

Making Sense of Sensory Integration in CdLS

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All of the information we receive about our world comes to us through our sensory systems. Many of the sensory processes take place within the nervous system at an unconscious level; we are not usually aware of them.

Humans have five traditional senses that are used by the brain to interpret and make sense of the environment; hearing, vision, touch, taste and smell. Sensory processing is how one takes input from the environment and their bodies to determine if or how they need to respond. Usually the nervous system can automatically filter out unimportant stimuli and provide enough internal regulation for the person to maintain focus and attention in spite of these external influences.

Besides having information from the five traditional senses, there are two powerful senses of the vestibular and proprioceptive systems. The vestibular system involves balance and the sense of movement within the inner ear, which gives an awareness of where the person's head and body are in space. The proprioceptive system involves the receptors in the joints and muscles to determine where the body parts are and what they are doing.

Individuals with Cornelia de Lange Syndrome (CdLS) often experience different degrees of difficulty with processing the information they receive from these seven senses.

Organization of the sense systems begin to function very early in life, even before birth. The basic senses are closely connected to each other and they interact with other complex systems of the brain as development proceeds. This organization of the senses is termed sensory processing.

A child with a sensory processing disorder will show more than one of the following signs:

- Overly sensitive to touch, movement, sights or sounds; irritable at being held, avoids certain textures of clothing and food
- Under-reactive to sensory stimulation; may seem oblivious to pain and body position
- Activity level that is unusually high or unusually low; may fluctuate from one extreme to the other
- Coordination problems, which can be seen in gross or fine motor activities
- Delays in speech, language, motor skills, or academic achievement



- Poor organization of behavior; impulsive or distractible
- Poor self concept; avoids tasks that are hard or embarrassing

Occupational and physical therapy, provided by qualified professionals who have received training in sensory processing theory and treatment, can help your child. Your child will be guided through activities that challenge their ability to respond appropriately to sensory input by making a successful, organized response. Therapy will begin with an evaluation by a qualified occupational or physical therapist, which may include a sensory assessment tool, such as the one by Winnie Dunn in *The Sensory Profile*. As part of the evaluation, the therapist will observe how the child responds to different stimuli in his or her environment.

From this information, the OT creates a “sensory diet” created to meet specific sensory needs. Some children need a specific sensory diet, and others may benefit from sensory strategies or tools without specific timed interventions. This diet is a group of sensory activities used in school and at home to prevent behaviors that often accompany dealing with sensory issues. This diet can be used either with a strict schedule or at frequent intervals as needed.

The sensory activities are intended to help the student obtain the best possible level of alertness to improve task focus and as strategies to manage stress. These activities are not to be used as a reward for good behavior. These activities should be incorporated in the child’s daily routine. Adults should try to read the student and provide the sensory diet before the inappropriate behavior begins. The OT should write this sensory therapy into the student’s Individualized Education Program (IEP) each year it is needed. Sensory strategies are used regularly without being in the IEP; additionally, sensory diets may change throughout the year. The OT can also advise and teach parents the therapies to use at home.

Where to find more information:

- The American Occupational Therapy Association, Inc: www.AOTA.org Phone: 301-652-2682
- Web site: Kinnealey, M., and Miller, L.J. (1993). Sensory Processing/Learning Disabilities. http://209.169.7.42/pdf/kinnealey_miller.pdf

