

# Independence -Day

## Tongue-touch controls give Ben a more satisfying, self-sufficient lifestyle.

By Maryann Girardi, P.T.

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en Merrill came to Spaulding Rehabilitation Hospital's Assistive Technology Center in Boston in February 1995 looking for a way to control his world. The 15-year-old had been born with spinal bifida. In September 1993, he sustained a C4 spinal cord injury as a result of complications of a surgery to place tissue expanders in preparation of scoliosis repair.

For the two years before his injury, Ben had experienced a progression of his scoliosis, retrocollis and generalized weakness. He was no longer able to ambulate and was using a power wheelchair with standard joystick for mobility. Although still able to use his upper extremities somewhat, he was becoming more dependent on others for assistance to get through his day. Transferring in and out of his wheelchair was accomplished by a family member lifting him.

After his injury, Ben participated in three months of acute rehabilitation and regained some strength of his upper extremities. But, for all intents and purposes, he was now completely dependent on others.

When he arrived at Spaulding, Ben was a ninth-grader in a public high school. He had a full-time aide to assist him in mobility and note-taking. The school provided him with DragonDictate and a computer to complete written work.

DragonDictate is a software system that enables the user to input text and data by voice. It listens to what is said and converts the speech into text within an existing Windows application. It also enables the user to edit and format the text within the application.

Its dictionary holds up to 120,000 words and is constantly being updated each time the software is used. This results in a custom dictionary specific to each user based on frequency of use. Unfortunately, it is a desktop system, and Ben was required to leave it in one room at school.

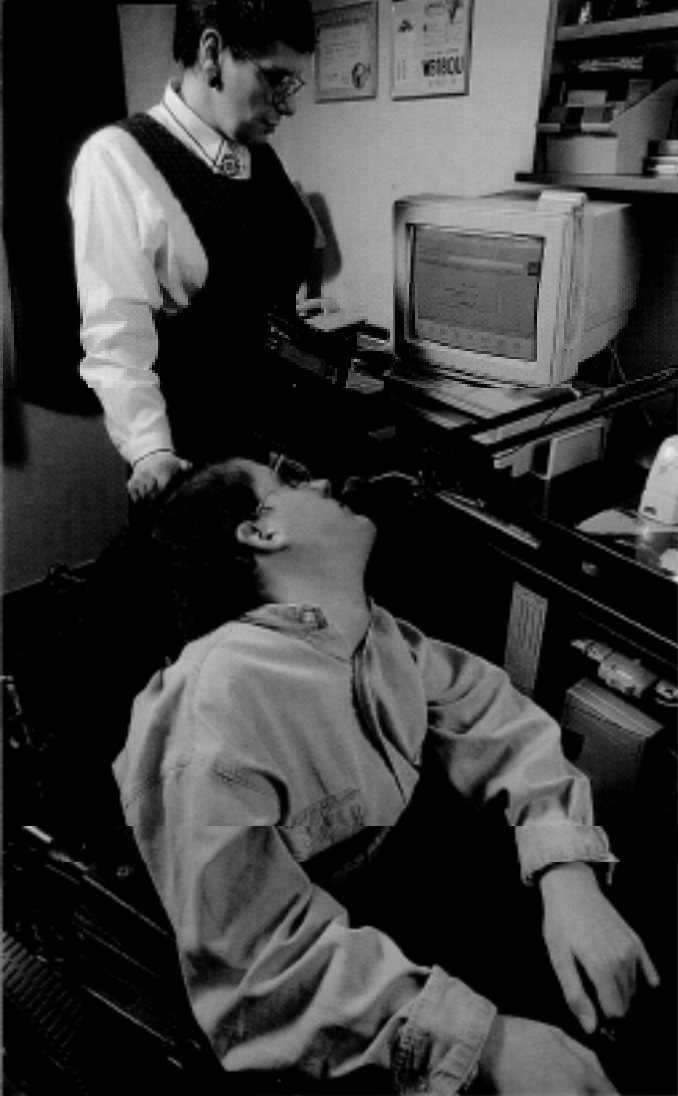
At home, Ben had some access to his environmental controls. He operated the television's remote control with his right thumb, but he was able to access only one key at a time. To increase the number of keys he could strike, his family would move the remote up and down in his hand.

### The Assessment

Ben was evaluated by the ATEC Clinical Team, which included occupational, physical, and speech and language therapists, as well as a rehab technologist. The evaluation focused on finding an access site, or a dependable movement Ben could easily and consistently perform. Once this site was determined, a system that could meet his goals could then be selected.

Ben had extremely limited head and neck movement because of his spinal curves, making head switches a nonviable option. Also, because of his spine, he did not have the breath support to

Ben Merrill and Maryann Girardi, his therapist in Spaulding Hospital's assistive technology program, worked closely to set up and test the TTK system. Initial testing was conducted at the hospital during Ben's spring break from school. Deciding what parts of his environment to control with it did not occur until after he returned home and analyzed his daily routine and needs.



# Ben's Independence

DragonDictate system), and drive his power wheelchair.

The TTK operates by transmitting a radio frequency to the UCS 1000, which is an integrated system of components mounted on the user's wheelchair. The components interact to provide the user with the ability to control his environment. The device comes with standard items, but it can change to accommodate specialized options.

## **This was the first time in more than two years Ben had control over where he was going and what he was doing.**

The UCS 1000 can provide auditory feedback to let the user know if he or she has successfully activated individual keys.

The TTK is a dental retainer with a nine-button keypad embedded in it. The buttons are "hit" by the user to move through a series of menus for controlling various devices. In the main menu, Ben could choose from, for example, his telephone, bed, room controls, chair or computer. When one of these is selected, another menu appears with specifics about the item's operation. For example, in the room menu, Ben can choose from the television, lights, climate and stereo. For each of these, he can turn them on or off, or go to another menu with more options, e.g., dim or brightness for the lights.

### **Using the Tongue Touch**

Ben was fitted with a temporary TTK and instructed how to use it.

Demonstration electronics were installed on his Invacare Jaguar power wheelchair so he could use both of his seating and positioning systems (one system is an Silhouette cushion with Avanti foam-in-place back; the other is a Silhouette cushion and straight back with a suspended body jacket). Within minutes of being fitted, he was accurately "hitting" the individual keys.

After a few practice "hits," Ben went on a trial run. Driving a power wheelchair with the TTK uses digital input, meaning the chair moves at one speed in a given direction. The system accommodates eight directions of movement (forward, backward, right, left and the diagonals between these), which is close to, but not as exact as, the precise navigation of a proportional joystick.

Ben adapted quickly and accurately navigated the hall independently. He moved in all directions and through a simple obstacle course without difficulties. This was the first time in more than two years Ben had control over where he was going and what he was doing.

We then tested Ben's ability to access the computer. Again, he had no problems using the TTK to emulate a mouse within various Windows applications. Ben then showed that he could independently use the TTK to access the UCS 1000 menu and select the various options within each screen.

Ben, his family and his local therapist went home and compiled a list of what Ben wanted to control. It was decided that he would need the motorized wheelchair, environmental control and computer packages. Ben already had an accessible phone, so this component was not requested. However, because his wheelchair was a few years old, the electronics would have to be upgraded.

The most important aspect was that

Ben's mother, Caroline, plays an active role in his equipment selection and use. With the TTK, Ben can access his computer and complete his homework and other tasks with minimal dependence on caretakers.

effectively use a sip-and-puff system. His extremities demonstrated extreme weakness and lacked any consistent voluntary movement to be considered as sites for individual switches.

Ben did have clear, consistent speech, which was sufficient to access an environmental control unit. However, this would not provide him the option of powered mobility. Ben also had excellent ability to use his eyes and mouth/tongue. Eye-scan systems could be used for computer use and environmental control, but this, too, would not provide him with powered mobility access.

Ben's mother was quite active in his care and had become aware of the TongueTouch Keypad (TTK), which could be used to control the environment and his power chair. The team at Spaulding agreed that the TTK may be a good option for Ben. The product tested was the newAbilities UCS 1000

TTKThe UCS 1000 processor would allow Ben to control his environment, access a computer (and thus the

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he would be able to move about his environment independently, including entering and leaving his home with the automatic door opener. Thus, he could be left alone without being at risk if there was an emergency.

Everyone was thrilled that this system was actually going to work for him, but now came the hard part-getting it paid for. The total cost without the wheelchair electronic upgrade was about \$12,000.

## The Funding Challenge

Ben was covered under private health insurance and state Medicaid in Maine. The team applied for prior authorization of payment from both, with the understanding that Medicaid would pay for only what the private insurance denied. Neither would pay for the DragonDictate software and computer he would need at home, so the family started looking for private funding.

A local DME dealer was contacted to process the claim, and he became the primary voice of the group to advocate for the system. A full team-evaluation report was generated. It detailed Ben's status, including prior functional status, procedures he had received, and previous technologies tried and why they failed. It also included detailed evaluations by each specialist, documenting his current functional level and inability to meet his goals with other systems.

The report was sent to both insurance companies, and both requested additional information about the TTK system and how it worked. They also requested a videotape of Ben using the system. After review, the system was approved by his private insurance at 80 percent, with Medicaid paying the balance.

Ben's local school nurse and the Kennebunkport, Maine, health council headed up local funding efforts. His church provided some of the funding for his DragonDictate software and home computer, and a

Ben's limited head and neck movement and lack of upper extremity strength left his tongue/mouth as the most viable access site. His tongue-touch keypad uses a radio frequency to access the ECU processor.



Jim Daniels

senior citizens group volunteered to raise the balance.

## Delivery

Ben received his UCS 1000 system in July 1996. The manufacturer installed the system at his home.

Although Ben still requires assistance in moving the TTK in and out of his mouth, he finally has some independence and control over his environment. He moves about on his own (including exiting and entering his home), controls his computer, and turns his music up loud. There have

been some minor problems, such as the door opening when he was trying to turn on the light, but the manufacturer fixed these problems quickly. Ben continues to use DragonDictate as his primary access to his computer, with the TTK complementing it for mouse movement.

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## Up On the Roof

The nine-button TongueTouch Keypad fits on the hard palate in the mouth and is molded for each individual user. It is especially useful for clients who have little or no motor skills in their extremities or little head and neck movement.

Dental acrylic molded from the individual's dental model to fit against the hard palate

Keyboard & RF transmitter circuitry

Tongue activated keys

Teeth clasp

