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Occupational Therapy and CdLS: Building on Strengths for a Lifetime

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For many of us, the term “occupational therapy” is confusing, especially as we search for its relationship to children. Is it to assist our child in learning an occupation by dividing the learning process in steps? Is it to develop an occupation by helping our child to expand his/her knowledge as it pertains to the activity on hand? Is it to provide assistance in learning an occupation by using technology, assistive devices, external support? To a certain extent, yes, it is all of that and more. The child’s ‘occupation,’ from the time of birth, is to develop, to learn, to play, to become independent, to be an active participant of a family, of a community. As such, then, occupational therapy will assist a child to develop and/or refine skills that will last a lifetime.

Occupational therapy is both an art and a science. It is defined as a profession that provides skilled intervention or treatment that helps an individual to develop, regain, or maintain skills needed to participate in all aspects of life in a meaningful and satisfying way. The practice of occupational therapy (assessment and intervention services) is provided by licensed occupational therapists. In many states, occupational therapy assistants will perform many of the services prescribed. These services will be based on a plan of care that uses sound clinical judgment informed by science, which emerges from research. At the time a child is diagnosed with CdLS, the initial referrals and assessments will center often on the immediate needs of the child. Once the child is medically stable, we can start identifying the other areas in need of intervention.

Meet Jack. Born at 36 weeks gestation, this wonderful boy was born with CdLS. With no major medical issues, Jack went home with his parents.

The occupational therapist will look at the physical needs of the child—the function of his/her upper extremities, the baby/child’s muscle control, posture, breathing pattern, and suck and swallow skills.

We will also look at the developmental milestones such as: ability of the child to bring the extremities to mid-line and the hands to the mouth, rolling over, following a moving object, crawling, moving from crawling to independent sitting, standing, walking. In some instances, the identification of passive exercises to stretch those muscles that may be tight, could/should be included. Often, a physical therapist will be responsible for the stretching exercises of both upper and lower extremities.

As the baby turns into a toddler and young child, these physical strengths and needs will continue to be monitored. The possible need for assistive devices that will allow the child to be more independent in activities of daily living will also be explored. The occupational



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therapist may indicate the need to explore adaptive splints. There are different types of splints. Some splints are used to passively stretch a digit, or a limb. Other splints are meant to assist the child in maintaining positions, to hold tools, to extend the reach.

Remember Jack? He was referred to Early Intervention Services. The occupational therapist in the team evaluated Jack and noticed that his upper extremities did not have the physical capabilities to meet at midline. It was also noted that Jack had a difficult time holding his head up. His suck was weak and he seemed to get 'tired' easily. The occupational therapist helped the parents understand the importance of holding Jack adequately so as to encourage development. The parents were encouraged to speak to Jack, to play with him by holding him close, by singing to him, by touching him.

The occupational therapist will look at how the child receives information from the environment. Are all senses ready to be stimulated and alerted? How does the child understand this input? Will the child be able to use this information to modify his/her behavior? Is the child able to maintain a self regulated state so that he/she can play or will they be fuzzy, difficult to calm? Can they 'motor plan' their moves so they are efficient and accurate in their moves? The theory of Sensory Integration, developed by A. Jean Ayres, PhD, OTR explains how sensory processing assists us with our daily life function and learning. The term sensory integration is used to explain what happens to our body when all senses work together producing a picture of who we are, where we are, and what is happening around us. It also helps us stay alert and ready to learn. For most of us, this brain function happens automatically; we are not aware that it is happening. Children expand on this skill as they complete 'ordinary activities' like playing and eating or as they explore their world as they move. Still, for others, the process of sensory integration is not an efficient one, it demands extra work from the individual and there is no guarantee it will work. In this case, the individual will be identified as experiencing dysfunction in sensory integration. When a child with CdLS already experiences difficulties in receiving information from the environment such as touching objects, moving in space, hearing sounds and/or alerting to noises, gathering distorted information through their visual system, they will more than likely experience dysfunction in sensory integration.

To work in this area, the family will need the assistance of an individual trained in sensory integration. This professional, usually a physical or an occupational therapist, and in some cases a speech and language pathologist, will share with the parents specific techniques that will assist the child in alerting or calming the systems to the level that the child will then be able to use this information in planning and executing motor skills, as well as staying modulated.

Jack has continued to grow and develop. The occupational therapist has identified a sitting arrangement that assists Jack in having his hands come to midline to play and to prepare him for when it is time to feed himself and write. The occupational therapist has also shared with the parents the importance of moving in space. A therapy ball has been introduced to the

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home program. Jack's parents learn how to encourage development by placing him on the ball. They learn the importance of sharing with Jack what loud sounds are all about: "It's the vacuum cleaner, Jack. It will go away as soon as Dad finishes cleaning the carpet." Jack is learning to receive the sensory information from the environment, integrate it, and learn from it.

The occupational therapist will look at how the baby/child is able to engage and share with others. This part of social-skills development has its initial stages when the child is a baby. We know that the physical and environmental issues affecting the baby will influence how they are able to engage with others. It is therefore very important that we assess all areas of development as we look at the total child.

Jack is also learning to use gestures to communicate not only his wants and needs, but also his emotional state. His parents are guiding him through maintaining back and forth communication in a relationship-based model.

As the child continues to develop, the occupational therapist will maintain a close eye at how this wonderful person absorbs the information needed to develop his/her cognitive skills. Once more, the need for assistive devices and adequate positioning will be assessed. Equally important, the occupational therapist will continue to encourage the development and integration of all senses to support higher levels of learning.

Jack gets to preschool. His parents have been looking forward to this day! They have worked with their team to assure that he can be a happy, interdependent, productive little guy. Jack is ready. He knows that his team of supporters will be there for him.

The "Jacks" and "Jackies" of the CdLS community benefit from the support and guidance both family and professionals can provide them. As professionals, we also need to guide and educate other professionals who are not familiar with CdLS. We will find many more of these professionals as Jack grows. We will find them in the school system, we will find them in the pre-vocational trainings, we will find them in restaurants, and at church. It is our responsibility to share with them how beautiful our children are.

Jack is now a happy, productive, independent young man