

Module 1: Characteristics of Individuals with ASD

If You've Met One Person with ASD, You've Met One Person with ASD...

What is autism spectrum disorder?

Autism spectrum disorder (ASD) is a developmental disability that affects the way an individual's brain functions. There are two main areas that are affected when an individual has ASD:

- social-communication skills, and
- restricted and repetitive behaviors.

Social-Communication and Social Interaction Challenges	Restricted, Repetitive Patterns of Behavior
Social-emotional reciprocity	Stereotyped or repetitive motor movements, use of objects, or speech
Nonverbal communicative behaviors used for social interactions	Insistence on sameness, routines, or ritualized patterns of behavior
Developing, maintaining, and understanding relationships	Highly restricted, fixated interests
	Hyper- or hypo- reactivity to sensory input



It is estimated that 1 in 68 children and 1 in 42 boys in the United States have ASD.

CDC Facts about ASD

https://www.cdc.gov/ncbddd/autism/index.html

Individuals who have been diagnosed with ASD may have difficulty communicating with others, making friends and relating to other people. They may also have very narrow, intense interests and unusual reactions to sights, sounds, smells and touch. They may do the same things over and over again and get upset if their routine is interrupted or changes.

Doctors and researchers are trying to find out what causes ASD. There could be many different causes, but it is very likely that an individual's genes influence whether or not they have ASD. There are some families with more than one member who has ASD. Another factor that may influence whether or not someone has ASD is their environment.

There is no medical test that can help us decide if someone has ASD. A doctor or other qualified professional has to make that decision based on if the individual has specific social-communication and behavioral characteristics. One tool to identify the diagnostic criteria for ASD is from the Diagnostic and Statistical Manual-5, which outlines criteria for Autism Spectrum Disorder.

DSM-5 http://www.dsm5.org/Pages/Default.aspx

The diagram below describes what the social-communication and behavioral characteristics of an individual with ASD might look like, depending on the severity level of his/her diagnosis in that specific area:

Severity Level	Social Communication	Restricted, Repetitive Behaviors
Level 3: Requiring Very Substantial Support	Severe deficits in verbal and nonverbal social communication skills cause severe impairments in functioning, very limited initiation of social interactions, and minimal response to social overtures from others.	Inflexibility of behavior, extreme difficulty coping with change, or other restricted/repetitive behaviors markedly interfere with functioning in all spheres. Great distress/difficulty changing focus or action.
Level 2: Requiring Substantial Support	Marked deficits in verbal and nonverbal social communication skills; social impairments apparent even with supports in place; limited initiation of social interactions; and reduced or abnormal responses to social overtures from others.	Inflexibility of behavior, difficulty coping with change, or other restricted/repetitive behaviors appear frequently enough to be obvious to the casual observer and interfere with functioning in a variety of contexts. Distress and/or difficulty changing focus or action.
Level 1: Requiring Support	Without supports in place, deficits in social communication cause noticeable impairments. Difficulty initiating social interactions, and clear examples of atypical or unsuccessful response to social overtures of others. May appear to have decreased interest in social interactions.	Inflexibility of behavior causes significant interference with functioning in one or more contexts. Difficulty switching between activities. Problems of organization and planning hamper independence.

There is a saying that "if you've met one person with ASD, you've met one person with ASD." This means that people with ASD all share some basic things in common, but are also very different. This is why ASD stands for autism **spectrum** disorder. A spectrum is something that covers a broad range, but is still related. We must think about the person as a unique individual, no matter their diagnosis.

Here are links to some videos that describe what it's like to have ASD:

- https://www.youtube.com/watch?v=MPb5WPvpsU8
- https://www.youtube.com/watch?v=ZsRdpPMAvfs
- https://www.youtube.com/watch?v=CfbRuhG1sbE



Key Elements

1) Communication

Some people with ASD may not speak or have difficulty expressing their thoughts and feelings, but it does not mean that they cannot communicate. In fact, individuals with ASD may use their behavior to let us know what they are thinking and feeling. Having a functional way to communicate our wants, needs, likes and dislikes is critically important for everyone.

It's very important to remember that the brains of people with ASD work differently than the brains of people who do not have ASD. It may be difficult for someone with ASD to understand when we are speaking to them, particularly if we talk very quickly and use abstract language. It may be very helpful to use clear, concise language and not repeat what we are saying over and over again. We can help individuals with ASD learn and understand by using pictures, drawings or written words to communicate.

2) Social

One way we can support individuals with ASD to interpret and respond in social situations is through a story, or narrative, about that situation. The narrative does not have to be complicated, it just has to explain what happens in the situation and how most people respond. It can include pictures and words, just pictures or just words, depending on how the individual learns best. If you'd like to know more about writing a social narrative for someone with ASD, use this link: http://carolgraysocialstories.com/social-stories/

It's also very important for individuals with ASD to be able to have community activities that interest them. Sometimes, it may be very obvious what the person with ASD is interested in because he/she talks about it all of the time. Sometimes, it may be more difficult to understand

what interests the individual. Talk to the people who knows the person best, like his or her family members, and include these activities and interests in the individual's day.

3) Restricted/Repetitive Behaviors

Researchers have learned that individuals with ASD do the things they do because their brains work differently than others. One of the ways we can tell an individual's brain works differently is if he/she engages in repetitive behaviors or has restricted interests. Repetitive behaviors vary a lot from individual to individual. Some individuals with ASD may rock back and forth, some may repeat the same phrase over and over again, and some people may simply check the time repeatedly. Restricted interests also vary. Some individuals with ASD may be very interested in maps, or the weather, or a specific animal, or the universe. It can run the gamut. It's important to be aware that these restricted interests or activities might be an area of great knowledge for the individual with ASD and showing interest in this topic may be a way to build rapport and could lead to a potential career. However, keep in mind that it might be very difficult for the individual to switch from his/her topic of interest to other topics or activities.

If an individual repeats a behavior over and over again, it is important to ask yourself a few questions. Do you think the individual is trying to communicate something with his/her behavior? Or, does it look like the individual is just doing something that feels good to him/her? If the individual does not seem to be communicating anything with his/her behavior and they are not hurting themselves or anyone else, it may be absolutely fine to just let the individual do what they are doing.



Activity

1.	Discuss how the characteristics of ASD might impact an individual's ability to:	
		Get ready in the morning
		Do laundry
		Have a conversation with a new roommate
		Play a board game
		Go out to dinner with friends
		Participate in a community group
		Shop in a grocery store

2. Complete the "All About Me" worksheet for your client. Place the completed document in an easy-to-access area such as the individual's main file or their basic information folder so that new or unfamiliar people who come into their lives can become easily familiar with their interests, likes and dislikes. This information helps as a place to start to get to know the individual as well as a way to identify activities they might enjoy which could be planned.



Tips and Strategies

- Remember-if you've met one person with autism, you've met one person with autism!
 Everyone with autism is a unique individual with different strengths, preferences and challenges. Get to know the individual. Don't make assumptions.
- Be aware that an individual with ASD may have difficulty communicating or making social connections with others, but that does not mean that he or she has an intellectual disability.
- Learn how the individual communicates best. Is it spoken language? Pictures? Technology? Use this method to establish a connection with the individual.
- Don't repeat verbal information or make verbal demands over and over again. Give the individual time to process information.
- Don't rely on body language or facial expressions to communicate how you are feeling as these can be difficult for someone with autism to interpret.
- Understand that restricted interests and repetitive behaviors are part of having autism and what make the individual unique!



Resources and References-Module 1

Websites

Autism Research Institute http://www.autism.com/

Autism Speaks Adult Services https://www.autismspeaks.org/family-services/adults

CDC Facts about ASD https://www.cdc.gov/ncbddd/autism/index.html

National Autism Center http://www.nationalautismcenter.org/

Organization for Autism Research http://www.researchautism.org/

Books

Baker, J. (2005). Preparing for life: The complete guide for transitioning to adulthood for those with autism and Asperger's syndrome. Arlington, TX: Future Horizons.

Bernier, R., & Gerdts, J. (2010). *Autism spectrum disorders: A reference handbook.* Santa Barbara, CA: ABC-Clio.

Grandin, T., & Panek, R. (2013). *The autistic brain: Thinking across the spectrum.* New York: Houghton Mifflin Harcourt Publishing Company.

Silberman, S. (2015). *Neurotribes: The legacy of autism and the future of neurodiversity.* New York: Avery.

Volkmar, F., Paul, R., Klin, A., & Cohen, D. (Eds.). (2005). *Handbook of autism and pervasive developmental disorders*. Hoboken, NJ: Wiley and Sons, Inc.

Journal Articles

Happe, F., Ronald, A., & Plomin, R. (2006). Time to give up on a single explanation for autism. *Nature Neuroscience*, *9*, 1218 - 1220.

http://www.nature.com/neuro/journal/v9/n10/full/nn1770.html

Henninger, N., & Taylor, J. (2013). Outcomes in adults with autism spectrum disorders: A historical perspective. *Autism*, *17(1)*, 103-116. http://www.ncbi.nlm.nih.gov/pmc/articles/PMC3769945/

Matson., J.L., & LoVullo, S.V. (2009). Trends and topics in autism spectrum disorders research. *Research in Autism Spectrum Disorders*, *3*(1), 252-257. doi:10.1016/j.rasd.2008.06.005

Seltzer, M.M., Krauss, M.W., Shattuck, P.T., Orsmond, G., Swe, A., & Lord, C. (2003). The symptoms of autism spectrum disorders in adolescence and adulthood. *Journal of Autism and Developmental Disorders*, 33(6), 565-581. doi:10.1023/B:JADD.0000005995.02453.0b

Wong, C., Odom, S., Hume, K., Cox, A.W., Fettig, A., Kucharczyk, S., Brock, M.E., Plavnick, J.B., Fleury, V.P., & and Schultz, T.R. (2015). Evidence-based practices for children, youth, and young adults with autism spectrum disorder: A comprehensive review. *Journal of Autism and Developmental Disorders*, *45*(7), 1951-1966. doi/abs/10.1080/10459881003785506