

A Client Care Module: Understanding Autism

Instructions for the Learner

What will you learn?

After finishing this inservice, you will be able to:

- Name and describe at least six characteristics and signs of autism.
- Discuss at least two possible causes of autism.
- Explain at least three methods used to treat autism.
- Discuss the importance of early intervention for autistic children.
- Demonstrate your understanding of autism as you provide care to autistic clients.

We hope you enjoy this Inservice, "Understanding Autism." It's been prepared especially for nursing assistants like you. You work very hard, and we appreciate the effort you make to complete these educational materials. It shows your desire to continue learning and growing in your profession.

If you are studying the inservice on your own, please do the following:

- Read through all the material. You may find it useful to have a highlighting marker nearby as you read. Highlight any information that is new to you or that you feel is especially important.
- If you have questions about anything you read, please ask
- Take the quiz. Think about each statement and pick the best answer.
- Check with your supervisor for the right answers. You need <u>8</u>
 <u>correct</u> to pass!
- Print your name, write in the date, and then sign your name.
 - Keep the inservice information for yourself and turn in the quiz page to ________ no later than _______. Show your Inservice Club Membership Card to ______ so that it can be initialed.

THANK YOU!



A Client Care Module: Understanding Autism

All about Autism

Inside this issue:

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 Signs of Autism
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Throughout history, there have been some strange ideas about autism. In ancient Rome, doctors felt it was a form of insanity. During Medieval times, autistic people were considered to be possessed by demons. And, as recently as the 1960's, it was thought that autism was a psychological problem caused by uncaring mothers.

For decades, autistic children were considered "self-absorbed". In fact, the word "autism" comes from the Greek word for "self". But, what exactly is autism? Simply put, autism is a developmental disability that typically appears before the age of three. This neurological disorder affects a child's ability to interact and communicate with others in a socially accepted manner.

However, the definition for autism is not black and white. There are different degrees of autism—from mild to severe. So, while some people with autism may bang their heads on the table for hours, babble instead of using words or scream constantly, not everyone with autism displays these types of behavior.

Some autistic people have special talents in certain areas and may



Experts on autism agree that early intervention is the key to success. The earlier an autistic child can get into a treatment program, the better the results.

display exceptional abilities, particularly in the fields of math and music. There are also some very successful autistic people who are known as "high-functioning" autistics. For instance, Temple Grandin, Ph. D., is an animal scientist and author. She has written a book about her own experience as an autistic person. Autistic artist, Stephen Wiltshire, is well-known for his portraits of buildings and cars. He began sketching when he was 5 years old.

Keep reading to learn more about autism so that you can help your clients and their loved ones cope with this complex condition.

Autism IS NOT...

- a disease.
- a mental illness.
- caused by bad parenting.
- a term for unruly kids who choose to be uncontrollable.
- curable.



Autism IS...

- a developmental disorder of the brain that often appears before the age of three.
 Usually, autistic children seem to develop normally, but then start to backslide. They may suddenly stop talking altogether and often withdraw into a world of their own.
- a life-long condition that is treatable, especially with early diagnosis.

Some Facts on Autism

Autistic disorders are more common in children than diabetes, spina bifida, Down syndrome, and cancer—all put together!

- According to the Mayo Clinic, autism affects between 10 to 20 of every 10,000 people in the United States.
- Today, as many as 1.5 million Americans are thought to have some form of autism.
- Boys are about four times more likely than girls to have autism. Males account for more than 80% of autistic disorders in the U. S.

- Even though autism seems to affect more boys than girls, girls tend to be affected more severely, suffering with worse symptoms and a lower IQ.
- Autism is on the rise! The Autism Society of America reports that autism is growing at a rate of 10 to 17% a year. In the next 10 years, autism could affect about four million Americans.
- Today, the cost of autism is about 90 billion dollars a year. 90% of these costs are for services for adult autism.
- According to The Autism Society of America, in 10 years, the annual cost of autism will skyrocket to as much as 400 billion dollars.

- About 40% of children with autism don't talk at all.
- About 70 to 75% of people with autism also have mental retardation.
- Autism can be diagnosed as early as 18 months of age with an 83% accuracy.
- It is estimated that up to one in 175 primary school children are autistic.



Autism can happen to anyone—to both sexes, to all races, and to all socio-economic backgrounds.

Common Characteristics and Signs of Autism

The characteristics and signs of autism typically appear by age three. Some parents report sudden changes in their child's behavior, while others report that their child just doesn't appear to be making any progress.



Autism can range from mild to severe and symptoms can be very different for each person. No two people will have the exact same combination of symptoms. Sometimes the signs and characteristics of autism may improve as the child grows up, but for severe cases, there's usually little improvement.

The characteristics of autism can be grouped into three categories:

SOCIAL SKILLS

- Likes to be alone; may not be interested in other people at all; retreats into own world.
- Doesn't respond to his/her name or other verbal prompts; may appear deaf even though hearing tests are in normal range.
- Makes little or no eye contact.
- Has trouble interacting with other people; may not know how to play, talk or relate to others.
- May not like to cuddle or be cuddled; resists being held—may scream to be put down.
- May have trouble understanding others' feelings or talking about feelings.

LANGUAGE/COMMUNICATION SKILLS

- Learns to speak much later than other children and/or loses the ability to say words or phrases at any age.
- May not speak at all or may repeat words or phrases without understanding how to use them. This is called *echolalia*.
- Has trouble expressing needs; may not understand gestures like waving; may point instead of using words.

- Mixes up pronouns, for instance, might say "I" instead of "You" or vice versa.
- Unable to begin a conversation or keep one going.
- Fails to talk in a normal tone of voice, but uses a "flat" or "singsong" voice.

BEHAVIORAL ISSUES

- Repeats actions over and over again like rocking, hand-twisting or spinning.
- Resists the slightest of change in routine or moving around of objects. Likes things to always be the same.
- May have severe temper tantrums.
- May cause self-injury, like head-banging or biting.
- Has no fear of danger.
- May be less active than normal, though usually tends to be hyperactive.
- May be extremely over-sensitive or undersensitive to pain.
- May dislike certain sounds, textures or tastes.
- Likes to spin objects such as toy car wheels. May be fascinated with an object for hours at a time.

FIVE WARNING SIGNS OF AUTISM

- Not babbling or cooing by 12 months.
- Not gesturing (waving, pointing, or grasping) by 12 months.
- Not saying single words by 16 months.
- Not saying two-word phrases on own by 24 months.
- Loss of any language or social skill at any age.

According to the National Institute of Child Health and Human Development (NICHD)

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Comparing Normal & Autistic Infant Development

Infants with Autism

Language/Communication

- Avoid eye contact.
- Seem to be deaf.
- Begin to babble and talk, but then suddenly stop altogether.

Social Skills

- Seem unaware of the coming and going of others.
- May physically attack and injure others without being made angry.
- Appear to be distant, like "in a shell."

Behavior

- Remain fixated on a single object or activity for an extended period of time.
- Repeat actions like rocking or handflapping.
- Sniff or lick toys.
- Show no sensitivity to burns or bruises and may perform self-mutilation like eye gouging, and biting.

Infants without Autism

Language/Communication

- Study mother's face.
- Easily stimulated by sounds.
- Keep adding to vocabulary and expanding sentence structure.

Social Skills

- Cry when mother leaves the room and are anxious with strangers.
- Get upset when hungry or frustrated.
- Recognize familiar faces and smile.

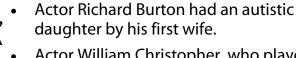
Behavior

- Move from one fascinating object or activity to another.
- Use body purposefully to reach or take objects.
- Explore and play with toys.
- Search for pleasure and avoid pain.

Adapted from a chart from the National Institute of Mental Health.
This comparison is not meant to be used as an assessment.

Famous People Affected by Autism

- Actor Sylvester Stallone has a son with autism.
- Actor Joe Mantegna has a daughter with autism.
- Opera singer Beverly Sills has a son with autism.
- Football player Dan Marino has a son with autism.



- Actor William Christopher, who played Father Mulcahy on the T.V. show MASH, has a son with autism.
- Singer Phoebe Snow has an autistic daughter.

From www.vaporia.com



What Causes Autism?

While autism has no **single** cause, it is generally accepted that it stems from some kind of abnormality in brain function. According to the Autism Society of America, brain scans done on autistic children show differences in the structure and shape of the brain when compared to normal children.

Researchers have several theories as to what may cause autism:



Heredity
—Several studies involving twins show that autism can be passed down through families. Other studies have scientists thinking that parents who have one child with autism may have a slightly higher risk of having another autistic child.

Medical conditions
 People who have certain conditions like Fragile X syndrome (most common form of inherited mental retardation) may be at a

higher risk for autism.

- Environmental factors— Researchers are checking into several factors that may cause problems during the brain's development such as viral infections, exposure to certain chemicals, and imbalances in metabolism.
- **Pregnancy problems**Even the slightest disturbance during pregnancy may cause problems. Scientists are studying mothers' health during pregnancy along with problems during the delivery for clues as to what might cause autism. According to recent research, harmful substances taken during pregnancy may result in a higher risk of autism.

Vaccines and Autism—Is there a Link?

Many are concerned that the MMR (Measles-Mumps-Rubella) vaccine may cause autism, but a recent study in Europe didn't find a link. Most scientists agree that more research is needed.

How to Diagnose Autism?

- It's not an easy task to diagnose autism because there are no medical tests to detect it.
- Doctors may use several medical tests to "rule out" other conditions and disorders such as hearing loss, mental retardation, and speech problems.
- Doctors who specialize in autism use several kinds of tools to determine whether or not a child has autism—from
- rating scales and checklists to observing the child's speech and behavior. They also need detailed information from the parents about the child's behavior and early development.
- To make a diagnosis, doctors must see "clear evidence" of poor social skills, language skills and behavioral issues (See page 3) before age three. Autistic children usually have some problems in each area.



Even though early intervention can help reduce symptoms, The National Institute of Mental Health estimates that only 50% of children are diagnosed before kindergarten!

How to Treat Autism?

- There is no one single treatment plan for autism because many times one particular plan is just not enough to help.
- However, a combination of early intervention programs, special education programs, parent involvement, and sometimes medication can help autistic children to live more normal lives.
- Most doctors agree on two things: that early intervention is very important, and that most people with autism respond well to highly specialized and structured programs.

Only children younger than age three qualify for "early intervention" help. However, it's never too late to begin a treatment program.

There are many types of treatment programs available, including:

Behaviorist—This approach is based on the "reward" system. It's usually time consuming,

highly structured, and focused on doing skills over and over again.

Developmental—Programs of this type focus on providing structure, being consistent, and changing the environment to meet the needs of the child.

Non-Standard—While scientists remain skeptical about the usefulness of these programs, they are still used by some parents and therapists. Holding Therapy is an example: The parent hugs the child for a long time even if the child resists. It's supposed to help the bond between parent and child.

Dietary—Some researchers think that adding vitamins like B6 and B12 and removing gluten from the diet may be helpful to those with autism.

Complementary—This approach includes music, art, and animal therapies, which may help with communication and social skills.

Medications—There are many medications that may help with issues like hyperactivity, anxiety, and sensory problems.

Other Problems and Conditions Related to Autism

- Many autistic children also have other problems, such as chronic diarrhea; liver and kidney troubles; and immune system issues.
- According to NIMH, about one third of children with autism develop lifelong seizures. The seizures usually begin in early childhood or adolescence.
- Autistics have problems with processing sensations and end up having "sensory overload." For example, many autistics can't stand the feel of their clothes to the point that the clothing causes actual pain. Also, autistics can't sense fear or dangerous situations.

The following four conditions are considered autistictype disorders:

- Asperger Syndrome
 — Differs from autism in that there is no language delay and there are less severe symptoms. Considered "high-functioning autism."
- **PDD-NOS**—Known as "atypical autism." Children who show signs of autism, but don't meet all the diagnostic criteria are given this label.
- Rett's Syndrome—Usually affects girls. It's genetic and the most common cause of severe physical and intellectual disability.
- CDD—Also known as "regressive autism." Children develop normally until about age 2 to 4. Then, they develop a condition that appears to be autism. They lose much of what they have learned.

Adults with Autism

- Like other children, autistic children grow up, experience adolescence, and then move into adulthood.
- When a person with autism reaches the age of 22, the public school's responsibility for providing special services ends. The family has to decide which type of living arrangement will work best for everyone. They also have to think about the best type of job for their adult child and arrange for government support services.
- Some autistic adults, particularly those who are high-functioning or those with Asperger Syndrome, can work successfully in regular jobs and live on their own. They still need encouragement and support since communication and social problems may cause them some difficulties.

For unknown reasons, approximately 20 to 30% of people with autism will develop epilepsy by the time they become adults.

- Other autistic adults continue to live at home, are placed in foster homes or a skill development home. (A skill development home teaches self-care and housekeeping skills along with arranging social activities.)
- And, some adults with autism live with other disabled people in group homes or apartments staffed by professionals who help them with basic needs like meal preparation, housekeeping and personal care.
- According to The Autism Society of America, about one third of all people with autism are able to live and work in the community with some measure of independence.
- Institutions are still available for those who need more intense and constant supervision.
 However, today, these residential facilities treat residents as "individuals with human needs" and offer recreation events along with simple, but "meaningful" work.

Did You Know That?

- Temple Grandin's mother was told by doctors to institutionalize Temple because of her autism. (This was the usual advise during the 1950's.) Fortunately for Temple, her mother refused. She placed her in a program for speech impaired children, where classes were very structured and very small. It worked well for Temple. By age 4, she could speak and, today, she is a well-known author.
- In her book, Thinking in Pictures, Temple
 Grandin refers to herself as a "pressure seeker."
 When she was six years old, she would wrap
 herself tightly in blankets and get under the sofa
 cushions because the pressure was relaxing and
 calming to her. As an adult, she created a

- "squeeze machine" which has two soft foam-padded sides that apply self-controlled pressure through an air valve.
- Every state has an early intervention program for children under age three. The program's services are written into an Individualized Family Service Plan (IFSP), which is reviewed at least once every six months.
- For children ages 3 to 21, a federal program called the Individuals with Disabilities Education Act (IDEA) guarantees free appropriate public education. Public schools must prepare and complete an Individualized Education Program (IEP), which is reviewed each year.



Tips to Help Those with Autism

For most people with autism (children and adults alike), it's very important to be consistent. They really like things to be the same. For example: Five year old, Sally, has a tantrum if her bedtime routine changes at all. She likes to brush her teeth, put on her pajamas and then get into bed for her story. Ted, age 25, now lives in a group home with other disabled adults. When he comes home for a visit, he rearranges all the living room furniture back to where it was placed when he lived at home with his parents. Ten year old



Carol likes her toys in a certain order and she becomes very upset if anyone disturbs them.

Regardless of age or intelligence level, many people with autism have problems staying organized. They may need extra help with their organizational skills. For example: John is a "straight A" student with a photographic memory, yet, he can't seem to remember to bring a pen to class. He might be reminded if a picture of a pen is taped to his notebook. Alice has the messiest desk. She will need your help to stay on track. To help her, you may need to teach her one step at a time how to keep things neat. Encourage her to keep just one area of her desk neat at first.

Try not to fuss or nag if an autistic client continues to be disorganized or forgetful. It will just make things worse. Instead, break down the

task into

steps and

smaller

- use different ways to get the message across, like using pictures, written notes, and even showing the person how to do the task.
- Most people with autism have trouble with abstract thinking. To them, everything is "black or white." It's important to keep things simple and specific. For example: If Sue slams the door, instead of saying "Why did you do that?," say "Sue, I didn't like the way you slammed the door when I asked you to come into the bathroom. Please shut it quietly."
- Remember, that social cues and facial expressions, like winking, and rolling of the eyes may not work with autistic people. Most times they are unable to understand what those cues mean. For example: Temple Grandin once mentioned that she couldn't see the jealous look on a spiteful co-worker's face as he tried to ruin her work. She said that she had to learn to see emotions like that.

- Keep in mind that most high-functioning autistics use and understand speech literally—word for word. Try to avoid using cute names, like sweetie, buddy, slick; don't call your clients by nicknames; avoid telling jokes as most have double meanings; try not to use phrases, like jump the gun, save your breath, your pulling my leg; avoid using sarcasm, such as, saying, "Wonderful!" after your client has spilled his milk.
- Try to avoid "verbal overload" with your autistic clients. Use shorter sentences and be clear when speaking.
 Remember to keep it simple.
- Since most autistics don't like change, it's always important to remember to prepare them ahead of time when a change in their routine or schedule must take

place.

The National Information
Center for Children & Youth
with Disabilities (NICHCY) has
created a handy resource
called State Resource
Sheets—disability related
resources in each state. Visit
their web site to see what's
available in your state.
http://nichcy.org/states.htm

More Tips to Help Those with Autism

- **Positive** reinforcement, such as, clapping your hands, while smiling, and rewards, such as a piece of candy or a special toy are helpful in teaching appropriate behavior. The key is to be consistent, that is, to use them all the time, not just every once in a while. For example: If you want Ann to point to what she wants instead of screaming for it, reward her with something special every time she points.
- Many times people with autism repeat back words or phrases that have been said to them (echolalia). They need to learn that words are used for communication. To help, try giving them what they say. For example: If your autistic client says "orange," then give him a real orange so that he can make the connection between the word and the object. Flashcards that

have both the printed word and a picture of the object are also helpful.

• Sometimes people with autism use echolalia to confirm what has been said. Repeating the word or phrase helps them to hear it. You can help by lengthening the hard consonant and vowel sounds of the words they repeat. For example: If your client says "ball," hold up a ball and say "bbb all."

- It's important to be aware that some autistic children and adults are very sensitive to noise—some are so sensitive that it causes pain. A sign of sensitivity is the frequent covering of ears with the hands. When someone has this problem, popping balloons sound like explosions; a hairdryer sounds = _____ like an airplane taking off. High pitched noises, like drills and blenders tend to be the most bothersome to those with autism. Keep in mind, though, that each person is different. What may bother one person, another may find enjoyable.
- People with autism who have visual sensitivities tend to flick their fingers in front of their eyes. The flicker of fluorescent lighting can be very distracting to those with this problem. Getting rid of fluorescent lighting may be helpful if your client has visual sensitivity.
- Overly sensitive skin is another problem for people with autism. Stiff and scratchy clothes may feel like sandpaper to them. They will feel more comfortable wearing soft, cotton clothes that cover most of their bodies. Wash new clothes several times and don't use fabric softeners or spray starch.

- Safety is a particular concern for those with autism. Many have no fear of danger, so it's important that they are in a safe environment. The following are some ways that you can help keep your clients safe: place locks on doors, cabinets, and windows; install an alarm on outer doors (as necessary); lock dangerous items away like detergents, cleaning supplies, and medications—even small items can be a hazard to a child; secure items like knives, scissors, and razor blades; make electrical outlets safe by covering them; use plastic door covers for doorknobs, faucets, ovens, and stove burners; move furniture away from shelves, bookcases or any place where one could climb.
- If your client is a "sweeper," that is, shoving things off of tables, you may want to keep furniture clear of breakables.
 Place them out of reach in bins or shelves.
- to secure eating utensils by tying them to nylon string and attaching them to the chair so that if they are thrown they won't hurt anyone.
- Try using labels, like photos, symbols, words, and signs for everyday items.

The Most Common Myths about Autism

<u>MYTH 1</u>: People who have autism can't show affection.

Even though people with autism may have "sensory overload," where even the clothes they wear cause discomfort, they still can hug and kiss. They process things differently than normal people. It's on their terms, when they are ready to do it.

MYTH 2: Autistics don't make eye contact.

Yes, they do make eye contact. It just may be different or less than the eye contact of a normal person.

<u>MYTH 3</u>: People with autism can't communicate.

This is not true! Many people with autism can speak—maybe not fluently, but they have communication skills, like sign language, use of pictures or specific sounds and grunts.



MYTH 4: All autistic individuals are mentally retarded.

While many "normal" people associate the word "autism" with the word "retarded," it's not true that ALL autistic people are retarded. It's been reported that about 70 to 75% of autistics have some degree of mental retardation. Many high-functioning autistics have average or above-average intelligence—scoring over 150 on IQ tests.

MYTH 5: Everyone with autism is the same.

False! No two people are exactly alike—normal or otherwise. Everyone is slightly different. Not all people with autism are like Dustin Hoffman's portrayal in "Rainman."

MYTH 6: Autistic people don't have emotions.

Not true! People with autism express themselves in different ways than "normal" people, but they still have emotions, like anger, anxiety, happiness, joy, love, and hate.

MYTH 7: Those with autism don't have sexual feelings.

Many do have sexual feelings particularly high-functioning autistics. They fall in love, get married, and even have children. However, they may continue to have trouble in social situations, which can make relationships difficult.

Time for a Chuckle!



Did you know that...Sean Connery played an autistic man in the movie Finding Forrester?

A TALE FROM A TEACHER—A true story!

Mrs. Bell, a veteran teacher of 15 years, had a very active and large third grade class. Among her 29 students, she had several with various disabilities, including Janie, an autistic child. For over two months, Janie focused only on clouds. Everything she said or did revolved around clouds. One day, Janie changed her focus to death. Everything she said or did revolved around death. On Valentine's Day, each student made a valentine for a special person. Janie wrote her valentine to Beethoven:

Roses are Red Violets are Blue You are Dead And I'm sad about it, too!



A Client Care Module: Understanding Autism

Are you "in the know" about autism? <u>Circle the best choice, or fill in your answer. Then check your answers with your supervisor!</u>

Since most people with autism don't like change, it's a good idea to prepare them

when a change in their routine or schedule must take place.

1. TRUE or FALSE

Autism is a contagious disease.

EMPLOYEE NAME (Please _l	print):	2. TRUE or FALSE Everyone who has autism has some degree of mental retardation.					
DATE:		3. TRUE		_	of the brain		
 I understand the information presented in this inservice. I have completed this inservice and answered at least eight of the test questions correctly. 		 Autism is a developmental disorder of the brain. 4. TRUE or FALSE The best way to treat autism is to take medications. 5. TRUE or FALSE People with autism don't have any emotions. 					
EMPLOYEE SIGNATURE:	_	A.	Verl	rson with autism repo palizing. olalia.	В.	or phrases, it's called: Back and forth. All of the above.	
SUPERVISOR SIGNATURE:	_	7. Many A.	autis Chro	i tic children also hav o onic diarrhea.	e other pro	blems, such as: Liver and kidney disease.	
		8. If you A.	Ove	istic client constantly rly sensitive to noise.	has his ha	All of the above. nds over his ears, he coul Hyper-sensitive to touch.	d be:
Inservice Credit:	1	C. 9. TRUE		ially sensitive.	D.	All of the above.	
Self Study Group Study	1 hour 1 hour		ople v	with autism can speak.			

File completed test in employee's personnel file.