

Making Sense of Sensory Integration:

How might family life be affected?

The fourth in a series from the audiotape *Making Sense of Sensory Integration* with Sharon Cermak EdD, OTR, FAOTA in conversation with Jane Koomar, PhD, OTR, FAOTA and Stacey Szklut, MS, OTR.

For biographical material on the presenters please refer to the first installment of this transcript.

Dr. Sharon Cermak: How do sensory integration problems affect family life?

Stacey Szklut, MS, OTR/L: Sensory integration problems can have a very big impact on family life. First of all, children will often try to really hold it together at school, where they know their performance is really important and they want to fit in with the group. Sometimes children, who may not manifest many of their sensory integration problems at school, will fall apart when they get home. They know they're in a safe environment and the impact and stress of their day may come out.

There are so many things that a family does that can be impacted, like sitting quietly to eat at meals. Some children with sensory integration problems just have a very difficult time sitting still, often due to low muscle tone and also needing to move to keep their sensory systems going. Also, they may have clumsiness in using utensils, or picking up their cups. So just getting through meal time can be very stressful for parents who feels like their child is beyond the age where she should be spilling things. Children may also be very sensitive to taste and smells and have a very limited repertoire of what they'll eat . This becomes another stress point, particularly when you go to relatives' homes and there are certain expectations about what your child will eat.

Dr. Jane Koomar: Relatives may say, "Why don't you just control your child? Why don't you just make them eat these things?" And so it can set up dichotomies within families that are very challenging to deal with, too. The stress on the parent is incredible, particularly a parent who doesn't have an understanding yet that this is something real for the child. Since the world is not a place that makes sense or because of his difficulties in processing sensory information, the world may be a frightening place.

Children with sensory integration disorders often respond by trying to control what's happening. These children can be very controlling in home environments and very demanding. The balance between managing behavior, which is often difficult for any parent, now coupled with a child who's having more difficulty with the environment, can be very difficult on a family unit as a whole.

The other thing I think of is the stress on the parents as they try to provide the child with services, particularly if a child is having difficulty at school. I've seen a lot of parents very stressed by trying to find the services that will really help their child academically be successful. The amount of time and attention that goes into that can really put a strain on their relationship as well. On the other hand, I've seen families pull it together because of their intuitive understanding and because of their willingness to really see the child as a child and their ability to adapt the environment. So I think you can see stresses go either way, where it pulls a family unit together, or puts a lot of stress on the unit.

Dr. Sharon Cermak: Jane, can you talk a little bit about some of the bathing, dressing and other activities of daily living that a family might experience in addition to mealtimes?

Dr. Jane Koomar: These are all important areas that can cause a lot of difficulty for families. Take bathing, for instance. Children who are sensitive to touch and temperature may be very bothered by taking their clothes off and getting into the water and then back out. If they're splashed at all, they may be very bothered by hair washing, both from the touch they receive as well as having their head tilted backward because they feel very insecure in space. Frequently parents find they need to structure the bath time in a very specific way so that the child can do it without tantrums or it being very stressful.

With dressing, many children have a lot of difficulty and will ask for help. It can be a real issue in the morning. You have several children, you're trying to get everyone out the door and this child who may be able to dress is not really staying focused on it or doing it in a very slow manner. It can create a lot of conflicts, especially before a parent understands the child is truly having difficulty. One of the things that often happens is that a child with sensory integration problems, if they really put 100% effort into doing something, they get it done. But none of us can put out that kind of effort all the time. When a parent or a teacher sees a child do something once in awhile, they think "Oh, she can do it and maybe she's just not motivated, she's just not trying". So parents often attribute a behavioral reason when a task is hard or left undone.

Dr. Sharon Cermak: So you're saying many of the things that look like behavioral issues really may reflect problems in sensory integration?

Stacey Szklut, MS, OTR/L: I think it's really helpful for families to understand that, and for relatives too, who may be expecting the parents to discipline a child. It may be that the parent is just protecting the child who really needs help.

Dr. Jane Koomar: I think very often when a child has sensory integration problems you will hear people saying, "Oh, his mother is too protective". I find, by and large, a parent who responds appropriately to a child in need, who does need extra protection, does need extra help.

Dr. Sharon Cermak: What about things like transitions in family gatherings and parties. How could sensory integration problems be manifest in those activities? Stacey?

Stacey Szklut, MS, OTR/L: These can be very challenging situations for a child who's not processing information well. There's often a lot of noise, chaos, and a lack of predictability. Because the sensory world does not make sense to them, children with sensory integration disorders would much prefer an environment that's very predictable and the same from day to day. So, in terms of family gatherings, suddenly everything is different. Children are not only bombarded by new sounds, people and faces, they've lost their predictability and routine.

Transitions also pose a problem. Some children will be fine if the parent structures the day so that the child knows what to expect next and is given enough time to successfully complete those tasks. When suddenly the environment changes and the child is not able to adapt to that change or transition, the child becomes flustered, frustrated and upset.

Dr. Jane Koomar: Along those lines, so many things that are really fun for families, like going to Disney World or taking a trip skiing for a weekend, can be nightmares for a family with a child with sensory integration difficulties. You can end up feeling very different as a family and upset with your child because you want to do these things that you feel should be fun and pleasurable. In fact, they're not and they create chaos.

Dr. Sharon Cermak: How might a child's sensory sensitivities affect their relationships within the family?

Dr. Jane Koomar: Sensory sensitivities can impact in a variety of ways. Certainly *touch* is one with striking impact. A child might tend to pull away from being touched- only likes hugging and cuddling if he initiates it. That can be very difficult for parents. Also, it's not uncommon for one or both parents to have some of the same issues that the children do. So, you sometimes have interactions where it's difficult to get together for intimacy and hugging because both people want it on their own terms.

Sensory sensitivities can also impact in terms of *noise* level at home- not wanting the TV or the stereo at the same level as another sibling. Sometimes, we've encountered some major problems with sensitivity to *smell*. A parent will wear an after shave, perfume, or deodorant that is very offensive to the child, which will sometimes cause the child to start hitting the parent. This can create major barriers to their relationship until its figured out.

Stacey Szklut, MS, OTR/L: I recently evaluated a boy who was very sensitive to the sound of his sister's voice, particularly when she would sing. This was a huge family issue because every time his sister moved into a higher timber voice or began to sing, this boy would cry and usually ended up hitting and screaming at his sister. I've also had an experience where a child was very sensitive to his teacher's voice and really complained to his mother that he didn't like it when his teacher talked.

Dr. Sharon Cermak: Do you think most children are aware of what it is that bothers them?

Dr. Jane Koomar: I think sometimes they are aware of it and other times they are not. They're just aware of an agitation or a feeling that they are slightly out of control or they are not understanding what's happening in their environment. I feel our role as clinicians is to help them identify and understand what is happening for their own bodies and try to provide strategies so they can be more in control of what's happening.

Dr. Sharon Cermak: I agree. I find that even the most articulate children who can describe how bothered they are by certain sensations, for instance, how frustrating it is to not be good in gym class, can on certain days and times be overwhelmed enough that they can't put their discomfort into words. They become emotional and may act out. Only later when someone is helping them talk it through might they realize, oh yeah, it was the smells we had in the cafeteria today and then what happened at the school assembly and it all added together.

Stacey Szklut, MS, OTR/L: I think it really is important to help children understand what's going on with their bodies so they can understand why they're responding certain ways. My own son has had mild insecurity to movement, particularly when his head was tipped back, something we therapists call *gravitational insecurity (GI)*. One time he and my two younger daughters were on swings and they were really enjoying leaning their heads back and swinging, feeling the breeze blow through their hair. I looked at him because we've talked about his discomfort and said "Gee, Mike, I bet you'd like this." He looked at me and said "It's such a pain to be 'GI'. I'd rather have tactile defensiveness." It was really interesting to hear his perception. He said things like "I don't like to do those backwards things" and he was talking about backwards somersaults. He really had a good understanding of what it was that was bothering him.

