Clients’ Needs at Heart of Center’s Mission

Delivering, installing and testing innovative assistive technology and then training people with disabilities on how to use that equipment is all in a day’s work for Beverly Thorn. Beverly, the Center’s client services coordinator since 1999, recently described a typical workday, although sometimes her schedule can be as changeable, varied and unique as each individual with whom she interacts.

After reviewing notes from previous visits, Beverly’s first stop is at Pete’s house. Because of ALS (better known as “Lou Gehrig’s disease”), Pete no longer can use his arms, but his voice is still strong and he has control of his legs and feet.

Beverly’s tasks include delivering and installing specialized equipment, and training Pete on a speaker phone that is voice-activated for incoming calls and allows him to place outside calls via a single switch, 20-number scanning dialer.

To trigger scanning, Pete will use his foot to press a four-inch button switch that is placed on the floor. The scanner then illuminates each of its 20 stored numbers one at a time in turn. When Pete presses his foot switch, the number that is illuminated is automatically dialed. Emergency numbers and numbers that are frequently dialed are scanned ahead of less critical or less frequently used numbers.

Beverly tests each of Pete’s important phone numbers for family members and caregivers and makes and hangs a wall chart listing each name and corresponding numerical position for the phone numbers that

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Another Banner Year of Service
By Les Cory

In 2012, the Center for Rehabilitation Engineering (CRE) answered 1,148 requests for help from people with 50 different disabilities ranging alphabetically from ALS (104) to Williams Syndrome (2). We extend a special thanks to our donors and sponsors for all you enable the CRE to do. Without your help, nothing happens. Whether it’s one dollar, $50 or $1,000, your generosity is sincerely appreciated.

Since the establishment of the CRE in 1987, more than 3,300 people have been helped—most multiple times. In fact, the number of different service transactions now exceeds 15,000!

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CALLING ALL FLEA MARKET VENDORS! Plan now to sell your “stuff” at SHARE’s 19th Annual Classic Car Show and Flea Market. Reserve your space today!
Center's Mission  
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have been programmed into the phone.

The next installation and set-up is a lengthier task. Beverly supplies Pete with a VOICE ME-I R—a voice-controlled electronic device that she programs to control Pete’s TV and lights. The pair work together to program TV commands and a list of channels. They match up each voice command with a function that the VOICE ME performs. For example, the device lets Pete say, “power on” to turn the TV on, and other commands, such as “36” or “History,” to switch to those desired channels.

Pete uses the same process to indicate which lights he wants to go on and off.

Before Beverly leaves, Pete goes through the list a final time to verify that the devices follow commands with the correct results. Beverly notes that Pete will be left with the equipment to try out for about a week to determine its usefulness. Beverly says, “I remind each client that the devices are on loan, and as his condition and abilities change, it may have to be swapped out for different equipment to better allow him to accomplish his goals.”

Beverly adds, “He also knows that if problems arise, he can call us for help.”

Her next stop is a first visit abilities and needs assessment for “Amy.” Amy has experienced several minor strokes, has arthritis in her hands, and was experiencing pain in her shoulder. She walks with the help of a rolling walker.

“When I see someone for the first time, I ask what they would like to do more easily or what they want to do but can’t,” Beverly explains, adding that she also observes the individual’s abilities, sees how the home or facility is set up, and gives an overview of SHARE, noting that it is a “quality of life” organization.

When possible, she observes the person performing or attempting to perform actual tasks.

While watching Amy use her computer, Beverly notices that she is using a standard, older writing desk. In order to look at the monitor, Amy is looking up at it and has to stretch out her arm to reach out to touch the keyboard in front of her. She also is having a difficult time seeing the keys and operating the mouse.

Ultimately, Beverly recommends replacing the desk with an office computer desk and an attached keyboard and mouse tray. She also recommends that the keyboard’s position be lowered and moved closer to Amy’s body, alleviating her right shoulder strain.

Beverly supplies Amy with a Big Keys keyboard featuring one-square-inch keys that are easier to see and provide larger targets for her swollen, arthritic finger joints.

Lastly, Beverly replaces Amy’s mouse with a modified track ball. Unlike a mouse, the track ball remains stationary, resulting in less of a need for Amy to extend her arm. The modification makes it possible to click by means of an external switch that can be operated by either her left hand or foot, thereby easing overuse of her wrist and thumb.

Following the visit, Beverly’s out-of-office day is complete. When she returns to the UMass Dartmouth campus, she usually orders equipment for clients, checks her referrals, reviews her waiting list, and gathers up the equipment and written materials she will need for the next day.

“And then it starts all over,” Beverly says.

Remembering Dean Emeritus Donald Howard

IT IS WITH DEEP SADNESS that we note the passing of Dean Donald Howard. Don was an active member of the SHARE Foundation Board of Directors for nearly 25 years. He also served as a member of the board of the Center for Rehabilitation Engineering. Don was a positive contributor to both organizations, both of his energy and his resources.

Over the years, he was directly responsible for steering well over a million dollars in operating funds to the Center. We will miss his wry wit, his sage advice, and his warm words of encouragement.

Don was a one-man cheering section who seldom missed an opportunity to talk up our work. We honor his memory by carrying on the work that he helped us to begin.

The SHARE Foundation is a nonprofit 501(c)3 Massachusetts corporation with headquarters in Fairhaven, Mass. It was incorporated by three members of the Electrical Engineering faculty at UMass Dartmouth (then SMU) in 1982. Its primary purpose is to improve the quality of life of people with severe disabilities through the creative application of modern technology. It succeeds in its mission by directing 100% of its net income to the UMass Dartmouth Center for Rehabilitation Engineering. SHARE is governed and guided by an uncompensated 13-member Board of Directors.
Adaptive Equipment Dramatically Changes A Client’s Life

Lynn Lavoie, an occupational therapist, describes the late Pat Riley as “one of the most inspirational quadriplegics I’ve ever worked with. She always had a smile on her face.”

Lynn witnessed firsthand how equipment made possible by SHARE boosted Pat’s level of independence. The Center for Rehabilitation Engineering provided Pat a number of different assistive devices to improve her quality of life. Client services coordinator Beverly Thorn and Lynn worked collaboratively with Pat for several months, training her on the use of this specialized technology.

“Pat became a very proficient user of voice recognition software,” Beverly says. Thanks to a Center-loaned speech recognition system, Pat wrote letters, surfed the Internet, created a Facebook account, and was able to communicate with people she had not talked to for years.

Blink Once for “Yes”
By Les Cory

Early in March, I took a service call for a nonworking call system at the home of a man with ALS who can neither speak nor use his hands. The call switch, wirelessly connected to a call bell, enables him to summon his wife, Jean, primarily in the night, when he might need to be turned or suctioned. It turned out that the switch, which he operated by turning his head, only needed to be adjusted.

I asked Jean how Bob communicated his basic wants and needs, and she showed me how he blinked his eyes once or twice, respectively, to answer yes/no questions. This far-too-common scheme is barbaric. Glancing left or right to indicate “yes” is so much faster and less fatiguing. No response at all means the answer is “no.” Try it yourself. See how soon you tire of blinking your eyes.

Despite her inability to use her hands, the Center made it possible for Pat to make and receive phone calls unassisted by merely pressing her head against a switch. The switch, mounted on a Center for Rehabilitation pillow board, was interfaced to an AmeriPhone hands-free scanning telephone. By means of this technology, Pat was able to call her husband on the phone independently every evening.

She also could turn her TV on and off, change channels, and adjust the volume via a voice controlled VOICE ME infrared TV controller. Pat was looking forward to operating her room’s heat/air conditioner unit using similar voice recognition software, but unfortunately became ill and passed away before that could happen.

“The technology from SHARE changed Pat’s life dramatically,” Lynn says.

Twenty minutes later, I left them with an eye gaze (ETran) board with which Bob can now spell anything he wants to say by merely shifting his eye gaze from letter to letter on the board. No more 20 questions. I don’t know how many of these boards we have given away, but I am sure it’s more than 300. These simple boards, made by volunteer Fred Texeira, have arguably had as great a positive impact on our clients’ quality of life as anything we have supplied.

Through the eye board, Bob told me of his former employment and places he had lived and visited. He was an avid fisherman and built his own boat. The eye board made conversation possible in a way that blinking his eyes never could. Our thanks to Fred Texeira for “share-ing” his invention with us.

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Unfortunately, the number of people on the waiting list is also at a record high. Due in large measure to the state of the economy, people with disabilities are turning to the CRE in increasing numbers.

A waiting list of 35 people is more or less normal as items are ordered, shipped, designed, built and modified. But, as of April 1st, the number waiting is 115, and that’s no April Fool’s joke. The waiting list is now bigger than the total number of people served in our first five years of service. The price of a latte has never been more important.
WITH OUR THANKS We extend our gratitude to the many supporters who have donated to SHARE over the past few months. Your generous gifts are making it possible for us to provide the opportunity for independent communication to more children and adults with disabilities.

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SHARE Clients Have Books Published

Barbara Bates was an engineering professional in the semi-conductor industry until a head injury in 1984 left her totally blind.

“I felt like the world had fallen out from under me, and SHARE was there and provided resources at a time when I needed them,” she recalls.

SHARE provided Barbara with a computer, monitor, keyboard, speech synthesizer and printer. Special software provided by SHARE spoke what she typed.

Bob Branco remembers meeting SHARE founders Les Cory and Phil Viall while a student at then-Southeastern Massachusetts University. Branco, who is blind, began using a Center-provided computer about 13 years ago and uses JAWS speech software that lets him hear what he types on the screen.

Barbara and Bob recently had books published. Barbara's first novel, Asterice, was published by Eternal Press in California. The science fiction thriller centers on ice from an asteroid that can boost human metabolism, but also contains an alien virus capable of altering human DNA with disastrous results. The story unfolds as four infected people try to stop the process and save humanity.

Bob's latest book, My Home Away from Home: Life at Perkins School for the Blind, is available at Amazon.com. The book is about the time Bob spent at Perkins School from Grades 5 to 12. “There are a lot more opportunities for blind people now but they need to make more of an effort to prove themselves…I think that’s always going to be true,” Bob adds.