



## Mainstream technology increases independence, aids recovery

► *Monifa Brooks, M.D., and Gabriella Stiefbold, O.T.R.*

**M**ainstream technology is an increasingly important aspect of Electronic Aids to Daily Living (EADLs). EADL devices can be accessed by an individual with a disability, such as a voice-activated TV remote or switch-activated light dimmer. The use of mainstream devices improves patient acceptance of EADLs, and makes these aids more affordable and accessible than devices specifically marketed for the disability community.

Having access to the same equipment as their able-bodied family and friends is a great equalizer for persons with disabilities. The significant psychological and social benefits of

using mainstream technology can assist the rehabilitative process and enhance communication, in addition to helping patients resume normal roles and facilitate integration back into the community. These devices can provide outlets for creativity, paths for education and a foundation for recovery.

A comprehensive needs assessment can determine which devices and control mechanisms are most suitable based on a patient's abilities. Individuals with upper extremity movement, including those with a low cervical spinal injury or stroke, can often use larger switch targets or master direct access to controls. Equipment can be modified with

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## Civil rights for persons with disabilities

► *Bruce M. Gans, M.D.*

While in the United States often forget that in emerging nations, persons with disabilities face barriers of access to community and health care services and a lack of respect for their civil rights. Recently, I spoke at a meeting in Brasilia, Brazil, and observed that, while this modern city offers many amenities for people with disabilities, the surrounding areas I toured had few accommodations to meet the needs of its disabled citizens. In these less developed regions of the world, disability is associated with extreme poverty and mortality. Infants with congenital disorders are not allowed to survive and individuals with disabling conditions are unable or unwelcome to participate in society. Even if they are able to work at all, they may be relegated to begging on the street.

The international rehabilitation community is acutely aware of these outrageous conditions. Unfortunately, I suspect that most of the United States' rehabilitation community is largely unaware of the International Convention on the Rights of Persons with Disabilities. This United Nations resolution was approved by committee in August and could be in force as early as 2008. The resolution calls on governments to improve and promote access to education, employment, health care and rehabilitation for persons with disabilities through civil rights legislation. It targets the removal of physical and social obstacles that prevent full participation in public life. The resolution has been supported with great passion by international advocates for the disabled.

The International Convention also encourages a fundamental change in perspective, from one of charity to one of civil rights for persons with disabilities. That change has already occurred in the United States with the Rehabilitation Act of 1973 and was reinforced by the passage of the Americans with Disabilities Act in 1990.

We have come a long way since Vietnam veterans chained their wheelchairs together and demonstrators crawled up the Capitol steps in Washington, D.C., to protest their unequal treatment; however, more needs to be done. For example, advocates are seeking to change the language of the current laws to remove the legal barrier of proving a person is disabled and broaden the protection afforded by these acts. The language would be modified from prohibiting discrimination "against an individual with a disability" to prohibiting discrimination "on the basis of disability." While we are still learning what it takes for a country to provide physical and social access for people with disabilities, we need to shed our long tradition of isolationism and participate in the international community's efforts to advance the rights of people with disabilities everywhere.

We should support global initiatives for the civil rights of people with disabilities. We need to urge our leaders to vote in favor of the International Convention on the Rights of Persons with Disabilities at the United Nations. Its statement of values is a moral compass, a foundation for advocates to successfully argue for systemic countrywide change.

Access to health care and funding for rehabilitation for all is crucial to full global civil rights. We have a social and moral obligation to advocate for the highest quality of life possible for all people.

# New hope for patients with severe brain injury

▶ Jonathan Fellus, M.D.

**A** new collaboration among key institutions is providing important treatment options and increasing hope for recovery for patients in minimally conscious (MCS) or vegetative states (VS). The partnership between the International Brain Research Foundation, Inc. (IBRF), and the New York University-Bellevue Medical Center (NYU-BMC) began in April 2006. The result has been an innovative multifaceted treatment program at Kessler's Severe Disorders of Consciousness (SDOC) initiative, a division of the larger brain injury department at Kessler. The SDOC's high-profile cases have included patients who have recovered from comas or regained function and received significant press coverage.

The SDOC has as many as four patients in treatment at any given time. To date, improved awareness or communication has been noted in all individuals enrolled in the SDOC program. One patient has even learned to respond to simple questions using rudimentary communication methods. In 2007, Kessler anticipates publishing up to eight strong case studies and plans to begin a formal study tracking results of the SDOC program.

## Innovative interventions

The treatment protocol components include multifaceted treatment modalities, such as:

**Dietary supplements.** Patients are placed on a regimen of B-12 vitamins, omega-3 fatty acids and antioxidants. These interventions are believed to repair brain damage, enhance brain chemistry, support healing and create building blocks for neurotransmitters.

**Electrical stimulation.** Adminis-

tration of electrical stimulation through the median nerve of the arm stimulates the central nervous system, increases cerebral blood flow and raises levels of dopamine. This treatment technique has been associated with awakening from MCS or VS in pilot studies conducted at East Carolina University, the University of Virginia and other neurosurgical centers.

**Pharmacologic therapy.** Various agents offer specific effects that promote wakefulness and thus may improve patient outcomes. Stimulants enhance plasticity or neurorecovery. For example, amphetamines and dopaminergic agents enhance norepinephrine and dopamine levels and increase catecholamine activity. Modafinil, a psychostimulant, induces wakefulness. The effects of these agents are monitored with highly specific and sensitive electroencephalogram (qEEG) technology, which can be performed at bedside and repeated as often as desired.

Additionally, it has been theorized that, in some settings, the brain produces an abundance of opioids to perpetuate VS as a protective strategy. Administration of specific agents to counteract these effects has been associated with arousal and wakening in numerous studies of animals and humans. Naltrexone, for example, blocks transmission of endorphins in much the same way that it blocks opiates, such as morphine. Administration of acetylcholinesterase inhibitors enhances acetylcholine activity, contributing to brain stem excitatory pathways. Other approaches are aimed at activating glutamate, which directs excitatory activity in the brain.

The cumulative effect of pharmacologic treatment is the up-regulation of pathways that stimulate arousal and awareness and down-regulation of pathways that suppress consciousness. These outcomes facilitate functional recovery and promote participation in recovery therapy.

## Monitoring improvements

As the IBRF-developed protocols are applied in Kessler's clinical environment, subtle changes in brain electrical function are measured by qEEG technology to record minute progressions toward normal brain activity. This assessment also provides immediate feedback to quantify the effects of changes in the pharmacologic regimen, stimulation and/or rehabilitation techniques.

The qEEG has been used for decades to assess various aspects of brain injury. Today, enhanced computer technology allows investigators to compare the brain waves of SDOC patients with tens of thousands of normal and abnormal EEG signatures in the IBRF data banks. This information helps determine whether progress is being made toward normal brain activity.

The goal of treatment for a patient in a MCS or VS is to reach maximal wakefulness and consciousness, and this multimodal approach has promise to achieve this. Feedback from the qEEG provides both emotional reassurance to a patient's family that the patient is making progress and important information to clinicians to guide treatment decisions.

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# “ThinkFirst” to prevent traumatic injury

► An interview with Sandra De leon, R.N., C.R.R.N.

**A** national program dedicated to preventing brain and spinal cord injuries in young people, ThinkFirst has reached 8 million children aged 5 through 18 years since it was founded in the 1970s. Health educators and individuals who have experienced traumatic injury serve as program facilitators. They receive training at one of six centers in the United States. ThinkFirst New Jersey has been sponsored by the Henry H. Kessler Foundation since 1992. It has trained facilitators from New York, Connecticut, New Jersey and Delaware, as well as individuals from Seoul, South Korea.

ThinkFirst New Jersey director Sandra De leon recently spoke with *Focus on Rehabilitation* about the organization and its impact on the community.

## How was ThinkFirst started?

ThinkFirst was created by two neurosurgeons. They knew that the majority of traumatic injuries could be prevented by “thinking first.” To help young people consider the potential ramifications of their actions, they developed an educational program focused on choices.

The central message is that individuals have the choice to engage in behaviors that keep them safe or participate in actions that risk injury. Today, the program exists in every state, where directors conduct monthly meetings to set goals and share ideas.

## How did you get involved?

I came on board with Kessler Institute in 1990 and wanted to participate in programs to prevent head and spinal cord injuries.

## What does ThinkFirst New Jersey seek to accomplish?

We recruit and train people in the community to provide educational programs. We teach young people about the real dangers that they face every day when they don’t wear seat belts in motor vehicles or helmets when riding bicycles or motorcycles.

In our programs, four health educators direct programs in each section of the state. They partner with individuals who have had traumatic injuries and who serve as the Voice for Injury Prevention (VIP).

## How do the health professional and the VIP collaborate?

The health educator and the VIP work as a team during the 45-minute program, typically presented during a classroom session. First, the health educator explains the anatomy of the brain and spinal cord, discusses the fragility of these essential organs and reviews what happens when the brain or the spinal cord is damaged. Young people learn that damage to nerve tissue is irreversible and is very different from a broken limb, for example.

The VIP then joins the health care professional and explains that because of his or her choice—not wearing a helmet or drinking and driving, for example—it is now necessary to live with the consequences of this choice.

## What key causes of injuries does ThinkFirst seek to prevent?

In New Jersey, the leading cause of both spinal cord injury and traumatic brain injury is motor vehicle crashes. For spinal cord injuries, the

second most common cause in people under 30 is violence. Diving and water-related accidents are also common causes of injury in young adults.

For traumatic brain injury in children under 16, the second most common cause is not wearing a helmet while riding a bicycle. It is for this reason that we emphasize wearing seat belts first and wearing helmets second.

## What age groups does ThinkFirst target?

Programs exist for young people in kindergarten through high school. A special curriculum for children in kindergarten through third grade uses cartoon videos and other age-appropriate materials. This program is typically presented by teachers or administrators.

## How often are programs presented?

Last year we sent facilitators to 42 schools and reached more than 20,000 students. We also made presentations at after-school programs, health fairs and high school driver-education classes. Demand far exceeds the number of requests we can accommodate, so we have a waiting list. ThinkFirst New Jersey could easily require full-time staff.

## What other activities are sponsored by ThinkFirst?

With the onset of summer, good weather and an extended holiday weekend, Memorial Day has the highest incidence of brain and spinal cord injury, so we offer special programs prior to this holiday. We also present our annual awards and reinforce our “think first” message.

We have a poster contest; last year 42 posters were displayed at

# Depression after traumatic injury: Impact on rehabilitation

► Karen Kepler, D.O., Ph.D., and Joyce Fichtenbaum, Ph.D.

Kessler Institute. These represented the winning entries from each school. Each of the artists whose work is displayed receives a \$100 prize. Visitors, staff and patients vote for one overall winner, who receives an additional \$250 award. The poster competition is one of our most successful programs.

## How is ThinkFirst funded?

Our funding comes from the Henry H. Kessler Foundation, which pays for materials used in the programs, as well as honoraria and mileage reimbursement for the program presenters.

## How can people get involved with ThinkFirst?

Go to the ThinkFirst.org web site. The national organization will put people in touch with regional outreach efforts.

Additionally, individuals may wish to make donations to the national organization. Such contributions help to pay for the web site and the curriculum materials. The ThinkFirst theme “Use your mind to protect your body” is a powerful message.

I helped develop the web site, in collaboration with others in the national organization. As someone who works in the rehabilitation setting, it's been wonderful to be involved with an organization that prevents such injuries!

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**U**p to one half of patients who have had a traumatic brain injury (TBI) or spinal cord injury (SCI) experience a depressive syndrome, which adds to the challenges of rehabilitation and recovery. These individuals are also at increased risk of suicidal ideation or suicide. Those with preexisting psychological issues may have more difficulty coping with their injuries. In addition, family distress and conflict can exacerbate psychological disturbances.

## Challenges of diagnosis

Symptoms of depression in patients with TBI or SCI resemble those of the general population; however, diagnosis and treatment of psychological disorders are complicated by these injuries' effect on patients' sense of self. With TBI, changes occur to the individual's core identity and the coping mechanisms that aid in recovery. Patients with SCI may also experience changes in self-perception; cognitive and emotional abilities that may aid recovery, however, often remain in place, as long as no concomitant TBI has occurred.

Secondary medical complications may result in depressive symptomology or may signal depression and demonstrate its negative impact on self-care.

Research indicates that depression can also be caused by the physical insult to brain tissue associated with TBI. This makes it difficult to differentiate between biological and psychological sources. Additionally, TBI alone can lead to symptoms that resemble those of depression, including sleep disturbance and changes in appetite and libido. In the SCI patient, medication side effects and the need to be turned at night to prevent decubitus

ulcers or pressure ulcers may result in appetite and sleep disturbances that mimic the biological effects of depression.

Patients with TBI may be aware of an impairment of higher function and mourn the loss of these abilities. SCI patients grieve the effects of their injury on everyday functioning (e.g., ambulation, self-care, bowel and bladder function, and sexuality).

## The role of psychotherapy

While pharmacologic intervention is often necessary for the treatment of depression, it does not address the cognitive, social or environmental factors critical to recovery. Psychotherapy is essential to address motivation and compliance with rehabilitation and establish behavior patterns to contribute to future success.

Psychotherapy focuses on establishing hope and patient goals, as well as developing and reinforcing skills to improve the individual's ability to adapt to the disability. Underlying issues of psychological health may undermine the rehabilitation process and must be addressed.

After major injury, psychotherapy helps patients come to terms with issues such as self-blame or other attributions to the cause of the injury. Patients frequently search for answers as to why the injury occurred, often finding comfort in religious beliefs. Patients may seek justification for their catastrophes and develop unrealistic ideations about their futures based on an expectation of great rewards from the tragedy (e.g., something good will surely come of this injury). Many hold on to the hope that medical advances will provide a cure. Psychotherapy encourages patients to combine realistic expectations with hope for the

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# The long view: Taking a responsible position

► *Bruce M. Gans, M.D.*

Several years ago, I attended a National Institutes of Health workshop that had been convened to establish a research agenda for pediatric critical-care medicine. Here, surrounded by leaders in that field, I realized the differences in the perception of time held by our two specialities—and the implications of on patient care.

In the critical care setting, clinicians look for immediate responses to treatment that are measured in minutes or hours. In rehabilitation medicine, we expect that improvements in our patients' conditions will occur in days, weeks or months.

Similarly, we take for granted the differences in the planning horizons of public policy makers, businesses and individuals.

Familiar institutions use very different timelines when they plan and implement strategic decisions. Religious institutions, for example, have perhaps the longest planning vision, sometimes looking ahead hundreds of years. Educational institutions tend to look far into the future, as well. With relatively stable administrative structures and governing bodies, both types of organizations are able to set long-term goals for building facilities, expanding programs, establishing large endowments and reserving funds to secure future economic viability.

While governments sometimes plan with a future measured in decades, many political institutions have a shorter-term vision that is marked by the desire of legislators currently in office to secure their reelection. Governmental bureaucracies tend to have a planning horizon that conforms to the presidential or gubernatorial cycles. Civil service employees may be able

to look far into the future with security, but no appointed government official would be foolish enough to plan beyond the next administration change.

Small businesses often will plan on a quarterly basis to secure short-term financial results. It is less common to see them make the long-term investments in research and infrastructure that are typically seen in large corporations, because of the delay in a payoff for the invested resources.

Individually, our own personal perspectives vary in how we plan for the future. Some of us live paycheck to paycheck while others engage in

Communities should be building more rehabilitation hospitals; yet we see steep declines

long-term goal attainment and even estate planning.

How do these different planning perspectives apply to the fields of health and rehabilitation? If we were to take the long view and plan far in advance for the future, our motto would surely be: "An ounce of prevention is worth a pound of cure." As a society, we understand that a small amount of spending today can provide tremendous returns in improved health tomorrow.

But is that how our government agencies act? When it comes to medical rehabilitation policies, it seems our federal government is focused on short-term planning rather than the preferred long view.

The population of the United States is aging, taking advantage of

the advances in health care that help people to survive formerly fatal conditions and enjoy longer lives. Over time, this group will need more rehabilitation services than did prior generations.

Despite this, federal government planners seem to be ignoring the incoming tsunami of aging baby boomers. Private insurers are eager to avoid expending resources for appropriate rehabilitation services, rather than perceiving their value for future cost savings.

Instead of engaging in long-term planning with our field, we see the government cutting funding for rehabilitation. Hospital beds are closing because of the 75% Rule, and postservice denials from Medicare are restricting economic access by patients in need. Our communities should be building more rehabilitation hospitals to meet future needs, yet we are experiencing sharp reductions in rehabilitation capacity and services.

Our government has a responsibility to maintain the long view in our public policy. With regard to rehabilitation policies, this means providing access to long-term medical care in the most cost-effective and responsible manner.

We need to work with policy makers to find a smarter way to constrain unnecessary expenses, to improve rehabilitation services and to stop the decline in the capacity of rehabilitation hospitals. For the sake of our patients and our profession, let's not continue making shortsighted decisions.

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## Mainstream technology increases independence

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splints with pegs, or adapted pointers for uses with the hand, mouth or head. Individuals with very limited movement, such as those with higher cervical spinal cord injuries or individuals with later stages of amyotrophic lateral sclerosis (ALS), can often operate devices through head, breath or voice control.

### Opening new doors

Two mainstream technologies commonly used by individuals with disabilities are cell phones and computers. Particularly for many newly injured individuals, maintaining contact with family and friends via phone and email is essential to their emotional well-being and recovery.

Voice activation capability has made cell phones increasingly accessible to individuals with minimal or no upper extremity movement. Wireless Bluetooth technology, which uses radio frequencies to transmit, allows hands-free access via a special ear piece. By grossly tapping the earpiece switch, the user can start or end a call. For individuals with very limited or no upper extremity movement, specialty controls, such as a pneumatic (sip/puff) switch, turn the headset on and off. Voice activation can also control standard phone options, text messaging and other features.

Bluetooth technology has current and future applications with computers, printers, faxes, cameras and PDAs, offering significant potential for access to these devices; this technology has already been integrated into power wheelchair controls. It is possible to envision a day when persons with disabilities can control the many details of their lives with a small microphone clipped to their shirt or wheelchair, through which people can access such things as ATM machines in the community.

### Access to computers

Computers are popular with individuals with disabilities. Low technology or inexpensive adaptations, such as typing pegs and mouth sticks can be used to access a standard keyboard and mouse. Higher technology alternatives are also available, including voice-activated systems, head-controlled devices and, for individuals with limited head or upper extremity movement, systems that function with minimal eye or facial movements.

With voice recognition software, individuals with adequate phonation and consistent vocalization can write documents at a rate equivalent to typing. After training, this software recognizes and incorporates an individual's specific speech patterns; training the software is a lengthy process for which clinicians should prepare their patients. Individuals with poor voice output, such as in the case of respiratory compromise, can use mouse emulators controlled by head, mouth or even eye movement.

PDAs, iPods and electronic readers (e-books) are also popular mainstream devices. These devices are easy to access for those with limited upper extremity function through touch pads, voice activation, Bluetooth, adapted pegs or mouth sticks.

Voice-activated remote controls for TV and entertainment systems, touch lamps and automatic faucets are other examples of mainstream technologies that can help individuals with disabilities live a fuller, more enjoyable life.

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## Depression after traumatic injury

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future. It helps individuals work actively to accomplish self-generated goals for improved quality of life.

When patients arrive home, delayed onset of depression may occur as they confront issues of finances, mobility, accessibility, role changes, and occupational and interpersonal functioning. Services should be provided to help manage patients' concerns and eliminate obstacles to rehabilitation and long-term recovery.

Health care providers should be aware that depressive episodes can be triggered by the anniversary of the injury, especially on the first year following an accident. Symptoms of irritability or sadness should be closely monitored at such times.

Psychotherapists can encourage patients to take some commemorative action that can aid in closure and acceptance.

Depressive episodes that need to be addressed can occur in both the inpatient and outpatient settings. Key elements in the recovery process include gaining a new sense of self, developing a sense of control, and setting realistic expectations and goals for independence, even if it has to be at the wheel-chair level. The patient may need to accept dependence for certain activities and understand absolutes. At the same time, the individual needs to maintain hope for quality-of-life improvements. Long-term psychological well-being depends on successful coping strategies and external support networks, including psychotherapy as needed, to overcome unforeseen obstacles to success.

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# Improving acquisition and retention of information in persons with Multiple Sclerosis

► John DeLuca, Ph.D.

**M**ultiple sclerosis (MS) results in significant memory impairment, primarily in the ability to acquire new information. New rehabilitation techniques have significant implications for cognitive rehabilitation of learning and for reduction of memory problems in individuals with MS.

Story memory technique (SMT) has been shown to improve the strength of encoding information (or learning) in patients with MS, as well as in individuals who have experienced traumatic brain injury. Patients learn to visualize and contextualize material, ultimately increasing and improving memory (i.e., recall and recognition). In a 2005 study conducted at Kessler Medical Rehabilitation Research and Education Corporation (KMRREC) by Chiaravalloti, DeLuca et al, use of this technique resulted in improvements that were significantly higher in patients with moderate-to-severe memory than in a placebo group.

Acquisition of new information is also improved when patients are required to *self-generate* answers to questions. A 2003 study by Chiaravalloti and DeLuca conducted at Kessler evaluated this learning technique. The 31 patients with MS were

presented with sentences and asked to generate a missing word in each. In a comparative arm of the study, an underlined word was provided in each sentence. Participants with MS and healthy controls demonstrated significantly enhanced recall of self-generated material in comparison to provided material. They retained cognitive improvements at the one-week follow-up.

In the rehabilitation setting, these techniques may be used during physical exercise, as the clinician provides increasingly less complete instructions until the patient can self-generate an entire exercise sequence. Similarly, family members can facilitate the patient's memory in tasks such as remembering a shopping list.

## Duration and frequency of training sessions

An ongoing study at KMRREC is investigating the impact of timing and frequency of training sessions to improve the ability to acquire new information in patients with MS. Previous trials, such as that published by Hillary et al in 2003, have evaluated this aspect of learning in persons with traumatic brain injury. They reported that multiple short learning sessions spaced over time

produce results (i.e., improved recall and recognition) that are superior to those obtained in a single long session.

Additional studies are needed to determine what intervals between training sessions yield the most significant results overall. Additionally, researchers do not yet know whether these intervention techniques depend on the individual patient characteristics (e.g., severity of memory impairment) or specific tasks (e.g., learning to cook a new meal versus learning a new task at work).

New learning in rehabilitation can be significantly improved by adapting the manner in which the information is presented. These techniques can successfully be incorporated into daily living skills. Their application to cognitive rehabilitation strategies holds the promise of maximizing residual memory skills in persons with MS who suffer from impaired learning and memory.

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