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Camp Talk:

Listen Up - These Special Kids Have Something to Say!

by Ondine Brooks Kuraoka, MSW

Like any other summer camp, San Diego's Camp Talk is a place to make new friends, have fun in the water and learn new skills. But Camp Talk is also where kids who use communication devices can feel normal, like just one in the crowd.

All the kids attending Camp Talk need an augmentative communication device to add to their natural speech. Augmentative communication devices range from simple recorded messages activated by a switch or button to laptop computers with specialized voice output. Since the early eighties, this technology has opened the floodgates of communication to thousands of people with severe speech impairments.

Brian Emery's First Sentences

At age ten, Brian Emery of San Diego formed his first sentences with the help of an augmentative communication device, plunging into a language explosion that hasn't stopped since.

Emery does not have a clear-cut diagnosis, but developmental dysphasia seems to fit best; he can hear but can't speak. Though sign language enabled Emery to communicate with his family and teachers during his early childhood, his social circle was limited to the signing community.

Emery received a laptop communication device when he was eight years old. At first he simply explored the device like a toy, but was soon was able to use his communication device better than his parents, becoming computer literate in the process. Two years later he had achieved the pot of gold: communication with anyone and everyone!

There was just one problem: Emery felt self-conscious because he never saw anyone else using a communication device. When Christina Emery, Brian's mother, found out about Camp Talk, she knew they had discovered a missing piece of an essential social experience.

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Camp Talk was founded by Pro-Speech, a private speech therapy practice in San Diego. The day camp takes place at the Youth Aquatic Center on Fiesta Island at Mission Bay and is funded by Pro-Speech; it is run entirely by highly qualified volunteers.

Something to Talk About

Some families travel from Oregon and Washington to participate in Camp Talk , the only camp of its kind in Southern California. The campers' diagnoses often include autism, Down syndrome or cerebral palsy. The camp has a one-to-one ratio; each camper has an aide, called a communication partner, to facilitate communication across all activities.

Heidi Nebeker, a speech therapist and the director of Camp Talk, explained the reason for starting the camp. "This may be the only time during the year our campers get to see other kids using the same device they do. When they're at camp it's the norm; the other kids provide great modeling and everyone involved sees that it's very functional."

Camp Talk's goal is a simple one: to give the kids something to talk about and a way to say it. All of the communication activities are imbedded in typical camp activities.

The day begins with an opening and welcome, during which the kids introduce themselves and sing songs. There is one water-based activity every day, including swimming, canoeing or sailing. Exploring the tide pools is also popular; the kids can touch sea urchins and sometimes even small sharks. Part of each day is devoted to literacy activities. Campers might participate in a story, "shouting" out a particular line. And, of course, there are a variety of arts and crafts.

Social Synergy

The Youth Aquatic Center simultaneously hosts Camp Talk and a Boy Scout camp, creating a social synergy between the two sets of campers. Isabelle Moore of Lakeside, whose daughter Jessica, 12, attends Camp Talk, says, "The Boy Scouts were interested because the kids' devices use very sophisticated technology. They hear the audio and they see the pictures and there are so many ways to use it- it's very intriguing.

"The kids were drawn into conversation with Jessica because the device offers visuals help the communication along." The Scouts' interest fostered a sense of pride in Jessica, who felt happy to be understood and for the social opportunity. The Scouts also invited the kids to go canoeing and sailing with them, a definite highlight.

Jessica the Mermaid

Jessica, who has cerebral palsy, loved her role as a mermaid in a camp play. But the most exciting part of camp for her was seeing all the other kids using their communication devices.

"Jessica used to be embarrassed to use her device because she thought she was the only person with anything like it. At camp she began to feel more confident and started to understand that it was a tool that could work for her in an everyday setting. She now takes it with her to church, where she talks to some of her peers. The response has been really positive," Moore says.

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Inspiring Guest Speakers

One of Camp Talk's guest speakers was Jennifer Johnson, a world-class Paralympics swimmer. Johnson has cerebral palsy and uses a communication device. She is completely unable to talk, but with the aid of her device she is able to express herself with eloquence and humor.

"Some children with special needs put limitations on themselves; they have a different perspective in their approach to the world. When they see someone else who has realized their dreams, it inspires them," Moore says.

Like Johnson, most adults with severe speech impairments didn't have the advantage of this life-changing technology as children. Camp Talk's guest speakers help the kids to see that their device gives them the gift of communication; they can use it as a tool to accomplish much more than most people think, including themselves.

Emery, now 13, has attended Camp Talk for the past two summers. He has been using his communication device for 5 years. "Brian looks forward to Camp Talk every year," his mother says.

"His favorite activity is kayaking. But the best part of Camp Talk is that he doesn't feel different when he is there. Brian just wants to be like every other teenager and Camp Talk is a great place for that to happen."

Michelle Peña's daughter Jessica, of El Cajon, turns 15 in May. She has made friends at Camp Talk each year. As I interviewed her mother, Jessica pointed to her camp pages on her device, remembering fun times. "They would play communication games like 'Fishing;' they would say, 'I'm looking for a word that starts with C,' and the kids would find it on their computers," Peña says.

The campers enjoy having their say, and are able to pick which activities they want to do, whether it's sailing, arts and crafts, or swimming at the beach. Jessica, who has Trisomy 9p (an extra piece of a chromosome on chromosome number nine), often says she doesn't want to go anywhere, but when it's time for camp she's filled with excitement. This will be her fourth year; she's been attending since the Camp Talk's first session.

Time for Parents to Chat, Too

Peña was grateful for the parents' get-togethers, scheduled one hour every day before taking the kids home. "We could talk over different experiences and learn about new pages to add to their computers. They had specialists to teach us about different devices, too."

Peña had high praise for the communication partners. "Excellent speech communications students come from different colleges to help; they love the kids and are wonderful volunteers."

Nebeker says, "The best part of camp is to see the kids gain confidence in their ability to be communicators and have power over their situation." Three cheers for these lucky campers – they have something to say!

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Camp Talk 2005 Theme: “Pirates’ Treasure”

Camp Talk is open to children who use augmentative speech devices, from age six through the end of high school. This summer, the theme is “Pirates’ Treasure!”

Camps are scheduled for the first two weeks of August 2005. The camp takes place at the Youth Aquatic Center at Mission Bay from 9 a.m. to 3 p.m., Monday through Friday.

For more information and an application, log on to <http://www.pro-speech.com/talk.html> or call the Pro-Speech office at 619-574-8181. Each parent is interviewed before admission to the camp to discuss any medical needs.

Points to Consider:

According to the National Institute on Disability and Rehabilitation Research, there are 2.5 million people in the United States whose speech is difficult to understand. Of that number, 237,000 have severe speech impairments.

World-renowned astrophysicist Stephen Hawking uses a communication device. He has a diagnosis of ALS (amyotrophic lateral sclerosis, also known as Lou Gehrig’s disease).

Joanne Kaufmann, a spokesperson for Dynavox, a company that manufactures augmentative communication devices, states that only six percent of the children who need a device actually receive one.

Great local resource:

Assistive Technology Resource Center, 6153 Fairmount Avenue, Ste. 150, San Diego, CA 92120. The Center is open to the community and has a variety of augmentative communication devices on display.

For more information log on at <http://ucpsd.org/new/assistive.htm>, or contact Joy Cole, Technology Programs Coordinator, 858-278-5420.

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Ondine Brooks Kuraoka, MSW, is a freelance writer in San Diego. She offers a quote from Ray Bradbury: “We are cups, constantly and quietly being filled. The trick is, knowing how to tip ourselves over and let the beautiful stuff out.” Her website is www.sandiegofreelancewriter.com.