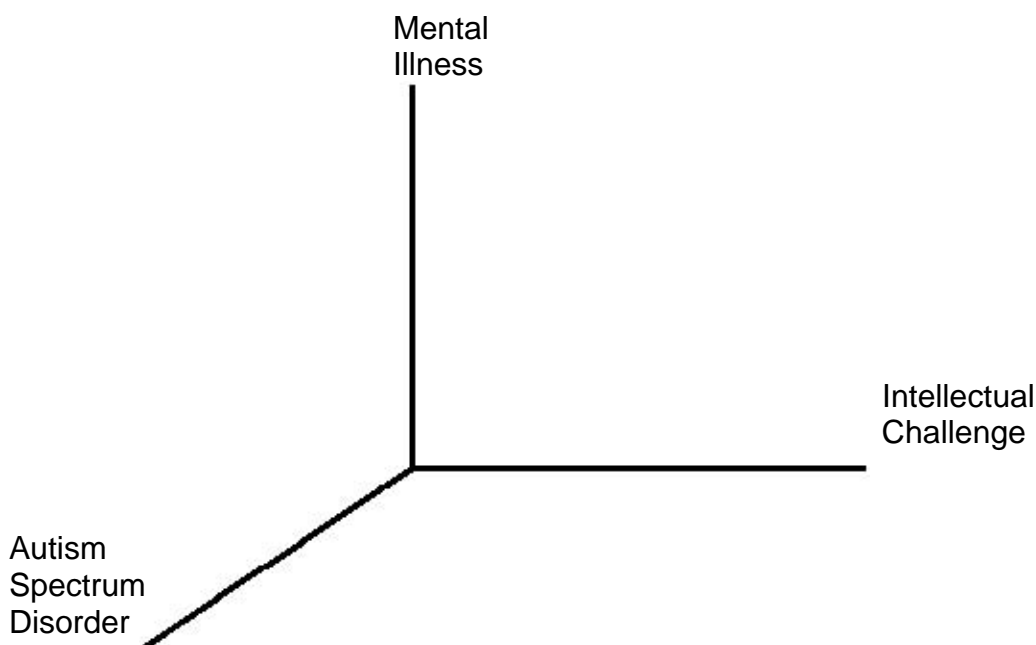


Figure 1 - Heuristic model showing the relation between Autism Spectrum Disorder, Intellectual Challenge, and Mental Illness.

Some MCSS Regions and individual agencies, that the government funds to support individuals with developmental disabilities have interpreted Developmental Services funding criteria as applying to only to persons having an Intellectual Challenge.

The special support needs of individuals with ASD, with or without an Intellectual Challenge have not generally been recognized within the Developmental Services Sector. While it must be said that there are many enlightened professional service providers, professionals and MCSS authorities, ignorance of the special needs of persons with Autism Spectrum Disorder is prevalent.

The fact that persons with ASD are not generally seen as having special support needs was reflected in the lack of ASD representation on the recent “stakeholder” advisory committee, established by the previous Minister of Community and Social Services (MCSS). This committee was formed to help establish the new policy framework for transforming Developmental Services. While there were multiple representations from other stakeholder groups, we can only conclude from the lack of ASD representation that the MCSS does not recognize individuals with ASD as having special support needs.

The Autism Society of Ontario, along with agencies specializing in providing supports and services to individuals with ASD and their families, such as KPAS and the Geneva Centre, were left to provide written input in response to “discussion documents” produced in the course of the development of the new policy framework. Without specialized input for ASD at this important advisory committee, it seems likely that important requirements for persons with ASD may have been overlooked. While the opportunity to have direct

input into the initial formulation of the new policy framework has passed, in cooperation with the ASO and individually, we will look for every opportunity to make the case for persons with ASD and their families as the framework is finalized and implemented. We encourage readers to do the same, and to engage other concerned parties in this process.

Last year, Robert Hart, current Chair of the Board of Kerry's Place Autism Services and former Chair of the Autism Society of Ontario, wrote a letter to the Deputy Minister of Community and Social Services, pointing out this shortcoming in the composition of the advisory committee. Mr. Hart pointed out the distinct needs of individuals with ASD suggesting that the Developmental Services Advisory Committee would benefit by representation from someone with expertise in supporting individuals with ASD and their families.

While this letter did not have any immediate impact in terms of increasing representatives with ASD related expertise on that committee, recently there does seem to be an increase in such representation on various advisory committees and reference groups initiated by both MCSS and the Ministry of Children and Youth Services (MCYS); so perhaps the point is beginning to be made.

Since all conditions listed under ASD in the DSM-IV are developmental disabilities, it seems clear that all should qualify for Developmental Services funding. Unfortunately individuals with Asperger's Syndrome are often excluded from Developmental Services funding if they are unfortunate enough to live in certain parts of the province. Those interested in creating awareness of, and advocating for the rights of individuals with ASD must continue to work hard to overcome and the support shortcomings and discrimination facing many individuals with ASD and their families. We must collaborate to develop common understandings about the distinct and also very real support needs of persons with ASD and their families

One group of parents has been very successful in arguing for the rights of their children to "treatment." Parents arguing for access to "Intensive Behavioural Intervention" (IBI) have been very effective. They must be congratulated for the progress they have made in leveraging access to an important treatment for their children.

Since IBI does not "cure" the neurological condition(s) underlying ASD, with or without the benefits of IBI, most individuals with ASD will likely continue to live with social and sensory challenges even if they develop good coping skills in other areas. In fact, some professionals are reporting that some of their clients with a diagnosis of Asperger's Syndrome would likely have retained a diagnosis of classic Autism but for the benefits of IBI. Unfortunately, many of these individuals still have high support needs. Depending on where they live, some of these "high needs" individuals with Asperger's Syndrome are being denied access to MCSS funding for which they would have qualified with their previous diagnosis.

Some families spend so much time and effort on IBI and other supposed "cures" for their child, that they neglect balance in their own lives, their marriages and the lives of their other children. Even when children benefit greatly, they are often left with sensory, social and other challenges. The support that they may need from a strong supportive integrative family can be jeopardized if parents are divorced and siblings become disaffected. Respite, sibling support groups, information workshops, and other forms of community outreach are required in addition to IBI. We need to place the benefits of IBI in context while promoting a broader range of more balanced supports across all ages.

Those of us that are interested in a balanced "best practices" approach to the support of individuals with ASD and their families must be more assertive in informing the public about the special needs of individuals with ASD and the benefits of well researched interventions, while raising cautions about fads and interventions based on anecdotal evidence. We must continue to work hard to overcome the discrimination that results in some individuals not qualifying for Developmental Services funding, irrespective of need, because of arbitrary interpretations of eligibility based solely on results of an "intelligence test." We must continue to collaborate with individuals, family members, and increasing numbers of enlightened service providers, professionals and Ministry personnel to develop common understandings about the distinct, but very real support needs of persons with ASD and their families.