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ABSTRACT

This paper reviews the characteristics and needs of students with high functioning autism. First, it lists 18 common characteristics of autism, then it stresses that autism is defined by the general pattern of characteristics. Next, it discusses how people with high functioning autism differ from those with autism. These differences include higher cognitive abilities, more normal language functioning, better social functioning, a tendency toward specialization, and a generally better prognosis as a functioning adult. Discussion of the diagnostic process notes the negative connotations of the term "autism," and the frequent use of the terms "Pervasive Developmental Disorder" or "Asperger Syndrome," instead, for this high functioning group. Other diagnostic concerns include the need for observation in natural settings, overlap of symptoms with other disorders, the importance of early diagnosis, and a lack of knowledge about autism by many professional psychologists. A section on behavior management of autistic children stresses their need for routine and structure, management of transitions, their tendency to learn best by doing, ways to substitute more suitable behaviors for undesirable ones, and the need to avoid overstimulation. Specific ways to manage misbehavior are also suggested, such as ignoring the behavior, positive reinforcement, physical prompting, and unemotional discipline. (Contains 14 references.) (DB)

HIGH FUNCTIONING AUTISM

Vicki Reed

What do you think of when you hear the word autism? If someone is familiar with the term at all they usually think of one of two scenarios. Either they picture someone who is profoundly retarded, staring blankly into space, totally uninterested in people, spinning things, or they picture Dustin Hoffman in the movie Rainman with his fantastic math abilities.

In reality autism runs the spectrum from mild to severe. People who are mildly affected are rarely thought of as being autistic. They are more likely labeled weird, eccentric, or strange. Even mental health professionals seem to have difficulty with diagnosing high functioning autism.

What are the characteristics of autism? First and foremost it is characterized by deficits in communication and socialization or basically an abnormal way of relating to people and objects. Think of autism more as the way somebody is rather than something they have. A more positive view is rather than looking at it as a deficit think of it as a person who develops differently and looks at the world differently.

Common Characteristics of Autism

- Social deficits. A child may take no notice of other children or can't interact appropriately. They often act much more appropriate with adults than peers.

- Resists change in routine. Transitions are nightmares for these children and their caregivers. They need to have a definite beginning and end to their activities. They can have extreme tantrums if their routine is disrupted.

- Inappropriate laughing or giggling. For example if they see someone get hurt. Or they find something hysterically funny that no one else sees funny at all.

- Inappropriate attachment to objects or strange play such as lining things up or acting out the same scenario over and over. They are often said to lack in imaginative play although it may be they just don't have imaginative play like the "normal" person does.

- Avoids eye contact. Many autistic people do this but definitely not all. It is such a misperception that an autistic person won't look at you that I have seen the diagnosis "thrown out" because the child has good eye contact despite the fact the child shows every other autistic trait. This is a tricky decision when working with autistic children. For some children turning them to look at you forces them to reconnect and stop "acting autistic". For others it makes for a total sensory overload. Autistic people tend to be one channel people. "I can listen or I can look but not both."

- Non affectionate. Again, this is often true but some autistic children are quite affectionate.

- Indicates needs by gesture such as taking an adult's hand and using it to get what they want.

- Language difficulties. Language is usually late or there is no language. Mixing pronouns is common. ("Do you want juice" adult asks. Child replies "you want juice" instead of "I want juice"). Shows echoholia. Is unable to maintain a conversation or discuss feelings. Another big red

flag is the child had some speech as a baby then totally loses it.(Differs from Kleffner Syndrome which is a disorder when the child has had full functional language for some time and begins losing it all. Treatment is with steroids.)

- Perseverates. Constant repeating of questions. Many parents who anguished over whether their child will talk sometimes wonder what they asked for! Experts say echoholia should not be discouraged for the most part. Enough language is getting through for them to repeat what they heard. If you inhibit echoholia then their learning of speech could be negatively affected.

- They will often repeat things over and over. To them this is not weird. Think of teenagers playing same song again and again (which is expected and tolerated by the way)

- They takes things very literally. Watch statements like "Let's roll." "Put your eyes on the board." "Crack the window," Don't use sarcasm i.e. "great" when milk gets spilled.

- Self stimulation behaviors such as toe walking, hand flapping, hand shaking.

- Uneven development. For example may have good gross motor skills but poor small motor skills. May be very high cognitively in one area but low in another.

- Physical overactivity. This is a problem in mild cases because it is often confused with plain old Attention Deficit Disorder.

- Tantrums, rage, difficult behavior. With younger children I believe this is often because they understand but can't make you understand. These behaviors can ease as they get older and either acquire language or learn other ways to make their needs known (or they are big enough to go get what they want themselves!)

- Sensory extremes. They may appear deaf but can hear a potato chip bag rattle a mile away. One child said he wouldn't go out in the rain because it sounded like gunfire, another said it bothered him hearing people blink. With touch they may not feel it at all or a slight graze can send them into hysterics. (They usually hate haircuts) The sense of smell can be extreme as well. One theory of autism is that the normal brain is trapped in a sensory system gone awry.

- Fixations. Common obsessive items are flags, fans, characters, and warning signs. These usually change over time.

- Excellent memory.

Remember that having one of these traits does not make you autistic but not having one or more of these doesn't mean you aren't autistic. You have to look at the total picture.

High Functioning Autism

How does high functioning autism differ from classic autism? First, it is far more common. These people are usually found in main stream settings. Many near normals are never diagnosed. They are viewed as "odd" "eccentric", or receive some other psychiatric diagnosis. Many have jobs, marry, have children. Here are some ways people with high functioning autism differ:

1. They have higher cognitive abilities, usually normal to superior. Many read at a very early age. They usually do well in school academically. This can be a problem because teachers and others can be "blinded by their strengths" and fail to take their needs into account. One mother stated "the good news is he's bright and the bad news is he's bright." They are often viewed as manipulative because they view the world differently.

2. They have more normal language functioning. However, they continue to have trouble with the non concrete. They often don't "get" jokes. They have a harder time following abstract conversation and often have a difficult time taking turns in conversation. Often they revert to their areas of special interest. They can be hyperverbal (talk too much!).

3. They have better social functioning but this usually remains the most problematic area throughout their lives. Often they relate much better to adults than to other children. They can't "read" others and often have difficulty making and keeping friends.

4. They often become fixated on a specific intellectual area and may gravitate towards this area for jobs as an adult. (This all consuming interest may be of benefit to society) One helpful strategy is to take full advantage of their interest in managing their behavior.

5. They have a better prognosis as functioning adult.

Diagnosing the High Functioning Autism Child

Why is a high functioning autism definition so difficult to get? For one thing there seems to be almost a conspiracy in the professional world to avoid using the term autistic whenever possible. Pervasive Development Disorder (PDD) is often given as a diagnosis without ever telling parents, teachers, etc. that this if often used interchangeably for autism (technically autism is a subset of PDD). It is common to hear parents say after receiving a PDD diagnosis "thank goodness it wasn't autism". PDD, among the autism community, is simply another word for a child showing some traits of autism but not enough for the professionals to call the child autistic. Autistic-like is another term used. You may hear it called residual autism or near normal autism. The most recent label is Asperger's Syndrome. Another term used is more able autistic person. The big question is whether these are true separate diagnosis or merely a continuum with no definite distinction.

Under DSM-III, 91% of children displaying autistic traits were labeled autistic. With the DSM-IV only 59% would receive that label. The criteria has been narrowed. For the first time Asperger Syndrome is given as a separate, distinct diagnosis.

Why is there a reluctance to use the word autism and/or why are children not diagnosed more often with autism? First, autism has very negative connotations. Hopeless and no cure are synonymous in many people's mind for autism.

Secondly, many mental health professionals don't ask the right questions. Many parents don't know enough to add up all these weird little behaviors into a package. Parents say there is a problem with tantrums or speech. They don't say everywhere we go we have to look at every flag or my child has a fit if I make a right turn instead of a left. Also, by the time many children are being professionally evaluated they no longer exhibit some of the autistic behaviors they showed at age two or three. For example, by age five a child at an initial appearance seemed to have appropriate speech. No one would know unless they asked that he didn't speak until he was three, was echoholic, mixed pronouns and so on. The only real way to diagnose an adult is to ask what they were like as a child. (The fact that a high functioning child and a low functioning child at look alike age makes it even more crucial to get to these children early and not make assumption they are low functioning.)

The process of professional evaluations may not be conducive to getting an appropriate diagnosis. Often children are seen once for a short duration and thirty minutes doesn't tell much. Or the testing itself is artificial and doesn't really show the problems. Examples found on some standard tests are questions such as does child use a knife to cut his food, does he make his bed, etc. These tests need to be updated for the nineties to things such as can the child order food from a drive in window, program the VCR, and so on. A child was asked if he knew the days of the week. His reply? "yes" (he received a zero because he didn't name them). Since one of the biggest problems with autism is lack of appropriate social skills with peers, examing the child alone doesn't tell you much. A favorite story is of a child who during the testing played with a Fisher Price family and doll house. The doctor saw it as wonderfully imaginative play when in reality he was acting out the Fisher Price Little People video that he watched twenty times a day and memorized. Had the doctor seen him play the next day he would have heard the characters speak the same lines in the same way. The child was merely acting out the videos. Another child received a zero because he would not string beads when asked to however, as soon as the test was over and no one was watching he put them on the string in about five seconds flat. Much better results are obtained if someone can observe the child in a more natural setting such as home, school, or day care.

Another problem is that many of the "symptoms" overlap with other labels. These children are usually physically overactive like ADHD children. There's a thin line between stimming (self stimulation behaviors) and complex tics as shown with children with Tourettes. They have compulsions like children with obsessive compulsive disorder (OCD). All of these different types of children are prone to tantrums and impulsive behaviors.

Finally, I believe many professionals don't really know much about autism. I'm not sure why since it's fairly common One psychologist told me she always labels autism as "language delayed" because "there is nothing the parents can do about it anyway". She didn't see anything to gain but "upsetting the parents" by diagnosing. Pediatricians especially need to become more educated as they are usually on the front line when parents become concerned about their child's development. I do believe this is changing and professionals are beginning to learn more and more about autism. It used to be this way with Tourette's syndrome. Within the past decade it has gone from an obscure disorder to one most people on the street know something about.

The ways of managing behavior for children with autism, ADD, Tourettes, and other diagnosis tends to be much the same. For instance, behavior modification is considered by many to be the treatment of choice. However, it is helpful to have an appropriate diagnosis of not ADD because there are some things you know and do differently with an autistic child. It may be more useful to get services and insurance companies are more likely to pay since autism is recognized as a medical disorder while ADD often is not. From a parent's perspective there is also just some relief at being able to put a name on what is wrong with your child. Like trying on a pair of jeans. Some labels seem ok but just don't fit right everywhere then suddenly you step in a pair and know this is it. Many parents report that when they finally learn about autism a bell goes off-"ding", that's my child they're talking about.

It is essential to get the diagnosis as soon as possible because the earlier the intervention the greater the chance for improvement. To those of you in day care settings and schools you are doing things with 3 and 4 year olds that can make a tremendous difference but time is of the essence. Most studies show a significant factor in later success is an education/treatment program that begins before age three, while the brain is still developing. Studies have shown that an effective teaching program does not have to be unreasonable amounts of time. Usually it needs to be followed every day but the duration is relatively short, an hour perhaps.

BEHAVIOR MANAGEMENT OF AUTISTIC CHILDREN

Autism doesn't mean, as people use to say, that everything is hopeless. Some children seem to almost totally recover. Others, while still retaining autistic traits, are able to be very functional. They can attend college and/or have a job, get married, have children and essentially just lead a normal life. Others may need to have some support. Someone might drive, get a job, and maintain relative independence, yet still need to live at home. Some will always be dependent totally. However, in most all cases there **is** improvement over time. Once more, the earlier you can intervene with these children the more success you will have. Ages three and four are considered crucial ages. This doesn't mean you can't do something with older children (or even adults) it's just not the optimal.

People need to realize that a child with autism has a disorder which makes him behave or respond differently from other students. Too often these children are viewed as manipulative or some other term that misses the point that these children respond differently to the world and its stimuli.

From personal experience as well as from talking with many other parents, I have concluded that the toddler years are the most stressful. You are coming to grips with the realization your child has a disability while your child hasn't matured enough or hasn't been taught yet certain things. Because of these factors, tantrums may occur more frequently and be more severe.

So, what helps in managing the behavior of these children?
First, medication may be helpful. Ritalin, and other stimulants, are often a disaster (I want to count adverse reaction to ritalin as a sign of autism). Other drugs including Prozac, Anafranil and Clonidine may be helpful. Obviously, a doctor needs to be involved in making medication decisions. However, you must realize that while medication can be useful it alone will not solve all behavior problems.

These children thrive on routine and structure. The more you can make your home, school, or day care more structured the happier the child will be (use lots of charts and pictures). There is a limit

however to what you can do. You cannot realistically do everything an autistic child wants. Because they have such good memory they may want everything in a certain order and there is no way you can possibly remember how it should go. Sometimes the question is how far do you want, or should you go to accommodate the child. Some things you may decide the child will have to learn to handle. Also, be warned that if you set up a routine you will pay a price if you don't follow it for whatever reason. Any good EBD teacher knows a special program in the auditorium will throw these children for a loop.

Transitions are very tough for these children. They want a definite ending and beginning. Find ways to bring closure to what they are doing. Because most of these children are visual by nature cues such as cards and pictures may work. I have found the usual means of getting "normal" children to make transitions are not always helpful. As an example you say "Johnny in five minutes it will be snack time". Try it but don't be surprised if this doesn't work. Johnny may just ignore you or go immediately into a full flung tantrum.

Be ready to forsake traditional ways of doing things. Don't presume anything and be willing to try anything. Here's a bedtime example. The plan of easing the child quietly into bed through the routine of a bath, pajamas, and story may not work (but of course try it first!). Instead, very boisterous play just before bedtime may work great. Don't presume they learn by the normal ways of observation and imitation. Another example. Autistic children were given an ice cream cone and they had no idea what to do with it. They had only eaten it with a spoon and couldn't figure out to lick it.

You may have to make adjustments in other ways as well. When using time out try using a sand type egg timer or an oil and water keychain rather than a bell which many autistic children can't tolerate hearing. The normal conversational wait is two seconds. Studies have shown that almost all children responded to a conversation question if given long enough. The average response time was fourteen seconds. Auditory learners sometimes report that they can't take notes and listen at the same time. Likewise with some autistic children they can't hear you if they look at you.

These children tend to learn best by doing. They receive input from muscles and joints while auditory and visual inputs are often ignored or not registered more often than other types of sensory stimuli. They can react with alarm and resistance to new things. Be patient and understanding to help deal with poor sensory perceptions of which fear is often dominant. However, don't totally avoid everything. Desensitation is often helpful so you may need to gently make them do some things they would otherwise prefer not to.

Look to substitute more suitable behaviors for undesirable ones. For instance, give a flashlight to flick instead of the room lights. One high school boy was given a hand press to squeeze which substituted for hand flapping. The flapping identified him as weird while the press brought on responses like," hey, he's working out. Try working with a child who is doing self stimulation behaviors by saying "that makes you feel good. Let's make it look better".

Try to look at the function a behavior might serve. One view of self stimulation behavior is that it is a way of blocking out a reality the child finds painful. Another belief is that this movement helps an autistic person with movement or communication (such as when you snap your fingers while you are trying to remember something) or helps reduce anxiety. Observe the child's behavior. Flicking things

may mean he may have visual processing problems. If he puts his hands over ears he may be hypersensitive to sounds.

Avoid overstimulation when possible. Remember often these children have a overreaction to all sensory stimulia. A red flag goes up when I talk to parents and they say their child has a huge tantrum just walking in to Walmart **not** over buying a toy. Many children find these settings just too much. The smells, hum of the florescent lights, people brushing by them are too much. Here's a test you may find useful. Take an out of control child to a darker area. If behavior decreases you can usually assume they were overstimulated. This doesn't mean this child will never be able to go to Walmart but you may have to work up to it. View it like desensitization of a person with a phobia. Drive up and park outside several times. Go just to the door without going in. Go in and come right back out and so on until the child can master the sensations. Or wait a year and try later.

There are other ways to help avoid overstimulation. Provide him with a place to relax and be alone. In the classroom or day care this could be a box or a partioned off area. Maybe add a beanbag reading area. Consider using ear plugs with or without music.

Remember all senses can be overloaded. For example smell and taste. Autistic children often have a very limited number of things they will eat. A plastic cup may be a no no because they have a strong odor to them. One child hated a teacher because she smelled "so strong".

Allow the child to dress in soft clothes that cover much of the body. Get with an Occupational Therapist to learn more about sensory integration therapy such as "brushing". The child often can't label his feelings or tell you why he feels a certain way. An example from the book There's A Boy in Here is that he hated the number twenty four because that bus was late so he hated any connection with that number. If he found out his teacher was twenty four years old that would be enough to decide he didn't like her. Negative feelings are often associated with a place or object rather than a person. Their moods can shift suddenly so they may be laughing one moment and having a tantrum the next.

By the way some people view these accommodations as "preferential treatment" for someone who is acting badly. Instead accommodating needs to be viewed as making the same sort of arrangements you would make for someone in a wheelchair or who was a diabetic. Often the people at school who really need this information (bus drivers, cafeteria workers) are left out.

Get the child a computer. Computers are great for these children. They help them learn and help them stay connected. Another good reason is that these children gravitate to jobs with computers. They work better in these types of jobs that are less "people orientated", more technical. I've also heard the Internet has been a godsend for autistic individuals. They are better socially in a chat room than with someone in person.

Keep them connected. Sometimes it is essential for autistic children, as with most of us, to be alone. However it is also important to get them involved in other activities even if you may have to use a bit more pressure to do so. Gymnastics, horseback riding, and swimming are all great activities for these children. Obviously team sports such as soccer and baseball can be difficult.

Don't take their behavior personally. By the virtue of their handicap they are egocentric and have trouble reading behavior of others. Try to remember these children are not (well, not usually) being

bad on purpose. Here's one example. An autistic child hangs back to use the swings alone then comes back late to class. It may look like purposeful bad behavior when in fact the child needs the sensory sensations that come from swinging.

Specific Ways to Manage Misbehavior

What is usually the first thing people try to do when they want to manage a behavior? Punishment. This doesn't work because it is based on the belief that if the child is punished he won't do whatever it was again. This is a flawed premise because these children don't know what they should do or do it to get the response you give (even if you think its an unpleasant response).

- ***Ignoring.*** This is one of the most effective measures. This doesn't mean letting the child have his way. Usually it means ignoring the misbehavior when you haven't **let** them have their way i.e. screaming and tantrums. This may take a lot of perseverance. With a normal child you might have to ignore a couple of times and then you might see a difference. It may take longer with an autistic child to see the difference but it often will come.

  Remember there are two different types of ignoring. The first is when you ignore as a response. In other words you **do** alter your behavior such as walking away, turning your head, or leaving the room. The second way of ignoring is to continue on exactly as you were. In other words you do not let the child's behavior alter your behavior. This is sometimes a better route to go if the child is getting satisfaction of seeing a certain response from you but both of these methods are useful depending on the child and the situation.

- ***Positive reinforcement.*** Combine this with ignoring. Ignore all the negative behavior and then praise or otherwise reward the first sign of positive behavior. But if the child is "in a state" be aware any word can set them off.

- ***Physical prompting.*** I strongly recommend Catherine Maurice's book Let me Hear Your Voice (she shows many examples). Often times this means forcing them to do what you need them to do. For example putting the spoon in their hand and raising their hand to their mouth to eat. It is very important that this is done calmly, matter of factly. It should not be done punitively or angrily.

- ***Discipline unemotionally.*** With lots of these children **any** strong emotions set them off-good as well as bad.

- ***Visualization***. Trying saying "picture yourself dressed and sitting at the breakfast table".

- ***Write it down to help stop and switch***. One child became very upset whenever anything was broke. He would talk about it and if nothing was done ended up in a rage. He was given a notebook to write down anything broken he saw and was then able to remain calm. Also, this is a useful way to end repetitive questioning. Another way is to have them write the question. You write the answer or you write his repetitive question and have him write a reply. Another way is to use popsickle sticks. "You can ask me the question 5 times. Take a stick each time he asks.

I hope this information will be useful to those of you who are currently working with autistic. For others of you, perhaps in the future, some child will cross your path and you will recognize and remember the traits of high functioning autism. There are many good resources out there and more seem to be appearing all the time. If you have a child you suspect has autistic tendencies, write the Autism Research Institute at 4182 Adams Avenue, San Diego, CA 92116 and ask for their diagnostic evaluation form. This can be completed and returned from them with a score that indicates if, and how severe, the autism is. Obviously there are limitations with a pencil and paper only evaluation but it would be a place to start.

I would also strongly suggest signing up for a couple of newsletters. Both are quite inexpensive and full of helpful information. One is the MAPP (P.O. Box 524, Crown Point, IN 46307) which was begun by Susan Moreno, the parent of a high functioning autistic child. The other is The Morning News by educator Carol Gray (Jenison High School, 2140 Bauer Road, Jenison, MI 49428). In addition to the newsletter, I would recommend purchasing her Comic Strip Conversations and Social Stories. These are wonderfully useful in both managing behavior difficulties and developing social skills.

Thank you for your time and attention.

Resources:

Book list.

Games: Hi ho Cherry-o, Chutes and Ladders, Mind your Manners

Computer games: Thinking Things.

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Emergence: Labeled Autistic — Temple Grandin

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Let Me Hear Your Voice — Catherine Maurice

Dancing in the Rain — Annabel Stehli
Georgiana Organization, Inc
P.O. Box 2607, Westport CT
06880.

The Siege: The first 8 years of an autistic child — C.C. Park

Movement Differences and Diversity in Autism/Retardation — DRI press
PO 5202, Madison, WI 53705

MAAP Newsletter (More Advanced Autistic Persons) ($8 private subscription) — PO Box 524
Crown Point, IN 46307

Technical Assistance Manual on Autism for Ky Schools — Nancy Dalrymple
(502) 564-2672

Helping People with Autism Manage their Behavior — Nancy Dalrymple

Morning News
Comic Strip Conversations — Carol Grey (address in your packet)

Autism Society — information in your packet

Teaching Children with Autism
Disney World Accommodations — Kathleen Ann Quill
(407) 824-4321

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