

## **2. Case Studies**

Speech is so much second nature to most people that they cannot imagine what it would be like to be without it. The following vignettes suggest the anger, frustration, helplessness, and despair of not being able to express one's thoughts and feelings by any reliable means for years on end. They are included because they describe actual people whose lives have been changed by assistive communication technologies. OTA thanks Ms. Carol Nugent, Director of Speech and Language Pathology at the Good Samaritan Hospital in Portland, Oreg., for telling us most of these stories. With the exception of Ricky Hoyt, whose real name is used (with permission), all names and some identifying details have been changed to protect the privacy of those involved.

Joey Crandall's mother was watching TV one afternoon last spring in Portland, Oreg., when a short feature came on about the speech language pathology department at the Rehabilitation Institute of the Good Samaritan Hospital there. That one feature is why this 1&year-old, whose normal language development began and ended while he was still a toddler, is learning to communicate with others for the first time since he was old enough to go to school.

Joey has been unable to communicate because the carotids, the two major arteries that furnish blood to the head and brain, did not form properly before his birth. Because of their weakness, he was only 3 when he had a cerebrovascular accident, what is commonly called a stroke. He now walks, although he must drag one leg through with every step. He has occasional seizures, and the best he has been able to do in the way of talking is to make noisy cries. Despite the boy's having had 7 years of conventional speech therapy, even those in his family do not always know what his cries mean.

Upon Joey's arrival at Good Samaritan, one of the first objectives of the assessment team was to determine what parts of his body the child might use to link him to a system that would serve him in the place of speech. His left hand was nearly

useless, so that was out. He could not hold a pencil with his right hand, even with finger splints, but the rehabilitation staff became persuaded that he could gain sufficient control of it to be able to turn a switch or buttons on and off. The result is that Joey now has a HandiVoice 110, a portable synthetic voice communication aid with a touch-sensitive keyboard.

Paid for by a local organization, the Scottish Rite Institute of Childhood Aphasia in Portland, Oreg. (1 of 25 such institutes in the United States), this device was selected for Joey because he has so long been isolated in his own private world that he needs the feedback he gets from hearing the machine respond out loud to his touching it to encourage him to emerge from his shell. Within a week or so of getting the aid he was already programming it to say things like "I want a cookie" and "Where is Mom?"

Taking the initiative is, indeed, a lot of what Joey is discovering having the HandiVoice is all about. Tommy, his 6-year-old brother, and Lisa, his 8-year-old sister, had grown accustomed to talking for Joey. With the help of the Scottish Rite Institute, they all attend therapy together so that the younger children will come to understand that, though they may explain or amplify when necessary, it is Joey who should be in charge of what he wants to say.

Joey had been in public school, but enjoying only what his speech therapist termed "a haphazard experience." Because he had never been able to actively participate in class, he had never really learned to read, write, spell, or do arithmetic.

At the private school where he was enrolled after getting his HandiVoice, Joey has the benefit of a teacher familiar with nonvocal youngsters who is willing to coordinate her program for speaking pupils with special teaching strategies for him. Though no one yet knows how much lost time he can make up for (the intelligence of people in Joey's situation is hard to test), the plan is to help him progress as rapidly as his communication system allows.

Bryan Wilson is another client of Good Samaritan. Bryan was delivering newspapers after school when he was struck by a hit-and-run driver who was later apprehended by the police and convicted. He was then just about to celebrate his 15th birthday, and, as this was written, has recently turned 18.

Bryan now needs a cane to walk, which he can do only with difficulty. The brain damage from the accident was such that his hand and finger functions are limited and he has yet to regain his speech. Nonetheless, Bryan was able to graduate with his high school class in June 1981, and, after spending the summer helping his 17-year-old brother, Sam, to paint houses (Sam would position him on the floor so he could do the trim), he entered Portland State University that fall.

Little of this would probably have been possible had Bryan been injured in 1968 instead of 1978. Bryan uses a small, portable, battery-powered tape typewriter called a Canon Communicator, which he wears suspended from his belt buckle, for informal face-to-face conversations and a second machine, called a Portatel, with a lighted display for work in class. (Bryan is fortunate that the funding of these devices was not a problem—he qualified for worker's compensation and was also covered by the liability insurance of the driver who injured him. )

At Good Samaritan's Rehabilitation Institute assistive communication is arranged not only for the young. Although the Rehabilitation Institute counts among its clients people like 16-year-old Sue Jones, whose loss of muscular control and speech 2 years ago resulted from a high fever during a bout of toxic shock syndrome, and 25-year-old Jack Brown, who was left paraplegic and severely speech-impaired by a motorcycle accident, Good Samaritan also has older speech-impaired clients.

One, Earl Higginson, now in his forties, had two strokes within 5 months—the first on the left side of his brain, the second on the right side—about 8 years ago. Complications developed after his second stroke that threatened to drown him in his own saliva, and surgeons were forced to tie off his vocal cords to prevent fluid from flooding his lungs. While this procedure is usually re-

versible, the damage to the cords was permanent by the time Higginson was sufficiently recovered to undergo the restorative surgery. After long months of convalescence, it was clear that he was as alert and intellectually competent as ever, but that his prospects of being able to talk again were extremely poor.

Higginson cannot use his left arm, has some residual difficulties in walking, and lost his position as an accountant soon after he became ill. Yet he is not an invalid and now rides the public bus alone to and from a new full-time job that, although not as demanding as his old one, gives him the satisfaction of again being able to support his wife and daughters and entails the considerable responsibilities of handling payroll and inventory for his employer. He has been able to assume these responsibilities by learning to use a Canon Communicator for written communication and a HandiVoice 110 for telephoning. Both devices were bought for him with vocational rehabilitation funds.

Rosalie Hathaway's case is sadder, but is included here because it represents many others.

Until 1974 when she had a massive stroke, Mrs. Hathaway lived in the San Francisco Bay area with her husband and two daughters, who were then in the third and fifth grades. Since that time she has been confined to a nursing home in a small eastern Oregon town. She was taken there to be near her mother, and because her husband thought it best for the children not to visit her.

If his decision seems callous, it should be said that, since her brain hemorrhage, Mrs. Hathaway, who was 41, when this was written, is completely paralyzed below her neck and above it has constant tremors. In addition, her vision is poor, and she has severe difficulties in swallowing. Her meals must be pureed and spoon-fed to her and, nonetheless, take her 40 minutes to consume. Even that is a triumph. Before an arduous swallowing retraining program, she had to be fed by stomach tube.

Mrs. Hathaway, however, is by no means completely debilitated. Though the only sounds she can make are squawks, her mental faculties are intact, and she can still read and spell. Apart from

a large screen television that she can watch both from her bed and a wheelchair, her greatest material joy is a portable device called a Zygo 100. It has an electronic memory that allows her to compose whatever she wants to say, a message display large enough for her to see, and a buzzer so that she can summon attention when she is ready to have the text read.

How does a woman who cannot so much as feed herself operate a machine? That was not an easy problem for the rehabilitation team at Good Samaritan to solve. They found that there was only one muscle, in her chin, over which she had some control. Using this muscle to control the Zygo's switches, Mrs. Hathaway is able to guide the device's indicator to the items she selects on the electronic communications board, and has made truly remarkable progress. Whereas it took

her about 20 minutes to compose a sentence a year ago, it now takes her about 3, and she is still gaining speed as ways are found to better adapt the system to her needs.

Mrs. Hathaway's ability to express herself again has reduced the time her nurses must spend in caring for her by about a third. She can now alert them to impending bladder infections, threatened bedsores, and other problems before they become acute.

But most of all, her communication system has enabled her to share everything from her fantasies and her reactions to what she sees on television to what she wants to have her mother tell her daughters when she writes to them on her behalf. Hathaway is the first to say that this system has enhanced the quality of her life.

## RICKY HOYT'S STORY

When their first child was born in 1962, it wasn't obvious to the Hoyts that anything was wrong. But Ricky didn't develop as most babies do, and within a year the Hoyts—who live in Westfield, Mass.—were to learn of a disorder they had never heard of. Pediatricians told them that Ricky had a very serious case of cerebral palsy. He would never walk or be able to feed himself and was mentally retarded. "Put him in an institution," the pediatricians advised the Hoyts, "he will always be a vegetable."

Two decades later, it is true, as predicted, that Ricky cannot walk or feed himself. The Hoyts felt intuitively, however, that their son was bright. So when their minister told them they had a choice between really going to bat for him or feeling sorry for themselves forever, they decided to seek out the best professional help available.

Because the Hoyts live in Massachusetts, they took the child to the cerebral palsy unit at Children's Hospital in Boston soon after they were told of his prognosis. There, he was seen periodically by a team of rehabilitation experts, and Judy Hoyt, his mother, was instructed in how to provide the little boy with daily therapy sessions at home.

"In those days," she recalls, "a technique called 'brushing and icing' was part of the standard treatment for cerebral palsy kids like Ricky," who, in addition to their other problems, were seriously speech-impaired. The idea was that cracked ice regularly applied to their mouths and throats with a toothbrush would reduce the flaccidity of the speech-producing muscles and eventually enable these children to talk.

"Ricky and I did all his physical therapy sessions together and enjoyed most of them, but both of us hated this," she recalls. "Besides, it became very evident that we weren't getting anywhere. Ricky was 7 or 8 when the speech therapist at Children's finally had the guts to say 'Hey, this child is really never going to speak and we need to be looking for other ways for him to communicate.' To hear him say it, at last, came as a relief."

Meanwhile, Ricky had long since begun to do such things as look at the refrigerator when he was hungry or thirsty, or at the window when he wanted to go out. So Judy, more confident than ever that the child was not stupid, had already begun her own program to give Ricky a foundation for language skills.

A psychologist at Children's Hospital in Boston had suggested to her that, since Ricky couldn't even crawl, she bring the material world to him by rubbing his body with a variety of objects—some hard, some soft, some smooth, some rough—so that he could explore these sensory realities for himself. Eventually, she hit on cutting letters out of sandpaper to enable him to learn the alphabet and begin to learn to spell. As it happened, the psychologist was a wheelchair user. This further convinced the Hoyts that handicapped people could succeed. And it was a bonus that they drew the courage from their counseling sessions with him to have another baby. Their second son Robby, was born to the couple when Ricky was 2 and a third son, Russell, when Ricky was 6.

But, the arrival of Russell is getting ahead of the story. It is characteristic of Judy that, when Ricky was 4, she arranged to enroll him in a church-sponsored nursery school and kindergarten in exchange for her caring for the teachers' children and the children of several women who agreed to fulfill his special needs of toileting, feeding, and play during the hours he was away from home.

Judy also taught her disabled son to swim (and has since taught other disabled youngsters to swim as well). The head control Ricky gained in the process is probably largely responsible for his being able to operate both the switches that control his electric wheelchair and those for what the Hoyts call "the hope machine."

The "hope machine" is more formally known as the Tufts Interactive Communicator—the TIC for short. This machine, developed at Tufts University, uses a lighted letter display board and paper strip printer to enable nonvocal people, otherwise incapable of writing, to communicate. Had it not been for Ricky, this device might not exist.

In addition to being seen by therapists at the Children's Hospital in Boston, Ricky was also regularly seen by an occupational therapist at a cerebral palsy clinic closer to his home. One day, Judy went to a conference there, where she met Richard Foulds, then a graduate student in rehabilitation engineering at Tufts. Foulds has been toying with building a communication system for severely

physically handicapped nonvocal people, and once the occupational therapist introduced him to Ricky, he agreed to try to make the concept a reality.

First, however, there was a major obstacle to overcome. The parts to build prototypes and a production model would cost about \$5,000, and at that point neither Foulds nor his university had the funds. Through a dinner dance their church sponsored and a series of bake sales, yard sales, and other activities, the Hoyts and their neighbors raised the money. Foulds began to design the machine in earnest when Ricky was 8. When Ricky was 10, the first TIC ever made for practical use became his for keeps.

The Hoyts were, of course, elated. Only one hurdle remained: except for a special education program described by Judy as "not very systematic," they had never been able to get Ricky into public school. They had succeeded in pressuring the authorities to move the special education program from space in an old age hospital into the back room of an actual school. But every time they attempted to have Ricky go to classes with able-bodied youngsters of normal intelligence, school officials adamantly refused.

Still undaunted, the Hoyts resorted to a kind of "back door" approach. They hired tutors, among them some youngsters who were proficient at science and arithmetic. These children came to like Ricky and to realize that he was as capable of learning as they were. "He doesn't need to be in a special class," they told their teachers. And so even before Ricky was 12—when the law in Massachusetts changed to make "mainstreaming" his right and he was admitted to fifth grade—he was allowed to attend regular classes in science and arithmetic. With the change in the law and Ricky's TIC, the schools could also no longer believe that his parents might be answering for him when he was tested. The answers Ricky programmed the device to produce were unmistakably his own.

Ricky is 21 now. He graduated from high school with the class of 1983, is taking two courses at Westfield State College in Westfield, Mass., and has been admitted to Boston University. He plans a major in computer programming and will enter

the University in January 1984. Meanwhile, he has been supplied with new communication equipment, designed and assembled by Richard Foulds

and his colleagues at Tufts University, largely from Radio Shack components, which has both synthetic voice and print-out capabilities.