UNDERSTANDING AUTISM

INTRODUCTION

Autism is a chronic neurological disorder that severely affects an individual’s ability to understand, communicate, and interact with other people. Autism begins to develop in early childhood, and the cause (or causes) of autism is not known. There are approximately 400,000 individuals in the United States who suffer from autism, and although some people with autism may be able to function independently, there is no cure for autism and many people who have this disorder will need lifelong care and supervision.

OBJECTIVES

When the learner has finished this module, she/he will be able to:

1. Identify the correct definition of autism.
2. Identify three areas of behavior difficulties characteristic of people with autism.
3. Identify social behaviors characteristic of people with autism.
4. Identify communication behaviors characteristic of people with autism.
5. Identify physical behaviors that are characteristic of people with autism.
6. Identify how autism is diagnosed.
7. Identify the possible causes of autism.
8. Identify important aspects of working with autistic clients.
9. Identify the possible causes of emotional outbursts from autistic clients.
10. Identify how to handle emotional outbursts

WHAT IS AUTISM?

Autism is a severe, chronic, disability that profoundly affects an individual’s ability to function socially. There are degrees of autism and some people with a mild form of the disorder can have friends, hold a job, etc. But many individuals who have autism are severely limited in their ability to understand other people, they are severely limited in their ability to communicate with people, and they have no capacity – or a very limited capacity - to interact in ways that most people find meaningful or socially acceptable.

In this module, the following definition of autism will be used:

Autism is a chronic disability that severely affects an individual’s ability to communicate and interact.

Of course there are many diseases and disorders, both physical and psychological that can impair someone’s ability to interact. However, the person who suffers from autism has some very distinct characteristics that make this disorder unique and easily recognizable. The person who has autism a) has greatly diminished social skills, b) cannot communicate in ways that the people around him/her consider normal and
comprehensible, and c) often has physical behaviors that are seen as bizarre and abnormal. Taken together, these isolate the person who has autism; a person who has this disorder is often described as “living completely in their own world.”

- **Diminished social skills:** People who have autism often have very poor or almost absent social skills because they cannot understand other people. When someone smiles at them, they do not know what this means. When someone talks to them, they do not “hear” the tone of voice that indicates that the speaker is happy or angry. If a parent hugs a child with autism, the child will not interpret this as a gesture of affection, or if the parent was to raise his/her hand as if to strike the child, the child would not understand. This problem is made worse because the person with autism does not have the ability - or has a very limited ability - of knowing that other people have their own feelings, thoughts, and emotions. If you were to tell someone with autism that you were worried or frightened, it is very unlikely that person would understand. People with autism certainly have their own intellectual and emotional life, but they cannot share it and they cannot understand anyone else’s. Many people with autism prefer to be alone and have no interest in, or need for socializing. They may be able to empathize, but they cannot do so in ways that most of us comprehend. They do not understand social behavior and they cannot respond to social behavior, or they cannot respond in ways most people can understand.

- **Communicating:** For many people with autism the ability to communicate can be severely limited. Although each person with autism is different, there are certain communication behaviors that are common to the disorder. People with autism often do not make eye contact. When someone speaks to them they act as if they did not hear. If they do hear, they do not respond or they respond in inappropriate ways. Many people with autism never talk, and if they do talk what they say does not make sense to the people they are speaking to and/or does not seem to be related to what is happening. The person with autism also may not have the ability to use gestures to communicate. The speech of someone with autism can seem bizarre; they may repeat a phrase over and over, they mimic what someone else is saying instead of initiating their own speech, or they use one group of words to respond to every situation.

- **Physical behavior:** The behavior of someone with autism is typically the most disturbing aspect of the disorder for parents and caretakers. As was mentioned before, each person with autism is different, but there are behaviors that are common to the disorder. Aside from the lack of social interaction, their behavior is often obsessive; they will watch the same movie over and over, they will play with one toy for hours and hours, or they will constantly arrange and rearrange their favorite objects. Their motor behavior is often repetitive; people with autism have odd (odd to the observer) motions or movements that they repeat when they are upset or stressed, motions such rocking back and forth, flapping their hands, etc. Their behavior is often rigid and inflexible; people with autism have routines that they don’t vary from and they can become extremely upset if these routines
are changed or disrupted. And their behavior often seems *inappropriate*; if they are upset by a small change in a routine they can act very aggressively. They may completely ignore sensory input - a very loud noise, intense physical discomfort, a cut that is bleeding – that most people would find very unpleasant, but they will become extremely upset if a piece of clothing doesn’t fit quite right or when a parent brushes their hair. The child autism is often hypersensitive to what most people would consider “normal” physical sensations.

The signs of autism usually begin early in life. A baby who will eventually develop autism does not respond to cuddling, an older child with autism will not respond when you call his/her name or will not make eye contact with others, and this child is often withdrawn and does not like to play with other children or adults. The child with autism starts to speak - if the child does speak - much later than other children, and the child’s verbal skills are very poor and/or abnormal. Some of the characteristic behaviors of autism such as poor social skills, repetitive motions, inflexible adherence to routines, etc., begin to be obvious at a young age, as well, and unfortunately the majority of children with autism will not spontaneously change or improve as they get older.

**Learning Break:** Some people with autism may have a unique skill such as an extensive memory. However, the person who suffers from autism but who also has a deep, broad, and brilliant set of talents in several areas such as mathematics, music - the autistic savant made famous by the movie Rain Man - is a very, very rare phenomenon, and some people with autism suffer from mental retardation, as well.

Because the person with autism has communication skills and social skills that are severely handicapped, she/he is very isolated. The person with autism cannot and does not interact in ways that most people can easily understand or find meaningful.

**HOW IS AUTISM DIAGNOSED?**

There is no blood test or x-ray or physical test that can be used to diagnose autism. Autism is diagnosed by observing behavior. Physicians and psychologists use the American Psychiatric Association’s diagnostic criteria to look at a child's social interaction, the child’s communication skills, and the child’s behavior. For example, a child may be diagnosed as having autism if:

- The child never or rarely interacts with other children.
- The child does not speak.
- The child has stereotyped repetitive body motions.

The diagnosis of autism will be made if the child has six or more characteristic behaviors from the three categories (social interaction, communication, behaviors) that are used to evaluate for autism. The child should also be evaluated to make sure that the
abnormal social, speech, and communication behaviors are not caused by a metabolic disorder, a toxic exposure (e.g., lead poisoning) or another neurological disorder.

**Learning Break:** The incidence of autism has increased tremendously in the past 30 years. Some people believe that this phenomenon has been caused by increased exposure to environmental toxins. However, most experts believe that greater awareness about autism has simply allowed physicians and psychologists to more accurately identify people with autism.

**WHAT CAUSES AUTISM?**

No one knows what causes autism. It was once thought that autism was due to parents that did not provide the child with affection and attention, parents who never touched or interacted with the child. However, it has been proved that neglectful, emotionally abusive, and emotionally distant parenting does *not* cause autism.

Researchers and physicians now believe that autism is a neurological disorder caused by abnormal brain functioning or abnormal brain structures. How and why the brain functions abnormally, or how the brain structures are damaged is unknown, but the most likely causes are a) genetic factors, b) infections, c) complications during pregnancy, and d) exposures to toxins.

- **Genetic factors:** There is strong evidence that autism is, to some degree, an inherited, genetic disorder. One researcher found that a child who has a sibling with autism is almost 19% more likely to develop the disorder than a child who does not have a sibling with autism. However, no single gene has been identified that causes autism. It may be that there are multiple genes involved in the development of the disorder and an environmental “trigger” stimulates these vulnerable genes in a susceptible child. Autism is more common in males by a 3-4:1 ratio. At this point, researchers believe that genetics plays a big part in autism but they have not been able to use this knowledge to accurately predict who will, or will not develop autism.

- **Infections:** Some research has suggested that infections such as rubella (commonly called German measles) may cause autism if the infection occurs in a woman who is pregnant: the infection may damage vital parts of the brain of the unborn child and result in autism. Infections may contribute to the development of autism, but this theory has not yet been proved true.

- **Complications during pregnancy:** Some complications of pregnancy such as cigarette smoking, low birth weight, advanced age of the mother, etc. have been associated with an increased risk of developing autism.

- **Exposures to toxins:** Toxins in the environment such as mercury and additives that are placed in plastics may increase the risk of developing autism. However, at this time there is no clear evidence that exposure to toxins causes autism.
Learning Break: Tiny amounts of mercury were once used as a preservative in vaccines that were given to children. An article in a very prominent scientific journal claimed that this mercury preservative was the cause of many cases of autism, and there was an enormous controversy about the safety of these vaccines. However, the author of this article falsified the data, and the medical and scientific community has shown that vaccines do not cause autism.

HOW IS AUTISM TREATED?

There is no cure for autism, but there are treatments. These treatments are non-medical interventions such as speech therapy, special education, behavioral therapy, etc. that help improve behavioral, verbal and social skills, and medical interventions such as special diets, special food supplements, and medications. There are literally dozens and dozens of different treatments that have been used for helping people with autism, and describing them all here would be impossible. The key point to remember is that each person with autism is different: the most effective treatment is the one that works. You should also remember that although autism cannot be cured, treatment can make living with the disorder much more tolerable.

WORKING WITH THE PERSON WHO HAS AUTISM

Working with a person who has autism can be challenging, but as with most challenging situations knowledge and preparation are the keys to a successful experience. The following are important points to remember. If you keep these in mind, working with someone with autism will not be terribly difficult.

- Adaptation: Most of us have a reasonable ability to adapt to the environment. The person who has autism has a limited ability to do so. You must, as much as is reasonably possible, adapt the environment to suit the needs of the person who has autism. Determine what level and type of stimulation that person can tolerate. Safety is also very important. People with autism may not be able to protect themselves from danger, so the environment must be made safe. Of course, there will be many situations in which the environment cannot be adapted. A crowded shopping mall would probably provide too much stimulation for someone who has autism and there would be too many opportunities for self-injury. In that situation the environment can’t be changed, so the sensible thing would be to avoid the mall.

- Communication: Although many people who have autism have a limited ability to communicate, they do communicate, but not in ways that are easily understood. When you are working with someone who has autism, you will need to learn how that person communicates, and that is a process that takes time and patience. For example, when the client wants something he/she likes - a particular food for example - the client may have one phrase that is used to express pleasure, but that phrase may not - to anyone else - be associated with food or eating. The other part of communication that important when working with a client who has autism is
praise. Research has shown that people who have autism respond much better to praise than to criticism or strict discipline. Your communication should also be clear, simple, and consistent.

- **Routine:** Routines are typically very important to a person who has autism. They are most comfortable with rigid schedules and they thrive on predictability. As a caretaker you must learn what routines are important for the client who has autism and make sure these routines are not disrupted. A change can be extremely upsetting. If a change in a routine must be made, it should be done slowly and gradually and only after other discussion with other health care professionals and caretakers.

- **Meltdowns:** People who have autism - and especially children who have autism - are more prone to behavioral outbursts, and they may have intense meltdowns characterized by screaming, crying, intense physical activity, and attempts at self-harm. Handling these situations involves three steps. First, make sure that the client does not injure herself/himself or others cause damage to property. Second, everyone involved in the care of this person should use the same approach, and the best approach is to not be confrontational and do not respond: many times the meltdown will simply have to run its course. And third, look for the reason. The reason may have been a change in routine or a physical sensation that the client with autism found very noxious. It may also be that the client was frustrated; perhaps she/he could not tell you what they were feeling, did not get what they wanted and could not ask for it, or made a request for something and the request was not understood. Poor communication is often the reason why these outbursts happen.
SUMMARY

Autism is a chronic disability that severely affects an individual’s ability to communicate and interact. The exact cause of autism is not known, but it is probably caused by a complex interaction of genetic and environmental factors. Autism must be diagnosed by observing behavior, and physicians and psychologists look for characteristic changes in social behavior, communication skills, and physical behavior. Typical signs of autism include lack of interest or ability to socially interact, lack of speech or very diminished capacity for speech, and behaviors that appear, to the outsider, to be bizarre, obsessive, and repetitive. Because of these social, communication, and behavioral characteristics, the person with an autistic disorder cannot interact in ways that most people understand or find meaningful; in many ways the person with autism lives completely in their own world.

Autism cannot be cured, but there are degrees of the disorder that are not intensely disruptive and every person who has autism can, with support, treatment, and understanding, be helped. Working with an autistic client requires you to understand the disorder. But it also requires you to understand that although there are similarities among people with autism - the need for a rigid, predictable schedule, the lack of ability to adapt to change, the apparent lack of ability to interact and communicate – each person with an autistic disorder expresses these characteristics in her/his own way.