



# CdLS Foundation

Cornelia de Lange Syndrome Foundation, Inc.  
*Reaching Out, Providing Help, Giving Hope*

## Helping Children with CdLS Stay Focused in School

*answered by Mary Morse, Ph.D. (updated 8-10)*

**Q.** My child's teacher reports that he has difficulty moving from one activity to another. She also says my child is easily distracted and often becomes anxious during school activities. Do you have any suggestions?

**A.** By and large, attention is related to the ability to manage states of arousal which, in turn, is both a neurological and a motivational function. Neurologically, a child needs to be prepared to receive, organize and interpret incoming sensory information. To do this involves, (a) the ability to withdraw attention from some other event in the environment (i.e., preservative behaviors), (b) knowing what to attend to and, (c) inhibiting competing events occurring at the same time. Simultaneously, no one can sustain attention if they do not find the activity motivating. When children perceive the activity as pleasurable and interesting, they find the activity reinforcing. Young children must have immediate payoff.

Concurrently, when children become anxious, they engage in more stereotypic behaviors. In my experience, children with CdLS easily become anxious. Some may withdraw into their own personal world, while others demonstrate a range of frenetic motor movements -- running, twirling, sweeping items off shelves, etc.

From an educational perspective, children seem to do better when they can anticipate what is to occur and when they have some type of communication system. They also seem more settled when they are not rushed and when they have a sense of competency as related to the task.

I suggest controlling the type, intensity and duration of sensory information so the demands of the task are clear -- especially for new sensory-motor tasks. When children feel overwhelmed, the tendency is to revert to behaviors that provide comfort; such as twirling or staring at their hands. I also suggest providing sensory input gradually to avoid over-stimulation, recognizing that sensory input may be cumulative. An exaggerated response may be a result of the whole day's input and not just a single touch or type of sensory experience.

### **Ideas to Assist School Staff**

I am in hopes that some of the following ideas will be of help to you and your son's teacher: Your child may benefit from "calming" activities that many occupational therapists (not all) are trained in. I have seen tremendous changes in hyperactive type behavior when these calming techniques are used at regular intervals throughout the day. Indeed, the techniques are referred to as a "sensory diet."



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It may be helpful for your child to have an area to go to for "sensory-break." One of the children with CdLS I see regularly has a small blocked-off area in the classroom. This little den has no visual stimulation (all gray), blocks out a lot of classroom noise, has many soft pillows, and a weighted vest is available. When he feels anxious, he goes into his little area. We know the level of his anxiety depending on whether he reaches for the weighted vest as a request to place it over him or if he just settles into the pillows. The technique does not work for all children, but this child has learned to recognize when he has had enough and knows what he can do about it. Sometimes he needs encouragement to come out but, as time goes by, he uses his den more and more appropriately. This technique seemed preferable to running frantically about the room and banging his head on the floor. The area was never used as punishment.

## **Schedule Systems Can Help**

Schedule systems work extremely well with children who may have a difficult time perceiving routine and/or those who become stressed when the routine is changed and/or those who may have difficulty understanding the full range of language used to describe what is going to occur.

There are many different schedule systems, the choice of which depends on the child's strongest level of receptive communication (not developing level), i.e., objects, object-symbols, photographs, drawings and/or printed words understanding. The system is most effective if it is (a) physically accessible to the child but in a quiet area, (b) when teacher and child review what activities will be done during the day each morning (scripting the name label of each activity) and (c) literally showing the child if the schedule changes via words and changing the object/ object-symbol or photograph sequence. The Foundation office has a general description of "calendar systems" prepared some years ago.

Introduce new experiences carefully. Choose activities and materials based on other familiar activities and materials. Teaching a new motor pattern by using familiar materials or using new materials while enjoying a familiar motor pattern helps to make new experiences less scary.

## **Organize Activities in Sequence**

Organize activities so your child literally can see what needs to be done and in what order. For example: In a pasting activity there are three major steps-selecting the material to be pasted, getting the paste onto the material and placing the pasted material onto the designated background.

Create an activity sequence setup in a defined area (i.e., non-patterned place mat or work tray) with a clear sequence of steps, a clear beginning and ending, and motor-friendly materials. The adult facilitator uses his/her own hand in a slow, theatrical manner to demonstrate how to do the activity. It is especially helpful when the demonstration shows



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the rhythmical aspect of the activity and the vocal language corresponds to the motor movements.

For example, the adult might perform the individual motor movements and simultaneously say "pick, dip, paste," then pause to allow your child time to process what he saw and heard. The adult repeats the activity several times and then pauses at the beginning with his hand held in such a manner to suggest that the child join in.

If he feels the need to ride the adult's hand to understand the motor acts, I suggest allowing it for several rounds, keeping the language and the movement to the same rhythm. After several rounds, say "(Name of child) do" and use your own hand to point to the steps. Gradually fade all assistance.

I have observed that activities such as circle are sometimes difficult. If that is so for your child, he may find that listening to action songs, watching others, maintaining position in space and having his hands moved to be overwhelming. In this situation, it might be better to allow him to get used to the routine and the activity without active motor participation. Later, assist him with the motor movements - simplifying them initially. Such assistance might be more effective if the adult sits behind your child and allows him to ride the adult's hand.

This hand-under-hand technique will allow him to feel the natural motion without having the tactile interference of someone holding onto his hand. Additionally, your child can monitor his own state of arousal by keeping his hands on the adult or removing his hands.