

## **DEVELOPMENTAL NEEDS OF CHILDREN WITH CdLS**

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Each child with CdLS is a unique individual who brings to the table a complex array of strengths and challenges, along with their own personality. Thus there can never be one program that is best for children with CdLS. The goal of this article is to provide guiding principles to help prioritize the varied developmental, therapeutic and educational needs of children with CdLS.

In order for a child to be ready to learn, he needs to feel well and be healthy. For a long time, children with CdLS were known for self--injurious behavior, which has decreased greatly once doctors recognized the high incidence of reflux and began treating it. If a child seems irritable, extra---sensitive to the world around him or uncomfortable, it's necessary to rule out underlying medical problems, such as reflux, poor sleep, toothache, or constipation, to name a few possibilities. Even when a child with CdLS has the ability to communicate with words, he doesn't always use his words to describe pain. How he registers pain can also be unusual: small irritations can be excruciating, while more painful experiences hardly register. Thus to ensure good health, your child needs a doctor to regularly review his health and treat medical problems appropriately.

The second priority relates to developmental care. This means ensuring that foundational skills in the areas of motor control, communication and socialization are nurtured appropriately and progress is tracked. Without foundational skills, more advanced skills cannot develop well.

When a child's physical or cognitive limitations prevent the ready acquisition of a foundational skill, there may be ways of compensating for that lack of ability so further skills can begin to develop.

Early in development, motor control involves postural stability, usually acquired in the first year of life. Postural stability is needed to support the head and neck to eat comfortably, use hands to manipulate objects, provide core stability for crawling and walking, and make face---to---face contact to communicate and socialize. Visual motor coordination and fine motor control are keys to manipulating toys, performing daily living skills and developing writing.



To compensate for poor motor control, stable seating and a tray in front of a seat can reduce the amount of energy a child expends to maintain posture. Adaptive utensils and toys can ease the coordination needed for drawing, feeding and playing. Once a child can get around and reach for whatever interests him, a whole new world of exploration opens. If a child can't get around or reach for objects because of a missing limb, you need to bring the world to him. Modern technology has opened many doors for children with mobility limitations. Finding a therapist with the knowledge and creativity to serve these needs is important.

Another foundational skill is communication, which is accessing others not only to get one's needs met, but also to share interests, feelings, experiences, hopes, and dreams. Later, language helps children connect with others, maintain friendships, and effectively problem solve.

Many children with CdLS have trouble figuring out how to effectively communicate with others. Sometimes this is because language is too abstract and more basic means of communicating are needed. For others, difficulty communicating can be related to having autism, where communication difficulties are related to impairments in social interaction. Forms of communication that need to be considered when children can't use words to communicate include object choice, photographs or pictures, simple gestures, or sign language. When children have severe levels of disability or autism, these modes of communication need to be practiced over and over again before a child 'gets' it.

Social engagement is also foundational to learning. From infancy, babies prefer to look at faces more than at objects. By 12 to 18 months, they are skilled observers of the behaviors of others, and imitators of the people around them. They assume our stances, gestures, tone of voice, and our good and bad habits. We even start seeing ourselves in their play. They pay attention to our voices and pair the words they hear to the direction of our gaze. They enjoy peek-a-boo, chase and ball play, which are foundational skills for back and forth play, taking turns and, later, social interaction and conversation.

When children seem less interested in people around them, parents and therapist need to find activities that motivate social interest and communication, e.g. physical play, roughhousing, tickling, music, or taking turns with a preferred activity (e.g. if they like to make razzing sounds, you razz then they razz and you razz then they razz for what seems like forever). When children play repetitively with toys, and avoid



pretend play, they need to be taught appropriate play. When they're not interested in kids their age, play with peers needs to be structured and facilitated.

The last priority includes intervention and environmental support. Therapists need to identify the child's strengths and use those strengths to optimize learning. They also need to identify areas of disability in order to help compensate for shortfalls and remediate them. The art of intervention involves making therapy motivating, fun and a part of everyday routines.

Environmental support includes providing a structure that is calm and organized in a way that your child can best maintain readiness for learning. Structure can include a schedule to assure time is set aside for work, playtime and relaxation. It also means organizing living spaces to allow ready access to needed materials, but to have other materials put away in order to promote attention to the relevant activity, and minimize distractions.

Finally in any therapeutic interaction, be mindful of what the goal is during that particular activity. If the goal is back and forth play, don't worry about posture. Although therapy becomes a part of you and your child's lives, it's important that you don't allow it to take over your lives. Your child needs time to rest, as do you and your family. Not every activity needs to be educational; it can just be fun.

*Learning is a process that continues throughout life. Patience will be needed. A few steps backwards and periods of plateau are to be expected. Small steps forward are to be celebrated. Long plateaus or persistent regression should not occur and if they do, the therapy team, educators and physicians need to look closely for a reason. Remember, the ultimate goal is for your child to reach his potential while maintaining mental wellness, a good quality of life and happiness while getting there.*

