Creating a “Culture of Emergency Preparedness” for People with Disabilities in Massachusetts

The term “emergency preparedness” (EP) is most commonly associated with high impact, visible events like blizzards, floods, hurricanes and wildfires. According to the University of South Carolina Hazard and Vulnerability Research Institute, 91% of Americans live in areas that are at risk for either natural or manmade disasters, so virtually everyone is susceptible. Airborne communicable viruses, such as the much-discussed H1N1 flu, can also become emergencies without safeguards in place.

The Shriver Center UCEDD’s Senior Project Manager, Sue Wolf-Fordham, JD, is working to improve emergency preparedness (EP) awareness and responsiveness among individuals with disabilities, their families, support networks, and local community members. The Shriver Center’s EP projects include working with the National Association of State Directors of Developmental Disabilities Services (NASDDDS) to develop an online tool for developmental disability service providers, consulting to the Massachusetts Department of Developmental Services, membership on a Massachusetts EP Task Force, and training Shriver Center LEND fellows to aid their organizations and families in EP by stressing themes of access and equality.

Wolf-Fordham also serves as project director on the Shriver Center’s grant from the Deborah Munroe Noonan Memorial Research Fund. The grant helps Massachusetts realize its EP goals by funding the development of a curriculum and EP training materials for the families of children with disabilities and special health care needs.

“Parents attending our workshop will fill in a workbook of emergency tools designed to help them create an emergency plan. The curriculum will be developed collaboratively with parents of children with disabilities and special health care needs, and will also include input from emergency responders. Folks in the trenches will be developing materials for other folks in the trenches,” Wolf-Fordham explains.

Shriver Center UCEDD Director Charles Hamad, PhD, who is the principal investigator for the EP training initiative for families, also notes that EP became more essential after events like Hurricane Katrina as the fallout increasingly showed that people with disabilities could be severely endangered if updated EP policies did not include them. “It seemed like nothing was being done for high risk populations at that time,” Hamad said. He adds that EP and risk management skills must be practiced and repeated like fire drills. “The best way to maximize the chance that risk management practices will be actively incorporated into the routines of people with disabilities is to overlay a quality assurance system that requires frequent review, practice, and evaluation. While there is general support for the importance of having emergency planning for people with disabilities, more research and information is needed to prove its efficacy,” Hamad elaborates.

continued on page 2
Wolf-Fordham adds that we can learn much by examining practices in other countries. In Cuba, national citizen preparedness drills help increase hurricane survival rates by creating a “culture of preparedness.” Japan, meanwhile, sets up earthquake preparedness centers, while Israel emphasizes terrorism safety through an emergency communication model. “These countries all make EP a part of their national consciousness,” Wolf-Fordham emphasizes. “We must do the same. The more exposure people have to EP, the more it will help them,” adding that people typically do not panic in emergencies as is widely thought, but instead try to help each other.

In addition to planning for communication and support needs during emergencies, one way to be prepared is by creating what Wolf-Fordham calls a “go-bag”: an easily portable kit filled with enough supplies to survive the initial stages of an emergency. (See accompanying sidebar for a list of recommended items). “EP is actually easy if it’s done steadily over time. It’s the same principle as having a bag ready for the hospital when you are expecting. First responders may not reach you for 72 hours, so plan to be self-sufficient for at least that long,” Wolf-Fordham remarks. Establishing connections with neighbors, peers, or social groups to check in with or assist during an emergency is also imperative. Some towns offer “locator” forms that, when filled out by someone with a disability, will provide all pertinent information to emergency personnel whenever that person dials 911.

“If you are vulnerable before an emergency, whether you have a disability, are elderly, homeless, or a small child, an emergency could worsen that vulnerability,” Wolf-Fordham continues. “Think about it like this: many home owners purchase homeowners’ insurance. Applying that logic to disabilities, power wheelchairs might require backup batteries, and you should have backup support systems if you use personal care attendants. Just try and answer all the ‘what-if’s’ you can.”

What Goes In A “Go Bag”?

Anyone can create a go bag at anytime. Wolf-Fordham recommends including the following:

- Canned or non-perishable food items and bottled water (also for pets)
- Plastic cutlery and a manual can-opener
- An up-to-date list of all medications and dosages. (Ask your doctor about receiving an extra supply of medication in case of emergencies)
- First-Aid kit
- Batteries
- Corded landline phone (This is important because cell phones can be knocked out by power loss during natural disasters)
- Lantern or manually-operated flashlight
- Adaptive equipment and detailed information on it in case you become separated from it (i.e., manufacturer, model number, size, color, etc. for wheelchairs, walkers, etc.)
- Personal identification
- A post-evacuation meeting place.
- Key phone numbers

Emergency Preparedness Project Director Susan Wolf-Fordham (L) after the drill.

Preparing a Go-Bag early saves valuable time during an emergency.
A Look Back at the Origin of Risk Management for People with Disabilities

It’s been said that to appreciate the present, one must first understand the past. The time was 1972—a time when institutions were common homes for people with disabilities, largely excluded from the outside world. And it was in 1972 that Steven Staugaitis, Ph.D., currently assistant professor at the Eunice Kennedy Shriver Center and faculty member in the Center for Developmental Disabilities Education and Research (CDDER) program, began his distinguished career in risk management (RM) and quality improvement, thanks in large part to his experiences in those same institutions.

To emphasize the progress achieved over these past 40 years, Dr. Staugaitis recently recounted some of his past memories that stand out vividly in stark contrast to today’s system of care for people with disabilities.

“Conditions were absolutely deplorable when I started,” said Dr. Staugaitis, who previously worked at the Agency on Health Research and Quality (AHRQ) on Long Island and helped move some people from the now-infamous Willowbrook Center, and later from Connecticut’s two large training schools. “Women with intellectual disabilities would wait naked in hallways for showers given by male staffers. I once saw 50 people standing naked in a room filled with urine and feces. It was horribly degrading.”

These jarring early incidents helped shape Staugaitis’s future attitudes and decisions when he was later appointed director of the Southbury Training School. “It was an exciting opportunity, but plenty of problems existed at the facility: 1,200 residents, 2,500 staff, 120 buildings, budgetary concerns, union demands, and splits between families who did and did not want the facility closed,” he remembered.

The national atmosphere was beginning to support change, but Staugaitis knew that change would not come easily. “We had to offer the community something in return, and create opportunities for positive interactions. Fortunately, we were also the region’s largest employer.”

The school employed its own ambulance, fire, and police departments; a system of mutual aid during emergencies was established as a first step at positive engagement.

Dr. Staugaitis focused on improving the quality of life and lessen individual risk at Southbury. “Horrible incidents were still occurring; physical and sexual abuse, people physically assaulted, others experiencing what we refer to as ‘preventable deaths’,” he said. After leaving the training school to manage community-based programs he continued to see many of these same types of unfortunate and depressing incidents. In one case, an individual was strangled to death after becoming trapped by a bedrail. On the day following this incident, Dr. Staugaitis read something that forever altered his mindset on risk management.

“A plane had crashed, and the National Transportation Safety Board focused more on determining the cause than assigning blame. That was a ‘lightbulb’ moment; if we focused like that, tragedies could be prevented,” he said, adding that traditional policy involved employee discipline and frequently firing the worker responsible. A subsequent investigation into the bedrail death found that a supervisor had incorrectly assembled the bed when maintenance was not available to do so. This incident and its resolution exemplify the merits of a method Staugaitis strongly endorses, “root cause analysis,” which holds that determining the “root cause” of such incidents allows for corrective action or improvements to prevent similar mistakes. Such essential practices are particularly valuable to individuals with disabilities.

“The presence of intellectual and other disabilities leads to increased vulnerability to harm, above and beyond that of the general population. Understanding and mitigating these special risks remains a basic and fundamental obligation of the service system designed to support and assist this special population of citizens,” Staugaitis wrote in an October 2008 article on comprehensive risk management. As such, Staugaitis developed a web-based course in 2009 entitled Root Cause Analysis in Developmental Disabilities. He continues to advocate for adapting successful risk management strategies used by other industries, particularly the medical community’s idea of so-called “never events.”

“The medical industry has decided that some hospital errors are inexcusable—they should ‘never’ happen—and mandates reporting and preventative action when they do occur,” he explained, citing operating on wrong body parts or leaving medical instruments inside a patient. “Our field would benefit from something similar, and should implement a shared approach system-wide. We must emphasize a ‘culture of safety’ and ensure that everyone pulls toward the same goal.”

3 Ibid.
Picture the following scene from my life: I’m lying shirtless on a clear backboard, rolling down a small conveyor belt inside a yellow and black striped tent. Two men wearing white full-body HAZMAT suits and face masks stand one on each side. Two others at the entrance help me disrobe to a bathing suit and transfer from my wheelchair. For me, this certainly was a first!

My experience was part of an outdoor chemical decontamination drill that took place at Cambridge Hospital as part of an annual emergency preparedness requirement for all Massachusetts that involved members of that city’s police and fire departments. The cold and drizzly weather added to my nervousness about the process. Fourteen other people also took part in the exercise. The backboard and conveyor belt made up the tent’s “immobile” section, designated for people with physical disabilities, but also parents who needed to accompany small children through the process. Men’s and women’s group shower stalls were just inside the tent for “mobile” participants.

My clothes and other accessories were stored in a clear plastic bag to be returned later. (We were told afterward that clothes are responsible for 80 to 90 percent of contamination, and would be cut off in an actual emergency).

One of the men in HAZMAT suits beside me leaned over.

“Here’s the soap,” he said as streams of white fell down my body.

“Cold water next,” said his partner as I jolted upon contact.

“Warm now,” the first continued and it soothed.

I continued down the belt and started to see out the far end of the tent. The board stopped moving, and somebody toweled me off. I sat up and saw my wheelchair off to the left. A first responder gently but firmly grabbed me around the chest and instructed others on how to safely lower me into the chair.

After redressing inside, I discovered only 25 minutes had passed; shorter than I expected. Thanks to the complete professionalism and respect of everyone involved, it proved a unique and smooth experience that I won’t soon forget.

One of the chief goals of our visit was to provide feedback on how the hospital could efficiently and effectively assist people with and without disabilities during an actual emergency. We provided input into their development of pictorial signage that would offer visual cues of the each step in the decontamination process.

One month later, I attended a second similar drill at Somerville Hospital, focusing on radiation decontamination. The procedure was largely identical; radiation wands provided emergency personnel with fictional exposure levels and helped suggest the best available treatment options. The previously mentioned signs were field-tested and improvements suggested, largely centering on the need for greater clarity and brevity in describing the activity depicted.

I would like to sincerely thank everyone involved in both drills, and wish them continued success in the future. My positive experiences have led to a sustained and deepened interest in how emergency preparedness impacts individuals with disabilities.
Self-advocacy has “always seemed like a calling” to 31-year-old Nate Trull of Fairhaven, Massachusetts. Trull answers that call as Chairperson of Powerhouse, a Massachusetts support organization that helps individuals with disabilities become more proactive in advocating for their needs by supplying information and resources on a variety of topics. “Helping people gain knowledge and learn how to apply it increases their own awareness and independence in the long run,” he elaborated.

Trull’s awareness and perspective is uniquely personal, as he has a disability himself. “If I can be a positive example to others, that’s good,” he said. “But they must also take the first step and help themselves.”

Additionally, Trull collaborates with the Shriver Center and similar organizations at locations around the state on conducting emergency preparedness workshops for people with disabilities. “I have been associated with the Shriver Center since May 2007, and I really enjoy it,” he commented, noting that Anne Fracht, current Vice Chairperson of the Massachusetts Developmental Disabilities Council (MDDC) gave his name to the Shriver Center as a possible candidate. “I try to let people know what can happen in an emergency, and how they should be prepared as much as possible for anything that may happen, he said.” Trull recently videotaped one of these workshop sessions at the Shriver Center for later use.

Trull previously served as a six-year member of the Massachusetts Developmental Disability Council, and, in that capacity, campaigned for and established signage showing accessible ramp and parking locations at the Fall River campus of Bristol Community College.

Furthermore, he has attended and organized several Massachusetts State House rallies. One particularly proud moment came when he received the Massachusetts Department of Developmental Services Annual Human Rights Award in 2008 for his assistance in calming a child with autism who had become disoriented and agitated. “I started counting and talking with him to keep him focused,” Trull remembered. “Erin McGaffigan (formerly of the Shriver Center) was with me, and submitted my name for recognition. I thought it was just going to be a certificate, but it turned out to be a large plaque,” he laughed. State Senator Mark Montigny also endorsed the award. Trull sees his role as a self-advocacy worker continuing in the future. “I am a go-getter,” he emphasized. For anyone lucky enough to attend one of Trull’s emergency preparedness workshops, that can-do spirit is plain to see.

(For more information about Powerhouse, please visit http://tiny.cc/wndq3.)
Shriver Center CDDER Project Coordinator Courtney Noblett, MPA, and her colleagues completed a six-month Falls Reduction pilot study for the Massachusetts Department of Developmental Services (DDS) at the end of August, 2009 as part of a year-long safety campaign to raise awareness about falls risks and reduce fall related injuries. The study came about when DDS requested CDDER examine centrally reported injury data to determine why injury rates were so high. The pilot tracked all falls across six provider agencies, enrolled approximately 900 people with intellectual or developmental disabilities, piloted an underutilized feature of the current injury reporting system, studied potential risk factors for falling, and suggested feasible improvements.

“Our primary age group consisted of any adult 22 years of age or older in day or residential settings who received services through DDS,” Noblett explained. She added the study did not include data from individuals with disabilities living with relatives or independently since those falls are generally only known if self-reported.

DDS currently sends all injury reports to a central database. In examining those reports, we found that 35% of all reported injuries in the year reviewed were related to a fall. Conducting the pilot helped us get behind those numbers and look for patterns where falls occurred and whether certain locations, such as bathrooms, bedrooms, kitchens, stairs, etc., placed individuals with intellectual or developmental disabilities at a higher risk. Research on this population was very limited before our work began; it primarily focused on the elderly,” Noblett elaborated.

Data analysis continues, but preliminary results are available. During the six month pilot period, 473 falls were reported among participants resulting in a rate of 51 falls per 100 people. About 24 percent of participants receiving residential or day support experienced one or more falls during the pilot. However, data also suggests a 33 percent reduction in the rate of falls for adults in residential and/or day services from the first month of the pilot to the next five. Below, Noblett described some of the methods used for data collection.

“We used each provider agency’s injury data as a baseline, and examined how many of those injuries resulted from falls. National statistics show that 30 percent of individuals with DD will fall each year, and that 15 percent of those falls result in injury requiring medical attention. “We used each provider agency’s injury data as a baseline, and examined how many of those injuries resulted from falls. National statistics show that 30 percent of individuals with DD will fall each year, and that 15 percent of those falls result in injury requiring medical attention.

Spotlight on Resources to Help Manage Risk and Promote Preparedness

For individuals with disabilities, preparing for emergencies and preventing other high-risk dangers, such as falls, are vitally important. Adequate safeguards must be in place should the need arise. With this in mind, here are a variety of local and national resources that provide practical information to address these concerns.

Web sites

Websites on Emergency Preparedness

The Disability Policy Consortium of Massachusetts (DPCMA)
The DPCMA promotes inclusion, independence and empowerment for individuals with disabilities by developing and publicizing policies designed to improve their participation in all aspects of life. Their Publications page includes a partial list of town-by-town emergency shelters in Massachusetts and describes how to create a Personal Emergency Preparedness Plan, along with other important information.

www.dpcma.org/Publications/tabid/423/Default.aspx

The National Organization on Disability (NOD)
The NOD works to improve the lives of over 54 million individuals with disabilities nationwide. It offers four free disability-specific brochures called Prepare Yourself: Disaster and Readiness Tips for People with Disabilities (available in text and PDF versions). Each pamphlet discusses specific emergency tips related to an individual’s disability, whether mobility, sensory, or cognitive/developmental in nature. A pamphlet for people who require service animals is also available.

http://tiny.cc/fmol7

Ready America: The US Government’s Official EP Site

This official government website offers a variety of valuable tips on ways individuals with disabilities can protect themselves in an emergency, including ensuring that government payments are not delayed by an emergency. Links to other resources are available as well.

www.ready.gov/america/getakit/disabled.html

Websites on Falls Prevention

CDDER “Never Events” Quality Brief

The Center for Developmental Disabilities Evaluation & Research (CDDER), located at the Eunice Kennedy Shriver Center and affiliated with UMass Medical School, published an online quality brief in May 2009 that deals with “never events.” That is, what types of extremely serious incidents should be classified as unacceptable for people with disabilities, and how can they be prevented (i.e., medical issues worsening due to being given wrong medications, falling in the hospital, etc.)? Other quality briefs are also available.

http://tiny.cc/jdvar

For more information about the Center for Developmental Disabilities Evaluation & Research, please visit: www.umassmed.edu/cdder/index.aspx

Centers for Disease Control (CDC) Fall Prevention Internet Podcasts

Podcasts allow fast dissemination of information online. The CDC’s most recent free two and a half minute podcast is entitled ”Preventing Older Adult Falls.” It outlines the severity of falls among older adults, identifies risk factors for falls, and suggests ways to prevent falls among individuals at greatest risk for falling. The podcast is available at the web site below by selecting “Falls – Older Adults” under “Topics.”

http://www2a.cdc.gov/podcasts/browse.asp

Fall Prevention Center of Excellence

Although primarily concerned with assisting falls prevention in California, this website has a wealth of informational resources available including electronic newsletters, yearly information archives, links to related studies, tips and DVDs available for purchase that could be applied both to individuals with disabilities and the elderly.

www.stopfalls.org
“National statistics show that 30 percent of individuals with DD will fall each year, and that 15 percent of those falls result in injury serious enough to warrant medical attention. Thus, we hypothesized that the reported amount represents 15% of total falls in the population served by DDS or approximately 10,000 falls each year.”

Thus, we reasoned that the reported amount represents 15 percent of total falls in the population served by DDS or approximately 10,000 falls each year. We also gave ‘post-fall assessments’ to the participants; these were used to determine if outside factors such as dizziness, loss of balance, seizure, tripping, or something else contributed to falls.

Each provider agency used different criteria in selecting participants for the pilot. One agency enrolled every individual in their day and industrial programs, while another only selected certain houses in their residential program. Falls prevention trainings then began at residential homes and provider agencies, as well as with direct care staff.

Such trainings sometimes led to immediate improvements. Noblett recalled one man who frequently fell out of bed reaching for something whose nightstand simply needed to be moved closer. Likewise, a staircase handrail was re-sanded because residents were not using it to avoid hurting their hands.

Additionally, the pilot study addressed a previous limitation in falls reporting. “DDS’s current incident management system only records falls that result in a serious injury, like the need for hospitalization. But many falls are simply stumbles, and people can get right back up without visible signs. Our study noted those as well,” Noblett explained, since such stumbles can be the first indicator of someone at risk for a more serious injury resulting from a fall. She also added that staffers may know someone as a “frequent faller” by word of mouth, but often have no way to report it, since those falls didn’t result in serious injury.

CDDER has begun to present their findings locally and nationally, by taking part in a poster presentation at the annual AAIDD conference and presenting at the Reinventing Quality conference. CDDER also developed a brief in April, 2010 entitled Quality is No Accident that translates results from the pilot into an easy to read format with tools for managers to implement immediately into their programs to prevent falls. This brief was distributed throughout the DDS network.

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“My work gives me a great opportunity to improve someone’s quality of life on a regular basis. Helping them find workable solutions to prevent falls and injury is extremely rewarding,” Noblett reflected.

Training and enhanced data collection: The S.T.O.P. Falls Pilot

- 5 agencies, 6 months
- 910 DDS consumers participated, 814 were receiving residential and/or day programs supports
- Training provided at each agency
- Information collected for all falls (both injurious and non-injurious)
- 417 total falls reported during the pilot for consumers in residential and/or day programs (rate of 5.1 falls per 10 consumers)
Steven D. Staugaitis, PhD

**Research Interests**

Dr. Staugaitis’ position as a faculty member in the Shriver Center’s Center for Developmental Disabilities Education and Research (CDDER) program is an ideal fit. It continues his thirty-five-year association with both the psychology field and individuals with developmental disabilities, but also folds in his current specialty of risk management. Given CDDER’s close working relationship with the Massachusetts Department of Developmental Services (DDS), Staugaitis often contributes to the development of programs and policies designed to enhance services and management practices for individuals with developmental disabilities. His expertise in the risk management field has been sought by seven states to assist in their design and implementation of comprehensive incident reporting systems, data analysis and report generation, mortality review and analysis and the use of risk mitigation tools such as root cause analysis and failure mode and effects analysis. Additional research interests include: program assessment, data utilization and performance measurement.

**Activities**

Dr. Staugaitis has authored over 40 conference presentations, Web documents and journal articles during his diverse and acclaimed career. Audiences for his work have ranged from Shriver Center LEND Fellows, to the Developmental Disabilities Nurses Association, to the Massachusetts Executive Office of Health and Human Services, to the CMS Quality Conference in Baltimore, Maryland, among others. In addition, Staugaitis served as an invited member of the CMS and AHRQ Federal HCBS Measures Scan Technical Expert Panel from January 2007 to June 2008 and the more recent HCBS/CAHPS quality assessment project (June 2010).

**Career Influences and Vision for the Future**

Dr. Staugaitis’ interest in risk management is driven by a frustration with the traditional “blame-oriented” approach to managing adverse events. In his view, that leads to little positive change and does nothing systemically to prevent future incidents. Instead, he emphasizes understanding why such events occur. By doing so, everyone involved learns how to ensure the same event never happens again. This philosophy has made Dr. Staugaitis an invaluable asset on many advisory boards and committee panels, including serving as a past co-chair of a Connecticut Advisory Commission on Persons with Developmental Disabilities. Just as important, Dr. Staugaitis’ current role with the Shriver Center helps to ensure that his approach to risk management is passed on to others in the field.

Dr. Staugaitis has worked in the developmental disabilities and risk management fields at every major level during his career, whether as an educator, institution director, policy consultant or project director. His wide range of experience and practical knowledge will undoubtedly continue to provide lasting benefits to both fields in the future.

**Current Research Support**

Dr. Staugaitis’ recent past and ongoing research projects are funded with support from the National Institutes of Health (NIH), Centers on Disease Control (CDC) and the Center for Medicare and Medicaid Services (CMS), and include:

- Principal Investigator, CMS Real Choice Quality Improvement Grant, CMS, 2004-2008
- Principle Investigator, CDC SBIR, Root Cause Analysis in Developmental Disabilities, 2007-2009
- Principle Investigator, NIH STTR, Risk Management in Developmental Disabilities, March 2010-present
- Principle Investigator, NIH STTR, Root Cause Analysis for DD Program, 2006-present

**Selected Publications**

E.K. Shriver Center
LEND Fellows for 2009-2010

The following individuals recently completed Shriver Center LEND fellowships for the 2009-2010 academic year. We congratulate them for their scholarly efforts, and are pleased to share their backgrounds and the themes of their yearlong leadership projects.

Karen Benson, MA
Specialty: Psychology
Director of the Worcester Juvenile Resource Center, a joint partnership program serving adolescent males ages 13-18 who have been ordered there as a condition of their probation. Karen’s LEND project, entitled Assessing Knowledge and Attitudes of Juvenile Justice Professionals Working with Youth with Autism/Asperger Syndrome involved a survey to assess knowledge and attitudes about Asperger’s Syndrome among criminal justice professionals. Results will guide recommendations on training initiatives.

Holly Cavender-Wood, MA, CCC-SLP
Specialty: Speech-Language Pathology
Speech-language pathology supervision and practice at Children’s Hospital Boston working with medically fragile children (birth-three), Holly’s LEND project, Speech-Language Pathology in Early Intervention: Answering the Need for Organizational Champions, developed the role of the organizational champion in a bidirectional relationship with ASHA to coordinate program changes with professional organization recommendations in Early Intervention speech-language pathology practices.

Susan Crossley, BS
Specialty: Administration
Over 30 years of experience working with adults with disabilities and their families. Presently consulting in Massachusetts providing self-advocacy training and outreach to individuals moving into the Rolland settlement community. Sue’s LEND project, Supporting Choice: A Comprehensive Training Program for Support Brokers in MA, focused on creating an “individual choice” model for identifying, accessing and maintaining long term care in Massachusetts communities.

Aasma Khandekar, MD
Specialty: Pediatrics
Recently completed the third year of a developmental and behavioral pediatrics fellowship at Boston Medical Center. Interests in early literacy promotion, child advocacy, and immigrant parenting perspectives. Aasma’s LEND Project, Improving Early Literacy Promotion: A Quality Improvement Initiative for Reach Out and Read, involved the implementation of a multi-site, quality improvement (QI) process for reading-related anticipatory guidance by pediatric providers using the Reach Out and Read (ROR) model.

Mary Khetani, ScD, MAOT
Specialty: Occupational Therapy
Recently completed her doctorate in Rehabilitation Sciences from Boston University. Mary’s LEND project, Project HAMDARDI (Compassion): Community participation for South Asian families transitioning out of Part C Early Intervention services, focused on increasing mobilization of parents and community members to promote community participation among immigrant families transitioning out of Part C early intervention services.

Michelle McKiernan, JD, OTR/L
Specialty: Occupational Therapy, Law, Parent
Interest in childhood disabilities and diseases, along with improving advocacy for children with disabilities and their families. Mother of two young children with special health care needs. Michelle’s LEND project, A Web-based CME Program on Diagnosing Childhood Brain Tumors, involved the development of a continuing medical education (CME) program for pediatricians on childhood brain tumors.

Evelyn Milorin, BA
Specialty: Community Organizer, Parent
Currently working with the Boston Center for Independent Living. Current and former member of several state advocacy organizations. Former Open Fellow and Kennedy Fellow. Parent of 2 adults, one with autism. Evelyn’s LEND project is Understanding the Needs of the Aging and Disabled Populations in the Haitian Community, a radio series on healthcare-related matters of concern to elders and people with disabilities in the Greater Boston Haitian community.

Amanda Rossetti, BS
Specialty: Media Executive, Parent
Former director of interactive advertising for marketing services agency. Parent of two daughters, one with an autism spectrum disorder. Amanda’s LEND Project, The LiveAutism Project: Developing a Comprehensive Online Tool for the Autism Community, involved an implementation plan for an online community that will allow parents and professionals opportunities to inform, interact and share ideas about how to successfully navigate services and options available for people with ASDs and their families.

Nicola Smith, MD
Specialty: Pediatrics
Pediatrician who recently completed her second year of a developmental and behavioral pediatric fellowship at the Center for Children with Special Needs in Boston. Nicola’s LEND project, An Abbreviated Screening Instrument for Autism Spectrum Disorders, sought to test a new, abbreviated ASD screening instrument, the Parent Observations of Social Interactions (POSI) to assist in earlier identification of autism spectrum disorders (ASDs).

Kristen Tarsia, BA
Specialty: Psychology
Currently an administrator with longtime interests in the human services field, with an affinity for working with children and adults with disabilities. Kristen’s LEND project, Improving Transition Outcomes of Foster Youth with Disabilities, involved improving transition outcomes for foster youth with disabilities by piloting an expressive arts therapy project that will increase self determination for these youth through the development of individual visions for use in transition planning.

The Shriver Center Leadership Education in Neurodevelopmental and Related Disorders (LEND) program is an intensive 10-month program designed to enhance the knowledge and skills of future leaders, clinicians, and family members in interdisciplinary, family-centered, and culturally competent care of children with neurodevelopmental disabilities and their families. The program focuses on policy, legislation, leadership, and management skills; graduates are committed to improving the lives of children with developmental disabilities and their families by demonstrating excellence in clinical, scholarly, and professional disability efforts, and working as effective change agents at the program, institutional, community, regional and national levels.
**Grants Awarded**

**Linda Bandini, PhD.** Correlates of Physical Activity in Adolescents with Intellectual Disabilities, Eunice Kennedy National Institutes of Child Health and Human Development. (Period: 2009-2011).

**Journal Articles**


**Chapters & Other Publications**


**Conference Abstracts, Papers, & Invited Presentations**


Risk Management in New Zealand: Ian Axford Public Policy Fellow Alexandra Bonardi

Alexandra Bonardi, OTR/L, MHA expanded her interest in public policy by completing a six month Ian Axford Public Policy Fellowship in New Zealand. Bonardi, who also serves as Associate Director of the Center for Developmental Disabilities Education and Research (CDDER) at the Shriver Center, described her findings in a 2009 report entitled Balancing Individual Choice and Risk Management in Planning Services for People with Intellectual Disabilities. This interview looks back at her time there.

Do New Zealanders define risk management the same as Americans?

When Americans use the term “risk management,” many people may have similar definitions in mind. But in New Zealand, risk management is less likely to be accepted as a concept in human services. Instead, people may use phrases like “service planning” or “planning for the future” to convey the same idea. It can be tricky because some people may be thinking about the “risk management” concept, but it is not explicit.

Does that ever lead to problems?

It can. Many New Zealanders resent anything seen as “cotton-wooling” or government overprotection. They, like people with disabilities worldwide, want the freedom to live independent lives. But these laudable goals can cause tension, if, for example, the government feels it must ensure personal safety above all other factors. This is paralleled in the US as well.

Did you notice differences in how the US and New Zealand approach this topic?

We are very lucky to have partnerships between state provider agencies and research universities here in the US. The process can sometimes be difficult, but people recognize the benefits of working together. In New Zealand, mistrust still exists between the government, academics, and provider agencies, which limits constructive sharing of information. The ministry that oversees health and disability services is clear on the risk management goals in the health sector but less so in the disability sector. That said, some large provider agencies have developed some very progressive systems of data collection, analysis and staff training. For example, New Zealand has established a National Health Indicator, or NHI. It links data across systems to pull interesting and useful information when needed. That is extremely helpful. Here in the US, it can be frustrating when systems don’t talk to each other.

Did anything about your stay surprise you?

The issue of disability is a bit under the radar in New Zealand. The health sector seems to work in two directions, and people with intellectual disabilities are often pulled along. I was there during flu season, so the Ministry of Health was focused on managing the H1N1 outbreak, pulling people away from efforts to enhance disability supports. When I started asking about national health data for people with intellectual disabilities, it became clear that we had an opportunity to examine the data for this population—something not done before by the government.

What was most rewarding about your experience?

I considered risk management much more deeply than ever before; the subject knowledge is tremendously extensive. Working at New Zealand’s Ministry of Health was an invaluable learning opportunity and an unforgettable experience.

What is the next step in your work?

Over the past year, (2009-2010), the ministry has drafted a data report entitled Health Indicators for New Zealanders with Intellectual Disability and has asked me to participate in the peer review of the report before releasing it.

A photograph of Alexandra Bonardi, OTR/L, MHA, 2009 Ian Axford Fellow and Axford board members.
Tuesday, August 3, 2010 will go down as a landmark day for all Massachusetts residents diagnosed with autism spectrum disorders (ASDs) and their families. Thanks to a unanimous vote by both houses of the Massachusetts state legislature followed by Governor Deval Patrick’s historic signing of H.3809 (better known as “An Act Relative to Insurance Coverage for Autism,” or ARICA), Massachusetts is now the 23rd state requiring private health insurance companies to cover the diagnosis and treatment of ASDs, beginning in January 2011.

The University of Massachusetts Medical School/Eunice Kennedy Shriver Center LEND Program has a particularly special connection to this legislation; it is the brainchild of LEND alumna Amy K. Weinstock, MA who is the parent of a child with autism. Ms. Weinstock conceived of the bill in 2005 while completing her yearlong LEND capstone project that investigated national insurance policies and practices for ABA services for people with autism. She later became Chair of the Insurance Policy Committee for Advocates for Autism of Massachusetts (AFAM) where Ms. Weinstock would later enlist the expertise of three other LEND alumni, also parents of children with ASDs: Evelyne Milorin, BA (2010) who assisted with legislative advocacy in the bill’s early stages, Nan Leonard, JD, EdS, MHA, BCBA (2007) who used her legal skills to help draft the bill, and Maura Buckley, MPA (2008) who worked closely with local media to promote ARICA’s importance to children and families.

Ms. Weinstock’s tireless grassroots efforts were well timed; ARICA was actively embraced by the bill’s two main legislative champions, MA State Representative Barbara A. L’Italien and MA State Senate Majority Leader Frederick E. Bar. Ms. L’Italien is herself the parent of an adult child with an autism spectrum disorder (ASD). Momentum continued as AFAM partnered with the national organization, Autism Speaks with the assistance of another local parent and advocate, Judith Ursitti, Regional Director of State Advocacy Relations who added Massachusetts’ ARICA effort to the larger AutismVotes national push to enact autism insurance legislation in every state.

According to Ms. Weinstock, “Our bill is one of the most comprehensive of its kind; individuals with autism will have coverage for medically necessary treatment with no age caps or dollar limits. ARICA covers people with autism, because they are people with autism, whether they are 2 or 82. And the amount of treatment, just like chemotherapy and radiation for cancer patients, is based on medical necessity, not an arbitrary dollar cap.”

This collaborative effort from a host of passionate and dedicated advocates, legislators and families will make an amazing difference for honoring the civil rights of people with autism in Massachusetts, and we sincerely applaud all involved for their efforts!

For more information, please visit: http://afamaction.org/ins.html and http://tiny.cc/mdca7.