

# Frequently Asked Questions: Getting a Diagnosis of Autism Spectrum Disorder (ASD) in Adolescence or Adulthood?



By Kevin P. Stoddart, PhD & Lillian Burke, PhD, December 2012

Even though we have known about autism for several decades, it is still common for older youth or adults to come to the attention of clinicians while seeking assessment for a possible Autism Spectrum Disorder (ASD). Below are some of the most common questions from parents of youth or adults, or from the adults themselves, when seeking an ASD diagnosis.

## **What is the purpose of a diagnostic assessment in adulthood?**

The purpose of a diagnostic assessment is to provide individuals with a diagnostic label that will help them understand what is contributing to their lack of success with appropriate tasks of adulthood and will guide intervention. A diagnosis may provide access to funds or programs (e.g., disability benefits), promote a more positive self-understanding, provide opportunities to address co-existing concerns (e.g., sensory or organizational), and facilitate better

relationships (e.g., spousal and work relationships). It may also improve health (e.g., awareness of food sensitivities), provide opportunities to affiliate with those who also have similar struggles, enable individuals to receive specialist treatment, and alert them to the presence of, or potential for, mental health problems.

## **Who is qualified to diagnose a youth or adult with ASD?**

Medical doctors (GPs, psychiatrists) and psychologists are permitted to give a formal diagnosis. Social workers, occupational therapists, and speech-language pathologists may provide a professional opinion about the likelihood that an individual has the disorder. However, this impression must be confirmed by one of the previously mentioned professionals for this to be a formal diagnosis. Unfortunately, it can be difficult to find professionals who have experience diagnosing older youth and adults on the spectrum. Specialized ASD organizations such as Autism

Ontario, Aspergers Society of Ontario, and Autism Society Canada have on-line listings of professionals in Ontario and across Canada.

### **Is a diagnostic assessment covered under OHIP?**

A diagnosis provided by a medical doctor (e.g., psychiatrist) or a psychologist employed in a healthcare setting is covered under OHIP. The services of psychologists in community settings are covered under some employee benefits plans, but not by OHIP. These employee benefit plans may not fund the entire cost of a diagnostic assessment. Individuals in postsecondary education receiving OSAP can apply for special financial assistance for diagnostic assessments.

### **Is it useful for an older adult (40+) to be diagnosed with ASD?**

Sometimes it can be useful for an older adult to receive a diagnosis. If they are functioning well without a formal diagnosis, or if a diagnostic assessment would not mean any change in their self-perception, services available to them, or treatment approach used, a full assessment may not be necessary.

### **Should I do anything to prepare for the assessment?**

The assessor may want to see any

previous assessments you have had, if any. As a part of the assessment, developmental milestones will be discussed. Understandably, in adulthood these may be difficult for parents or other family members to remember. It is helpful to think of these beforehand and gather any records, such as report cards. Make a list of the characteristics, problems, or behaviours that are concerning you before the appointment. As well, write out any questions that you may have for the assessor.

### **Do I require a formal diagnosis to receive appropriate services?**

Although some ASD services in Ontario require a diagnosis before you can receive clinical services from them, many do not. Begin to explore those that do not require a diagnosis. Reading the literature on ASD or attending workshops can be helpful. Finally, begin to explore strategies that may be useful in interacting with an individual with ASD (for example, presenting information visually) and try them out. The success or lack of success of these interventions is useful in helping better understand your needs and is important information for the diagnostic assessment.

## **What is involved in the assessment process?**

The assessment process depends on the professional completing the assessment and the individual being assessed. Some doctors may not make a diagnosis immediately and will prefer instead to gather detailed information. Those who are familiar with ASD may feel confident making a diagnosis after one appointment.

During the interview(s), the assessor will want to know the characteristics that are concerning and the adult's medical and developmental history. Standardized tests may be a part of an assessment, especially if the diagnostician is a psychologist. Parents, family members or spouses may also be asked questions and to complete standardized questionnaires.

## **What are the clinical issues that should be assessed in adult ASD?**

When a person is referred for an ASD assessment, the assessor looks not only at the specific characteristics of the ASD, but also considers features of other alternative or concurrent disorders. Psychologists will review history and current behaviours and concerns, as well as administer a variety of measures to determine a diagnosis. Specific concerns to be addressed in adult assessment may include:

- Intellectual/Cognitive ability:

assesses intellectual abilities; specifically, verbal and perceptual processing abilities;

- Academic ability: provides information about individual academic achievement overall, and identifies areas of academic strengths and challenges;
- Memory and attention: examines ability to remember or recognize information in short- and long-term memory, as well as working memory, and determines an individual's ability to attend;
- Functional or Life-skills: assessment of functional abilities or daily living skills, with suggestions for areas in need of development;
- Executive Functioning: examines ability to plan, initiate, organize activities and tasks, self-monitor, and regulate behaviour and emotion;
- Mental Health: assessment of anxiety and depression relative to age and gender-matched peers, other mental health concerns such as obsessive and compulsive behaviours, and ability to identify and express emotions;
- Sensory Concerns: to gather information about sensory seeking and avoiding behaviours and specific sensory-related behaviours or concerns (and may result in referral for an occupational therapy (OT)

consultation);

- Disorder-specific characteristics: assessing characteristics of specific neuro-developmental disorders such as Asperger's Disorder, Autistic Disorder, or Attention Deficit Hyperactivity Disorder (ADHD).

### **I do not usually do well in testing situations. What should I do about this?**

Many adults with ASD do not function optimally in a testing situation for various reasons such as anxiety, inability to focus, or sensory distractions. Tell the individual that is assessing you what your experience has been, and if there are any strategies that have helped to address this problem in the past. A good assessment will usually contain a statement by the assessor about whether they feel the test results are representative of the individual's true abilities.

### **Is it possible that more than one person in the family has a form of ASD?**

Studies are increasingly pointing to a genetic basis for ASD. We are seeing multiple occurrences of the disorder in the same generation or across generations in families, with varying degrees of severity. Addressing this openly, as a family, may sometimes be stressful or, alternatively, bring feelings

of relief and greater understanding from family members. If you know or suspect there is a history of ASD or other similar symptoms in the family, this is useful information for the diagnostician to know.

### **Does it matter if the person is diagnosed with a specific ASD (such as Autism or Asperger's) as opposed to ASD generally?**

It is important to remember that eligibility for certain services may be in part determined by the specific ASD diagnosis an adult has been given.

Knowing the adult has some form of ASD is most important initially; over time, the specific labels used may change, and it isn't necessary to re-establish that a person has an ASD unless they feel the original diagnosis given did not reflect their real ASD profile. In such cases, the label can be "fine-tuned" if needed.

### **The person with suspected ASD already has another diagnosis. Will that diagnosis remain if they are identified with ASD?**

Sometimes, a label that is given before a diagnosis of an ASD addresses some of the specific problems that may be evident (for example, a learning disability). This label may however not account for the many behavioural, learning, or emotional characteristics

that ASD encompasses. Many people have concurrent diagnoses of an ASD and a Learning Disorder or some other disorder. It is helpful to think of the individual as having the diagnosis that is most inclusive of all the symptoms that he or she presents. Therefore, if a person has a diagnosis of an ASD and has some obsessive or compulsive features, these may be subsumed under the label of the ASD rather than the person also receiving an OCD diagnosis. If an individual has symptoms that are not fully explained by a diagnosis of ASD (such as severe depression or severe anxiety), these may be kept. All diagnoses may need specialized and focussed attention in the individual's treatment plan.

### **Who should I tell about the diagnosis?**

Any professional involved with the adult should know that they have been diagnosed with an ASD. Sometimes, if the person is mildly affected by ASD or Asperger Syndrome, it may not be necessary to tell others. Usually, however, telling people helps them understand the person better and interact more effectively with them.

### **It was recommended there be further assessments by other professionals after the diagnosis. Is this necessary?**

A question that should be asked

before agreeing to any assessment is: "What specifically can this process add to the treatment plan or approach?" Searching for assessment services may also delay active treatment. The major benefit of multiple assessments is that specific issues and concerns can be looked at from a multi-disciplinary perspective. Therefore, a person who has significant sensory processing issues may benefit from an OT assessment or consultation after they receive their diagnosis. If they need therapy to address anxiety or depression, however, they should not delay that therapy until after they see the OT.

### **I am a female with suspected ASD, but professionals and others have tended to discount my suspicions. What should I do?**

While diagnoses of ASD in males continue to increase, the referrals and diagnoses for women have not followed this pattern and females may be diagnosed later in life, especially if they are considered "high functioning". There are a few possible reasons for this, including socialization to a "gender role", better abilities to cope with stressful situations, and better developed social skills. Signs and symptoms of an ASD may be less obvious; therefore, it is important to see a diagnostician who is familiar with the presentation of ASD in females.

## **I have just been diagnosed. What's next?**

When anyone is diagnosed, the most important next step is for professionals and family members involved with the person to learn about the methods of support and intervention used with individuals with ASD and apply them to their interactions with this person. Local agencies specializing in developmental disabilities in general or ASD in particular, and resources on the Internet, are excellent places to look for this information. The diagnosis will also allow parents of adults to find support groups with those in similar situations.

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