



# CdLS Foundation

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

## Pathways to Independence

by Bruce Cleinman, M.A., Family Service Coordinator

*Operating at the highest level of independence is a goal for all children and one that continues through adulthood. This becomes especially challenging for individuals who have limb differences, as resourceful and creative solutions to accomplish the activities of daily living must be explored and often modified. Adaptive equipment to facilitate communication, feeding, hygiene or personal care, and recreation or leisure activities are just a few of the areas that can be targeted. While the journey to greater independence through the use of adaptive equipment or technology can be fraught with discouragement, confusion and disappointment, it is not without its rewards and victories, as six families recount in this article.*

### DENISE

Through the years Kena and Bill have used many adaptive devices with their 28 year old daughter to promote her independence. "The two devices that have probably had the biggest impact on Denise," Kena reports, "are her prosthesis and her swing."

Denise was fitted for her prosthesis at two. Her first ones were just arms with mitten-like hands that did not open. These were still good for holding cookies and toys. Then she had a pair with hooks. These were a little hard for her to operate because the hooks opened with a string that ran across her back. Then they progressed to the myoelectric prosthesis she has today. These have very real looking hands and operate with a micro switch placed inside the arm and activated with her finger.

Another device that is truly Denise's most prized possession is a net swing. It is really just a hammock with both ends and the back brought up into the hook. It has a spreader bar across the top and a solid cushion to form a swing. The swing is attached to a long chain and suspended from the ceiling with a swivel on an eyehook. It is attached to a hook in the middle of the family room so that Denise has a large area to swing. Bill also made a three-legged frame that they take when they go camping, enabling the swing to be set up anywhere. This is one of the few activities that Denise can do by herself and she absolutely loves it. "It has been the best thing we have ever bought her. If other parents are going to try this, be sure the eye bolt in the ceiling is very secure and check it for wear frequently, because the swinging does wear the bolts out."

Denise' family also used an adapted spoon that fit in her earlier prosthesis, allowing her to use a scoop dish to feed herself, and an M&M dispenser (filled with Fruit Loops). She quickly learned how to pull down the arm to acquire a snack for herself.



# CdLS Foundation

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

Kena notes that their philosophy with Denise has always been to "try almost anything and she will show us what she is capable of doing. My husband is very inventive, so we have been able to adapt many things through the years. But schools, therapists, and books of special needs equipment are also very helpful. If you have a need for something you must keep asking and searching until a solution is found."

## SARA

Sara is 21 years old. When she was five, she attended a regional program for special needs children, where the teacher and support staff always tried to include her in the normal tasks the other children were doing. This involved constant brainstorming and collaborating, especially with the occupational therapists, who were determined to get her to be as independent as possible. They started with feeding, because Sara loved to eat and that was very motivating for her and provided her with immediate gratification. The OT used splinting material, heated it to form a cone-shaped splint to fit around Sara's left arm and finger. She took another small piece of splint material and attached it to the splint in the shape of a tunnel that allowed a spoon handle to fit in. They curved the arm of the spoon so the food remained level when Sara brought it to her mouth, and attached a Velcro strap over her elbow to keep the splint on.

She became a pro in no time. Dishes and bowls with sides were put on non-slip mats so she could eat independently. Soon, they made another splint to accommodate a scoop so she could feed the class rabbit. They added a drumstick and she was drumming in music class. A marker placed into the splint enabled her to paint at the easel. She was using her limbs like the other kids.

Sara's family has also had good luck with a clip added to the splint to hold a piece of sandwich, cracker, etc. Now the school is using a lazy-susan device, placing three or four items on it to choose from. Sara loves spinning it to get to her favorite foods during lunch.

## DEVIN

Lynnette and Dean investigated the use of adaptive technology for their 13-year-old son, Devin, because they wanted him to be as independent as possible in the areas of feeding and drinking. Lynnette explained, "We felt he could do so much more if we were just able to give him the right tools."

They tried different approaches. Lynnette sewed homemade straps and used Velcro for one version of a feeding tool. Then Devin's OTs became involved and had them try things that worked for other children with CdLS. They explored many different versions of a feeding cuff, spoons, angles, feeding platforms, bowls, etc.



# CdLS Foundation

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

Devin's parents used the occupational therapy and physical therapy departments at school and their local Shriners Hospital to develop or refine these devices. Devin's feeding cuff is somewhat crude and cumbersome, but it gets the job done. Because he cannot scoop independently, due to the position of the spoon, Lynnette places his food on the spoon and he uses his other finger to guide it to his mouth. Devin now eats in the cafeteria with other students, and Lynnette reports that he has become more mature in their presence. He also has an adaptation of the feeding cuff for drawing and painting. He uses a name stamp with a loop on it to put his name on his papers instead of having someone else do it for him.

Lynnette and Dean's advice to other parents is to seek out every available resource. "The best information we got was from other parents. Never stop trying. If 100 things don't work, chances are number 101 will!"

## **BRIANNE**

Karen and Larry explored adaptive technologies for 11 -year-old Brianne to enable her to be able to be more independent when eating and to provide her with a way to communicate her needs. They sought help from everyone who works with Brianne, including her occupational and speech therapists, hearing teacher, teacher, and one-on-one aide at school.

The aT was instrumental in developing her eating utensil, while the others were helpful in developing her communication device. When they described what they wanted for the communication device, their aT made it for them. It consists of a board with removable pictures. When Brianne wants something, she brings that picture to her parents. The communication device works very well, Karen reports, when Brianne chooses to use it.

Brianne also loves playing with her light toys, which she activates with an adaptive switch. The toys were just a fun thing for her to do with her switch and reinforced "cause and effect," which she learned long ago.

Karen advises parents and caregivers to keep working with their child's therapists and staff that work with them at school and to brainstorm on the best device for your child.

"We tried some very expensive technological communication devices for Brianne, and this very simple one made by her aT has worked the best for us."

## **WILL**

Eleven-year-old Will's parents, Beth and Mark, sought out several adaptive technologies for Will with the hopes that his developmental skills and independence would increase.

They tried standers, communication devices, feeding devices and cuffs for painting, etc.

Most times they had input and assistance from various therapists in developing these.

Funding for most, like his communication device, wheelchair, and stander, has come from Medicaid, and school has helped with other things. They have also used a local engineering

302 West Main Street, #100 • Avon • CT • 06001-3681

800-753-2357 • [www.CdLSusa.org](http://www.CdLSusa.org)



# CdLS Foundation

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

school to create a feeding device and adaptive tricycle. They have grant money for special projects that their senior engineering students work on. The feeding device the students created was designed especially for Will.

According to Beth, not all of the equipment has been successful. The feeding device was designed with too much weight and Will doesn't tolerate it well. The communication device was too complicated and heavy and Will tended to use it as a toy. As soon as he got a wheelchair to give him sitting support, he learned to sit on his own. When he got a stander, he learned to stand on his own. So far none of the devices have really improved Will's ability to do more. "He tends to learn to do things in his own time in his own way."

Will's parents advise parents considering adaptive equipment to experiment and strive to find ways to help your child gain independence, but to remember that it's not always practical to fit these devices into everyday life. Also, "keep it simple. The easier [it is for everyone] to use and incorporate into life, the more likely it will bring about the benefit hoped for."

## ADRIAN

When eight-year old Adrian was only six months old, his parents, Beth and Alejandro, visited the state run Pediatric Limb Enhancement and Amputee Clinic to explore options for increasing their son's self-reliance. Since then, they have been back every six months. Beth reports that the clinic has helped to adapt virtually anything presented to them, including an adaptive rocking horse, walker, and bicycle. They have also worked with three different devices for his right arm. When he was very small, it was mostly for crawling, but as he has grown, they have become more and more fine motor oriented, allowing him to accomplish a host of tasks, including brushing his teeth, painting, playing musical instruments, mixing pudding, and cutting cookie dough. "We have dreams of a terminal device with pincer capabilities," Beth writes, "and Adrian's prosthetist has a lots of great ideas." The main thing, she advises, "is that we all need to think outside the box..."

Anything seems possible with the right people on your side! I would welcome questions from families."

*Adaptive devices can sometimes open up a world of opportunity for individuals with physical or developmental challenges. In these days of technological advancement no one needs to walk the path to greater independence, freedom and self-expression unaided or alone. The Foundation has information for those needing resources and services pertaining to adaptive equipment. A warm thank you goes out to the families for their contributions to this article.*