THE GIRTH of a NATION

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The University of Pittsburgh is an affirmative action, equal opportunity institution.
O ur school has many important functions and responsibilities, not the least of which is providing our students with the knowledge they need to be highly qualified health and rehabilitation professionals. We also want them to be informed, capable and responsible citizens.

To that end, I ask you to pay particular attention to the article “Hands-on Disability Studies.” (p. 18) It describes a new program here at SHRS that could meet a compelling need in the disability community; namely, the acute shortage of personal care assistants. The program is a unique mix of education, service and student support. Perhaps most important, it introduces our students to a process with the potential for enlightenment and cultural change.

Any attempt to characterize the problems associated with providing direct care for both people with disabilities and the senior population would almost certainly result in an understatement of the extent and gravity of them. The aging of our population, the impending retirement of the baby boomer generation, and the increasing numbers and longevity of people with disabilities insure that the need and demand for care is increasing and will be with us indefinitely. At the same time, resources for providing care are woefully inadequate and are likely to decline proportionately. The greatest burden of direct care for persons with disabilities and the elderly falls upon family members, and most disproportionately on wives, mothers, sisters and other female relatives. The cost of outside assistance is high. Ironically, the pay for such work is low, rarely exceeding minimum wage. Rarer still is the provision of benefits for the direct care worker.

We obviously do not have a solution to this seemingly intractable problem. However, we are in the process of developing a potential symbiosis that we believe can benefit both local individuals in need of services while providing unique educational experiences for our students. It may also provide some modest financial support of our students during their matriculation at SHRS.

I take delight in sharing with you our experiences to date and our plans and expectations. In the first instance, we have initiated a program to inform students about disability at the earliest opportunity. This has been implemented through a new course for undergraduates in the Rehabilitation Science program, “Practical Issues in Disability.” It provides both instruction and exposure to issues and conditions that are relevant to people with disabilities and to those who provide care and services for them. This course provides students with an early and accurate view of our several professions that will help them with their career decisions. Upon completion, students will have substantially exceeded the standard for direct care workers, enabling them to serve in this capacity should they choose to do so.

We are presently working to establish relations with state and county agencies to arrange for interested students to receive part-time work for compensation. A brief survey of students who participated in the first class (Fall 2003) suggests a strong disposition to participate in part-time, direct care activities. We may be in a position to execute a “triple play,” where students gain unique experience, have an opportunity for earning money, and provide badly needed services to this greatly underserved and often neglected group. If this experiment proves to be successful, it is quite likely that it can be reproduced widely at other institutions. When fully developed, this might provide a partial solution to the ever-growing national need for direct care services.

Finally, even students who may never work as personal attendants will have the experience of association with people with disabilities. We believe that this will enable them to look past the disabilities; to see and come to know and appreciate the people that they are meeting. This will expand our present understanding of diversity, and we shall all be the better for it.

As always, I will be interested to hear from you on this or other issues you may wish to discuss.

With kindest regards,

Clifford E. Brubaker
In his 2004 State of the Union address, President George W. Bush called for the computerization of the nation’s healthcare records. “By computerizing health records, we can avoid dangerous medical mistakes, reduce costs and improve care,” he said. The President’s vision has profound implications not only on how we collect, organize, analyze and protect patient information, but also on how we educate the health information professionals who will be entrusted with our electronic health information future. I’ve asked Dr. Mervat Abdelhak, Professor and Chair, Department of Health Information Management, to discuss the implications of this ambitious agenda.

Immediately following the State of the Union address, Linda Kloss, Executive Vice President and Chief Executive Officer of the American Health Information Management Association (AHIMA), sent a letter to the President on behalf of the organization’s 46,000 members. “I am delighted that we share the same vision for improving the nation’s healthcare system by improving the quality of health information and fully using all of the tools of information technology available to us,” she wrote.

As president-elect of the AHIMA, I share Linda’s enthusiasm for the measure. In our e-HIM future, health information from a host of sources and in a variety of media will be collected, linked and organized around a unique personal portable identifier. The U.S. Army is already testing a prototype system using the omnipresent dog tags. Healthcare providers will have instant access to our complete medical history – no matter what the treatment was or when and where it was delivered. At a macro level, access to health data will be invaluable to researchers and healthcare policy makers for use in outcomes measurement, finance, clinical trials, disease tracking and prevention.

However, there are several significant hurdles that must be overcome if this vision is to become reality. The first is the development of a standard electronic health record (EHR) that allows for the “interoperability” or sharing of healthcare data. Today, sharing of healthcare data is difficult, as anyone who has ever had to have records transferred from one healthcare facility to another can attest. The EHR must transcend vendor-specific technology and allow connectivity no matter what or where the application.

And before we can create an interoperable EHR, we must agree on a standardized lexicon for classifying and coding data on diseases and medical procedures. In prior “Access” columns, several of my colleagues here at SHRS have discussed the difficulties that result from inconsistent coding and classification, particularly in the area of reimbursement. The use of a common vocabulary is the only way to ensure consistency of content and messages.
Finally, all parties in the healthcare mix – payers and providers, the states as well as the federal government – must agree to adopt this system. If there isn’t compliance across the board, then the purpose of the EHR is undermined.

Fortunately, progress is being made on all fronts. The National Library of Medicine now has a standardized lexicon. The Department of Health and Human Services is in the process of considering recommendations for updating our current classification system for diseases and inpatient procedures – ICD-9 – that dates back to the Carter Administration. A better system – ICD-10 – is already in use in nearly every developed country in the world and if adopted here, could be implemented by 2006.

In addition, Health Level Seven (HL7), a leading health information standards organization, has working groups developing standards that can be used across systems for capturing, classifying and transmitting the data. All of the necessary parties have voluntarily taken a place at the table: providers, government officials, vendors and health information management professionals. A functional model is ready to be field-tested.

The vision is that a standard EHR will be in place by 2010. And with it will come a near-revolution on how healthcare is delivered. Providers will be able to access information no matter where they are – even if their practice takes them to 10 different locations on any given day. They will be able to quickly access pertinent material rather than poring through reams of data. As patient records are updated, new information will be instantly available to other members of the healthcare team.

Perhaps most important, the data will be organized to facilitate diagnosis and treatment. For example, the system can be designed to store normal ranges for a battery of lab tests and flag the physician if a patient’s test results fall outside acceptable levels. Taking it even a step further, the system could require the physician to document what action, if any, was taken to address the situation. Accountability can be built in.

Some may argue that such safeguards are too formulaic and restrict the physician’s ability to problem-solve. But a good system can have flexibility and overrides built in. It should be there to aid – not direct or second-guess – the physician. A good information system should lay out all the vital information; but it is the physician who uses that information to make a diagnosis or determine a treatment regimen.

The EHR will be more than a computerized repository of healthcare information. It will open up new channels for doctor-patient communications. E-mail will become the standard for everything from scheduling appointments to asking questions. Databases linked to a physician’s Web site will provide a level of information not available during a standard office visit. And of course, patients will have access to their own medical records – though in a “read-only” version. Patients will become better-educated consumers.

Some, of course, will question the security of an Internet-based health information system. But the security concerns are no different than they are today. There is nothing to stop someone from walking into a hospital, putting on a lab coat, and accessing patient records. If there is a will, there is a way. But safeguards are being integrated into the standard EHR, and new and better security measures will be developed in the coming years.

Not surprising, implementing the EHR system will be expensive. To date, the private sector has funded most of the developmental research. However, the White House’s proposed fiscal year 2005 budget calls for investing roughly $152 million for healthcare information technology. While this may be insufficient to cure all of the ills, it is a good start and underscores the government’s commitment to modernize the system. In addition, the Centers for Medicare and Medicaid Services (CMS) has announced that it plans to provide differential payment to clinicians who use an EHR to improve the quality and effectiveness of care. While the plan will not go into effect until an EHR standard has been developed, the CMS will support several demonstration projects in 2004.

There also will be enormous costs associated with implementing the system nationwide and educating the health information professionals who will manage it. And like other sectors of the health care industry, there is a significant shortage of HIM professionals. The Bureau of Labor Statistics estimates that over the next decade, 6,000 jobs will need to be filled each year, a 49 percent growth in the HIM workforce. Right now, there are not enough students enrolled in HIM programs to meet the demand.

But despite the technological, financial and manpower challenges, the return on investment in a standard EHR system will be considerable. An efficient, effective standard electronic health record system will lower health costs, reduce the incidence of medical errors, and save lives. It is an investment worth making.

We’d like to hear your reaction to this column. E-mail your comments to Karen Khan at ktkhan@shrs.pitt.edu They will be printed as space allows.

If you would like to make an online donation, log on to www.giveto.pitt.edu
Throughout history, sound has played a key role in world events. First, there was the shot heard round the world that permanently sealed the case for freedom. Then, there was the British Invasion that changed nearly everyone’s tune. And later still, there was the crash of the Berlin wall accompanied by a buzz of excitement and relief as Eastern Bloc countries received their first tastes of freedom in nearly a century.

Today the sounds of progress are emanating from Poland. And in suburban Warsaw, they can be heard with great volume and clarity at the newly constructed International Center for the Treatment of Hearing and Speech Disorders. Supported by the Polish government as well as by a coterie of educators and international leaders that includes France’s former first lady, Madame Mitterrand, the center is reaching out to children and adults with a wide variety of speech and hearing services.

“The Polish people have built a wonderful center,” says Dr. John Durrant, Professor, Department of Communication Science and Disorders. “They have successfully gathered money in just about every way imaginable, pulled together an exceptional group of clinicians under the leadership of a dynamic man – Dr. Henryk Skarżyński – and have ultimately created a self-sufficient facility that provides high-quality and sophisticated care.”

Configured to deliver a full range of outpatient and inpatient otolaryngology services, as well as rehabilitation support in the areas of speech and audiology, the facility features state-of-the-art operating rooms, teaching and treatment areas, and a hotel wing for families of patients being treated at the center. The facility maintains strong linkages with numerous Polish healthcare institutions, and is also directly connected to numerous institutions of higher learning.

According to Durrant, “As a country, Poland has done an exceptional job of integrating into the post-Cold War economy. They are collaborating closely with the U.S. and many European countries, and have made incredible progress in upgrading their healthcare system. If there’s a weak link, it’s a lag in their educational system in training clinicians to enter the audiology field. Dr. Skarżyński recognized this and reached out to a number of international educators, such as myself, for assistance.”

Since May of 2003, Durrant has been making periodic trips to Warsaw to teach classes at the center. He has been joined by educators and researchers from a number of other world-renowned institutions who share his passion for helping the Poles develop a care delivery model that best serves their needs.

“Our goal is to help establish the basic science background that’s necessary to support the development of educational programs in specialty areas, such as audiology and speech pathology,” Durrant explains. “We also are working toward establishing a core group of Polish practitioners who have training that’s commensurate with the U.S. educational model. To do this, we’ve been identifying the individuals who are providing services and helping them to acquire knowledge that will allow them to be more effective practitioners.”

It is hoped that the efforts of Durrant and his colleagues will attract more Poles into the audiology and related professions and ultimately, will increase the demand for educators in these areas. “Poland has a stellar history of scientific accomplishment,” observes Durrant. “They have the basis for an exceptional healthcare system. We’re there to help them build on their accomplishments and to assist in refining their programs. They want to be our full partners in the practice of audiology and speech pathology. Working together, we’re effectively planting the seeds to allow the Poles to do just that, including an active role in research in the discipline.”

For more information, contact John Durrant at durrant@pitt.edu.
The More You Know

Diabetes Awareness Fair Raises Profile of Disease

The American Diabetes Association estimates that 18.2 million Americans have diabetes. And, amazingly, about a third of them do not even know it.

One major reason so many people with diabetes remain undiagnosed has to do with its symptoms; on the surface, many of them do not appear serious. Typical symptoms include excessive thirst, irritability, fatigue or frequent urination – each of which could be confused with the effects of overwork, stress or aging.

Healthcare professionals also agree that low public awareness and a dearth of free or low-cost screening programs share a significant portion of the blame.

But in November of last year, Lisa McDermott, Clinical Instructor, Department of Sports Medicine and Nutrition, along with other University of Pittsburgh faculty members, took steps to begin to bring diabetes out from the shadows.

As part of National Diabetes Month, McDermott organized the University’s first Diabetes Awareness Fair, held in the Petersen Events Center. Clinicians from the University of Pittsburgh Diabetes Institute were on hand to perform blood glucose screenings, and representatives from a score of pharmaceutical companies and health aid manufacturers offered literature on diabetes and its treatment.

According to McDermott, early detection is a crucial step in managing the disease. “If the disease is detected early and well-managed, most people can live active, healthy lives.”

If the disease is detected early and well-managed, most people can live active, healthy lives. Increasing public awareness of the disease and arming people with knowledge is one of the important components of preventing or prolonging the development of long term, debilitating diabetes complications.”

The fair also had two special guests: Pittsburgh Steeler Kendall Simmons and Pitt Panther Dan Stevens. Both are proof that diabetes does not have to come in the way of a healthy, active lifestyle.

Explains McDermott, “Kendall Simmons and Dan Stevens are particularly important to the process of raising awareness because they demonstrate that diabetes does not have to define who you are. By eating healthy, well-balanced meals and snacks and participating in diabetes self-management, diabetes does not have to be perceived as an obstacle in life.”

While Dan Stevens was diagnosed with diabetes as a child, Kendall Simmons was only diagnosed with the disease in the last year. Says Simmons, “At first, it was a blow to me. I lost about 30 pounds and had a rough time. But I’ve learned that the disease is what I make it. I’m not going to let diabetes ruin my life. No one would know that I have the disease unless I tell them. And right now, I feel like the perfect person to educate people about the disease.”

“I’ve found that it’s half mental and half nutritional,” notes Stevens. “You’ve got to keep your eyes on your goals in life, just like anyone else, and you’ve got to watch your diet. It’s all about management. But you can only begin managing diabetes once you know you have it.”
Scholars serving as Secretary of the National Society of Collegiate Department of Communication Science and Disorders, is an undergraduate student in the Department of Occupational Therapy, each were awarded a master’s degree student in the Department of Communication Science and Disorders, and Marie-Lys Cattanach, editor of Communication Science and Disorders, has been named the University of South Carolina. Completing a pre-doctoral Fellowship at the Medical student scholar in the Presidential Scholars Program and is Communication Science and Disorders, was recognized as a Martin Brodsky, a doctoral student in the Department of Communication Science and Disorders, was based Fibromyalgia Educational Material” at the American Chair, and Dr. Terry Starz presented “The Literacy of Web-Occupational Therapy, a doctoral student in the Department of Hazel Breland, Class Acts Student News Move it or Lose it physically active on a pays off. Those that regular exercise performance-based measures. assessed over the next 14 years walking– affected their general health. Following the conclusion of the a three-year study to assess how physical activity – primarily regular period. The research began in 1982, when participants were enrolled in life helps maintain functional ability as you age. The long-term study – the first to prove the link between physical activity and functionality – followed 171 post-menopausal women over a 17-year period. The research begun in 1982, when participants were enrolled in a three-year study to assess how physical activity – primarily regular walking – affected their general health. Following the conclusion of the original survey, the participants’ functionality was assessed over the next 14 years using both self-reporting and performance-based measures. The findings indicate that regular exercise pays off. Those women who were physically active on a regular basis during the life of the study had a noticeably higher level of functional status than those who were either inactive or who exercised sporadically. "Functional status relates directly to what a person can do for him or her self, so having a high functional status means the person is more likely to be able to live independently,” explains Dr. Jennifer S. Brach, Assistant Professor, Department of Physical Therapy. "Regular physical activity, which can be as simple as walking, not only helps people to live longer and healthier, it helps them to live with fewer limitations and a better quality of life. People living longer, this research confirms that everyone, young and old alike, will benefit from regular physical activity.” The research findings were published in the November 2003 issue of Archives of Internal Medicine. For more information, contact Jennifer Brach at jbrach@pitt.edu

Elizabeth Dames, a doctoral student in the Department of Physical Therapy, was honored with the Jessie Wright Award, which is the highest distinction given to a graduate of the Physical Therapy program who “displays superior academic achievement and displays the potential of becoming an outstanding clinician.” Tish Gaffney, a third year student in the Department of Communication Science and Disorders, served as the national board representative for the National Association of Future Doctors of Audiology (NAFDA). She was also elected as national Secretary. O’Neil Guthrie, a doctoral student in Department of Communication Science and Disorders, received the Young Scientist Travel Award from the Association for Research in Otologyngology. He presented a paper entitled “Autometallographical Amplification of Intracellular Anti-cancer Platinum Molecules” at the conference in February. Sharon Gwinn, a doctoral student in the Department of Communication Science and Disorders, Dr. Joan C. Rogers, Professor and Chair, Dr. Marjo Holm, Professor, Dr. Terry Starz and Dr. Molly Vogt presented “Activity Limitations in Knee Osteoarthritis (KOA): Concordance of Current Assessment Nomenclature and the International Classification of Functioning Disability and Health (ICF) Nomenclature” at the American College of Rheumatology/Association of Rheumatology Health Professionals annual meeting in Orlando, FL in October. William Hula, a doctoral student in the Department of Communication Science and Disorders, gave a poster presentation to the International Society for Quality of Life Research titled “Causal Modeling of the Relationships Between Patient-reported Communication Difficulty, Associated Psychological Distress, and Participation Restrictions” in Prague, Czech Republic. Melissa Lauffer, a doctoral student in the Department of Physical Therapy, was given the CRS Leadership Award. The award is given to an individual who demonstrates leadership potential by successfully heading activities related to professional or community service. Tamara Mills, a doctoral student in the Department of Occupational Therapy, was invited to attend a dinner reception hosted by Chancellor Mark Nordenberg in October to honor student leaders who have devoted their talent and achievement to the University of Pittsburgh. Kelly Naylor, a doctoral student in the Department of Physical Therapy, was given the Patricia Leahy Memorial Award. The award is given to a student who “demonstrates a special interest in neurology, and a love of family and friends.” Katie Rentschler, a student in Department of Communication Science and Disorders, presented “Characterizing the Functionality of Dysarthric Speech using Comprehension Measures” at the American Speech-Language-Hearing Association (ASHA) Convention. Xiaoming Zeng, a doctoral student in the Department of Health Information Management, received the Dissertation Assistance Award from the Foundation of Research and Education (FORE) in the American Health Information Class Acts

Hazel Beland, a doctoral student in the Department of Occupational Therapy, Dr. Joan C. Rogers, Professor and Chair, and Dr. Terry Starz presented “The Literacy of Web-based Fibromyalgia Educational Material” at the American College of Rheumatology/Association of Rheumatology Health Professionals annual meeting in Orlando, FL in October.

Martin Brodsky, a doctoral student in the Department of Communication Science and Disorders, was recognized as a student scholar in the Presidential Scholars Program and is completing a pre-doctoral Fellowship at the Medical University of South Carolina.

David Byrne, a doctoral student in the Department of Communication Science and Disorders, has been named the editor of Spectrum: A publication of the National Hearing Conservation Association.

Marie-Iys Cattanach, a master’s degree student in the Department of Communication Science and Disorders, and Jamie Scheller, an undergraduate student in the Department of Occupational Therapy, each were awarded the Anne Pascaiso Scholarship.

Jessica Cleaver, an undergraduate student in the Department of Communication Science and Disorders, is serving as Secretary of the National Society of Collegiate Scholars.
Learning to ADAPT

In September of last year, students taking the course "Individual and Social Aspects of Disability" taught by Dr. Miriam Hertz, Assistant Professor, Department of Health Information Management, learned first-hand what it means to be a disability advocate. Many of them joined thousands of disability rights activists and supporters for a rally on Congress to demand the passage of the Medicaid Community-based Attendant Services and Supports Act, also known as MiCASSA.

The rally was the culmination of a march organized by the national grassroots disability rights organization, ADAPT, that had begun two weeks earlier in Philadelphia. It was estimated that close to 20,000 people participated in the rally, making it the largest disability rights gathering on Congress since the passage of the Americans with Disabilities Act (ADA) in 1990.

Under current Medicaid policy, states are required to provide long-term care services to people with disabilities and the elderly. However, these services are only compensated if the person lives in a nursing home. Supporters of MiCASSA argue that home-based services are far lower than the costs associated with living in a nursing home and that people with disabilities should have the right to choose where they live.

"The works of the speakers and performers, the energy of the supporters, and the overall scene was something that many of us had never witnessed," remembers Tamara Mills, one of the students who attended the rally. "It led to a lot of discussion and insight."

The Department of Physical Therapy graduated its first class of doctoral students in December 2003. The Doctor of Physical Therapy (DPT) will now be recognized as the entry-level degree for physical therapy at the University of Pittsburgh.

The 37-member class gathered with their family and friends for a Recognition Day ceremony in the Frick Fine Arts Building. Dr. David Greathouse, Professor and Chair, School of Physical Therapy, and Associate Dean, College of Health Sciences, at Belmont University, gave the keynote address. He was a member of the last graduating class of the renowned D.T. Watson school (FACETS, Fall 2002).

Several students were also recognized for their achievements during the ceremony. Elizabeth Dames received the Jessie Wright Award, which is the highest distinction given to a graduate of the Physical Therapy program who "displays superior academic achievement and displays the potential of becoming an outstanding clinician."

Melissa Lauffer was given the CRS Leadership Award, which is given to a student who demonstrates leadership potential by successfully heading activities related to professional or community service that lead to significant accomplishments.

Kelly Naylor received the Patricia Leahy Memorial Award, given to a student who "demonstrates a special interest in neurology and a love of family and friends."

Alexandra Jeffords, a student in the Department of Rehabilitation Science and Technology, was the Featured Artist in Disability World, a bimonthly web-zine of international disability news and views, in December. She was recognized for her work on tiny 1:12" scale wheelchairs.

IN MEMORIAM

Betty Allen Halliwell
D.T. Watson '48
Riding High

It seems fitting that when Catherine McLean Armstrong, a master’s degree student in the Department of Rehabilitation Science and Technology, received a call notifying her of a nomination to the Allegheny County Port Authority Board of Directors, she was riding a bus.

At the deceptively young age of 23, the Yale graduate is a far cry from the average County-appointed board member. Armstrong is the only one who rides the bus system on a regular basis. She is also female, visually impaired, and extremely well-informed on disability transportation issues.

Armstrong says that the Port Authority has been doing a good job addressing the needs of passengers with disabilities, but she admits, it could be doing more.

“The Port Authority has been buying low-floor buses - or, buses with one step rather than three – for several years. These buses use ramps for wheelchair users instead of hydraulic lifts which can be manually deployed in the event of malfunction,” she explains.

“Low-floor buses are also much easier for people to board who have arthritis or are on crutches.”

In addition, all of the drivers receive ongoing training based on an ADA-compliant driver manual. According to regulations, every driver must be able to help with the wheelchair tie-downs with which all the buses have been retrofitted. They also have to call out all of the stops for people.

But despite the training, ADA compliance isn’t always the norm for Port Authority bus drivers. One of the most blatant breaches in compliance is when buses intentionally pass up riders with disabilities. “It only takes a couple of minutes to accommodate someone in a wheelchair,” Armstrong argues, “But some drivers just don’t care to take the time.”

She describes one particularly ugly incident when a wheelchair-user was arrested for blocking a bus whose driver refused to manually deploy a ramp and allow him to ride. “The gentleman was trying to make a point. We all deserve the right to something as basic as access to bus transportation. Some Port Authority drivers would rather ignore the issue than address the problem.

“Drivers’ attitudes need to change about people with disabilities, but that’s a very long-term goal. I’m not sure that any number of sensitivity classes could change the attitudes of some drivers,” she continues.

While Armstrong believes that the problem with insensitivity isn’t systemic – “There are a lot of fantastic drivers,” she notes – she thinks that drivers need to be mindful of the importance of bus transportation to riders with disabilities.

“Picking up people with disabilities and calling out the stops is really important. Whether or not some drivers realize it, people with disabilities have responsibilities like everyone else. Getting passed up by a bus and having to wait an hour for another one could lose someone their job.”

Armstrong credits her time at SHRS for helping her to grow into her new role. Over the past year, she has conducted a national research survey on accessibility barriers for wheelchair users who ride buses, which has added to her credibility in the boardroom. “I bring two perspectives to any discussion on disability-related transportation issues. Not only can I speak from my experience as a daily bus rider; I also bring my perspectives to any discussion on disability-related transportation issues. Not only can I speak from my experience as a daily bus rider; I also bring my experiences in academia to the table.”

She also acknowledges that the school has broadened her personal awareness of the challenges faced by people with disabilities other than her own. “At SHRS, I’m around people with many different types of disabilities. I’ve learned from their insights. It’s my goal to help make public transportation better for everyone.”

Students Don White Coats

The 21 students in the Doctorate in Audiology program along with faculty, family and friends from around the country gathered in the Frick Fine Arts building October 4th for the First Annual University of Pittsburgh White Coat Ceremony for Audiology (FACETS Winter 2002). Begun in 1989 at Columbia University, the White Coat Ceremony is a “rite of passage” for clinical doctoral students and emphasizes the importance of the mission of the institution: education, research, patient care and service.

Two students, Jennifer Vargo and Patricia Gaffney, were instrumental in starting the University of Pittsburgh Chapter of the National Association of Future Doctors of Audiology (NAFDA), a prerequisite to holding the ceremony. The two had attended a meeting of NAFDA and, according to Vargo, “We determined that having a chapter on campus would assist us, both professionally and personally.”

Elaine Mormer, Audiology Clinical Coordinator and Instructor, notes that “there was an air of excitement at the event because it was the first such ceremony for the department, and because Dean Brubaker and department chair Dr. Malcolm McNeil gave opening remarks that were so uplifting.” The ceremony was “absolutely student-inspired and initiated,” states Mormer, who is also the chapter advisor.

Along with students receiving their white coats, Vargo, now president of the university’s NAFDA chapter, led them in the Audiology Oath. The Audiology Foundation of America donated the doctoral coats, pins and otoscopes. Keynote speaker for the event was Angela Loavenbruck, past president of the American Academy of Audiology.

A reception followed the ceremony and the students organized dinner and dancing aboard the Gateway Clipper that evening.

The Au.D. Program was established in the Department of Communication Science and Disorders in 2001. The first graduating class will receive their degrees this Summer.
The challenge of providing age-friendly healthcare support to the elderly in countries that are already straining to provide social, economic and healthcare support is of particular interest to Gabriel Romano Vargas, a recent graduate of the master’s degree program in the Department of Health Information Management (HIM).

As a physical therapy undergraduate student at the University of Santo Tomas in the Philippines, he became aware of the special healthcare needs of the elderly. Romano Vargas brought this interest to his graduate studies at SHRS where, under the guidance of Dr. Jane Mazzoni-Maddigan, he focused on aging and long-term care, disability studies, and healthcare systems research and earned a degree in Healthcare Supervision and Management.

Explains Romano Vargas, “As I’ve studied aging and global healthcare for the elderly, I’ve been struck by the lack of infrastructure and support systems for older people in developing countries. My classes in international rehabilitation with Dr. Kate Seelman and independent study in global aging and disability with Dr. Miriam Hertz greatly increased my knowledge about the present level of healthcare support compared with where that level should be. These were further reinforced by a long-term care administrative internship I completed in July 2002 with Kane Regional Center administrator John Neiderberger. The more I became aware of these facts, the more I’ve wanted to make an impact.”

So when it came time to complete his graduate internship, Romano Vargas went to the one place his impact would be felt the most: the headquarters of the WHO in Geneva, Switzerland.

During the eight-week internship in the summer of 2003, Romano Vargas worked in the WHO’s Aging and Life (ALC) Course program under the direct supervision of ALC Senior Technical Officer Irene Hoskins and Dr. Alexandre Kalache, ALC Coordinator. He was assigned to research systems and models of best practice designed to create international age-friendly healthcare standards and improved access to healthcare for the elderly and people with disabilities.

“The major focus of the program’s research is primary healthcare centers, usually the first point of entry into any healthcare system. By examining how services are delivered at the first point of access, we can begin to assess overall education and training, management systems, and physical accessibility in these centers, and compare the findings to recognized best practices.

“Much of my work focused on creating a toolkit that developing countries could utilize to conform their health systems to age-friendly standards. The WHO has been working with several developing nations to test how health systems could evolve to accommodate the elderly. They’ve conducted several focus groups around the world to begin to determine the areas that require the most attention in the transition. Based on these findings, the WHO is developing a comprehensive toolkit that will help implement change.”

The toolkit goes into three major areas of primary healthcare: (1) information, education and training; (2) community-based healthcare management systems; and, (3) physical environment. Everything is closely examined, from the availability of adaptive devices to the width of the doorways. It also includes hours of operation, medical records management, and training programs to health professionals.

“The world’s population has always been in the shape of a pyramid, with far more young than elderly. However, the pyramid is becoming inverted, and developing countries must be ready to make the adjustment,” explains Romano Vargas.

“The internship really solidified my commitment to the study of aging standards, disability issues and healthcare systems. It made me realize that ultimately I want to work in countries with emerging economies to help them design healthcare systems that will support people of all ages. There is no such thing as a standard patient and healthcare must be available to everyone.”
Living in
In any given year, nearly 600,000 international students call America’s colleges and universities home. They come to the United States to master our language and take in our culture. They come to experience the American way. And they come to learn.

The University of Pittsburgh prides itself on its rich, diverse international student base. Last year, Pitt enrolled 1,731 international students, many of them studying in the School of Health and Rehabilitation Sciences (SHRS). And like their American counterparts, they are among the best and the brightest, wanting to study in programs that are on the cutting edge of research and technology. They choose SHRS because it is one-of-a-kind.

Min-Mei Shih, a master’s degree student from Taiwan in the Department of Occupational Therapy, is just one of the students who travels every year to SHRS for its unique curriculum. She traveled here four months ago because OT is still in its infancy in Taiwan. “The field of occupational therapy was basically created here in the United States, so coming to SHRS was my best chance to be on the front lines of research,” she explains.

So far, the experience has been an eye-opener. “In my home country, students don’t participate in class; they’re very passive. And if they do answer questions, it is in a very rigid fashion. All students basically answer questions in the same way.”

Of the difference between Taiwanese and American students, she explains, “Students here have creativity. Everyone has a unique answer to a question and isn’t afraid to voice an opinion. I think it’s a much better environment because teachers know almost immediately if the class understands a lecture. Feedback is a good thing.”

For Shih, the differences in the kitchen have been as substantial as those in the classroom. The food, she says, has been the most awkward adjustment. “Not only are ingredients in dishes much different, but so is meal preparation. For instance, we don’t use ovens very much in Taiwan. It’s been very difficult to get used to.”

However, she has taken to one American delicacy: pizza.
One Million Taiwanese Golfers - and Growing

Fellow Taiwanese student Yung-Shen Tsai, a doctoral student in the Sports Medicine and Nutrition program, came to the U.S. for similar reasons. “We don’t have a sports medicine Ph.D. program yet in Taiwan,” says Tsai.

There are also few Taiwanese physical therapists with a golf specialization. With the sport in the midst of a boom, Tsai anticipates that the investment he is making in his education will pay off. “There is no knowledge about how to treat golf-related injuries in Taiwan, in a period when more people are golfing than ever before,” he explains. “At New York University, where I completed my master’s degree, I met another student studying golf-related injuries and I saw it as an immediate opportunity. Given the maturity of the golf biomechanics program at the UPMC Center for Sports Medicine, this was the obvious place to come.”

While the study of golf-related injuries is challenging, Tsai finds the game itself even more so. “Golf is hard,” a slightly embarrassed Tsai admits. “When I first went out, I missed a lot of shots.” Shaking his head, he concedes, “Golf’s not my game.”

While Tsai has lived in the U.S. for six years, he says the language can still be a problem. “I’ve lived in Taipei and New York and was in the military in Taiwan, so I’ve learned to adapt,” he points out. “But the language is something that you’re either really good with or not. I’ve been in the U.S. for a long time but it still gives me trouble.”

Curriculum is Key

On the other hand, Wiltrud Fassbinder, a doctoral student in the Department of Communication Science and Disorders, seems to be about as American as an international student can become. “This is my life,” he explains. “I came here because there is no speech-language pathology curriculum in Germany. SHRS is a leader in cognitive neuroscience research. I’ve now been here nine years.”

Fassbinder is unsure whether he will return to live and work in Germany. It would be easier to find a job if I had a degree in a discipline like psychology rather than a degree from the Department of Communication Science and Disorders,” he explains. “Academic unemployment is high in Germany, and this degree is quite incompatible with the German system. It might hurt in the job seeking process. It’s difficult to tell how a job hunt in Germany would go for someone with my qualifications.”

Sara Piva, a doctoral student and research associate in the Department of Physical Therapy, and Eliana Chavez, a doctoral student in the Department of Rehabilitation Science and Technology, also both came to America because a graduate program in their respective disciplines was not available in their home country. Brazil. They’ve been so impressed with SHRS that they’ve stayed at the school and are earning doctorates.

Piva and her husband came to SHRS five years ago to study at the world-renowned PT program. And while she doesn’t admit to having had to make many adjustments, she’s made one significant sacrifice in coming to America: Piva left behind her own physical therapy clinic in Brazil to advance her education here in America. She remembers that when she first arrived in the U.S., “The change in diet and my problems with English were certainly noticeable. But I knew I would adapt. In the beginning, I couldn’t understand much of what was said in my classes, and some instructors had a hard time understanding my questions. Language was difficult, but scientific writing proved to be much more of a challenge.”

While Piva’s family would have preferred that she and her husband had stayed in Brazil, they supported her decision. Matter-of-factly, she notes, “They recognize that it’s a small world and people are similar no matter where you live. There are good people and bad people everywhere. They supported me because they were convinced that this was the very best opportunity available and they wanted me to pursue it.”

Piva doesn’t expect to return to Brazil after earning her doctorate. She’s grown accustomed to doing research and doesn’t believe the same opportunities
and advanced research facilities will be available in her home country anytime soon.

**But Return Home, They Do**

Conversely, Turki Al-Hamid, a paramedic student in the Emergency Medicine program, is destined to return to Saudi Arabia when his studies are complete; his sense of duty to pass on his knowledge to other Saudi Arabians who have been less fortunate overrides any other motivation.

“There aren’t many opportunities for students at home to learn about being a paramedic,” Al-Hamid explains. “I feel that it is my obligation to give back because I’ve received so much.” Al-Hamid has been accepted in the master’s degree program in Emergency Medicine and, on completion, will return to Saudi Arabia to teach at King Abdul Aziz Medical City.

There’s also another motivation for Al-Hamid to return home. His family, with whom he is very close, has never seen his third son, who was born here.

Al-Hamid says his family has always been supportive of his dreams. “It was my father,” he remembers, “who convinced me to come here to earn my EMT in 1991. He has always been impressed with the U.S. and wants to visit. From the beginning, he has supported my decision to study here. These little things can sometimes really help.”

Like other international students, it was the language that caused him the most problems upon arrival. Some were amusing.

Al-Hamid relates that when he first came to the U.S. in 1991 to get his EMT from Minnesota State University, he could never seem to remember how to order a chicken sandwich when he went to a restaurant. The words just wouldn’t come out; he could only order by drawing it.

“laughs Al-Hamid, “That was funny. I did a lot of drawing that year.”

**More than Studying**

Andi Saptono and Reza Ferrydiansyah, two master’s degree students in the Department of Health Information Management from Indonesia, have been equally pleased – and amused – with some of their experiences. The two friends, who have been stateside for only three months, recently joined the Pittsburgh Council for International Visitors (PCIV), which they jokingly call the Party Club for International Visitors.

“The organization hosts gatherings every two weeks at places in the Pittsburgh area like Phipps Conservatory and Fallingwater. This gives us an opportunity to meet other people from all around the world,” explains Saptono.

“As much as we have a good time, the club also allows us to meet people who are sharing the same experiences living in America.”

Fortunately for Saptono and Ferrydiansyah, language has not been a challenge. Ferrydiansyah spent three years in Australia as a child and Saptono comes from Jakarta, which, he says, is “as cosmopolitan as any American city.”

“The weather has been one of the biggest shocks,”
confesses Ferrydiansyah. “In Indonesia, we have either rain or shine.” Saptono agrees. “We come from a tropical climate. We don’t know winter. Before I got here, I’d never seen snow.”

The exchange rate has also been a cause for adjustments. “Right now the conversion ratio between rupees and dollars is 10,000:1. It’s made a difference in buying power,” he notes.

While they both say that their families backed their decisions to study in America, Ferrydiansyah admits that his mother was a little worried for his safety. “My mother was concerned that I could be the victim of racism or crime. Most people get their opinions about American life from movies and television, which aren’t an accurate reflection of real life here. I’ve explained this to her, and the longer I’m here and safe, the calmer she’s become. Mothers will be mothers.”

Neither have had problems since they’ve been here and don’t anticipate they will. Explains Ferrydiansyah, “A lot of people here are really open-minded and I’ve been impressed with the people I’ve met.” The greatest danger, they joke, is crossing the street. “We’re used to people driving on the left side of the street,” says Saptono with a smile.

From North of the Border

Even students like Jason Mihalik and Natalie Senese, both Sports Medicine and Nutrition master’s degree students from nearby Canada, have seen the advantages of an SHRS education.

Explains Mihalik, “Canada lacks any accredited programs in sports medicine/athletic training and the program here comes highly recommended. The advances in research and the new facilities, coupled with reputable faculty, lured me in and the UPMC Center for Sports Medicine sealed the deal.”

Adds Senese, “Besides the great reputation, SHRS is also close to home. Sports medicine is not as specialized in Canada as it is in the U.S., so the opportunity to come to SHRS really worked well with my needs.”
Surprisingly, the duo admit to some culture shock when they crossed the border. For Mihalik, it was the absence of near round-the-clock hockey.

“In Canada, hockey is broadcast on CBC, which is the equivalent of CBS, and can be viewed by everyone who owns a TV. It’s also available both in English and French. ‘Hockey Night in Canada’ on Saturday night is viewed almost religiously,” he explains. “Also, in Canada you can expect four solid pages devoted to hockey in the sports section of the newspaper. Here, on the other hand, you open the sports section to find a half-page blurb on the Penguins and the NHL and two pages of local high school football, four pages of college football, and three pages of NFL coverage.”

He continues, in frustration, “If that’s not an adjustment, what is?”

As Mihalik explains it, just coming to the U.S. for an education was a mental adjustment for him and his family. “Unlike in America, where kids are expected to just pick-up and move across the country to attend college, in Canada this trend is not the norm. I had some first-rate colleges and universities very close to my home in Montreal, but I chose SHRS because I thought the experience and opportunity was too good to pass up.

“I think my family is divided on whether or not it was a good move to come to the U.S. But, given the global climate, it certainly makes for good holiday dinner conversation.”

Senese isn’t as rabid a hockey fan as Mihalik, but sports still play a crucial role in her life. She initially came to the U.S. as an undergraduate on a rowing scholarship to Mercyhurst College in Erie. And like other international students, she would not have had the same opportunities in Canada as she’s had at SHRS.

“Sports medicine is just not as specialized anywhere in Canada as it is at SHRS,” says Senese. “And at Pitt, I’ve been able to stay active in sports. I work as an athletic trainer with the swimming and diving team at Pitt and have been able to put my training into practice. I’ve been able to help athletes through some tough rehabilitation. When a group of athletes has a successful season, it’s good knowing that my expertise made a contribution.”

The experience of studying abroad is unique for everyone. But, whether they walk away and have a positive impact on their home countries or stay to contribute to the country they’ve grown to love, each international student will have gained a lifetime of memories and a world-class degree.

Jongbae Kim, a doctoral student from South Korea in the Department of Rehabilitation Science and Technology and a wheelchair user, will never forget the convenience of wide-scale accessible public transportation. And Mohammed Al-Sulaiti, a student in the Emergency Medicine program, will return to Qatar knowing he’s the only person in the country with an Emergency Medicine degree. But Sara Piva will take home something far more memorable than the experiences of her peers. This winter, she and her husband had their first baby.
Personal care assistants (PCAs) are very much in demand. Their job is to assist people with minor to severe disabilities in all the activities of their daily life. They can act as arms and legs, helping with everything from personal hygiene to driving to meal preparation. They can also be at the ready in case of an emergency situation; in some instances, PCAs live with their “consumers,” making themselves available 24 hours a day. They often become close, trusted friends.
Unfortunately, qualified PCAs are in very short supply. In Allegheny County alone, over 113,000 people have severe disabilities, yet only about 700 are assisted by a state-subsidized agency.

One reason for the shortage is the high turnover rate of PCAs. The pay is low and there is no opportunity for advancement. Also, fringe benefits are often limited to Workers and Unemployment Compensation. Couple these factors with the long, erratic hours and the high incidence of injury - mostly the result of the strenuous lifting that the job demands - and it is easy to understand why demand for quality PCAs far outpaces supply.

As a result, individuals with disabilities and their families are continually searching for qualified and reliable personal assistants. And to some, SHRS has always seemed like the perfect source for part-time PCAs. Its students are interested in the rehabilitation and disability fields, have limited earning power, and typically have blocks of free time on their hands.

Sondra Balouris Brubaker, Instructor, Department of Rehabilitation Science and Technology, recalls, “As we began to be approached by people about the possibility of our students working as part-time PCAs, we immediately saw the connection between the need and what our students had to offer. About a year ago, we formally began to look internally to try to address the challenge.

“We have undergraduate students who are interested in the health sciences and would like to get into graduate programs in physical therapy and occupational therapy. However, they need hands-on experience with people who have disabilities to be accepted into many of these programs. Working part-time as a personal attendant would give these students that experience.”

Dr. Anthony Delitto, Associate Professor and Chair, Department of Physical Therapy agrees. “Many students who apply for the physical therapy graduate program have only dealt with people who have temporary impairments,” he notes. “Learning how to relate to people who deal with impairments every day on an emotional level, is a special skill. I’ve always thought that introducing some of these undergraduates to part-time PCA work would be a great idea.”

Based on the feedback from faculty and people in the community, Brubaker decided to create an interactive class between students, individuals with disabilities, and their personal assistants. Her hope was to change students’ attitudes about disability and to encourage them to consider part-time PCA employment. Brubaker arranged a lesson plan and began teaching “Practical Issues in Disability,” an elective course, in the Fall semester of 2003.

The course takes a well-rounded approach to disability studies – from the history of the Independent Living Movement to issues of professionalism and confidentiality.

However, Brubaker believes the most significant learning occurs outside of the classroom.

One of the highlights of the class, she says, is a series of home visits. Students, divided into groups of four, are invited into the homes of people in the community with a disability. They’re encouraged to ask detailed questions about daily activities, use of assistive technology, and home modifications. After the visit, the groups return to the classroom to share their experiences.

“During the classroom discussion it becomes clear that a deeper connection has been made between the students and the individual,” says Brubaker. “Students no longer see people with disabilities in a detached way. For one thing, the home visit now places the student as ‘the visitor.’

“Within a short period of time, however, the initial tension is replaced by friendly and in some instances, lively conversation. It doesn’t usually take long for the conversation to drift away from the disability to exchanges related to relationships with family and friends – not unlike the conversations the students would normally be having among themselves.”

She continues, “One of our groups was actually enjoying themselves so much they invited themselves for dinner.”

Based on her class discussions, the extremely positive student responses to an informal survey at the end of the semester didn’t come as a surprise. When asked if the shortage of PCA services is a significant national problem, all but one responded ‘yes.’ And perhaps more telling, 21 students out of the 24-person class said they would make themselves available for part-time work during free hours, if provided a stipend.

Adds Brubaker, “It is difficult to predict what may come of their interest in personal assistant service, but I like to think their perceptions have changed. And ultimately, we would like to see behavioral change as well.”

For more information, contact Sondra Balouris Brubaker at sab992@pitt.edu.
Dr. Betty Jane McWilliams was a recipient of the University of Pittsburgh 2004 Distinguished Alumni Fellows Award. One of three professors to be honored with the award, McWilliams is a professor emerita in the Department of Communication Science and Disorders and an internationally recognized expert in speech pathology and audiology.

McWilliams received her M.A. and Ph.D. degrees from Pitt in 1950 and 1953, respectively, and has served as the director of four clinical programs, including 20 years of service in the University of Pittsburgh Cleft-Palate-Craniofacial Center. She also taught for nearly 30 years in Pitt’s Department of Communication, until her retirement in 1991.

McWilliams has been president of the American Cleft-Palate-Craniofacial Association, the Cleft Palate Foundation, and the Pennsylvania Federation of the Cleft Palate Clinics. She is a Fellow of the American Speech-Language-Hearing Association and the American College of Dentists.

Dr. Connie Tompkins, Professor, Department of Communication Science and Disorders, was honored as one of this year’s recipients of the Chancellor’s Distinguished Research Award.

Dr. Scott Yaruss, Associate Professor, Department of Communication Science and Disorders, was a finalist for the Chancellor’s Distinguished Teaching Award.

Faculty News

Dr. Nancy Baker, Assistant Professor, Department of Occupational Therapy and Dr. Mark Redfern presented “Developing an Instrument to Measure Keyboarding Style: Obtaining Content Validity” at the 47th Annual Meeting of the Human Factors and Ergonomics Society in Denver, CO in October.

Dr. Michael Boninger, Associate Professor, Department of Rehabilitation Science and Technology, was recently honored with the 2003 VA Stars and Stripes Healthcare Network Annual Award for Outstanding Achievement in Clinical Research.

Dr. Lynette Chandler, Adjunct Associate Professor, Department of Occupational Therapy, and graduate student Mary Andrews presented “Movement Assessment of Pre-ambulatory Children” in the Pathways to Excellence Continuing Education Series.

Denise Chisholm, Assistant Professor, and graduate students Trina Collins, Tiffany Moseray and Daniel Sopata represented the Department of Occupational Therapy in the “Investing Now: Hands-on Science” program in January.

Dr. Rory Cooper, Professor and Chair, Department of Rehabilitation Science and Technology, was named November’s “Cool Engineer of the Month” by the Junior Engineer Technical Society.

Dr. John Durrant, Professor, Department of Communication Science and Disorders, was an invited lecturer for the continuing education program on auditory steady-state responses applications in audiology given to ear-nose-throat services/departments at teaching hospitals in Beijing, Shanghai and Guangzhou, Peoples Republic of China, in December. He was also a guest speaker at the Weinberg Lecture Series at Purdue University in September and an invited speaker at the 4th Annual Innovations in Clinical Communication Sciences Conference at James-Madison University in October in Virginia.

Dr. Margo Holm, Professor, Department of Occupational Therapy, presented “Evidence-based Practice: Skills for School-based Practice” over several months last Fall to occupational therapists and physical therapists at the Bucks County Intermediate Unit. She presented a similar seminar titled “Evidence-based Practice: Skills for Pediatric Practice” at the Melmark School in Berwyn, PA in November.

Dr. Malcolm McNeil, Professor and Chair, Department of Communication Science and Disorders, was elected chairman of the Board of Governors for the Academy of Aphasia. He also received the Honors Award from the National Student Speech-Language-Hearing Association. This award is the highest honor bestowed by the association, and is the result of his tireless efforts to provide education and pre-professional opportunities for students in communication science programs.

Shelley Myers, Research Associate, Department of Communication Science and Disorders, received a scholarship to attend the VA National Center for Rehabilitation Auditory Research inaugural national conference. She presented “Physiological Plasticity of the Auditory System as Measured by Mis-matched Negativity” at the conference.

Dr. Catherine Palmer, Associate Professor, Department of Communication Science and Disorders, was named chair of the 2005 American Academy of Audiology Convention in Washington, D.C.

Dr. Sheila Pratt, Assistant Professor, Department of Communication Science and Disorders, was named president of the Academy of Rehabilitative Audiology.

Dr. Joan C. Rogers, Professor and Chair; Dr. Margo Holm, Professor, Department of Occupational Therapy and Dr. Lynn Goodacre presented “Assistive Technologies for People with Rheumatic Diseases” at the American College of Rheumatology/Academy of Rheumatology Health Professionals annual meeting in Orlando, FL in October. Rogers also presented “Active Living with Rheumatoid Arthritis: The Changing Landscape of Rheumatoid Arthritis” at the Media Breakfast in New York in September. She was appointed Newsletter Editor for the Association of Rheumatology Health Professionals.

Mark Schmeler, Director, Center for Assistive Technology was recognized as the 2003 Distinguished Teacher in the Department of Rehabilitation Science and Technology. Annmarie Kelleher was recognized as the 2003 Outstanding Staff Member in the department.

Department of Occupational Therapy faculty members Dr. Joan C. Rogers, Dr. Margo Holm, Dr. Carmella Battaglia, Dr. Nancy Baker, Dr. Elizabeth Skidmore and Denise Chisholm and graduate students Erica Kopcha, Ketki Desai, Tamara Mills, Mark Schmeler and Sharon Gwinn presented at the 26th Annual Pennsylvania Occupational Therapy Conference in October. The department also hosted members of the American Society of Hand Therapists who presented an “Advanced Splinting Workshop” on advanced static and dynamic splints for upper extremity injuries in November.
Customized Joysticks

Dr. Donald Spaeth, Adjunct Assistant Professor, Department of Rehabilitation Science and Technology, is one of the co-investigators on the multi-faceted project. One component involves evaluating customized joysticks for people experiencing spasticity or tremors. Pointing to the need for customization, Spaeth uses the eyewear analogy. “The optometrist doesn’t give you ‘one-size-fits-all’ glasses; he or she designs it specifically for your eyesight.”

Likewise, people who use wheeled mobility are unique. “A goal is to make users of wheelchairs who have experienced TBI become more independent and self-sufficient,” notes Spaeth, who is also Associate Director of Engineering at the VA R&D Center of Excellence at HERL.

With the assistance of research associate and co-investigator Dan Ding, the conventional movement-sensing joystick (MSJ) is computer-programmed to recognize and discard unintentional commands when a wheelchair user experiences a tremor.

The joystick can be reoriented in software to compensate for hand positioning. If the user pushes the joystick sideways when they intended to go forward, the joystick microcontroller can change the angle of the input. “This is akin to correcting prescription eyewear for an astigmatism,” Spaeth points out.

He indicates that the VA Health Administration is currently pursuing a patent on the joystick, which is now in its third iteration, with the National Technology Transfer Center.

Each Patient Requires an Individual Course of Treatment

As many as 6.5 million Americans alive today have had a traumatic brain injury. Many of these individuals have been left with significant cognitive, behavioral and communicative disabilities. Each individual reacts differently to their injury, their rehabilitation, and the ability to return to what equates to a normal life. Damage to vision and attending skills can make successfully maneuvering a wheelchair very difficult.

“In the past, researchers and clinicians have experimented with headgear to assist the wheelchair user in successfully driving their vehicle, despite vision loss,” says Spaeth. But the equipment – including restraints and confining headgear required to use ultrasound, infrared and other technologies – was cumbersome and stigmatizing. “They appeared more disabled than they really were, and this was a significant drawback to successful application of the technology.”

Using sophisticated stereo laser lithography, Spaeth and research associates Karl Brown and Alex Bevly have developed a head-position monitor that features a clear plastic shell, which fits around the back of the head and is relatively unobtrusive. Stereo laser lithography uses computer modeling and a liquid polymer resin, hardened with a laser beam, to produce three-dimensional shapes. “If it can be drawn on a computer, it can be created in 3D,” notes Spaeth.

Within the shell wall are small Hall effect transistors that detect a tiny magnet clipped to the wheelchair user’s hair. The transistors can detect the position of the head and communicate to a microcontroller in the joystick. “If you’re not looking in the direction the joystick is pointed,” says Spaeth, “the chair won’t move.”

Practice, Practice, Practice

When an individual suffers a TBI or has multiple sclerosis or another disability that requires the use of a wheelchair, they may qualify for a power or power-assisted chair under their insurance policy. However, because of the cost, a licensed therapist or clinician must certify that the individual is appropriate for the motorized chair and capable of using it properly.

“Young people often practice for months before they get their first driver’s license,” says Spaeth, “But we expect users of power-assisted wheelchairs to become proficient in one or two visits to a clinic where space is often at a premium. In addition, they likely won’t be prepared for every situation they may encounter using the wheelchair in the real world.”

To accommodate this reality, Spaeth and his team are developing a virtual, computer-based wheelchair-driving simulator that will allow the user to practice intricate maneuvers and mundane moves. Using their movement sensing and algorithm-equipped joysticks, wheelchair users can practice making sharp turns, navigating small spaces that require them to back up and reposition the chair; or other difficult maneuvers, all while sitting at the computer. Spaeth suggests that this program could one day be Internet-based, making it widely available to wheelchair users.

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THE GIRTH of a NATION
The Changing Shape of America
If you are one of the millions of Americans who started off the new year with a resolution to lose weight, history is on your side. Not in the sense that you’ll finally lose weight and keep it off. In reality, even the most successful obesity programs result in only modest weight losses – roughly five percent of the starting weight. Rather, you are one of many who, over the last thousand years, have turned to diets and diet gurus to shed those hard-to-lose pounds.

The first documented dieter was William the Conqueror, better known for winning the Battle of Hastings than the battle of the bulge. Legend has it that a millennium before The Drinking Man’s Diet hit the best-seller list, William took to his bed and consumed nothing but alcohol in an effort to lose weight.

The portrait of a young Lord Byron that hangs in the National Portrait Gallery in London shows a thin, almost delicate, dreamer. But by age 23, Byron had ballooned to a hefty 194 pounds. To trim down to a weight more appropriate for a romantic poet, he followed a strategy later espoused in the 1998 book, Lose Weight with Apple Vinegar. He drenched his food in the bitter brew. He chronicled the impact of the weight loss on his love life in one of his best-known works, the canto Don Juan.

Yet for Byron, like countless other dieters, the weight loss didn’t last. Within six years of his vinegar diet, his friend Percy Blythe Shelley reported that Byron had “grown fat, with hair long and turning gray, looking older than in his years, sunk in promiscuity.”

Looking for the Magic Bullet

William the Conqueror and Lord Byron were looking for what Judy Dodd, Adjunct Assistant Professor, Clinical Dietetics and Nutrition program, describes as “the magic bullet.” Rather than following the nutritionally sound, “eat less, exercise more” regimen, they wanted a quick fix that would offer dramatic results. And over the years, there has been no shortage of doctors and self-proclaimed experts who have been willing to satisfy the dieter’s appetite for a “can’t fail” weight loss recipe.

Long before Drs. Atkins and Agatston, there was Dr. James Salisbury, whose high protein diet consisted of hot water and minced meat patties – the now famous Salisbury steak. Another low-carb proponent was London undertaker William Banting, who in the 1860s lost 50 pounds on a diet of lean meat, dry toast, soft-boiled eggs and vegetables. His book, Letter on Corpulence, became a best-seller, and by the 1880s, “banting” was the most popular weight loss strategy in America.

On the low fat side of the scale were Reverend Sylvester Graham and Dr. John Harvey Kellogg. Graham, nicknamed Dr. Sawdust, did not prescribe his Spartan diet of brown bread, “graham” crackers, vegetables and water, for weight loss. By 1850, plumper bodies were the ideal. Admission to the “Fat Men’s Club of Connecticut” was reserved for successful business executives, and the 200-lb. stage actress Lillian Russell was the embodiment of feminine pulchritude. The Reverend Graham was a moralist. He believed that gluttony led to lust and the rearing of unhealthy children. Only the thin could find their way into heaven.

Kellogg, the staff physician at the Battle Creek Sanatorium in Michigan, led the crusade for vegetarianism, pure foods, and colon cleansing. His creations, granola and toasted flakes, remain staples on breakfast tables today. He was a fan of slow chewing, a philosophy later also espoused by businessman Horace Fletcher. Fletcher’s followers masticated each mouthful 50 times - as long as six minutes for some vegetables. Their anthem: “I choose to chew because I wish to do/The sort of thing that nature had in view.”

Calories Count

Nineteenth century Americans prided themselves on their country’s bounty and reveled in their ability to bolt down vast quantities of food in a single sitting. Europeans were amazed at the size of our meals and the speed at which we consumed them.

But slowly, and almost inexplicably, fat fell out of
fashion. By the late 1800s, adjectives like "porcine," "jumbo" and "butterball" were being used to describe the overweight. In 1903, that bastion of obesity, the "Fat Men's Club of Connecticut," closed its doors. By World War I, being fat was viewed not only as unattractive; it was considered unpatriotic.

Diet and Health with a Key to the Calories by Dr. Lulu Hunt Peters, billed as "the best-known and best-loved woman physician in America," topped the sales chart in 1918. Her plan called for several days of fasting followed by a 1,200 calorie a day diet. Another popular diet of the time was the 18-day Hollywood diet, which allowed a mere 585 calories a day, mainly from grapefruit, oranges, eggs and Melba toast. Weight monitoring also became commonplace as Health-O-Meter and Detecto scales found their way into America’s bathrooms.

Those for whom dieting wasn’t enough turned to weight loss devices. For women, there was the "La Grecque Corset," which promised to not only shape the hips and belly, but to permanently slendrize as well. The first gut buster was George Burwell’s “Boston Bon-Contour Obesity Belt,” which zapped the belly with jolts of electricity. The Gardner Reducing Machine used two rolls to “massage away” the fat.

And turn of the century dieters were not immune to the sort of weight loss pills and potions that continue to be found on the pages of today’s gossip tabloids. Readers were inundated with ads for “Densmore’s Corpulency Cure,” “Dr. Gordon’s Elegant Pills” and “Allan’s Anti-Fat.” The Ladies Home Journal promoted drinking Kissingen and Vichy mineral waters before meals to balance acid and alkaline. A two pound per week weight loss was promised. In 1910, Phytoline weight loss tablets—a compound of arsenic, strychnine, caffeine and pokeberries—were popular. The arsenic sped up the digestive tract. The pokeberries were a laxative.

Following World War I, an estimated 100,000 Americans tried diet pills containing dinitrophenol, a chemical used in the manufacture of dyes, insecticides and explosives. Munitions factory workers, it was said, had lost weight two pound per week weight loss was promised. In 1910, Phytoline weight loss tablets—a compound of arsenic, strychnine, caffeine and pokeberries—were popular. The arsenic sped up the digestive tract. The pokeberries were a laxative.

Following World War I, an estimated 100,000 Americans tried diet pills containing dinitrophenol, a chemical used in the manufacture of dyes, insecticides and explosives. Munitions factory workers, it was said, had lost weight after exposure to the chemical. However, their popularity proved short-lived as reports surfaced of several cases of death and temporary blindness.

Even the tobacco industry attempted to cash in on the diet phenomenon. “Reach for a Lucky instead of a sweet,” was a 1920s ad slogan for Lucky Strike cigarettes.

We Are What We Eat

According to historian Peter N. Stearns, the author of Fat History, the nation’s preoccupation with its collective weight in the years surrounding WWI was timely. "You could say that people started to getting increasingly concerned about dieting right around the time they should have," he said.

Pioneered the concept that food composition, dietary intake and health were related. Atwater warned against, "the evils of overeating," cautioning that it could result in "an excess of fatty tissue, perhaps in general disability, perhaps in actual disease."

In 1906, the federal Pure Food and Drug Act was passed, the first in a long series of regulations to protect the American public from tainted, adulterated and unsafe foods. The need for federal oversight of the food supply was driven home by Upton Sinclair’s novel, The Jungle, a shocking exposé of unsanitary conditions in the American meat packing industry. Americans were outraged with its depiction of unsanitary conditions and the use of chemicals and dyes to mask spoiled beef.

The 1900s also saw a shift in how Americans accessed their food supply. With the industrial revolution, we were transformed from a largely agrarian society to a nation of city dwellers. Grocery chains like Kroger and the Great Atlantic & Pacific Tea Company (A&P) replaced the family farm as the primary food source.

By 1910, newspaper food ads were becoming commonplace. Quaker Oats, for example, ran a weekly, full-page ad touting the importance of oatmeal in a child’s diet. "In the homes of the educated, the prosperous, the competent" read one ad, "seven out of eight regularly serve oatmeal."

Editorial features on food also became popular. In 1915, housewives were taught how to make homemade mayonnaise and French salad dressing. Ten years later; white sauce was the rage, recommended for everything on the plate, particularly vegetables.

At around the same time, the first food-buying guide was issued. Published by Caroline Hunt, a nutritionist, it divided food into five groups—meat, cereals, vegetables, fatty foods and sugar. A later version, issued in the Depression-era 1930s, emphasized making economical choices. It characterized food as “protective” - high in vitamins and minerals - or “high energy.” One of the lower cost food plans developed at the time was the basis for the contemporary food stamp program.

During World War II, food rationing resulted in

Today, almost 65 percent of adults in the U.S. are overweight, as are 15 percent of children age six through nine. Yet billions of dollars are spent each year on diet books and related paraphernalia.

“Food was abundant. Public transportation and sedentary jobs were on the rise.”

The federal government entered the food fray in 1894 when W. O. Atwater of the U.S. Department of Agriculture (USDA) developed tables on the dietary composition of commonly available foods. While specific vitamin and mineral requirements were unknown at the time, Atwater and sugar. A later version, issued in the Depression-era 1930s, emphasized making economical choices. It characterized food as “protective” - high in vitamins and minerals - or “high energy.” One of the lower cost food plans developed at the time was the basis for the contemporary food stamp program.

During World War II, food rationing resulted in
shortages of butter, margarine, sugar, lard, shortening, oils and assorted fresh meats. Home cooks had to adapt their recipes to accommodate the war reality. Recipes and articles emphasized canned meats, dried beans and peas, eggs and organ meats such as tongue and liver for protein. The National Nutrition Conference developed Recommended Dietary Allowances (RDAs), which specified caloric intake as well as essential nutrients, and a “Basic Seven” nutritional guideline, which helped Americans deal with the dietary realities resulting from the food shortages.

In 1950, the Associated Press took a look back at the century’s first 50 years of eating. Its conclusion: “While Americans still love their meat, we are no longer the meat-and-potatoes nation we once were.” Replacing them, wrote food editor Cecily Brownstone, were “other members of the vegetable clan, or a ‘tossed salad’—that abhorrence of a lot of ordinary men and the delight of gourmets.”

Building the Pyramid

The now-familiar Food Guide Pyramid was not introduced until 1992. But its foundation was laid in 1956 with the unveiling of the “Basic Four,” a refinement of the war-years plan. It was the first guide to make recommendations regarding the essential nutrients that were part of a balanced diet. It was not intended to be an exhaustive guide; it only showed the minimum daily requirements. The assumption was that people would make up for any deficiencies in calories or nutrients by eating more food.

In 1979, a “Hassle-free Guide” was created that included fats, sweets and alcohol. This new group of foods came with a warning. Use only in moderation. But the guide remained fundamental, offering information only on minimal requirements rather than a whole diet strategy.

Not that there was a dearth of diet options. The 1970s saw the debut of such well-known diet experts as Robert Atkins, whose Diet Revolution advocated all-you-can-eat quantities of meat and fat. Nathan Pritikin, whose program was the antithesis of Atkins, and Herman Tarnower, who published the low-cal Scarsdale diet and later perished at the hands of a jilted lover. You could eat like an astronaut or dine like a Beverly Hills celebrity— if you were willing to follow Judy Mael’s fruit-heavy, food combining regimen. Perhaps the most ill advised diet of the time was osteopath Robert Linn’s Last Chance Diet. Its centerpiece was a diet beverage made from animal hides and tendons. The combination proved deadly. Fifty-eight deaths were
ultimately attributed to the low-cal, nutrient-deficient concoction.

Nutrients, on the other hand, were the building blocks in the construction of the Food Pyramid. In conceiving the pyramid, the USDA looked at the various sources of essential vitamins and minerals and then combined this information with data about how Americans eat. The foods were then stacked in order of nutritional priority.

While the pyramid is a visual reflection of the meat, dairy, fats, bread, fruits and vegetables that are the essential components of a healthy diet, it can be easily misunderstood. For example, the pyramid calls for six grain servings daily. But what constitutes a serving? To the average consumer, a bagel at breakfast would fit the bill for one serving. But in reality, a “grain serving” under USDA guidelines is 72 calories - equivalent to three-fourths of a slice of store-bought bread. A bagel could have as many as 500 calories. In reality, your grain requirement could be met while you’re still in your pajamas.

A recent study by the Centers for Disease Control and Prevention underscores how this misunderstanding weighs on our collective waistline. In the past 30 years, men have increased their average caloric intake seven percent, and women, 22 percent. For both sexes, roughly half of those calories come from carbs – that bagel from breakfast, sandwich for lunch and heaping plate of pasta for the evening meal. In 1971, the average woman consumed 1,542 calories daily, slightly under the 1600 calories recommended by the USDA. Today, the average woman consumes 1,877 calories daily. And men are no better. Thirty years ago, men were exceeding their daily recommendation of 2,200 calories by 250 calories. Today, they’re topping it by 418 calories. It’s little wonder that the obesity rate has more than doubled since 1971.

Today, almost 65 percent of adults in the U.S. are overweight, as are 15 percent of children age six through nine. Yet billions of dollars are spent each year on diet books and related paraphernalia. This seeming disconnect was underscored in a trend survey conducted by the American Dietetic Association (ADA) in 2000. Forty percent of those questioned recognized the importance of a healthy diet. But just because they recognized it didn’t mean they changed their unhealthy eating ways. As Judy Dodd sees it, “When it comes right down to it, taste and convenience are the two criteria people use to make food choices. Nutrition considerations are secondary at best.”

Dodd echoes the ADA when she says the solution to the fattening of America is as easy as A-B-C. “A” is aiming for fitness and being physically active every day. ‘B’ is building a healthy base, letting the pyramid guide food choices, and ‘C’ is choosing sensibly.

She emphasizes that people need to take small steps. “Drastic doesn’t work,” she says. “It’s really a matter of portion control; of understanding what is appropriate given your lifestyle.”

Dodd encourages her students in the Department of Clinical Dietetics and Nutrition to understand that choice is critical to good nutrition. “The students need to understand that their role is not to deny people access to foods they love even if they are laden with fat, sodium or empty calories,” she explains. “Rather, it’s teaching them how much of these foods they can eat and how often.”

Recognizing that children often mirror the behavior of the adults around them, Dodd and her colleague, Kim Crawford, Program Director and Instructor, Sports Medicine and Nutrition, recently completed a pilot program with preschool-age children (FACETS, Winter 2003). While the goal was to get physical and nutritional education incorporated into the early childhood curriculum, the pair admits to an ulterior motive. “Parents are more receptive to addressing health issues in their kids than themselves. If kids come home enthusiastic about exercise and nutrition, we may get everyone in the whole family involved.”

Crawford has seen first-hand the damage that can result when teens become obsessed about diet and exercise, especially young women. “We call it the Female Athlete Triad,” she explains. “Its components include disordered eating, deficiencies in bone mineral density, and menstrual irregularities.”

It is this interconnectedness between diet and exercise that prompted SHRS to begin the process of merging the departments of Clinical Dietetics and Nutrition and Sports Medicine/Athletic Training into a unified Sports Medicine and Nutrition program.
Nail Patella Syndrome

Common Occupational Therapy Practices Shed Light on a Rare Genetic Disorder

In July 2002, Nail Patella Syndrome Worldwide held its fifth International Symposium in Pittsburgh. For two days, patients, families and clinicians had an opportunity to explore and discuss every aspect of this rare and unusual condition. Nail Patella Syndrome (NPS) is a genetic disorder characterized by nail and skeletal deformities. It occurs in about one in 50,000 people, and it is inherited in an autosomal dominant manner, which means the risk of transmission is 50 percent per pregnancy regardless of gender. In 12 percent of the cases, the disease is the result of a new or spontaneous mutation. It is found throughout the world in all ethnic groups.

NPS manifests itself in a wide range of symptoms and severity. The most noticeable characteristic is the absence or underdevelopment of fingernails, especially the thumb nail. Skeletal anomalies also may include underdevelopment of the patella (kneecaps), iliac horns or spurs on the pelvic bones, permanently dislocated elbows which affect the mobility and rotation of the wrists, twisted legs or club feet, and curvature of the spine. It appears that several other medical conditions are closely associated with NPS, including kidney problems, glaucoma and digestive disorders.

UPMC’s Dr. Adele Towers has a son with NPS and was instrumental in bringing the conference to Pittsburgh. “The International Symposium is an excellent opportunity for NPS patients and their families to gather lots of information,” says Towers. “This is most often a condition that runs in families, and so the conference has a certain ‘family reunion’ atmosphere.”

As an internist specializing in geriatrics, Towers is attuned to the important role that occupational therapy plays in measuring and improving function. So as plans were underway for the 2002 conference, she noticed the glaring absence of occupational therapists in the broad mix of medical participants.

Towers contacted Dr. Margo Holm, Professor, Department of Occupational Therapy, and asked if she could help conference participants begin to look at the syndrome’s affect on function. As Holm began to study the clinical features of the syndrome, she selected tools that would provide data on how elbow and knee involvement – present in over 70 percent of NPS patients – affects function. She then turned to Ketki Desai, an occupational therapy doctoral candidate, to implement the first-ever study of how Nail Patella Syndrome impacts functional participation in everyday activities.

Desai – with the help of Emily Eckel and Dr. Tamara Mills – collected data at the Pittsburgh conference. The study involved 32 women and 13 men, ranging from 12 to 69 years of age. All of them had either elbow or knee involvement, with 67 percent having both. Data collection began with a Health Assessment Questionnaire – 21 questions which delved into patients’ level of mobility, self-care and domestic life.

“This group consistently rated themselves with a very low level of difficulty in performing everyday tasks,” says Desai. “We were most likely dealing with a representative group of the most highly functional NPS patients – because they were able to travel to the conference.” However, many participants indicated some level of difficulty with bending, lifting and wrist turning activities.

The next step in this study involved the Keitel test – a performance-based assessment of the range of motion of upper and lower extremities. Participants were assessed on their ability to flex and extend knees, rise from a chair, and position their hands in various ways.

Desai wanted to take a closer look at hand function, so she also used the Jepsen Taylor Hand Test, a performance-based assessment of supinating rotation of the wrist. Participants were timed as they turned cards, simulating page-turning.

“The number one complaint among the patients we worked with was the elbow,” notes Holm. “For some with NPS, cutting meat, buttoning a shirt and opening a jar are quite challenging. And just imagine trying to go to a drive-thru ATM machine without the ability to rotate the elbow and wrist joints.”

Holm describes the occupational therapy strategies that can be used for intervention with NPS patients. “It is clear that many of the participants in our study already employ adaptive strategies to assist them with everyday tasks. However, an occupational therapist can offer compensatory approaches such as toilet seat lifts and kitchen devices as well as restorative approaches such as exercise or splinting. And some basic educational approaches can help NPS patients really make the most of their physical functionality.”

Dr. Iain McIntosh, a geneticist at Johns Hopkins University who identified the gene for NPS, is the leading researcher on this condition, also known as Illic Horn Syndrome, Hereditary Onycho Osteodysplasia (HOOD), Fong’s Disease and Turner-Kieser Syndrome. McIntosh has invited Desai to share her findings with colleagues around the world and to continue and expand the occupational therapy study in conjunction with the ongoing work at Johns Hopkins.

The results of the data collected in Pittsburgh were presented at the 6th International Symposium on Nail Patella Syndrome in June 2003 in St. Louis, Missouri, and later at the First Medical Conference for NPS-UK in August 2003 in Chester, England.

“Ultimately, the more information we gather about NPS, the more we can help patients get the kind of medical services they need,” notes Towers. “The folks who came back to the 2003 conference in St. Louis were very excited by the results of the 2002 occupational therapy study. They told us that no one had ever asked them about functionality before – and no one knows better than they do what an impact NPS has on day to day life.”

For more information, contact Margo Holm at mbholm@pitt.edu
THE REAL WORLD

They’ve sat through hundreds of hours of lectures. They’ve pored through dozens of textbooks. Now comes the time to put that knowledge to work.

The Challenges and Rewards of Clinical Education in Rehabilitation Science and Technology

Graduate students Jongbae Kim, Beth Ann Kaminski, and Emily Zipfel are members of the CAT team.
When you set out to buy a car, you want to kick the tires, look under the hood, and inhale that new car smell. Of course, a test drive is essential.

It’s no different for people who use wheelchairs, scooters, or other personal mobility devices. Unlike most drivers, they may spend their entire waking day in their chair, so it better be comfortable and have the features required by their particular functional needs.

Enter the Center for Assistive Technology (CAT), a virtual showroom of personal mobility systems. Clients have the opportunity to view and test-drive a variety of devices from manual and power wheelchairs to scooters.

The CAT also offers an array of other services including augmentative communication devices (speech output devices), computer access, and audiology services including assistive listening, alerting devices, and hearing aid dispensing.

Graduate students Jongbae Kim, Beth Ann Kaminski, and Emily Zipfel are members of the CAT team. The students are enrolled in a four-credit course on the clinical aspects of wheelchair seating and mobility. Rather than the traditional method of teaching, students spend Tuesday afternoons in the CAT working with real people with specific needs. Class convenes after clinic and the students present their cases and are assigned readings or asked to research evidence that supports the interventions they are seeking for clients.
A Day at the Clinic

Under the supervision of Mark Schmeler, Director of the CAT, students assist clinicians in interviewing clients at the outset of their visit. They ask questions to determine how the client currently gets around, how well they can fulfill their daily routine because of mobility limitations, and how a device might augment function and participation. It is also important to know how someone uses a mobility device – indoors or outdoors – whether they transport the vehicle and how specific customizing that might be required, the accessibility of their home, and what they like or don’t like about their current device.

Each client also meets with a CAT physician who performs a brief physical to evaluate motor strength, determine the extent of their physical movement, learn the range of physicians they see regularly and answer any questions. The physician, a specialist in physical medicine and rehabilitation, can then address any medical issues and certify that the device is medically necessary in order for the client to get the wheelchair or other device.

Once all of the relevant information is gathered, clients then evaluate various mobility devices to determine their functionality and comfort. Often, assistive technology equipment suppliers are also present to assist clinicians and students in answering questions and demonstrating features, like seat elevators that allow clients to do simple tasks like getting a soda from a vending machine.
Clinician Rosemarie Cooper demonstrates features of a scooter to client Terese Purner-Kime.

Kim uses the elevator seat on his wheelchair to reach the vending machine.
Welcome to the Machine Shop

Unlike many other assistive technology providers, the CAT maintains an on-site machine shop to customize and modify commercially available assistive devices for maximum comfort and efficiency. It's akin to a conversion van shop. This not only ensures a quality device, it also can save days or weeks in delivering or installing a device.

The customization can be a simple modification to the chair like adapting a lap tray, or in one unique case, a client using a power-operated wheelchair had a baby. The team first modified an infant car seat to fit an adapter for her chair and later, as the child grew, replaced it with a baby bike seat so Mom could more easily care for her child.
It’s More Than Just the Chair

While the chair or scooter is the essential piece of equipment, other elements go into ensuring that the mobility device is properly outfitted for the driver. For example, as noted in the Fall 2001 issue of FACETS, the proper seat cushion is vital to the comfort and good health of the driver.

This is particularly true for people who experience no sensation in their lower bodies. The CAT offers pressure mapping as one way to ensure that weight in the buttocks area is balanced evenly over the entire seat to prevent pressure sores. A thin mat filled with sensors is placed between the client and the cushion that maps the pressure points on a computer monitor. Hot spots mean too much pressure is being placed in a certain area. A simple solution like filling the cushion with more air can make the difference.

The CAT also can assist clients in selecting proper backrests, steering devices, and other options.

Mark McCartney of the CAT lifts Kim to slip a thin mat between him and the seat cushion to perform pressure mapping. The procedure reveals that his cushion has lost air and is causing hot spots.
Now For the Test Drive

Using a new wheelchair or scooter is like driving a new car. The client needs to know its features, what all the buttons and knobs are for, and get a feel for the vehicle. Students assist clients in maneuvering up and down hallways, in and out of elevators, up and down ramps, and on busy city sidewalks and curb cuts until they’re comfortable with the new device.

In addition, once they use the vehicle in real world settings, they may find they need to return to the showroom and evaluate other options. Once a potential device is chosen, a visit to the home at this point is vital to fully ensure the equipment is a viable option.

John Ochoa test drives a demo wheelchair with the help of clinician Annmarie Kelleher.
Debra "D.J." Stemmler, Clinical Coordinator, demonstrates the functionality of her PDA and modified office desk.

A Unique Environment

The roles of people affiliated with the CAT often seem interchangeable. Debra "D.J." Stemmler, Clinical Coordinator, uses a wheelchair and has had it and her office modified by the CAT to accommodate her needs.

The CAT members mounted a PDA that includes a cell phone onto the arm of her chair, which also has a seat elevator. When Jongbae Kim, who himself uses a wheelchair, took a trip to South Korea, he returned with a keyboard for Stemmler that is much smaller than average, but doesn’t sacrifice the size of the keys.

But accommodation isn’t always high tech: Stemmler tied a red strap around the office door handle that allows her to easily close up shop at the end of the day.
Where’s the BOSS?

“In this new paradigm, you not only measure what people can do, which is important.

You also measure what people think and feel about their condition; how they experience their health state.”

The story. A laundry worker at a local hospital suffered a stroke. After several months of physical rehabilitation, he was back on the job but still clearly exhibiting dysarthria, a serious speech impairment. He hadn’t been referred for or sought treatment for his speech disorder because, in fact, it really didn’t much matter to him. By and large, the demands of his job did not require articulate speech. He was able to communicate with his family and his level of physical functioning permitted him to perform his work duties without much difficulty.

Imagine, in the hypothetical, that same stroke survivor was a trial attorney – someone for whom speech and cognition is the essence of his or her profession. For many stroke survivors, physical limitations are not their primary concern when it comes to resuming anything close to a normal life.

However, most stroke clinical trial endpoints are narrowly focused on physical aspects of functioning, and rarely examine communication and/or cognitive functioning as an indicator of treatment success. “This is particularly true of studies designed to assess pharmacological treatments for acute stroke,” states Dr. Patrick Doyle, Associate Professor, Department of Communication Science and Disorders.

The VA Supports Research

Following a stint with the World Health Organization (WHO) in Geneva, Switzerland, working on the “International Classification of Functioning, Disability and Health” (see accompanying sidebar), Doyle developed a model for assessing health outcomes in stroke survivors that included aspects of communicative, cognitive and social functioning, and psychological well-being – health concepts rarely considered in the development of measures designed to examine stroke outcomes. To examine the validity of the model, Doyle and his colleague, Dr. Malcolm McNeil, Professor and Chair, Department of Communication Science and Disorders, applied for and were awarded a $980,000 VA Rehabilitation Research and Development grant in 2001 to develop an assessment tool based upon the model.

“The premise was that the cognitive, psychological and social consequences of stroke were equal to if not more debilitating than the physical consequences for many individuals,” states McNeil. “And that these aspects of functioning could be measured with equal precision.”

What has resulted is the Burden of Stroke Scale (BOSS), a health-status assessment instrument designed to measure patient-reported difficulty in multiple domains of functioning.
the psychological distress associated with specific functional limitations and the general well-being of stroke survivors. Simply stated, “It provides a more complete description of the burden of a stroke,” says Doyle, who also serves as Associate Director for Research at the VA Pittsburgh Healthcare System’s Geriatric Research Education and Clinical Center (GRECC).

The BOSS is consistent with recent developments in the health outcomes arena, where healthcare providers are placing increasing emphasis on Patient Reported Outcomes, or PROs. Notes Doyle, “In this new paradigm, you not only measure what people can do – which is important. You also measure what people think and feel about their condition; how they experience their health state.”

What Questions to Ask?

Phase One of the project included meeting with a sizeable number of relevant stakeholders – stroke survivors, caregivers and healthcare professionals – to begin developing the questions that would target those aspects of functioning and well-being most important to stroke survivors. From that research came a long version of the questionnaire – 112 questions – that was administered to 281 stroke survivors and a control group of 250 age-matched adults recruited from collaborating hospitals nationwide.

This phase of the research, in turn, resulted in a more focused questionnaire with 64 questions covering the physical, cognitive and psychological consequences of a stroke.

In the area of Cognitive Activity Limitations, for example, the BOSS Communication Difficulty Scale asks patients to judge how difficult it is for them to talk, understand what people say, and be understood by others, and how such difficulties impact their daily emotional state, their

Continues on page 38
self-satisfaction, and their participation in valued life activities.

“Such scales are not new to the broader health status assessment literature,” Doyle points out. “But their application to stroke outcomes remains limited.”

The current study is multi-sited, including Veterans Administration Hospitals in Gainesville, Salt Lake City, Phoenix, as well as Pittsburgh, and the Aphasia Center of California.

**Longitudinal Study Underway**

As Doyle and McNeil continue to refine the instruments, they are evaluating another 200 patients at three, six, and 12 months post-stroke, with the goal of demonstrating the instruments’ ability to detect changes in a patient’s physical, cognitive and psychological status. This phase of the research will be completed in September 2004.

Meanwhile, the data from Phase One appears to support the validity of the proposed model, and the precision with which its concepts (i.e., physical functioning, cognitive functioning, psychological well-being) can be measured in stroke survivors. These findings are currently in press in the Journal of Clinical Epidemiology.

McNeil, who is also a Senior Research Scientist at the VA, tells of a woman who experienced paralysis following a stroke and was unable to perform the chores and household work that had been a part of the fabric of her life.

A primary goal of rehabilitation, therefore, was to return the woman to her previous level of physical function. “As it turned out, she detested housework and wanted to focus her rehabilitation on regaining communication skills,” says McNeil.

Patients for this and other studies are being recruited from the VA, the UPMC Stroke Institute, the UPMC Rehabilitation Institute, HealthSouth Harmarville and HealthSouth Watson Institute.

**Next Steps**

The longitudinal study is near completion and Doyle and McNeil have already applied for another grant to continue the research. Future development will transfer the questionnaire to a touch screen and employ item-difficulty algorithms that will permit the BOSS to be self-administered as well as present only those items within the patient’s ability level. This form of “dynamic” or “computer adaptive testing” will further reduce the number of items required to obtain a valid and precise score estimate, and permit the BOSS to be used in a variety of clinical and research settings.

But Doyle and McNeil consider the BOSS to be more than just an outcome measurement tool. “In the future, we see the BOSS as an important tool to focus rehabilitation efforts and as a measure for clinicians to be able to alter medical, pharmacological and behavior interventions,” states McNeil.

For more information, contact Patrick Doyle at patrick.doyle@med.va.gov or Malcolm McNeil at mcneil@csd.pitt.edu
Joyce Bender is the CEO and founder of Bender Consulting Services, Inc., a firm that provides competitive employment opportunities for people with disabilities. In 2003, her work in the disability employment arena was recognized with the Bush Administration’s New Freedom Initiative Award, presented to her by U.S. Secretary of Labor Elaine Chao. We’ve asked Joyce to discuss the barriers she faces in her efforts to integrate people with disabilities into the workforce.

Q: What is the scope of the problem?
A: In the US today, the unemployment rate for people with severe disabilities is approximately 70 percent. Yet we have companies that have spent millions of dollars to become accessible. They boast that their building is barrier-free. They have unbelievable ramps. They have T-T-Y, Braille signage, and accessible restrooms. They have everything but one thing — people with disabilities working there. They may be barrier-free, but they’re also “people with disabilities” free.

Q: Why is that?
A: Primarily, it’s attitude. They think of people with disabilities as sick people. And why would you hire someone who is sick? Companies want people who will deliver a return of their investment; who will add to their bottom line. So when they think of hiring someone who is sick? Companies don’t want someone who is somehow inferior with a disability — someone they view as sick — they think they’ll be hiring someone who is somehow inferior or their other employees.

Q: What is it going to take to change this attitude?
A: Two things. Education and experience. It’s amazing to me how little people understand the realities of disability. For example, I have an employee who is blind and as part of his job, travels across the United States. I had someone ask me, “How can he do that?” They couldn’t even envision how a person who is blind could get on an airplane and travel from one city to another. In another instance, I had a person from the deaf community go on an interview with a very large corporation. When I followed up with the hiring manager, he said he was impressed with the candidate, but questioned how the candidate would travel to work, as if deafness was a barrier to driving a car or taking public transportation.

Education is key. Employers have to understand that with assistive technology, a person with a disability can be just as productive as a person without a disability. And they have to understand that making the necessary accommodation for an employee with a disability isn’t that expensive. It has been well documented that the average cost of an accommodation is $500.

I think the situation will change when larger numbers of people with disabilities actually enter the workforce. The situation is not dissimilar to when women and people of color first became part of the workplace. They, too, were confronted with all sorts of misperceptions. But over time, as more and more people are hired, it becomes commonplace.

Q: Is there a large pool of qualified people with disabilities who are ready to enter the workforce?
A: Absolutely. At my firm, we have a database of over 2,000 qualified people with disabilities who are unable to find employment. And by qualified, I mean people with bachelor’s or master’s degrees or the appropriate technical certification. When I go out and talk to employers, I point out that when they see a candidate with a disability, he or she is most like entry-level in terms of on-the-job experience, but highly qualified academically. Many of them have had multiple internships. Still, some employers will argue with me, saying, “We can’t hire an entry-level person. We need someone who can hit the ground running – someone who can immediately be productive.” But when they take the time to review the resume and interview the person, they come back to me saying, “This person is more qualified and has more skills than some of my employees who have been here several years.” In reality, some of the candidates are overqualified for entry-level positions.

Q: Does this mean that people with disabilities are undervaluing themselves?
A: Yes. People with disabilities tend to fall into one of two categories. They are either unemployed or underemployed. For example, I had one young man with a master’s degree who stated on his resume that because of his severe disability, he would accept a salary as low as $12,000. He equated his disability with a lack of economic worth. And unfortunately, the prospective employers sometimes share that view.

Q: Right now, it is a very competitive job market. Is it realistic to think that all things being equal, a company would hire someone with a disability over someone without a disability?
A: Absolutely. I think people with disabilities can compete equally in the marketplace. And if they can’t, they shouldn’t be hired. We’re not looking for charity – just equal opportunity.
Life Income Gifts

Did you know that you can help to build the future of the School of Health and Rehabilitation Sciences while receiving an annual income and a substantial income tax deduction?

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