Looking at Self-Stimulation in the Pursuit of Leisure

or I'm Okay, You Have a Mannerism

By Kate Moss Hurst, Family Specialist and Robbie Blaha, Teacher Trainer TSBVI, Texas DeafBlind Outreach

Originally published in the Spring 1993 P.S. NEWS!!! Volume V. No. 3 published by TSBVI DeafBlind Outreach

Thanks to My Colleagues

Note from Kate Moss Hurst: This article was originally published in the early 1990s in the old “P.S.News!” newsletter Outreach Programs published. Even though it has been around for a while, I still think it is worth revisiting. At the time it was written, medical technology had not shown us all the things we have since learned about the brain, stress hormones, and resiliency. But the pioneers like Dr. Jan van Dijk and Dr. Lilli Nielsen were already figuring things out when it comes to individuals with visual impairments and DeafBlindness. They knew that self-stimulation was in response to sensory deprivation for students with visual impairments and DeafBlindness. Now science is validating what they proposed.

I began to think of this article with the intention of writing about leisure skills. I had no idea I would end with an article on self-stimulation. I hope this article shows some of the prejudice that seems to exist in our thinking about this topic. We have to understand what a normal human activity self-stimulation is and address these behaviors accordingly.

I would also like to thank Gretchen Stone, Ann Silverrain, and Barbara Bellemo-Edusei for their contributions to this work. These women, along with Robbie Blaha, formed a study group back in 1985 after attending a conference in Tallahassee conducted by Dr. Jan van Dijk. Challenged by both the information and the values conveyed by van Dijk in discussing children with DeafBlindness, they worked to digest rather complex information about the human brain, the nervous system, and the implications this information has in teaching children with DeafBlindness. Their discussions, and the papers generated as a result of this study group, were invaluable to me in beginning to understanding the effects of sensory deprivation on the central nervous system and how it relates to the way children with DeafBlindness respond to the world.
Leisure Time

Leisure time, the time free from work or duties, is important to all human beings. Leisure time is the time for doing something that will relax us or energize us, so that we can renew ourselves to face the demands of our lives. It is something we require as much as food or sleep to stay healthy and sane.

We all have different ways of spending our leisure time. What might be a leisure activity for me (reading a mystery) might not be leisure to you. We know and accept this about each other. When considering "leisure skills" for children with DeafBlindness, however, we often focus on activities which do not relax or positively energize them. We spend their time getting them to participate in "play work" as one young man with DeafBlindness terms it. Learning to play games, participate in arts and sports activities, or other pursuits as a part of their educational programming may be beneficial for children in many ways, but these activities don't necessarily meet their needs for "leisure".

The type of activities that often do provide relaxation or amusement for these individuals includes behaviors that we find unacceptable: flicking your hand in front of your eyes, pulling threads out of your clothes, making repetitive sounds, etc. These behaviors are considered self-stimulation, and as such, are often perceived negatively because they do not look "normal," may interfere with learning and can often become self-injurious. Yet these behaviors serve a positive purpose for these individuals as well.

Changing our perception of these self-stimulation behaviors may be the most reasonable course to take in addressing this issue, especially if this change of perception also helps us find ways to give more information to the child who is DeafBlind and consequently reduce his need to find stimulation on his own. These behaviors may also hold the key to information about his/her personal preferences, which we may tap into to select more appropriate choices for typical leisure options.

Stimulating Experiences

Most of our "leisure activities" are nothing more than self-stimulation behaviors that have become highly ritualized over time and made socially acceptable. There is nothing intrinsically valuable or reasonable about leisure pursuits such as bungee jumping, playing cards, dancing, playing video games, listening to music, smoking, etc.

People participate in these different activities because they find them to be pleasurable and because the activities alter their physical state. Each activity provides us with a particular type of sensory input (see Chart). There is not necessarily a great difference in so-called self-stimulation behaviors and some of these activities, beyond the fact that some are more socially acceptable and "normal" in appearance than others. For example, what is really so different about banging a table and banging a drum, rocking to music and rocking to silence, making repetitive sounds and imitating bird calls, spinning for no apparent reason and spinning in a ride at the amusement park?

Each day, a good portion of our energy is spent in self-stimulation. Just look at the people around you. You are in a room with your family watching television or at a meeting with a group of co-workers. Although you are seemingly engaged in the same activity, your daughter or
colleague is playing with her hair. Your son or your office-mate is shaking his leg and tapping out rhythms on the arm of the chair. Your husband is flipping channels with the remote or your boss is flipping papers. If you ask them what they were doing, they would likely reply that they are watching television or having an important meeting. They would be less likely to say they were channel surfing, twirling their hair, practicing the drum part for "Wipe Out," or fanning their papers.

Each of us, even those of us with more intact central nervous systems, tolerates differing degrees of stimulation. Look at the difference in the preferred musical tastes (and intensity levels) between the teenager and the forty-year-old. Although most teenagers enjoy megawatt rock concert with all the trimmings, most adults are more inclined to seek out softer music or silence in a dimly lit room. In the same way, children with DeafBlindness vary in the amount and intensity of stimulation they need.

If we come to accept that self-stimulation is an important and valid activity for individuals without disabilities, then we must begin to revise our thinking about addressing self-stimulatory behaviors in individuals with DeafBlindness.

**Can this behavior be stopped?**

In looking for the answer to this question, first take a look at yourself. Try this little exercise. Identify one of your own deeply cherished self-stimulatory behaviors such as cracking your knuckles, humming, sliding a charm on your necklace, etc. Try to keep track of how many times during the course of a 24 hour period you engage in this behavior. Then spend the next 24 hours refraining from this behavior. If you succeed, then try to extinguish that particular behavior for a year. Stop this behavior under all kinds of circumstances: times of stress, times of idleness, etc. Once you have completed this exercise, answer the question for yourself. Your answer will either be a resounding "no" or a "maybe, if" depending on your particular success in completing the exercise.

Children with DeafBlindness (just like you and me) participate in self-stimulatory behavior to calm, to energize, to get feedback, etc. Most of the time you can't completely extinguish the behavior, and perhaps you shouldn't, because it does serve a purpose.

**Can this behavior be redirected?**

Most parents find that their child is more likely to participate in self-stimulatory behaviors when he/she is idle or stressed. Interacting with your child in some way may break up the self-stimulation. If the behavior appears in response to stress, finding ways to help him relax (e.g., massage, being wrapped up in a quilt, etc.) may reduce the amount of time spent in the behavior you find inappropriate or harmful. If your child is left alone, however, it is likely he/she will re-engage in this activity as soon as the opportunity presents itself.

**Can this behavior be "contained" by allowing it in certain locations or at certain times?**

Some behaviors may present problems because they are considered socially inappropriate. Those of us who are smokers have learned to refrain from our favorite self-stimulation behavior on flights, but we all know exactly where to go in the airport for that last cigarette before the flight leaves.
With some effort, many children can learn to remove themselves to their bedroom or a private place when engaging in self-stimulation that is not considered socially acceptable. Using calendar symbols to represent this favored activity and scheduling the activity as part of the child's day may help the child refrain from this particular self-stimulation behavior for increasingly longer periods of time and stay involved in other kinds of activities. Can this behavior be modified or expanded into more "socially acceptable" self-stimulatory behaviors?

Self-stimulatory behaviors are valuable because they tell you how your child takes in information. If your child likes to burrow down inside the cushions of the couch, be held or hugged a lot, enjoys massage, etc., you can assume that he is motivated by information he receives proprioceptively. If your child likes to vocalize, listen to music, or bang things together next to his ear, you can assume he is motivated by information he receives through hearing.

These behaviors can be used as a way to explore the individual's preferred sensory channels for receiving information from the world. With this information we may identify preferred sensory experiences around which we can develop more "mainstream" leisure activities that our children will also come to view as "leisure." For example, if a child enjoys the visual sensation of lights we can find age-appropriate toys that might be motivating to him. In addition to familiar toys such as Lite-Brite, consider lava lamps, continuous wave machines, lighted drafting tables for drawing, and even some Nintendo-type games. You might also consider extracurricular events such as visiting arcades, decorating with lights for appropriate holidays or lying in a hammock under a tree watching the play of light through the leaves.

Take time to observe the types of self-stimulation that your child participates in and when this behavior occurs. Watch him/her and make notes about what you see and when you see it. Then try to see if there is any pattern to these behaviors that would give some insight to the type or types of stimulation he/she prefers and the purpose it serves. At the same time note what types of activities he/she finds aversive.

When you have a good understanding about his/her preferences, begin to brainstorm ways that you can offer other stimulatory activities, modify or expand on the preferred self-stimulation. Ask for help from your child's teacher, physical therapist, occupational therapist, and others. Look at children of the same age, and try to find toys or activities that may make the self-stimulatory behavior appear more "normal."

Sometimes your child's favorite self-stimulation activity can be modified or expanded in a way that will make it more socially acceptable. For example, everyone knows the "nail-biters," but do you recognize them when they become "the manicurists?" Several of my friends substitute the more acceptable behavior of nail care for their favorite activity of nail biting. They carry a complete manicure set with them at all times and can often be seen in meetings quietly filing or clipping a nail. They buff, cream, and polish. They examine their nails for chips, snags, splits. They are rewarded by others who admire their efforts instead of being held in low esteem as nervous nail-biter types.

You should realize, however, that generally your child will need support from you to seek out these more acceptable behaviors. Their first preference will usually be for the behavior they have developed on their own.
Can the environment be engineered to make this behavior safer if the behavior is detrimental to the child or those around him/her?

People who like to jump off things are great examples of engineering the environment to make a dangerous self-stimulation behavior safer. These folks (skate-boarders, skydivers, skiers, etc.) have developed elaborate ways of placing themselves in extremely dangerous activities and surviving. We have industries based on protective clothing and equipment that will allow them to hurl themselves through space and make a safe landing.

Frequently, the best you can do is provide protection for children who put themselves in danger of bodily harm by participating in self-stimulation activities that are excessive to the point of creating physical danger to themselves or others. Splints, helmets and other devices sometimes must be used temporarily to protect the child and others around him/her.

In addition to providing protection from the effects of the behavior, it is important to look at the cause of the behavior. Often times these behaviors erupt in response to real physical problems that the child is not capable of communicating to you. These behaviors might indicate pain or decrease of sensation, as in the case of retina detachment or ear infections. It's very important to the health and safety of the child to seek out appropriate medical examinations when this type of behavior emerges or escalates.

Emotional and environmental conditions may also provoke increases in self-injurious behaviors. One individual I knew exhibited a dramatic increase in self-stimulatory behavior after the death of her father. The amount and intensity of the behavior posed concerns for her safety and the safety of others. Since there was no physiological basis for her behavior, the family spent a lot of time with her looking at pictures of her dad, going to the cemetery, and trying to participate in activities that were associated with her father. After a period of time, the behaviors decreased to levels that were comparable with the period before her father's death.

Changes in schedules, moves to new environments, and so forth, can also bring about increases in self-stimulatory behavior. Helping the child anticipate these changes and providing as much consistency as possible through familiar routines during times of change, may help reduce this type of behavior.

Conclusion

Like you and I, children with DeafBlindness have a need to participate in self-stimulatory activities. Because their behaviors appear very different from our own and can interfere with learning or become dangerous, they are viewed negatively by many people. Changing our perception about these behaviors may help us respond to them in a better way.

There are a number of ways to intervene. Keep the child involved with others during the course of the day. Help him/her contain the behavior, or engineer the environment to make the behavior safer. Schedule times in the day for your child to engage in the preferred activity. Look at ways the behavior can be adapted, so it will appear more "normal." Use the information these behaviors tell you about your child's preferred channels of sensory input, to develop recreational and social pursuits that may be enjoyable for him/her, even if these activities will not entirely meet his/her "leisure" needs. Finally, accept that you will probably never completely extinguish
the behavior without having it replaced by another self-stimulatory behavior. Self-stimulation is common to all humans and serves an important purpose.

---

**Chart - Our brain seeks out stimulation through the channels of our senses. Each of us seeks out this stimulation in a variety of ways. Society accepts some of these behaviors without question, yet feels very differently about others. In some cases this acceptance seems to be arbitrary. The chart shows examples of how individuals typically fulfill this craving for stimulation and how some self-stimulation behaviors of children with DeafBlindness parallel these behaviors.**

<table>
<thead>
<tr>
<th>Sensory Channels</th>
<th>Miss Manners’ Guide to Appropriate Self-Stimulation</th>
<th>Creative Variations Which May Plug You Into a Written Behavior Plan</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Tactile:</strong> Information received by touch (throughout body surface) includes sensitivity to light touch, pressure, pain, and temperature.</td>
<td>Twirling hair, drumming fingers, playing with condensation on a drinking glass, fingering fabrics, rubbing eyes, pulling on beard</td>
<td>Pulling hair, lying in front of the air vent, slapping face/ear, playing with spit, rubbing head</td>
</tr>
<tr>
<td><strong>Proprioceptive:</strong> Information about the relative positions of parts of the body. This information comes through sensations arising in the muscles, joints, ligaments, and receptors associated with the bones.</td>
<td>Snuggling in quilts, cracking knuckles, jiggling/crossing legs, sitting on your leg</td>
<td>Burrowing into furniture, wrapping arms inside tee-shirts, wrist flapping</td>
</tr>
<tr>
<td><strong>Visual:</strong> Information received through the eyes/seeing.</td>
<td>Gazing at your fingernails, hands and rings, watching television without the sound, window shopping, flipping through magazines, eye pressing</td>
<td>Flicking hand in front of eyes, flipping pages of books, light gazing, playing with transparent or shiny objects, eye poking</td>
</tr>
<tr>
<td><strong>Auditory:</strong> Information received through the ear/hearing.</td>
<td>Humming/whistling, tapping a pencil on a surface, playing background music</td>
<td>Vocalizing or making sounds, banging on objects, tapping objects together next to ear</td>
</tr>
<tr>
<td><strong>Olfactory:</strong> Information received through the nose/smelling.</td>
<td>Wearing perfume, sniffing magic markers, scratch and sniff stickers, burning incense</td>
<td>Rubbing feces on the body and smelling, smelling other peoples' hands or shoes</td>
</tr>
<tr>
<td><strong>Gustatory:</strong> Information received through the tongue/lips, tasting. Closely tied to the sense of smell.</td>
<td>Chewing flavored toothpicks, sucking on mints/hard candy, smoking, chewing on hair, sucking on pens/jewelry</td>
<td>Mouthing objects, chewing on hair, sucking on fingers, licking objects</td>
</tr>
<tr>
<td><strong>Vestibular:</strong> Information received through receptors in the inner ear which enables us to detect motion, especially acceleration and deceleration. Closely tied to the visual system which provides information to the vestibule located in the inner ear.</td>
<td>Rocking in chairs or rocking body, amusement park rides, dancing, twisting on bar stools, skating, sliding</td>
<td>Rocking body, spinning, twirling in swings, head rocking</td>
</tr>
</tbody>
</table>
Resources and Additional Reading


Wiley, David. It's more than a game: acquiring skills for leisure time, *VISIONS*, TSBVI, Outreach Department, May 1993