

# FINDING A VOICE FOR DANIEL

by Cheryl Fields, TeamRehab Report

photographs by J.T. Miller

*“People shouldn’t have to go through what we went through,” says Brenda Klauditz about her struggle to find a suitable communication system and school for her 8-year-old son. Daniel Klauditz has cerebral palsy and is unable to communicate verbally. To his mother’s anguish, it wasn’t until this past September that she was able to locate a school eager to work with his electronic communication device. Klauditz shared her story with TeamRehab Report from her home in South Toms River, N.J.*

**T**he Klauditzes had been told at Daniel’s birth that he would be physically and mentally retarded, but they assumed their son would just be slower to develop than other children.

“We were in Long Beach, Calif., when Daniel was born,” Klauditz recalls, speaking in her soft voice and British accent. “It was a traumatic birth, and he was in the hospital for five-and-a-half weeks, but nobody had the guts to tell us what was wrong. In a way, we didn’t want to know. Unless you ask, nobody really tells you.”

Brenda and her husband, Ed, moved to New Jersey when Daniel was 10 months old. Because of extensive paperwork, it took more than a year before they were able to enroll him in an intervention program. It was then that they learned he had cerebral palsy and would probably never verbally communicate in a practical or functional capacity. By this time, Daniel was almost 2.

“He was really young when he started communicating with me. He’d moan a lot. He would moan if the channel on the telly [TV] wasn’t the right one, and he’d moan for this or that. I would rush around trying to figure out what it was that he wanted. We understood each other.”

She began looking for an augmentative and alternative communication (AAC) device for Daniel, but couldn’t find anyone who would say he was a candidate for one. Most of the specialists who evaluated Daniel, particularly the teachers and therapists at his school, were not familiar with AAC devices.

Klauditz recalls the tremendous resistance she

encountered at Daniel’s school. “One woman told me that Daniel would have to be able to play Parcheesi and copy the sounds you make on a drum before he could learn to use a computer.”

Although no one at the school actually came out and told her that Daniel was mentally retarded, Klauditz says they treated him as though he did not have normal mental abilities.

## **The Evaluation Process**

In an effort to assess her son’s intelligence and potential to use a communication device, Klauditz drove him all over the Northeast for evaluations.

“He’d be in the car for hours. When we got there, he’d be tired and hungry and yet be expected to perform. When he was younger, he didn’t have the stamina. You’d take him all that way and he couldn’t do it. Really, I think the team should come to the child’s home. I know it’s more expensive that way, but there should be some way to come up with the money to pay for this.”

Daniel performed poorly at many of his evaluations. In addition to the fatigue he suffered from the journey to the assessment facilities, he sometimes had trouble following the instruc-



**Daniel Klauditz, 8, of South Toms River, N.J., is learning to speak for himself, thanks to his Light Talker and the efforts of a diligent team.**



**Brenda Klauditz, Daniel's mother, is an integral part of the team that is implementing her son's AAC intervention.**

tions of the assessment teams, leading them to believe that he didn't understand what he was being asked to do.

"The therapists want the child to go from A to B to C. But if a child wants to go from A to F, you have to let him go. I have a 2-year-old now and if I asked him to hit a switch to make a toy run, I'd not be able to make him do it. These people are asking handicapped kids to do things that even ordinary kids won't do."

Ultimately, Klauditz decided that the evaluations were not an accurate indication of her son's capabilities. She had seen him do things at home which let her know that he was not mentally retarded, but without the ability to speak, it was hard for him to prove his intelligence to others.

When Daniel was 6, his mother bought a Light Talker, an AAC device with speech and written output that is operated by a light sensor. Klauditz had been introduced to the Light Talker by a Prentke Romich sales representative

who came to her home when Daniel was 3 or 4, but at the time, she couldn't see how it was appropriate for Daniel.

It was determined that the Light Talker was the best communications device for Daniel only after he had been assessed at Children's Seashore House in Atlantic City, N.J., in November 1988 and at the Cerebral Palsy Association of Middlesex County in Edison, N.J., in February 1989. His parents purchased the Light Talker in 1989. The \$6,000 device and mounting system was funded in part by the Rainbow Foundation in New Monmouth, N.J.

Although the Children's Seashore House and the Cerebral Palsy Association said the Light Talker was perfect for Daniel, Klauditz says the speech therapist and teachers at her son's school told her it was not appropriate.

"I said I'm going to buy the Light Talker now, whether he's ready or not," Klauditz says. By then, she and her husband had decided it was their responsibility to see that Daniel was given every opportunity to fulfill his potential.

"To be honest, lots of parents accept what people tell them about their child. Parents don't know what the children need. They're in the therapist's hands. I've learned that you have to believe in your own child."

Even after she bought the Light Talker, Klauditz says the teacher and therapists at Daniel's school were reluctant to use it.

"I said, 'Tell me why, in your opinion, it's not the right tool for Daniel.' They told me it's not in the right position, it's hard to program and that it's too hard to repair. I told them

***"The therapists want the child to go from A to B to C. But if a child wants to go from A to F, you have to let him go. I have a 2-year-old now and if I ask him to hit a switch to make a toy run, I'd not be able to make him do it. These people are asking handicapped kids to do things that even ordinary kids won't do." -Brenda Klauditz***



Daniel wouldn't be the one programming it or repairing it, so what's the problem? It got to the point where we were screaming at each other. We finally had to get a lawyer to force them to use it."

Klauditz says one of her greatest frustrations has been interacting with therapists and other professionals who are unwilling to admit their own limitations and lack of knowledge about certain pieces of assistive technology. She also says some evaluators expect too much of the children.

"People are evaluating children based upon what they have available in their particular facility because that's what they know. They shouldn't be frightened to say they don't know. And they shouldn't assume the child isn't ready or is retarded. The child is never ready.

"You can't expect children to do things if the reward isn't big enough. Some people don't realize how physically demanding it is to use these communication devices. Maybe these people should try using the devices at the same speed they demand the children to."

This past September, Daniel was relocated to the Jackson Regional Day School, in Jackson, N.J., where he is now using his Light Talker and learning to read. His parents, teacher and speech therapist are working cooperatively to teach him how to maximize the capabilities of the device.

"His teacher, speech therapist and personal assistant are great," says Klauditz. "Most aren't willing to spend this much time with a child. You don't meet people like this often."

## THE SCHOOL TEAM'S CHALLENGE

**B**arbara Dincher O'Neill, M.S., C.C.C.-S.L.P., is Daniel's speech therapist. Prior to meeting Daniel she had never worked with a Light Talker, although she did have some basic familiarity with the Touch Talker, a similar device activated by touch.

O'Neill says the challenge for therapists like her is to stay abreast of the current technology and take advantage of every training opportunity that comes along.

"There are many new developments in the field of AAC that therapists need to become familiar with," she says. "You learn how beneficial networking is. Talking to speech therapists who service children with special needs, like Daniel, enables me to brainstorm ideas."

O'Neill adds that the support and training she has received from the Prentke Romich Co., manufacturer of the Light Talker, have been invaluable to her work with Daniel, especially the 24-hour assistance they offer via an 800 phone number.

"There are also many conferences

that offer courses," says O'Neill about training opportunities. "My [school] district paid for myself and the classroom teacher to receive the training we needed.

"More and more schools [like Regional Day School] are starting to enroll students who are more involved. You just have to get out there and get the training. You're really on your own."

In addition to being his speech therapist, O'Neill is Daniel's school monitor. Her responsibilities include coordinating all of his therapy services, implementation of his individual education plan and maintaining communication with his parents.

Veronica "Ronnie" Hulse is Daniel's teacher. She has a bachelor's degree in elementary education, a master's degree in special education and is certified to teach grades K-8. Daniel is her first student to use a Light Talker.

"It has been an exciting experience," she told *TeamRehab Report*. "I just took the plunge. Most teachers say they're afraid of the Light Talker, but it's really not

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Daniel's teacher, Veronica Hulse, says some teachers are intimidated by communication devices,

## THE SCHOOL TEAM'S CHALLENGE

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—Brenda Klauditz*

something to be afraid of."

Hulse says New Jersey's Manchester School District has been supportive about training programs for teachers of children with disabilities. "I've worked for Manchester for seven years and have never been denied an opportunity for additional training," she says.

Hulse believes this situation is unusual, and encourages teachers in less supportive districts to insist upon more training opportunities.

"I would encourage them to speak to their superintendents. Have them go out into the field to see what is available for children with language disabilities," she says.

Hulse also urges teachers and therapists to enlist support and input from parents.

"Parents have a lot to say with special education these days," she notes. "Daniel's mother, Brenda, for example, is a very forceful lady. She's very competent, very loving and only looking out for whatever is best for Daniel.

"She's also very outspoken and I appreciate that. I don't want to be a mind reader. I need her to be perfectly honest with me. I understand her position. As a mother, she has an awesome responsibility because she has a very bright youngster and wants him to be a fully productive member of society."

Daniel is presently using a 128-overlay on his Light Talker. "He manages to get his points across with this board," Hulse says. "He understands everything I say to him and catches jokes that most children at his level wouldn't."

"He was a little hoardy about his things when he first came here," she explains. But now he's different. He shares with the other children in the class. They respect his space, and he respects them. He talks to them and sometimes he'll even play a song on his Light Talker if he knows it will make a certain child happy. He's changed, he seems very relaxed. I think he's moving along well."

Cognitively, Hulse says, Daniel is more advanced than the other six children in her class. He is reading at a high, first grade level, can add and subtract, and has learned to put together small stories. He can also tell time to within five minutes.

Overall, Hulse is pleased with Daniel's progress and says he seems happy with it as well. She adds that he might not have progressed as rapidly without his personal assistant, Marie Dasilva. "She is an exceptional assistant and Daniel has come to love and trust her," Hulse says.

Jo Ann Puleo, principal of the school, says she too has noticed a change in Daniel since he came to Regional Day School. She says his disposition is extremely positive and he appears to like school now.

### Looking Toward the Future

Daniel's parents, teacher and therapists hope that eventually he will be mainstreamed. His mother says the successful application of his Light Talker and the cooperation of his new professional team has accelerated the mainstreaming process. It has also created other options that once were closed to him.

"People used to look over Daniel as if he wasn't even there," Klauditz says. "Now they acknowledge his presence. . . . Without this computer, my child would have no job prospects, nothing. Now, I tell him, he can become an accountant or work for AT&T. The Light Talker is not only his computer, it is his voice and future."  
—C.F.