

Down Syndrome/Autism – A Dual Diagnosis

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There is a small, but consistent and significant, portion of the children with Down Syndrome who also become labeled as autistic. Once parents have come to terms with the diagnosis of Down syndrome and all it entails, the addition of yet another label, another set of obstacles, often becomes overwhelming. In this article, I hope to provide families with demystifying information regarding the label of 'Autistic', proactive observation techniques to detect autistic-like or sensory behaviors, and practical ideas for eliminating the behaviors.

The label of Autistic, whether for a person with Down Syndrome or not, is a symptomatic label. This means you receive this label if you have a certain number of symptoms on a list. It is important to know that 'Autism' is not a disease; you cannot take a blood test or x-ray to detect it. What I see in my work with children and families is that many doctors throw around this label rather haphazardly because of a few symptoms. A parent may go to a doctor's appointment and bring up a few concerns to the doctor: the child rejects hugs and kisses from the parent, won't leave his shirt on, screams every time mom needs to vacuum the house, sits for hours by himself quietly humming while lining up cars in a neat row. The doctor observes the child in front of him--- he won't make eye contact, isn't responding to directions (seems almost not to hear), instead is quietly sitting while continually flipping the pages of a book ---- AH HAW Diagnosis- Autistic. Having the label or not having the label does not change the fact that the family is dealing with a number of behaviors and symptoms that need to be addressed. The earlier that parents can identify and eliminate the symptoms, the better the chance of the child developing without Autistic-like behaviors.

Autism is basically a dysfunction of the sensory channels. This means that some senses are hyper (over active) and some are low (under active). Because of this, there are atypical responses to different stimuli. We have five main sensory channels, and each of them may be affected with hyper or hypo sensitivities.

Sound

For example, it is common for those affected with autism to be hypersensitive to sound. Sound can actually cause pain and discomfort. Parents may notice the following: covering of ears with hands to block out the sound, extremely negative behavior in certain locations, physical withdrawal or auditory shut down in noisy environments, inconsolable crying that only stops when the child is removed from the noise, or hearing and reacting to sounds before others can even perceive them. If the sounds are too uncomfortable the child will learn to totally turn off the hearing and then cease to make progress in speech and language development-sometimes almost appearing deaf. Often when a person is hypersensitive to certain sounds there are other sounds to which they are hyposensitive, or that they do not process at all. This greatly affects speech, as it is the ability to hear and process tones well that culminates in the ability to produce sound and speech effectively. For onlookers observing this behavior, it appears strange and inappropriate, but most people would react the same way if they were dealing with auditory hypersensitivity. The solution is to address the problem of the hypersensitivity to sound, and the 'strange' behavior will dissipate.

Touch

Touch, or tactility- the ability to interpret tactile input- can be oversensitive, causing withdrawal or reactions to deep touch (hugs) or light touch (tickling, tags, clothing material), discomfort with haircuts or hair combing, aversion to water at certain temperatures, aversions to textures-both on the skin and in the mouth, or overactive gag reflex. Tactility can be hyposensitive, meaning the brain does not even acknowledge that something has impacted the system. Instead of overreaction, there is a lack of reaction. Parents may notice falling and bruising without the normal response, lack of response to hot and cold, lack of ticklish response, and lack of mouth response to hot and cold.

Smell

Hypersensitivity to odors can cause odd behaviors such as hand sniffing, object and person sniffing, aversion to food odors causing gagging or rejection of food. Hyposensitivity to odor can cause problems with lack of motivation to eat and inability to distinguish between edible and inedible objects.

Taste

Hypersensitivity to taste can cause gagging or rejection of food. Hyposensitivity to taste can cause lack of motivation to eat, and inability to distinguish between edible and inedible objects. Problems with appropriate sensory information for odors and smell can cause serious eating difficulties.

Sight

We have two main types of vision, peripheral and macular/central. Peripheral vision picks up on edges and motion. Central or macular vision is what we use to learn. We see details with it; we are able to line up rows and columns, and clearly distinguish letter, numbers, words, etc. When a person has overdeveloped, or hyper peripheral, vision they attend to 'odd' things- things which have edges and movement: dangling strings, fans, open and shutting doors/drawer, edges of walls, and often their hands/fingers. Underdeveloped macular vision, or hypo macular, vision causes difficulties such as lack of eye contact and lack of interest in pictures, books, television, etc.

Persons diagnosed with 'Autism' have some sort of unique combination of the above sensory dysfunctions. One of the most common profiles I find in a person labeled Autistic is: hypersensitive to light touch, hyposensitive to deep touch, hyper auditory, hyper peripheral vision and hypo macular vision. The scenario described earlier in this article between the doctor, mother and child could be ascribed to this set of dysfunctions. This type of person is not receiving information in the same way as you and I, and therefore, is not responding to stimuli in their environment as you and I would.

Sensory Play

The most likely reason a child with Down Syndrome would begin to be labeled 'Autistic' is because of something called "sensory play." Sensory stimulation, self stimulation behaviors, self-stim, and sensory play are all terms referring to the same type of actions. They are behaviors that a child engages in that are "odd," repetitive, sometimes obsessive, but they all involve inputting information into the 'broken' sensory channel. This is so negative because it reinforces what is already atypical. Sensory play does more than just stop the positive development for the moment, it seems to create endorphins in the brain--happy feelings. As the child engages in sensory play, he wants to do it more and more, he craves it, and often it can become an addiction.

There are many, many types and variations of sensory play. A majority of sensory play is visual, often stimulating the peripheral vision, but sensory play can also be auditory or tactile too. Following is a list of some common sensory play activities:

Repeatedly opening and shutting doors or drawers; flipping pages of books; flipping books or toys; flicking toys with fingertips; wiggling fingers in front of face; wiggling fingers at side of face; hand flapping; holding toys to the side of face and shaking; twirling or shaking strings and ropes; nose up to the TV.; watching TV. sideways; spinning wheels of cars; spinning toys; spinning self; head shaking; rocking; continuous humming; echolalia (repeating videos, ads, or conversation but not communicating); hand wringing; excessive touching/sweeping with fingertips; wall walking; non-language repetitive auditory sounds; banging; pounding; tongue sucking; tongue play; excessive picking of their own skin; pacing/walking in patterns or circles; lining up toys.

This is not meant to be a complete list, but rather a general description that may help parents when observing the behavior of their children. Most of these activities are not inappropriate in and of themselves. Some are even developmentally appropriate at certain stages. They become inappropriate and turn into sensory play when they are done repeatedly or obsessively. I have found in my experience that parents usually are very good judges of what might be potential sensory play. If I point out some behavior that they should try to eliminate, they often confess that they had a funny feeling about it, or thought it was not positive.

As the child spends more time in sensory play, they are undoing the positive developmental input that their parents or caregivers are trying to impart to them. Actually, it is even more serious than just undoing what is being put in currently. Sensory play can actually cause significant regression in developmental and cognitive ability of a child.

One of the most severe examples I ever assessed was a child who had a very involved family. They were spending a lot of time each day with him on his developmental progress. In addition, they were ensuring that he was supervised almost constantly so he could not engage in any type of sensory play. His short-term memory was growing; he was able to speak to me in short sentences; he was reading some words and he was very tuned in and following directions. I saw him about 4 months later. He was not following any directions, he was totally tuned out, engaging in sensory play constantly, his short-term memory had regressed by 2-3 years and he wasn't able to communicate at all with me.

What happened during the four months to cause this? His mother had given birth to a baby who was understandably taking up much of the family's time and energy. This child had been left to engage in sensory play as much as desired for four months. I am not sharing this to put any blame on the family. They were dealing with a real life situation. I am using it to illustrate the extreme urgency and importance of stopping any and all sensory play so that a child's development will continue progressing in a positive manner.

My suggestion is for parents to become expert observers of their children's play. If you notice some of the above-mentioned repetitive behaviors, try and immediately distract and redirect the child's attention to something more; appropriate. Changing this behavior at onset is relatively easy compared to the task of trying to change: it after it becomes addictive and obsessive. Along with eliminating the sensory play, it is of the utmost importance to have an evaluation of the child, which can pinpoint any sensory dysfunctions and provide you with specific methods of stimulation and activities to normalize the sensory channels. This will offer your child the very best possibility of eliminating the 'Autistic' symptoms, thereby providing them with the best possible opportunities for continuing in their development.

Normalizing the sensory channels is part of the plan for anyone with sensory dysfunction. I will give some quick, general ideas regarding appropriate sensory input for helping children develop optimally.

Hearing

I suggest the use of Samonas Sound Therapy, which has a proven track record in reducing sound sensitivities. It can also help normalize any frequencies which the child is not hearing enough. Used correctly, Samonas or pre Samonas Therapy should be done very gently with short durations for optimal results. In addition, parents can provide lots of good quality auditory input-reading stories to the child, having the child listen to stories on tape, and talking face to face to the child.

Touch

Parents can, for a few minutes several times a day, provide tactile input to their child. Apply deep pressure (squeezing), starting at the fingertips to shoulders and toes to thighs. Deep pressure often calms children who display 'Autistic-like' symptoms. Interact with deep hugs (bear hugs) lots of times a day. You can also provide light touch with tickling (fingertips) or feather on the limbs.

Smell

Provide the child with the opportunity to smell a variety of pleasant odors, i.e. orange oil, peppermint, coffee grounds.

Taste

Allow opportunity to taste sweet, sour and salty tastes to stimulate the taste buds. Use only minute amounts for a child that is hypersensitive to taste.

Vision

Provide lots of opportunity to develop good central/macular vision. Talk face to face often. Play catch, pop bubbles, practice tracking-hold a small toy away from the face and move it slowly side to side and up and down for the child to follow. Discourage inappropriate use of peripheral vision (described above in sensory play). Television, if monitored by parents, can be used to help develop central vision. The child must sit at least 3 feet away and look directly at it (not out of the corner of the eyes). Watch something of high interest to the child.

Stopping Sensory Play

By far, the most important thing you can do for a child diagnosed with 'Autism' is to stop all the sensory play and spend as much one on one time with them as possible. As stated previously, if you detect sensory play early, all you need to do is distract and redirect the child's activity. If this is done, it will not likely develop into anything more serious. However, if you are the parent of an older child who has some of these behaviors on a consistent basis, your job will be more difficult. By structuring the child's down time so that someone is with them, interacting, playing, etc., you will reduce the sensory play because there will be less time for the child to engage in it. Sometimes it means removal of certain types of toys that seem to increase the sensory play. Inputting the appropriate information to the sensory channels will help the child to gradually become interested in their environment in a more typical way. The stopping of sensory play in a child for whom it has become a way of life is difficult. Usually, though, this only lasts a certain amount of time, until the 'addiction' quality wears off from lack of stimulation. As the sensory play decreases the pay off for the parents is that they start to enjoy interacting and discovering a new side of their child, a child who is more "tuned in", less withdrawn, more interactive, and easier to teach.

Conclusion

Autism is just a word for a group of symptoms. If your child acquires the 'Autistic' label or begins to display sensory dysfunctions, you will need to address each of the individual issues. The good news is sensory problems respond very well to intervention, thereby eliminating the original symptoms.

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