International Program Gets Boost: Cost-Sharing from Brazil

The International Program at the UMMS/E.K. Shriver Center recently played an instrumental role in helping to expand a long-standing program of international cooperation with colleagues in Brazil.

Several Shriver faculty members partnered with Brazilian colleagues to establish a bi-national Institute for Studies on Behavior, Cognition, and Teaching. The new Institute substantially expands a bi-national program that has been evolving over the past two decades from occasional collaborations to ongoing joint programmatic activity. All of the interdisciplinary activities of the Institute are joined by a thematic focus on the analysis and development of symbolic processes and behavior across the life span. Participating disciplines include basic and applied behavior analysis, developmental psychology, neuropsychology, special education, and the speech and hearing sciences.

The primary impetus for the bi-national Institute was the recent announcement of new major project research funding availability from a consortium of federal and state sources in Brazil designed to accelerate the country's scientific and technological development, recognizing Brazil's growing political stability, economic power, and potential to contribute to science internationally. After an intense national competition open to all branches of science, more than 100 new institutes were selected for funding. Although virtually all grant awards supported projects in the physical and engineering sciences and biotechnology, one proposal emphasizing behavioral sciences was successful – that from the collaborative bi-national program involving the Shriver Center.

The new Institute is led by Dr. Deisy de Graças de Souza of the Federal University of São Carlos (USFCar) and Dr. Olavo de Faria Galvão of the Federal University of Pará (UFPA). Funds to support the Institute are administered by Brazil's National Council for Scientific and Technological Development. They will support more than 20 projects located at USFCar (the Institute's coordinating institution), UFPA, five other major research universities in Brazil (indicated by stars on the accompanying map), and the UMMS Shriver Center (see sidebar on page 2 for more details). Participating Shriver faculty include Drs. William McIlvane, Leo Buchanan, William Dube, and Richard Serna. The Brazilian universities are well-distributed across the country, giving Institute faculty access to a wide range of regional populations and research opportunities. Over the next three years, funds equivalent to about $1.2M will support acquisition of new research equipment, stipends for numerous student researchers, research supplies and other expenses, and project-related travel.

The Institute’s research activities are organized into three main tracks – basic, translational, and applied science. Broad basic science projects include studies of visual and auditory information processing in symbolic tasks, methods for effectively directing attention to relevant information in such tasks, and animal models of symbolic behavior and its prerequisites. Methods and findings from these studies are in turn translated to guide research projects investigating topics such as the development of symbolic behavior in infants and toddlers, speech perception and symbolic functioning in formerly deaf children who are recent recipients of cochlear implants, development of academic skills in children with learning challenges, and evaluation of continued on page 2

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of neurological status of individuals whose communication skills have been compromised by congenital or acquired neurodevelopmental disabilities. Applied science projects focus on the development of delivery systems to foster high-quality evidence-based practices in the classroom, clinic, and other settings focusing on improvement in functional communication skills. Skilled use of current and future information technology is a high priority for the Institute’s applied science programs.

Shriver Center faculty and programs have played and will continue to play a central role in the design, development, and functioning of the new Institute. Moreover, all of the Institute leaders, many other participating faculty members, and students have and will continue to study at the Shriver Center as visiting scientists, fellows, or post-doctoral trainees. Ongoing highly visible collaborations between Shriver Center faculty and their Brazilian colleagues helped to secure funding for the new Institute. For example, prior to submitting the Institute proposal, Drs. McIlvane, Buchanan, and Galvão secured funding from the U.S. National Institute of Environmental Health Sciences’ “Brain Disorders in the Developing World” competition to study the influence of mercury exposure on neurocognitive development in children of gold miners in north central Brazil. That funding led to supplemental funding from the David Rockefeller Center for Latin American Studies to include Dr. S. Allen Counter and students from Harvard University on the project. These prior successes and other similar ones may have provided important leverage in the national competition that led to the Institute award.

Dr. de Souza acknowledged the contributions of Shriver Center faculty and programs to the new Institute, commenting “although our Institute features a strong and productive Brazilian faculty, the committed participation of our colleagues from UMMS was certainly an influential reason that our proposal was successful in the competition with a number of other high-quality human science proposals.”

Dr. McIlvane reinforced this analysis, commenting, “We think that our bi-national Institute has the potential to become a model for building international collaboration between U.S. universities and those in the developing world. We have merged the different strengths of the U.S. and Brazilian systems in a way that allows both to be more productive together than either could be alone. As the Institute develops, we think that it will establish the foundation for new research and training projects that will contribute substantially to the growing UMMS focus on international health promotion.”
Collaborative Research on Lead Poisoning in Children in the Andes Mountains of Ecuador

Lead is a well-established neurotoxin that poses significant physiological and neurological health risks. Even at low exposure levels, lead is associated with adverse neurodevelopmental outcomes in children, including intellectual impairment, language disorders, attention deficits, memory problems, visual-spatial deficits, fine motor difficulties, and sensory-neural hearing loss. These health risks have prompted the United States Public Health Service to work toward eliminating elevated blood lead levels (BLLs) in children by 2010.

In some developing Latin American countries like Ecuador, poor villages often use lead glazing of ceramics as the primary income source for many families. More than 60% of Ecuador’s 13.5 million people live below the poverty line, so it is no surprise that some inhabitants of villages high in the Ecuadorian Andes subsist on the dangerous practice of lead glazing which leads to high levels of lead exposure. In an effort to determine the prevalence of neurosensory and neurocognitive effects of lead poisoning on children in these villages, Leo H. Buchanan, Ph.D., Director of the Shriver Center Audiology Department and UMMS Assistant Professor of Pediatrics, has served as Clinical and Research Audiologist on a multi-national, interdisciplinary field research team since 1995.

The team was astonished to find that the children in several of these villages had extreme lead poisoning, with some showing BLLs more than 10 times higher than the Centers for Disease Control and Prevention’s “action line” or risk level of 10 micrograms per deciliter. The team found the average BLL in the villages to be about 40-50 micrograms per deciliter during initial visits, ranging to an extreme of 128 micrograms per deciliter. “Children in particular concern us, because they are more vulnerable to the effects of lead and other neurotoxins since their central nervous systems are still developing. Any effects would be greater on a child’s developing brain than that of an adult,” Buchanan emphasized.

The team also discovered that not just adults participate in lead glazing, but children do as well. Lead contamination in the villages is primarily due to the lead glazing of clay roof tiles. To do this, the villagers extract lead acid from automobile batteries and make a lead slurry, which is applied to the tiles with bare hands and is then baked at a high temperature in open kilns. The resulting lead-contaminated smoke contributes to the high lead concentration in the soil, fruits, vegetables and milk of breastfeeding mothers in the villages.

The team informed parents of their children’s serious exposure to the adverse effects of lead poisoning, referred affected children to Ecuadorian physicians, and distributed nutritional supplements. The team also demonstrated prevention measures including proper hand and cloth washing, thorough cleaning of fruits and vegetables, keeping children and pregnant women away from lead-glazing ovens, and using protective masks. Levels have dropped significantly to about 20 micrograms per deciliter for the children with these practices in place.

The team also investigated possible effects of lead exposure on the inner ear and the auditory brainstem, since lead is reported to cause hearing loss and auditory brainstem dysfunction. Dr. Buchanan and colleagues surprisingly found no evidence of auditory neurosensory deficits despite the children’s high exposure to lead in the environment, contrary to previous studies. According to Dr. Buchanan, “We found some hearing loss, as you would in any population. But it was due to other factors such as genetics, impacted earwax, or excessive noise. There also were no auditory brainstem effects. Further investigations are warranted to determine if lead has an adverse effect on the higher cortical auditory system.” Although the team found no lead-associated hearing loss or auditory brainstem dysfunction in these highly lead-intoxicated children, the lead exposure was found to have an adverse effect on neurocognitive performance in the children.

The team is concurrently exploring mercury exposure in Andean gold-mining communities as well; both studies will continue, emphasizing preventative measures and monitoring lead and mercury exposure of the children in these Ecuadorian villages.
William J. McIlvane, PhD

Research Interests
Dr. McIlvane directs a broad research program that addresses a host of scientific problems related to understanding and correcting the behavior deficits of persons with neurodevelopmental disabilities. One focus is studying symbolic behaviors in communication (e.g., speaking, listening, reading, and writing) and developing methods to encourage the progressive and rapid learning of these behaviors. Another is adapting behavioral neuroscience methods—including animal modeling—to understand the brain processes used in symbolic behavior. Dr. McIlvane's program has also been developing valid nonverbal neuropsychological testing methods for use with people who do not understand verbal instructions. These methods have been adapted to advance the understanding of the behavioral profiles associated with disorders such as autism, depression, and neurotropic exposure. In addition, Dr. McIlvane's program has a strong research-to-practice emphasis. Methods emerging from his laboratory research are being used to teach practical skills in regular and special education classrooms in both the U.S. and Brazil.

Activities
Dr. McIlvane began his longstanding association with the Shriver Center in 1976, as a graduate research assistant. His prolific body of work includes over 100 journal articles, along with numerous book chapters, edited volumes, notes, reviews, abstracts and published conference proceedings. Dr. McIlvane is an associate editor of the Journal of Research in Mental Retardation and an editorial board member of the Developmental Disabilities Research Review. He has previously served as an associate editor of the American Journal on Mental Retardation and as an editorial board member with the Journal of the Experimental Analysis of Behavior, The Behavior Analyst, and Experimental Analysis of Human Behavior Bulletin. He has consulted as a reviewer to 22 journals and has served on a variety of grant and program review committees, including the NIH. Dr. McIlvane received the American Psychological Association's prestigious Don Hake Basic/Applied Research Award in 2003, and the Association for Behavior Analysis Continuing Contributions Award in 2001 with colleagues in the Shriver Center's Behavioral Technology Group.

Career Influences and Vision for the Future
Dr. McIlvane's career-long interests in child mental health, learning and memory, and health disparities were inspired by his first professional position, director of a learning center for children with learning disabilities and mental health issues at the Manhattan Children's Center in the New York State Department of Mental Health. From there, he came to the Shriver Center and Northeastern University to study basic learning process analysis with an emphasis on special populations. He received his first NIH grant in 1985 and has had continuous NIH funding since then. Dr. McIlvane's program has developed a noteworthy emphasis on international collaboration, most actively with colleagues in Brazil. He first traveled there in 1989 at the behest of one of his principal mentors, Dr. Murray Sidman, to attend an international conference on symbolic and other verbal relations. Twenty years later, he and several Shriver Center faculty members publish regularly with Brazilian colleagues and have recently joined with them to form a new bi-national research institute focusing on symbolic behavior (see page 1). In the future, he envisions a combined effort that will "replicate the essential elements of the IDDRIC and LEND programs within the superstructure of the new institute to study brain disorders in the developing world." This dual-country approach is likely to create new opportunities for training and research in intellectual and developmental disabilities to add to the U.S. effort while "recruiting an international system of truly developmental disabilities" as part of UMMS' broader international health initiative. Closer to home, Dr. McIlvane sees future Shriver Center development focusing on what he terms "the triple-A axis" representing a programmatic interface involving current programs in (1) Autism and related neurodevelopmental disabilities, and (2) Activity and nutrition for special populations: "Each of these lines connects well with important dimensions of the others, thus providing clear opportunities for new collaborations and even greater cohesiveness of our overall program."

Publications
Selected Peer Reviewed Articles and Books

Selected Chapters and Edited Volumes


Dr. McIlvane sees future Shriver Center development focusing on what he terms “the triple-A axis” representing a programmatic interface involving current programs in (1) Autism and related neurodevelopment disorders, (2) Assistive technologies, and (3) Activities and nutrition for special populations. “Each of these lines connects well with important dimensions of the others, thus providing clear opportunities for new collaborations and even greater cohesiveness of our overall program.”

Special Olympics International: An Opportunity to Broaden Access to Healthcare for Athletes Worldwide

Jim Gleason, MS, PT, Associate Director of the Shriver Center UCEDD, has spent the better part of his career evaluating and promoting physical activity in individuals with intellectual and developmental disabilities. His ongoing role since 2005 as the Global Clinical Coordinator for Special Olympics (SO) education and research activities honors the mission of Eunice Kennedy Shriver, founder of the SO program and our Center’s namesake. Mrs. Shriver is a tireless advocate for individuals with intellectual or developmental disabilities. Gleason specifically works with the Healthy Athletes Initiative and its FUNfitness program, conducting trainings and coordinating health screenings at a variety of SO events in the U.S. and abroad, including three SO World Games: 2005 in Nagano, Japan, 2007 in Shanghai, China, and earlier in 2009 in Boise, Idaho.

“It is remarkable how each event reinforces the most important aspects of this work. We meet athletes with intellectual disabilities from all over the world, as well as their coaches, therapists and medical practitioners who dedicate a significant portion of their lives to supporting people with intellectual disabilities in very meaningful ways. They are often trying to advance services for people with disabilities in their home countries,” he added. FUNFitness is just one type of screening offered, and examines a person’s aerobic condition, balance, flexibility, and functional strength. Screenings for other Healthy Athletes programs include: Opening Eyes (vision), Special Smiles (oral care), Healthy Hearing (auditory acuity), Health Promotion (overall health education), and Fit Feet (evaluating skin, bones and joints of the foot). The process poses logistical challenges, but also offers tangible benefits. “Communication is a huge issue, but many coaches and even some athletes are bilingual. We work in an environment where the athletes can see others involved in the tests that we do and learning the exercises that we recommend. When their turn comes, they follow our visual instructions and guidance. These screenings allow SO athletes to access health services they would not have had otherwise,” Gleason explained.

The numbers support that statement. As of 2009, over 700,000 free health screenings have been given, and over 760,000 professionals have been trained in over 100 countries. In some cases, screenings change lives, detecting previously undiagnosed oral cancers or offering free eyeglasses to correct vision. Special Olympics makes great efforts to advance the visibility, insight and needs of people with intellectual disabilities at each location, provides the general public with inspirational messages about the accomplishments of the athletes, and identifies ways society can better include them in community life, employment, school, and many other areas,” Gleason emphasized.

It appears that the broader audience for that message is listening. China’s President Hu Jintao attended several of the 2007 Shanghai events, while current U.S. Vice-President Joseph Biden attended the 2009 Idaho Games and used the opportunity to introduce Kareem Dale as the Obama Administration’s Special Assistant to the President for Disability Policy.

“A great spirit of optimism and hope surrounds the SO movement. The emphasis on accomplishment, overcoming adversity, and the importance of both recognizing and significantly reducing health disparities is extremely important to witness. We also have a tremendous opportunity to learn about health and therapy services available worldwide and the range of ways people with developmental disabilities experience life,” Gleason concluded.

U.S. Vice President Joe Biden is pictured here (back row center, 5th from right) at the FUNfitness Screening program held at the 2009 World Winter Games in Boise Idaho along with Special Olympics athletes from Team USA, their coaches, trainees from the US and Canada learning to implement the FUNfitness screening program, as well as Vicki Tilley (back row, 4th from left) Global Clinical Director, Jim Gleason (back row 2nd from right), and Samantha Smith (back row 1st from right) the Idaho Clinical Director. (Photo courtesy of Special Olympics, Inc.)
Asenze and Mpilonhle Projects: Making it Happen in South Africa

Asenze. Translated from Zulu, it means, “let’s make it happen.” That’s precisely what Dr. Kathleen Braden, developmental-behavioral pediatrician and Director of the Shriver Center LEND program, has been doing through two innovative humanitarian projects for children and adolescents at risk for developmental and health problems living in rural KwaZulu-Natal, South Africa’s poorest state.

The Asenze Project

The Asenze Project, funded by the National Institutes of Health, aims to measure the incidence and prevalence of developmental disabilities and the status of HIV in approximately 2000 preschool children (ages 4-7 years) living in five districts of KwaZulu-Natal. Dr. Braden joined the project as one of several consultants in September 2008 to supervise and assist in developmental and health assessments of local children. In addition, she has acted as a clinical resource to review testing results and medical aspects of the children’s care. Dr. Braden views her role as providing “an outsider’s perspective so that the full richness of the data can be understood.”

Dr. Braden cited numerous physical and cultural challenges in identifying households with children at risk. “To connect with families, data collectors and interviewer frequently traversed rugged terrain to arrive at rural homes without telephones, electricity or running water. Once there, they were often unable to meet directly with parents who had to work, so instead they met with other caregivers, which made capturing a child’s history difficult at times. Families needed to have transportation provided to get to the clinic. Assessments in the clinical center often took all morning, and included social, psychological, physical and neurological evaluations, as well as blood work. So there was much more to the work than just identifying a child’s disability,” Braden explained.

Children identified as HIV-positive were referred for medical care. Those confirmed as having developmental disabilities were referred for therapy. All will have their progress tracked entering school and measured again in two years.

The Mpilonhle Project

The Mpilonhle Project (meaning “a good life”) seeks to reduce the dramatic rates of teenage pregnancy and HIV-AIDS among the 9,800 South African teens attending 12 rural secondary schools near the town of Mtubatuba in the Umkhanyakude District through a strategic high school curriculum that includes education in healthy lifestyles, and provides HIV testing and counseling, health assessments, and computer training.

The project uses three mobile health units that rotate among four secondary schools each and are staffed by dedicated Mpilonhle nurses, health educators, counselors, and computer technicians.

In September 2008, Dr. Braden conducted “listening sessions” with school administrators, teachers, and students and learned that teen pregnancy is considered to be the most pressing health issue other than the spread of HIV; 14% of the adolescent girls that were screened were pregnant or already had 1-3 children of their own. These shocking statistics led Dr. Braden to begin developing a program to address the sexual and reproductive health of women in South Africa, the aim of which is to prevent health and emotional problems and support...
“To connect with families, data collectors and interviewers frequently traversed rugged terrain to arrive at rural homes without telephones, electricity or running water. Once there, they were often unable to meet directly with parents who had to work, so instead they met with other caregivers, which made capturing a child’s history difficult at times.”

the parenting practices of youths who become pregnant during their school years. The program would expand the present health curriculum to include more information on teenage pregnancy, its associated mental health issues, and what parenting involves. It would include developing a tiered infrastructure of 72 local volunteer resource teachers and more than 35 peer youth counselors in the schools, supported by Mpilonhle’s six nurse practitioners and three social workers. These teachers and youth counselors would be trained to identify students at risk for or struggling with problems related to pregnancy and parenting, and offer them support and interventions on an ongoing basis. The volunteers maintain cell phone contact with the Mpilonhle team for emergencies when the team is offsite.

Dr. Braden has approached a private foundation to fund the project and hopes to begin work on it within the year.

“My project will support the health of pregnant girls and reduce the fear, confusion, and mythology surrounding them,” Braden elaborated. “Anywhere from 30 to 50 percent of these high school students are orphans. They are extremely poor, and either raise themselves, care for their siblings, or live with other family members, due to the effect of AIDS on sick or dead parents and elders. While schools must abide by an official policy of inclusion for all children, there is no system in place to assist with or ensure the policy’s implementation. Therefore, considerable stigmatization exists of pregnant girls (and other youths with health, emotional or physical disabilities) in school. We expect our outcomes to demonstrate attitudinal changes among administrators, teachers and students, and empower these young women to guard themselves against unprotected sex, gender violence, and other commonly accepted high-risk situations.”

1 The Mpilonhle project is funded through the former Bush Administration’s President’s Emergency Plan for AIDS Relief (PEPFAR) program with start-up funding from the Angel Network founded by Oprah Winfrey and the Africa Outreach Project established by Oscar-winning actress and South African native Charlize Theron in partnership with the Entertainment Industry Foundation.

![Image](14x92 to 398x382)

Shown in clockwise order: Mpilonhle Health Counselor Phumelele Mthethwa takes a student’s blood pressure (top right); A group of students gather around health curriculum materials (bottom right); Principal Bheki Nomandla of Silethukukhanya High School holds up a sign that says “Do it because you can.” (Photos by Angie Buckland, copyright of Mpilonhle).
A Voice for the Southeast Asian Community

Shriver Center Consumer Advisory Council Member, Sidney Liang, MPA

Representing one of the largest Southeast Asian communities in the United States from Greater Lowell, MA, Sidney Liang has served on the Shriver Center Consumer Advisory Council (CAC) for the past year. Originally from Cambodia but in the U.S. for over 25 years, Liang not only helps guide decision-making at the Shriver Center, but also works tirelessly to aid his community and home country. “I inform [the CAC] about the Southeast Asian community’s attitudes and perceptions about certain topics, approaches, and methods of doing things. By sharing information, I also learn from other council members who share their thoughts and experiences as well.”

Liang is a 2006 Shriver Center LEND graduate and currently serves as Director of the Southeast Asian Resources for Culture and Health program (SEARCH) at the Lowell Community Health Center (LCHC), an organization he has been associated with for nine years. “The purpose of SEARCH is to provide health education, intervention, and prevention in both a culturally and linguistically appropriate manner,” Liang remarked.

Liang’s use of the word “linguistic” is particularly apt when one considers another occupation that Liang describes as his “main passion, besides his family”—hosting a radio and Internet show called Cambodian Voices. The show launched in 1992 and landed at a few different stations before settling down to its current location at the University of Massachusetts Lowell campus station, 91.5 FM WJUL. Radio at www.cambodianvoices.org. Liang also serves as the show’s executive producer and as an on-air personality.

In 2003, Liang was recognized by Lowell’s Vice Mayor Rita Mercier as an Outstanding Community Volunteer for his twelve years of service with the program. Still, he remains modest over his accomplishments. “I am not sure why I am doing this, but I love it, my community needs it, and I am glad I can,” he reflects.

Liang arrived in the U.S. in December 1983 following the death of his father and brother in 1975 at the hands of the Khmer Rouge as Cambodians struggled to oppose the regime. His mother and younger sister also made the journey. This traumatic time provided Liang with indelible memories that would shape all his future decisions. “The United States was not our final destination or our focal point. We were just running away from death. Rain or shine, we ran across rivers, thick forests, sharp grass, and over the dead beneath our feet,” he remembers.

Enduring these harrowing ordeals gave Liang a sharper focus for his work, helping Cambodian immigrants in Lowell recover from post-traumatic stress disorder (PTSD) stemming from their experiences with the Khmer Rouge. An integral part of Liang’s LEND studies focused on the mental health needs of his community as it does to this day. “I see many people healthy one day, then something interfaces with them and they get sick, shaken, afraid, and stay secluded from outsiders. Due to their PTSD, many people turn to alcohol and other distractions. This leads to diabetes, cholesterol and hypertension,” he explains.

In the face of disability, Liang describes how Cambodians must cope with even steeper challenges. “According to certain cultures, if someone is disabled either physically or mentally, it is because of Karma and they have to accept it. Once this happens, modern health care is not sought and therefore, danger to the patient is increased.”

Liang’s vision for the future is that one day such problems will be a thing of the past. “I would like to see partnerships between the U.S. and overseas countries regarding sharing resources, techniques, vaccines, and best practices. We are one world.”

Did you know?

There are an estimated 400 million children, youths and adults with disabilities living in developing countries.¹

Throughout the world, people with impairments or disabilities have on average higher illiteracy rates, fewer employment opportunities, greater difficulty accessing public buildings and transportation, and a greater likelihood of being institutionalized or experiencing social isolation than do people without impairments and disabilities.²

Disabilities are perceived as diversely around the world as the number of countries and cultures, with disability statistics counted and reported from as low as 0.2 % of a country’s population to as high as 20.9 % across 55 countries.³

¹ Disabilityworld.org
² United Nations Disabilities Statistics Compendium
³ Ibid.
“According to certain cultures, if someone is disabled either physically or mentally, it is because of Karma and they have to accept it. Once this happens, modern health care is not sought and therefore, danger to the patient is increased.”

**International Shriver Center LEND Fellows**

**Two International Fellowship Students “Lend” Insights from their Native Countries**

Andrea DeSousa and Oanh Thi Thu Bui bring international origins and sensibilities to the 2009 Shriver Center LEND Fellowship program. DeSousa is originally from Brazil, while Bui is from Vietnam. Both fellows bring unique perspectives to the LEND program.

DeSousa serves as a Family Literacy Coordinator for the Family Nurturing Center in Dorchester, Massachusetts. The position includes curriculum development, facilitating parent/child activity time, and case management. She pointed out cultural differences between the U.S. and Brazil. “In Brazil, the family is the center of things. Grandparents, aunts, uncles and cousins all live close by and help each other. If there is an individual with a disability, the family joins together and helps. They don’t see a great need for something like independent living,” she said.

Bui is the mother of a six-year-old daughter Tiny, diagnosed with metopic craniosynostosis, a disability resulting in severe cognitive, physical and social delays. She discussed cultural influences in a different way. “I remind myself all the time to stay positive. Coming from a culture where people with disabilities rarely integrate into society, I embrace the civil rights movement for people with disabilities in the U.S. and never let traditional cultural beliefs stop me from searching for services for my daughter,” she emphasized.

Both LEND fellows see the LEND program as a springboard to improve the health care and disability fields. “I am interested in telemedicine, a tool to connect vital U.S. medical staff with Vietnamese stakeholders to support families and children with special health care needs,” Bui explained. DeSousa’s goals also apply both to the U.S. and abroad. “I would like to establish a non-profit organization to help immigrant families access available information, so that families of children with disabilities can navigate the system, get the services they need, and feel they are at home,” she described. DeSousa also believes opening such a center in Brazil would reach other populations there, including abused and neglected children, children with disabilities, and victims of child prostitution. “We need to invest in children. They are the future; they all have abilities,” she elaborated.

**Bringing Behavioral Healthcare to Puerto Rico**

**Luis Caraballo, PsyD**

Psychology Fellow, UMass Medical School, 2004-2006

LEND Fellow, E. K. Shriver Center, 2005-2006

Assistant Professor, Department of Psychiatry at the University of Puerto Rico School of Medicine, San Juan, PR

Specialty in primary care psychology: integrating behavioral healthcare with mainstream family medicine to treat every aspect of healthcare: behavioral, emotional and physical

What is your current position?
I teach and oversee clinical practice for our psychology and psychiatry residents training to treat psychosomatic conditions by integrating mental health care with medical care. For example, we collaborate with neurosurgery and anesthesiology by using behavioral medicine to address pain management and similar issues.

What would you say are the biggest cultural differences between how disabilities (particularly, mental health) are viewed in Puerto Rico versus in the larger U.S.?
Even though Puerto Rico is a U.S. territory, we don’t have many resources. Therefore, families play a big cultural role in caring for family members with mental health needs. This often includes the extended family—aunts, uncles, and others. This is the rule, not the exception.

Doctors often use the familiar term “nervousness” when describing anxiety, depression, and psychotic conditions to family members. That is not a label, but everyone understands what that means. There is a subtle stigma regarding mental health concerns here, especially psychoses, which can be viewed as weaknesses. Physical and developmental disabilities, however, are less stigmatized and more integrated.

What do you see as a successful health care practice?
In my experience, you see success when health care practices are within university settings since more services tend to be offered. This, in turn, provides good quality, good outcomes, and better access to services.

What would you like to see improved?
Access. If we can place more behavioral health professionals in medical home practices, that would expand patient access and allow for easier patient visits. This is important for a small island like Puerto Rico.

What is the ultimate goal you would like to accomplish in your work?
Raising awareness about the need for high-quality behavioral health services is, to me, the other face of the broader health care picture. Increased public policy involvement by working with local representatives toward the goal of funding these vital services in Puerto Rico is a most important goal as well.
Disability Studies Down Under

CDDER’s Alexandra Bonardi Visits New Zealand as Ian Axford Public Policy Fellow

Alexandra Bonardi, OTR/L, MHA is literally half a world away from her regular position as Associate Director of the Center for Developmental Disabilities Education and Research (CDDER) at the Shriver Center. Since January 2009, she has been in New Zealand after receiving a prestigious six-month Ian Axford (New Zealand) Public Policy Fellowship. Despite the geographic distance, Bonardi feels that her current assignment is universally applicable.

“My project is called Balancing Individual Choice and Risk Management in Planning Services for People with Intellectual Disabilities,” she explained. “I am focusing specifically on laws and policies in New Zealand that affect how people receive services. Governments all over the world are challenged by issues related to promoting a person-centered approach to service delivery while still aiming for some level of standardization and accountability.”

Bonardi began the fellowship with some specific questions in the field of risk management, and hoped that her research would help provide the answers. “What is the organizational capacity for risk management? How is data collected, analyzed, and used? What training exists? How is risk management included in service planning? Is this primarily the role of clinicians and service coordinators? There are several more,” she commented.

New Zealand is no different than many other countries, however, in understanding and treating disabilities. Bonardi acknowledges those challenges, but still feels optimistic about the future. “In the intellectual disability world here, there seems to be little data that are currently being analyzed on a systemwide basis, except for financial data. I’m planning to use my time here to deepen my knowledge of the policy approaches that can be used to assure health and safety as [the government] shifts from simply funding service providers to truly being ‘of service’ to people with disabilities,” she stressed.
“Governments all over the world are challenged by issues related to promoting a person-centered approach to service delivery while still aiming for some level of standardization and accountability.”

Creating Access Abroad: Sue Wolf-Fordham’s Intrepid Work in Ukraine & Israel

Sue Wolf-Fordham, J.D., a 2008 LEND graduate and current senior project manager at the Shriver Center, has been deeply involved in international work for the past decade, having been the founder of two international programs that educate and support children with disabilities and their families.

In 1999, Wolf-Fordham co-founded the Special Needs Education Resource Center (ERC), a pioneering education and support center with her mother Judy Wolf, PhD, in partnership with organizations from the U.S. and abroad. The ERC promotes community inclusion and improved quality of life for children with disabilities and their families in Dnepropetrovsk (Dnep), Ukraine. Wolf-Fordham founded the ERC program after learning about injustices there against people with disabilities arising after Ukraine gained independence. “Few, if any, civil or educational rights existed as we know them in the U.S. for children with disabilities, and poverty increased their vulnerability,” she said. “I felt compelled to act.”

As the parent of two children with disabilities, Wolf-Fordham’s keen awareness of related advocacy and awareness issues is reflected in the ERC’s programs: an educational program for children with special needs, a fully accessible outdoor playground, and a training center for student-teachers and their professional counterparts, among others. ERC collaborators include Bet Hana Teacher Training College, Dnep; Gordon Teachers College, Haifa, Israel; Tufts University Eliot-Pearson Department of Child Development; and Jewish Family & Children’s Service, Waltham.

Wolf-Fordham was also the founder and former director of Yesodot, a support program of Jewish Vocational Service of Greater Boston for families whose children have disabilities. As part of her work with Yesodot, Wolf-Fordham created a connection between families of children with disabilities from Haifa, Israel and Boston, MA via e-mail in 2005. Boston parents later traveled to Haifa and learned about Israeli special education and disability systems. The project culminated in 2008 with a pilot trip to Israel by Bostonians with disabilities and special health care needs. They went sightseeing and met children with disabilities and their families. This experience proved to the American families that such community group trips to Israel are programatically and physically accessible, as well as meaningful. “There were accessible signs on pathways and trails where we walked in Old Jerusalem. We hiked along a mountaintop and even entered the Dead Sea. If a family or individual with a disability can solve the challenges of a long plane trip, once in Israel, an accessible trip is easy,” Wolf-Fordham emphasized. Thanks to Wolf-Fordham’s dedication, these two programs are well established and continue to serve their respective communities to this day.

“Witnessing the birth of a democracy has been life changing.”

Chapters & Other Publications


Conference Abstracts, Papers, & Invited Presentations


Pictured from left to right: Judy Wolf, PhD, two top ERC students Lonya and Olya, and Sue Wolf-Fordham, JD.
Disabilities transcend all economic, geographic and social boundaries worldwide. The current focus on global awareness makes now an ideal time to build greater public awareness and understanding about disabilities.

The following links explore the role of disability in several diverse fields: athletic competition, information referral, organizational policy, and structural accessibility.

**Publications**

**International Classification of Functioning, Disability and Health (ICF)**

The ICF is the World Health Organization’s (WHO) framework for measuring health and disability at both individual and population levels. It is available online in multiple languages. The ICF recognizes the experience of disability as being a universal human experience, and treats all health conditions, including disability, as equal.

[www.who.int/classifications/icf/en/](http://www.who.int/classifications/icf/en/)

**Web sites**

**Massachusetts Network of Information Providers (MNIP) Multicultural Resources**

Culturally-centered options to assist consumers in locating appropriate services. Groups include: agency listings, cultural competency reviews, immigrant and refugee assistance, interpreting or translation services, and more.

[www.disabilityinfo.org/MNIP/MCR/](http://www.disabilityinfo.org/MNIP/MCR/)

**Special Olympics International**

Promotes acceptance, advocacy, inclusion, and physical fitness for individuals with intellectual disabilities through athletic competitions. Includes research studies, global mirror sites, volunteering information, and personal experiences from the 2009 World Winter Games in Idaho, among other topics.

[www.specialolympics.org/](http://www.specialolympics.org/)

**World Health Organization (WHO)**

As the leading arm of the UN’s health program, examines disability in several ways, from the need for computer screen readers to recent publications, information on community-based rehab programs, and statistical breakdowns by global region.

[www.who.int/topics/disabilities/en/](http://www.who.int/topics/disabilities/en/)

**United Nations Convention on the Rights of Persons with Disabilities**

Although not legislation, this strong and influential statement represents a unified international commitment to people with disabilities.


**Institute for Human-Centered Design (IHCD)**

An unprecedented collection of case studies available through its fully accessible and searchable website. The case studies illustrate successful examples of universal/inclusive design in the built environment for a diverse audience from across the globe.

[www.universaldesigncasestudies.org](http://www.universaldesigncasestudies.org)