Shriver Center LEND Program Trains Leaders for the Future

With the myriad challenges and opportunities faced by individuals with disabilities and their families, there is an ever-increasing need to cultivate and train the next generation of leaders in the disability field. The Shriver Center Leadership Education in Neurodevelopmental and Related Disabilities (LEND) Program plays a pivotal role in this process.

The Shriver Center LEND Program provides graduate-level interdisciplinary training to improve the health and overall development of children, adolescents, and adults with disabilities. Trainees come from diverse professional disciplines and are prepared to assume leadership roles in their respective fields upon completion of the program. The Shriver Center is one of 43 affiliated institutions in 37 states with an established LEND Program. All LEND programs operate on five-year federal funding cycles through grant support from the Maternal and Child Health Bureau (MCHB), and must emphasize an interdisciplinary approach to leadership training as a cornerstone of their missions. A unique feature of the Shriver Center LEND Program is its dual track program that allows clinicians, other professionals, and family members to develop leadership skills in systems change and exemplary clinical service. Past LEND graduates have showcased these skills as architects of key disability-related legislation, leaders of advocacy groups, program directors, and founders of therapeutic centers, to name a few.

Advanced Leadership Fellowship Program

In this nine-month intensive academic and experiential program located at the Shriver Center in Charlestown, Massachusetts, fellows in the Advanced Leadership Program learn to radically rethink the ways in which health care, services, and supports are delivered to people with disabilities and their families. Fellows develop the knowledge, skills, and tools to make policy recommendations, support exemplary services, devise new training strategies, and lead systems change efforts.

“We accept approximately 10 fellows per academic year into an Advanced Leadership Program held here at the Shriver Center,” LEND Director Carol Curtin said. “It is a very competitive application process with more applicants than available fellowship slots. Our fellows cross all lines of diversity and experience levels, bringing their unique personal and professional experiences into the classroom,” Curtin continued. Virtually all fellows are connected to the disability field and have demonstrated leadership in some way prior to beginning the program.

The Advanced Leadership Fellowship track consists of seven “core” courses that fellows complete at the Shriver Center’s Charlestown campus before receiving a graduate certificate. (See page 7 for more specific information on the LEND curriculum). LEND fellows may also earn credit towards a Master’s Degree in Public Administration, thanks to a training partnership with the Moakley Center for Health Law and Policy.

LEND fellows meet every Friday to take part courses such “Disability Issues & the Legal Environment of Health Care” (pictured here) among others.

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Public Management at Suffolk University. (See article on page 6 for more on this collaboration).

The Shriver Center established the Advanced Leadership Fellowship track in the late 1990s, after seeing a need to expand beyond the clinical training program that previously existed. Dr. Kass Braden, who was the LEND Director at that time, recalled some early challenges: “There was much discussion among the faculty about exactly how to define leadership … Everyone agreed it was important, but could it be defined well enough to be taught in a classroom?” Braden recalled. “Gradually, we developed a curriculum, and established an academic partnership with Suffolk University to help provide credentials for the program. Integrating a common theme of leadership throughout several courses enabled us to approach the topic from different perspectives,” she elaborated.

Lee Vorderer, MA, a longtime LEND faculty member with a background in Special Education. She assisted in adding the leadership component to the curriculum, explaining, “It became clear that we could not expect the world to change its direction or priorities concerning individuals with disabilities simply by preparing clinicians to provide excellent interdisciplinary clinical care. We also had to include in the discussion an awareness of what was happening in the disability field, along with examining research findings that allowed for developing systemic solutions to ongoing problems. That philosophy remains a guiding principle of our LEND program today,” Vorderer said.

To date, 157 fellows have been trained in the Advanced Leadership Fellowship program. When asked how she gauges whether an applicant will succeed, LEND Director Curtin emphasized the importance of goal orientation. “Prospective fellows should have a clear idea of what they want to accomplish by participating in the LEND program. Coming into the program with a vision provides them with a focus in the program, and also demonstrates to us that they are committed to seeing their ideas through,” Curtin said. Vorderer agreed with Curtin’s assessment.

“The LEND program is about much more than simply accepting fellows. It’s about taking one’s vision and moving it forward in ways that work.”

**Leadership in Interdisciplinary Clinical Care Program**

The Leadership in Interdisciplinary Clinical Care Program supports and provides interdisciplinary clinical training to individuals at the Masters, Doctoral, and Post-Doctoral levels of study at two locations. One is located at the UMSS Medical School/UMass Memorial Health Care Center campus in Worcester. The second can be found at the Center for Children with Special Needs (CCSN), located at the Tufts Medical Center’s Floating Hospital for Children in Boston.

The UMSS Medical School Leadership in Interdisciplinary Clinical Care Training program provides interdisciplinary training of students, residents, and fellows from a number of disciplines. The length of training varies between one to six months, depending on the trainee’s current position in his or her academic program. Trainees represent the disciplines of Family Medicine and Community Health, Child Psychiatry, Pediatric Neurology, Pediatrics, Developmental Behavioral Pediatrics, Occupational Therapy, and Psychology. In addition to training on the Worcester campus, some training is conducted at the UMass Medical School-E.K. Shriver Center campus in Charlestown for master’s level Nutrition students.

LEND Clinical Training Coordinator for the Worcester training programs, Sue Swanson MA, CCC-SLP, notes that the positive feedback they have received from Child Psychiatry fellows “affirms that the LEND interdisciplinary clinical training is an invaluable part of their clinical experience and one that has significantly impacted how they provide services to children with neurodevelopmental disabilities and their families,” Swanson said. As an alumna of the Shriver Center LEND program herself, Swanson understands firsthand its importance and impact. “There is no question that my LEND training has supported my current...
Our fellows cross all lines of diversity and experience levels, bringing their unique personal and professional experiences into the classroom... virtually all students are connected to the disability field and have demonstrated leadership in some way prior to beginning the program.

work as the LEND Training Coordinator and clinical instructor.” Swanson stated. “Specifically, the LEND fellowship allowed me to develop a unique skill set that I have been able to use when collaborating with others in improving clinical services delivery, health care service, and community-building for children with neurodevelopmental disabilities. My teaching at UMass Medical School and my clinical work within the new Center for Autism and Neurodevelopmental Disorders (CANDO) clinic is the direct result of my LEND fellowship training,” Swanson elaborated.

The Center for Children with Special Needs (CCSN) at The Floating Hospital for Children, Tufts Medical Center in Boston is another interdisciplinary clinic that provides family-centered, culturally competent care for children and their families and trains its clinical trainees to assume leadership roles in their work. Trainee disciplines include: Child and Adolescent Psychiatry, Child Neurology, Developmental-Behavioral Pediatrics (DBP), Education, Family Medicine, Neuropsychology, General Pediatrics, Psychology, Speech-Language Pathology and Social Work. Trainees also include medical students from the Tufts University School of Medicine as well as graduate and undergraduate students from Tufts University. On any given day there may be individuals from other academic institutions or even other countries.

“One of the things that makes CCSN unique is the interaction of individuals across both disciplines and training levels; that is, people currently in pediatric practice may work closely with undergraduates in college,” Training Director Karen Miller, MD explained. “Everyone is given a role to assist in the clinic according to their level. This benefits all learners because it provides exposure to different perspectives and approaches rather than allowing trainees to remain isolated in their one particular discipline or specialty,” Dr. Miller elaborated.

Learning at CCSN takes place in several formats, including didactic instruction, teaching clinics, seeing patients with a variety of clinicians, and community-based educational activities such as observing at facilities for children with different disabilities, local schools, and Early Intervention programs. In addition, CCSN accepts one fellow in Developmental-Behavioral Pediatrics (DBP) per academic year for a three-year term. In their third year, that DBP fellow joins the Shriver Center LEND Advanced Leadership Fellowship Program to expand their knowledge of disability issues and policy. “We train DBP fellows to become leaders in the field at all levels including clinical research and advocacy for patients with developmental disabilities regionally and nationally,” Dr. Miller said.

Dr. Kass Braden was instrumental in creating the CCSN partnership in 1998 through her previous roles as the CCSN’s Medical Director. Braden elaborates, “Dr. Miller and other faculty at CCSN have done a wonderful job of bringing together masters and doctoral-level clinical trainees from a variety of disciplines, along with the residents and fellows in Pediatrics, Family Medicine, and other medical disciplines. Their work has helped significantly in the development and sustainability of a truly interdisciplinary training program.”

Moving into the Future

It is fitting that this issue discusses the evolution of the Shriver Center LEND program just as several key LEND faculty transition from the program. Jim Gleason, MS, PT, retired in summer 2014 before passing away in March of 2015 after a long illness. (See page 12 for more information on Gleason’s life and career). Kass Braden, MD retired in the fall of 2014. Lee Vorderer, MA will retire at the end of the 2015 academic year. LEND Director Carol Curtin spoke about the impact of these transitions in the faculty, as well as the future of the program. “It is never easy to see people leave who have such deep experience in their respective fields. Kass, Jim, and Lee have left a huge imprint on our program and we are extremely proud of their contributions to the program and their legacies. Leadership is always evolving, just like the policies and concepts covered in our courses. We will maintain the strong foundation that Kass, Lee, and Jim helped us build as our program continues to grow. By combining that foundation with the perspectives of new faculty and the continued support of our clinical partners at UMass Medical School and CCSN, I am confident we will continue our mission of training future leaders in the disability field,” Curtin said.

This year the Advanced Leadership Fellowship program welcomed three new faculty members: Alexandra Bonardi, OTR/L, MHA (a LEND alum herself), Philip Chase, PhD and Richard Robison, D.Min. The Leadership in Clinical Care program also welcomed Roula Choueiri, MD, the new Chief of Developmental–Behavioral Pediatrics at the University of Massachusetts Medical School in Worcester. Dr. Choueiri was previously at the CCSN at Tufts. These new faculty members bring a wealth of experience and expertise to the program’s curriculum.

We train DBP fellows to become leaders in the field at all levels including clinical research and advocacy for patients with developmental disabilities regionally and nationally,” —M.Y. (Class of 2002)
LEND Alumni Reflections on LEND’s Professional Influence

For every fellow, the LEND journey is a highly individualized and personal one. Typically, the LEND experience lays a foundation for professional success and advancement long after a fellow’s time in the classroom has ended. Over the years dozens of LEND fellows have been trailblazers in their respective fields supporting people with disabilities to lead healthier, more engaged lives in the community. Whether becoming university faculty, public administrators in local and state government, founders and directors of non-profits, leading health care clinicians, professional journal editors, philanthropic foundation managers, or myriad other leadership experiences in Massachusetts and beyond, LEND graduates are using their education and training to change systems and deliver high-quality impact.

The following four alumni highlight some of the diverse learning and experiential interests and outcomes for LEND fellows.

Kristie Hubbard (LEND Class of 2012)

Helping to Eliminate Health Disparities

Kristie Hubbard, PhD, MPH, RD, was a doctoral candidate at the Friedman School of Nutrition Science & Policy at Tufts University when she participated in the LEND program in 2011-2012. Her goal entering the program was to expand her research on nutrition to include children with disabilities. “LEND came along at a perfect time because it allowed me to get more of an in-depth focus on the life experiences of individuals with disabilities prior to specializing in just the nutrition aspects,” Hubbard explained.

Currently a member of the U.S. Department of Agriculture’s Food and Nutrition Services, Hubbard reflected on her experience stating, “A true strength of the LEND program is that you focus more on developing solutions to problems rather than just realizing that problems exist. In that way, I am now better equipped to serve as an advocate for individuals with disabilities, and I am truly grateful for that.”

Diane Maxson (LEND Class of 2004)

Making a Difference for Children with Special Needs

Prior to LEND, Diane Maxson, MS, MHA, OTR had worked for more than 10 years in the public school system as an occupational therapist. “I knew that there were kids who needed additional therapy services beyond what the school system could provide, or was required to provide. However, there was no access to those services in the community.” To address this gap, she decided while in the LEND program to create a business plan for a company she had been imagining to provide a wide range of services to help children and families function at their best.

By virtue of this critical LEND activity, Maxson was able to open the Therapeutic Learning Center (TLC) in Canton just three months after her LEND graduation. Maxson credits faculty at the Shriver Center LEND Program and their colleagues at Suffolk University for helping her vision come true, “They really made me see that such an idea was possible.”

Julie Moran (LEND Class of 2006)

Advancing Aging Concerns of Individuals with Disabilities

Julie Moran, DO, had an interest in aging and developmental disabilities when she participated in the LEND program and “thought that the fellowship could enhance my training [to] specialize in this field and broaden my knowledge about intellectual disability in general. There’s currently no...
“Over the years dozens of LEND fellows have been trailblazers in their respective fields supporting people with disabilities to lead healthier, more engaged lives in the community.”

formal training available for people who want to specialize in treating adults with intellectual disabilities; it's entirely a homegrown operation.”

Moran currently serves as Director for the Aging and Developmental Disabilities Program, an outpatient consultation service supported by the Department of Developmental Services and based in Tewksbury and Worcester. She explains, “The common theme I address is change as a function of aging. Change may occur in memory, function, behavior, mood, or a combination of these factors.” LEND was an important part of the development of Moran’s specialty. Her focus on aging and disability is unique and her support for families makes a meaningful impact.

**Teresita Ramos (Class of 2011)**

*Providing legal services to low-income, immigrant Hispanic children with disabilities*

Teresita (“Tere”) Ramos, Esq., originally from Puerto Rico, is the parent of a daughter with special needs and has spent the last decade as a community activist on behalf of children with disabilities. She previously founded a special education and disabilities advocacy organization focused on the Hispanic community. During her LEND year, Ramos explored “the current early intervention model in Massachusetts and whether it would be feasible to change the way services are provided for children 0-3.”

Following LEND, Ramos attended Boston College Law School, earned her law degree, and was recently awarded an Equal Justice Works Fellowship hosted by the Disability Law Center in Boston. Her current work addresses widespread denial of education rights and empowers parents to enforce their rights through culturally competent advocacy training. In particular, she represents the legal needs of children from Hispanic communities who have disabilities. Reflecting on the benefit of her LEND studies, Ramos notes “LEND was the perfect preparation for my legal work. It helped me understand the history and current challenges in the disability community, as well as how to be more culturally competent to understand the different needs based on the disability as well as the cultural heritage of the individual.”

“A Life-Changing Experience That Creates Lifelong Connections

Each of these alumni also stressed the importance of maintaining a connection to the LEND program after their graduation, noting that it can lead to increased professional opportunities as well as outside growth. “The camaraderie of the LEND program is what I will remember more than anything,” Moran said, adding that she still keeps in touch with several members of her class to this day.

Maxson agreed, “I use my LEND connections all the time; you never know when they might be needed. Even just referring a busy parent to additional resources another fellow has access to can be useful.” In fact, she has hired other LEND alumni to work at TLC.

All four fellows wholeheartedly recommend the program. “It was life-changing and broadened both my thinking and future plans,” Hubbard concluded. Maxson agreed and said, “It was one of the best decisions I ever made. I encouraged one of my staff to pursue it, but this year’s class was filled.” Moran agreed, “The faculty were exceptional, and really brought individual skills and a collaborative spirit to everything we did. The LEND program is beneficial regardless of your goals.”

Ramos summed it up, saying “what is unique about LEND is the interdisciplinary nature of the program. There is no other program of its kind for anyone hoping to work with the disability community.”

“LEND was the perfect preparation for my legal work. It helped me understand the history and current challenges in the disability community, as well as how to be more culturally competent to understand the different needs based on the disability as well as the cultural heritage of the individual.”

**A true strength of the LEND program is that you focus more on developing solutions to problems rather than just realizing that problems exist.”**
Suffolk University Partnership Combines Academic Structure and Practical Experience

For about half of the fellows enrolled each year in the Shriver Center Advanced Leadership Fellowship program, their classroom extends far beyond the reaches of the Shriver Center’s Charlestown offices. Thanks to an ongoing partnership with nearby Suffolk University located in Boston, Advanced Leadership fellows may elect to take part simultaneously in Suffolk’s Masters in Public Administration (MPA) program with a concentration in Disability and Health Policy by applying credits earned during their LEND year as partial fulfillment toward that degree.

The partnership between Suffolk University and the Shriver Center came about by mutual agreement in 1999 when the Advanced Leadership Fellowship program was conceived. The first class of 10 fellows began at the Shriver Center in the fall of 1999. Of those ten, three enrolled at Suffolk towards what was then a Master’s in Health Administration (MHA) Degree. Since then, approximately five fellows enroll in the Suffolk MPA program each year.

Marie “Sandy” Matava, MPA is the Director of the Moakley Center for Public Management at Suffolk University and coordinates the Suffolk-Shriver Center LEND partnership, in addition to teaching in the program. Matava was part of the initial group who conceived of the idea of a partnership along with Shriver Center faculty member Lee Vorderer, DPA, ACSW, a professor in the Healthcare Administration Department at Suffolk University, who recently stepped down as Chair of the University’s Institute for Public Service.

“Everyone involved in helping to develop the Shriver Center LEND-Suffolk partnership already knew each other from previous employment. Since the funders were looking for a greater focus on leadership and professional credentials, we came up with the idea to include the academic, degree-oriented aspect of Suffolk with the more specific concept of a disability-centric leadership program at the Shriver Center. Once that idea formed, everything came together fairly quickly,” Matava remembered. “For a long time, Suffolk had the only combined Disability Studies and Public Management Program in the world. That was still the case when a partnership with the Shriver Center was first discussed, and it seemed like a natural fit given their establishment in disability education, research, and training. The partnership has worked out beautifully ever since,” Beinecke agreed.

When asked how the partnership has evolved over time, Beinecke credited the increased strength of academic coursework and the varied backgrounds fellows bring concerning disability. “It is usually very easy to tell when the LEND fellows appear in our MPA classes. They already have a connection to and passion for disability issues, and they bring that perspective to the coursework here as well. The academic workload here is slightly less intimidating to them as well, since they are already exposed to it,” Beinecke elaborated.

Shriver Center faculty member Lee Vorderer, MA agreed, citing the passion LEND fellows show and harness by participating in both programs. “We emphasize the importance of being able to write well, give effective presentations, do substantive research, and connect with individuals. At the conclusion of the program, fellows should be able to discuss disability-related concerns and issues with any size and type of audience, be it professionals, parents, or students. Fellows should leave our program knowing what they want their next step to be,” Vorderer said.

Matava agreed, stressing that the partnership also allows Shriver’s LEND fellows the opportunity to step outside their own perspectives and see things in a broader view. “Since disability is such a personal thing to everyone affected by it, it is easy to focus on only being around like-minded people. But really, disability can’t always be about the personal. You need to be able to put the issue of disability in effective context to truly make an impact,” Matava said. “Getting an MPA degree from Suffolk may not make someone a better speech therapist, for example, but it will enable them to better manage their speech therapy clinic.”

Likewise, Vorderer also credited Suffolk University with playing a critical role in the continued success of the Shriver Center LEND program. “On one level, Suffolk provides the academic infrastructure. That is an immense help, particularly when our fellows want to apply their coursework here toward an MPA degree. In addition, however, Beinecke and the other Suffolk LEND faculty are still on the ground making tangible differences on disability issues and not simply teaching about them,” she elaborated.

Elaine Gabovitch, MPA, Shriver Center LEND alum and current faculty member reflected on the importance of receiving her MPA through the Suffolk program. “I come from a family where not everyone attended college, so having the opportunity to both become a LEND fellow and earn an advanced degree was truly a life-changing experience for me,” Gabovitch explained. “Everyone’s circumstances are different, but I hope prospective LEND fellows realize how valuable this partnership with Suffolk can be. I often say that the LEND curriculum content is the indisputable core but the skills and experience gained through Suffolk courses are the toolkit to turn the learning into practice. It’s a powerful combination.”
"Getting an MPA degree from Suffolk may not make someone a better speech therapist, for example, but it will enable them to better manage their speech therapy clinic."

The Advanced Leadership Fellowship Curriculum

Over the course of the LEND year, all fellows must complete seven core courses offered at the Shriver Center's Charlestown campus. LEND fellows who successfully complete all seven courses receive a LEND Certificate. In addition, all fellows have the option of obtaining a graduate Certificate in Disability and Health Policy or may also earn a Master's in Public Administration (MPA) degree with a focus in Disability and Health Policy through Suffolk University by completing the coursework offered at the Shriver Center and additional coursework offered on the Suffolk Campus.

The Shriver Center LEND CORE curriculum (required for all fellows)

The United States Health System
Fellows are introduced to the major health issues and institutions in the United States with a focus on home health services, Medicaid/Medicare, managed care, medical home, integrated service delivery systems, and other health care changes.

Disability Issues and the Legal Environment of Health Care
This course provides an evaluation of the legal processes, public policies, and social issues that affect persons with developmental disabilities and their families.

Disability and Public Policy: Expanding Access
This course provides an opportunity to evaluate and understand many aspects of public policy and social issues that affect the lives of persons with developmental disabilities and their families.

Disability Informatics
Fellows consider how technology provides leaders extensive access to a rich array of information resources and many choices about how to communicate with their colleagues and the individuals they serve.

Family & Community Perspectives
Fellows participate in and learn about the day-to-day concerns of children, youth and adults with disabilities and their families and learn to apply concepts of family-centered care and cultural competence in their work.

MCH Leadership Capstone Project
LEND fellows explore an issue of their choosing by addressing an important need in the Maternal & Child Health or disability field. This is accomplished through a series of assignments designed to build skills in planning for the implementation of a strategic leadership project.

Strategic Leadership
Fellows examine and apply principles of leadership and management and self-reflection in order to expand their own and others' effectiveness.

Additional Required Courses for Fellows enrolled in the Suffolk University MPA Program

Foundations of Public Service Organizations
This course provides an overview of the field of public administration; the structure, functions, and processes of government organizations at various levels—federal, state, regional, and local—are examined.

Policy Analysis and Program Evaluation
Fellows explore how public programs and policies can be made more responsive, efficient, and effective through the use of social science research techniques and measurement of programmatic outcomes.

Quantitative Analysis
Fellows build upon the basic statistics and research designs established in Policy Analysis and Program Evaluation.

Nonprofits in the Community
Fellows learn to recognize organizational constituencies and learn to make the appropriate action decisions toward the maintenance of good community relations and mission achievement for non-profit and other public service organizations.

Managing Human Resources
This course offers a comprehensive approach to the study of Human Resource Management in the public and private sectors.

More information about the LEND core curriculum is available at shriver.umassmed.edu/programs/lend.
Faculty in the Advanced Leadership Fellowship Program

The Shriver Center is fortunate to have a well-rounded and dedicated interdisciplinary faculty leading and instructing in the program. The following faculty taught in the program during the 2014-2015 academic year.

**Alexandra Bonardi, OTR/L, MHA**
Clinical Assistant Professor, Department of Family Medicine and Community Health, UMMS.

*Research & Professional Interests:* Trends and patterns in health service utilization by individuals with developmental disabilities, health promotion for people with developmental disabilities, access to health services for people with intellectual disability and mental health or behavioral health concerns, adaptive equipment and technologies that enhance independence.

**Phillip N. Chase, PhD**
Professor, Department of Psychiatry, UMMS; Adjunct Professor, Simmons College; Director, Child and Adolescent Needs and Strength (CANS) Program.

*Research & Professional Interests:* Instructional design, acquisition of novel behavior, verbal behavior.

**Carol Curtin, MSW**
Interim Executive Director, UMMS Eunice Kennedy Shriver Center; Director, University Center for Excellence in Developmental Disabilities (UCEDD); Director, Leadership Education in Neurodevelopmental Disabilities (LEND) Program; Co-Director, Clinical and Translational Research Support Core of the UMMS Intellectual and Developmental Disabilities Research Center (IDDRC); Co-Director, Healthy Weight Research Network; Research Assistant Professor, Family Medicine and Community Health, UMMS; Lecturer in Pediatrics, Tufts University School of Medicine; Adjunct Professor, Department of Public Management, Suffolk University.

*Research & Professional Interests:* Obesity in special populations; physical activity, dietary patterns, and/or obesity in children with developmental disabilities; leadership training; family-centered care.

**Linda M. Long-Bellil, PhD, JD**
Project Director, Assistant Professor, Center for Health Policy & Research, UMMS.

*Research & Professional Interests:* Employment, health and disability.

**Richard Robison, D.Min**
Executive Director, Federation for Children with Special Needs.

*Research & Professional Interests:* Non-profit management, family support, special education policy and advocacy, disability awareness.

**John Rochford, MS**
Director, INDEX Program; Director of Technology, UMMS Shriver Center; Instructor in Family Medicine and Community Health, UMMS.

*Research & Professional Interests:* Web accessibility for people with disabilities, especially cognitive disabilities; instructional design of online courses and learning-management systems; improving the use of technology by people with intellectual disabilities; application of information technology in human services.

**Elaine M. Gabovitch, MPA**
Director, Family & Community Partnerships, LEND and UCEDD Programs; Family Faculty, LEND Program; Instructor, Family Medicine & Community Health, UMMS; Adjunct Professor, Department of Public Management, Suffolk University; State Team Leader, Massachusetts Act Early campaign; CDC Ambassador to Massachusetts, “Learn the Signs. Act Early.” Program.

*Research & Professional Interests:* Early identification of autism and other developmental disabilities, transition to adulthood for youth with special needs, family-centered care, community-based participatory research, cultural competence, health promotion.

**Partners at the Frank Sawyer School of Management, Suffolk University**

**Susan Crossley, MPA**
Adjunct Professor, Suffolk University.

*Research & Professional Interests:* Nonprofit management, creating community housing of choice.

**Lauren Hajjar, MS, MPA, PhD Candidate**
Brandeis University; Senior Fellow, Moakley Center for Public Management at Suffolk University.

*Research & Professional Interests:* Behavioral health, organizational change and development, adoption of evidence-based practices within public sector organizations.

**Marie M. (Sandy) Matava, MPA**
Suffolk-Shriver LEND Program Liaison; Director, the Moakley Center for Public Management; Instructor of Public Administration, Clinical Assistant Professor, Institute for Public Management, Suffolk University.

*Research & Professional Interests:* Human services management, HIV/AIDS services, public policy analysis, nonprofit strategic analysis and planning, client and community relations.

**Nicole Rivers, MPA**
Associate Director, the Moakley Center for Public Management, Adjunct Faculty, Institute for Public Service, Suffolk University.

*Research & Professional Interests:* City planning, program evaluation, strategic planning, organizational development.
The LEND Program’s Anchor: Administrative Assistant Carol Imposimato

It was the spring of 1969 when a newly minted graduate from Aquinas Junior College, Carol Imposimato arrived at the Shriver Center campus in Waltham, Massachusetts dressed in the fashion of the time: a starched pink suit with gold buttons and pristine white gloves, holding a resume carefully encased in plastic for an interview that would change her life. Forty-six years later, Carol is not only one of the longest-standing employees at the Shriver Center, but she is the steady anchor of the LEND program coordinating all the administrative aspects of the program and keeping things flowing smoothly since it began in 1999-2000.

Over the years, Carol has witnessed the growth of the center through several administrations, withstood the turbulent times for the disability civil rights movement and deinstitutionalization in the 70’s and 80’s, and helped run a range of continuing and new programs that also changed and grew with the times. She started out briefly as an administrative assistant during some of the darker days at the Walter E. Fernald School, the oldest institution for people with intellectual disabilities in the U.S., where one of her first tasks was the difficult job of transcribing tapes for an internal investigation that documented the sexual abuse of many residents. By fall 1969 when the Shriver Center officially opened for business, Carol was transferred to Shriver to support the interdisciplinary teams for the next 30 years in the Center’s Evaluation Clinic with such groundbreaking physician researchers as Drs. Margaret Bauman, Thomas Kemper, and Josephine Kety. By 1999, Carol began working as an administrator for the LEND program alongside recently-retired LEND Director Kass Braden, MD and the rest of the LEND faculty. Here, she became the essential cog in the wheel, playing an integral role in providing support for fellows throughout the year on administrative, logistical, and day-to-day issues, meeting faculty’s needs to keep their courses humming, and always grasping LEND activities through her expert coordination and event planning.

Carol remarked recently that her fondest memories are of the LEND fellows, their families, and the faculty over the years as the highlights of her work. She recalled the rush of recruitment activities at the start of each year with new candidates and the steady stream of supports she provided to both fellows and faculty throughout. End of the year graduation planning has always been a specialty of Carol’s, since she “…love(s) a party.” To that end, she personalizes the day with all the right touches to wrap up the year. She particularly enjoys meeting the families whom she has heard so much about over the year, watching how proud they are of their loved ones on that special day. Recalling memories of her Shriver Center LEND colleagues, she commented that she remembers their kindnesses most. “Through good times and bad times, we got each other through. That’s been the whole thing for me since 1969 – the friendships are what count. People here really care.”
Shriver Center Advisory Council Member Evelyn Hausslein Brings Family Perspective to LEND Class

Evelyn Hausslein, M.Ed., MMHS, has served as a longtime family mentor for the Family & Community Perspectives course in the Shriver Center LEND Program. Hausslein offers decades of experience as a parent and professional. She is the mother of three adult children, including a son, Tommy, who has an intellectual disability and cerebral palsy. She is Faculty Emeritus as former Dean of the Wheelock College Graduate School and former founding director of the Early Intervention Training Centers at the Federation for Children with Special Needs (FCSN) among her many other professional accomplishments. Hausslein is a valued member of the Shriver Center’s Consumer Advisory Council (CAC) in addition to her role as a mentor. She recently shared details about her involvement in both of these activities.

Q: Why do you believe it is important to be a mentor for the LEND Fellows?
A: When Tommy was born (he is 47 now), many people around my husband and me felt we must be experiencing regret and guilt over having a child with a disability. We felt many emotions, but never regret. As a mother, it’s important for me to show the fellows that families can survive a diagnosis of disability, and while it will unquestionably change their lives, it does not have to take over their lives. I also require the fellows to meet Tommy where he lives, so they can get to know him and observe his interactions, challenges, and routines.

Q: What do you enjoy most about mentoring the LEND Fellows?
A: Everyone that I have worked with over the years has been bright, articulate, and truly interesting. Family Faculty Elaine Gabovitch does a wonderful job stressing the importance of understanding family connections and dynamics. It also helps that the fellows receive background in disability policy and history, which can be hard to encapsulate beforehand. I have great admiration for the Shriver Center LEND program and serving as a mentor is a wonderful experience.

Q: From your role on the CAC, what makes the Shriver Center unique?
A: In my experience, many institutions that focus on disability have a relatively broad view of the term and don’t always have specific ideas or interventions in mind to try and assist individuals with disabilities. That is not the case at the Shriver Center, particularly when it comes to the “Health U” healthy eating and nutrition program or the Shriver Center’s work in the field of emergency preparedness. Both of these areas are consistently topics of discussion among my parent, professional, and personal contacts because they are issues we worry about. It is good to have somewhere to go for quality, relevant information on these topics.

Q: As a CAC member, what areas would you like to see the Shriver Center pursue next?
A: I think it would be beneficial to look at individuals with disabilities and their relationships and interactions with the elderly. My son Tommy’s employment situation includes individuals with disabilities, some elderly individuals, and staff. That is oftentimes the case for other individuals with disabilities as well. Those interactions can be very challenging on both sides, particularly because many people who are now elderly grew up in a time when the outlook and expectations for individuals with disabilities were much different. Tommy and another gentleman almost lost their jobs at the job site because co-existing with each other became difficult. Perhaps there are additional issues or research the Shriver Center could examine in those areas.

“Much of my knowledge of developmental disabilities and healthcare systems in the U.S. are due to the training I received in the LEND program. I have used that knowledge in all of my maternal and child health and leadership endeavors since. The training I received was great.”
— J.F. (Class of 2013)
“As a mother, it’s important for me to show the fellows that families can survive a diagnosis of disability, and while it unquestionably changes their lives, it does not have to take over their lives.”

What it Takes to Be Part of a Family: Mentor Family Keeps Nine Siblings Together Through International Adoption

Over a ten year period starting in 1998, Michelle Novelle, PhD set out on a mission to keep a family of Colombian siblings together who had been abandoned and left to raise and care for each other as very young children. Three at a time, she adopted the children and brought them from Colombia to her home in Roslindale where she and her husband provide the structure, sensitivity and love to help them learn how to be a family without the previously strong foundation provided by consistent, early human relationships. Two of the siblings have autism, one intensive and the other mild; most of the other children have acquired learning disabilities due to early childhood trauma.

Eight of the nine siblings are on Individual Education Plans (IEPs) at school. In addition to her significant responsibilities as a parent, Novelle also teaches and conducts university-level research and continues to visit orphanages in South America now as part of her work. Her research interests include the concept of “social orphans,” that is, children who live outside parental care despite the presence of at least one living biological parent. She has studied how social orphans experience “ambiguous loss,” an emerging concept characterized by the lack of closure and its resulting trauma.

The Novelle family's compelling and profound history has served as fertile ground for Shriver Center LEND fellows mentored by the entire family as a critical part of the Family & Community Perspectives Course. Novelle recently discussed her experience with us and talked about what she imparts to the fellows.

Q: What do you hope to show or teach the fellows during your time together?
A: All too often, I feel a disconnect exists between what someone can learn as part of a course, and what practical experience actually shows them. I've worked with four fellows so far, one per year. By taking part in the program, I help a new group of professionals understand specific challenges and daily issues faced by families of individuals with disabilities.

It's important to me that fellows understand the balancing act done by families of individuals with disabilities in a truly non-judgmental, empathetic way. For example, if my child with more severe autism has an appointment scheduled during something he looks forward to, that will likely cause irritability and mood swings for a day or more after the appointment. It is likely to result in tantrums and often unsafe behavior due to his acting out. So, is it essential to have the appointment that day or can I re-schedule?

Q: What's your biggest “takeaway” message to the fellows who have learned from your family?
A: When thinking about adoption and foster care, it’s important to remember that any child who has been abandoned or adopted has a history. Each person's story is different. If you’ve been abandoned, you’ve experienced trauma and loss. This may result in relational disorders with behaviors that should not be pathologized and “fixed,” but rather require teaching how to tolerate loss and its ambiguity for immigrant adoptive children. The struggle comes when you haven’t had a family, learning how to become a member of one. For example, one of our children was the primary caretaker until she was five years old. So that became her identity. Rather than strip her of that role, we take the attitude that she knows best, but gently offer to “take a break and we’ll help you get there.” We are all in this together.

Q: How does having two of your children on the autism spectrum impact your views on disability?
A: There is a widespread perception that a diagnosis of autism is always something sad or must be seen as a burden. That’s just not true. It’s definitely challenging, but my sons’ diagnoses of autism have made me see the world more like they do, which is truly a good thing.
Shriver Center faculty and staff are deeply saddened by the passing of Jim Gleason, MS, PT on March 8, 2015 after a three-year battle with cancer. We dedicate this issue to him.

Gleason came to the Shriver Center in 1987 after receiving his Master’s Degree in Physical Therapy from the Sargent College of Health & Rehabilitation Sciences in 1982. He retired from the Shriver Center in August 2014 after a 27-year career. Gleason initially served as Director of the Physical Therapy program for the Shriver Center LEND program, a position that meant providing clinical services to children with disabilities during the Center’s years as a clinical site. Beginning in 1990, he assumed the position of Associate UCEDD Director, and through that post collaborated with other colleagues to help shape the long-term goals and objectives of the Shriver Center UCEDD. In 2001-2002, Gleason participated in the strategic planning effort that resulted in the UCEDD’s focus on health promotion, physical activity, and nutrition for people with IDD, and participated in programs and projects that grew out of this strategic plan. These activities led to numerous publications and presentations on the topic both nationwide and internationally.

As the Shriver Center developed its Advanced Leadership Fellowship component of the LEND program, Gleason served as a faculty member, continuing his longtime interest in health and disability policy. He co-taught three classes with colleague Lee Vorderer: U.S. Health Systems, Disability Issues and the Legal Environment of Health Care, and Disability and Public Policy: Expanding Access. He also served as an adjunct professor in the Department of Public Management for Suffolk University and regularly guest-lectured there, as well as at Rhode Island College earlier in his career.

Just as importantly however, Gleason assisted individuals with disabilities outside of his work at the Shriver Center. He developed a longstanding relationship with Ironstone Farm by serving on its Board of Directors for its Challenge Unlimited program. The program uses horseback riding as both a therapeutic tool and recreational outlet for individuals with disabilities and their families. Since his passing, Ironstone Farm established a memorial scholarship in Gleason’s name that will provide funding for more individuals with disabilities to take part in this program.

Occasionally, Gleason’s work took on an international flair, as it did when he began an association with Special Olympics International’s Healthy Athletes program in 2004, a program that conducts a variety of health screenings for Special Olympics athletes at events in the United States and abroad. Gleason attended the opening ceremonies of the 2007 games in Shanghai, China, and also held several “Train the Trainer” workshops emphasizing how to successfully gather and interpret findings from these screenings throughout his tenure with the program.

Away from his professional responsibilities, Gleason also had several longtime passions. They included spending time with family and friends, gardening, cycling, fishing, genealogy, and a deep love for Irish music and culture. The latter saw him take part in several Irish bands over the years, most recently with the Stoneybatter Band, and provided memorable moments whenever and wherever he played. Faculty and fellows alike regularly attended his performances with great admiration for his talents.

Gleason’s career at the Shriver Center exemplified its overarching mission to improve the quality of life for individuals with disabilities and their families through education, research, and service. He represented the best of the LEND and UCEDD programs, and left an important legacy that will never be forgotten. The Shriver Center faculty and staff extend our deepest condolences to his family and friends.
“Through good times and bad times, we got each other through.”— Carol Imposimato
Emily Lauer, MA, Appointed Interim Director of CDDER

The Center for Developmental Disabilities Education and Research (CDDER) located at UMass Medical School–E.K. Shriver Center is pleased to announce Emily Lauer, MPH as its new Interim Director, effective September 2014. Lauer has been associated with CDDER for over 10 years, working on multiple projects including CDDER's long-standing Interagency Service Agreement (ISA) with the Massachusetts Department of Developmental Services (DDS).

Former CDDER Director Alixe Bonardi, MS, MHA, OTR/L will remain at the Shriver Center part-time to focus on her previous grant-funded projects and to serve as a faculty member in the LEND program. Bonardi will also serve as principal investigator (PI) on a two-year R21 grant from the Agency for Healthcare Research & Quality (AHRQ). Entitled A Deliberative Approach to Develop Autism Data Collection in Massachusetts, the grant will develop guidance for the Massachusetts Executive Office of Health and Human Services (EOHHS) on priorities for autism data collection, management and use from the perspective of the autism community. A “citizen’s jury” that includes individuals on the autism spectrum and other stakeholders will deliberate on the complex issues related to use of data for the purpose of coordinating support, improving research, and the issues of privacy and confidentiality of personal data. The outcome of this work will be a set of priorities for use when developing an integrated autism data system in Massachusetts. CDDER will partner with the nationally recognized Autism Self Advocacy Network (ASAN), as well as the Jefferson Center on this project.

Emergency Preparedness and Response Expands Training Available Through Online Simulation

Building on a successful Phase I project to design prototype online simulation-based modules to teach effective emergency planning and response for and with individuals with disabilities, Shriver Center and Praxis, Inc. researchers are embarking on Emergency Operations for Individuals with Disabilities (EOPD), Phase II, to develop a complete, commercially available course.

Funded by a National Institutes of Health (NIH) Small Business Technology Transfer (STTR) grant, #2R42HD069070-02, Phase II will expand upon the kinds of disabilities previously covered and develop new simulated scenarios to sharpen Emergency Medical Services (EMS) personnel skills regarding 1:1 interaction and communication with people with disabilities. EMS personnel can serve as a bridge between first responders and healthcare “first receivers.” Expanding EMS capabilities will enhance equitable and efficient response, augment emergency health services, and strengthen resilience for the whole community.

Shriver Center and Praxis, Inc. project team members include Charles Hamad, Ph.D. (PI); Janet Twyman, Ph.D., (Co-PI); Sue Wolf-Fordham, J.D., Project Manager; Christophe Gerard, Ph.D., Director of Technology; Harold Lobo, Ph.D., Instructional Designer; and Jennifer Brooks, B.A., Recruitment Coordinator.

“Snapshot” provides brief, periodic updates designed to detail new and ongoing projects, announce changes, or highlight achievements among the various departments at the Shriver Center.

Amy Weinstock, MA Represents Autism Insurance Resource Center on the Massachusetts Autism Commission

Amy Weinstock, MA, current Director of the Autism Insurance Resource Center was recently appointed to one of the 35 seats on the new Massachusetts Autism Commission. The Commission was created as a result of the passage of the Autism Omnibus Bill by the Massachusetts legislature in the summer of 2014. The Autism Commission will be located within the Massachusetts Executive Office of Health & Human Services, but will remain independent. The Commission’s primary focus will involve making policy recommendations on issues of importance involving individuals diagnosed with autism spectrum disorders (ASD), and investigating the range of services and supports necessary for and available to these individuals to achieve their full potential.

The AIRC’s primary function is to assist consumers and families who have questions or are looking for useful resources concerning the implementation, coverage, and specifics of the Massachusetts autism insurance law, “An Act Relative to Insurance Coverage for Autism” (ARICA). ARICA mandates that all private insurers cover the diagnosis and treatment of autism spectrum disorders for Massachusetts residents. The AIRC is a project of New England INDEX, located at the Shriver Center. Its website can be found at http://www.disabilityinfo.org/arica/

“...exceptional, and really brought individual skills and a collaborative spirit to everything we did. The LEND program is beneficial regardless of your goals.”
— J.M. (Class of 2006)
MA Act Early Reduces Early Identification Disparities with Local & National Partners

The Massachusetts Act Early state team recently collaborated on the following outreach projects designed to raise awareness of assisting individuals with ASD.

**Considering Culture in Autism Screening** is a comprehensive, case-based curriculum about cultural and linguistic competence for autism screening in pediatric practice. The flexible video-based curriculum was developed in collaboration between UMass Medical School-Shriver Center, Boston Medical Center, Tufts Medical Center, UMass Amherst, UMass Boston and Intercultural Productions.

**Developmental Screening in Massachusetts: An Alliance between Early Childhood Programs and Pediatricians** is a webinar developed through a collaboration between UMass Medical School and the Massachusetts Department of Early Education & Care that provides an overview of developmental screening in young children and offers referrals for those at risk for developmental delays and disorders. The archived webinar is available for CME to physicians and for non-CME for the general public throughout 2015.

Through a generous partnership with Boston Children’s Museum, MA Act Early has held its past two state team summit meetings at the museum. The first on October 28, 2014 brought together 40+ state team members to learn about the collective impact approach to increasing early identification of developmental concerns in the state. The second, a 2-day Summit Meeting and Peer-to-Peer Exchange with the Association of Maternal & Child Health Programs (AMCHP), the Association of University Centers on Disability (AUCD) and state teams from Massachusetts and six other states with over 60+ attendees brainstormed cultural barriers and solutions on the topic of Considering Culture in Autism Screening and Systems of Care.

One Care Webinar Series

The Shriver Center is supporting MassHealth in developing a learning website as a portal to One Care Learning activities for One Care plans and their network providers. Trainings are offered in multiple formats including live and recorded webinars, in-person conferences, with online modules coming soon. OneCare has also hosted two recent webinars:

**The LTS Coordinator: Role and Benefits for One Care Enrollees.** This webinar discusses making referrals to Independent Living and Long-Term Services (LTS) and Supports Coordinators, how to best explain this role to One Care enrollees, and the benefits of engaging LTS Coordinators on Interdisciplinary Care Teams. An overview of MassHealth’s vision for the role of LTS Coordinator will be outlined and highlighted with examples of how LTS Coordinators are working with enrollees and interdisciplinary care teams.

**Promoting Wellness for People with Disabilities.** This webinar discusses challenges and strategies involved in promoting wellness among individuals with disabilities. It also explores One Care services that can help support such wellness efforts.

The webinars include live-captioning for each event, accessible PowerPoint presentations, and, in one instance, live ASL interpretation. The webinars are primarily intended as a shared learning opportunity for plans and providers; however they are also publicly available and can be accessed anytime through a registration process at https://onecarelearning.ehs.state.ma.us.
Family Faculty Harnesses Power of Family and Community in LEND Course

Elaine Gabovitch, MPA, knows the value of seeing people with disabilities in the context of their families or communities rather than simply by defining someone by their diagnosis. As the mother of a young adult son with ASD, Gabovitch serves as Shriver Center LEND Family Faculty and strives each year to raise awareness among LEND fellows of the many ways systems of care can either help or hinder people with disabilities and their families for a course Gabovitch teaches entitled Family & Community Perspectives (FCP).

“The goal of the FCP course is for fellows to participate in the day-to-day lives of people with disabilities, their families and their community, so that they gain a better understanding about the changing circumstances that each faces throughout their lives,” Gabovitch said. “The high and low points, the challenges, needs and successes: all of these factors are essential when fellows attempt to develop workable, systems-level solutions to problems experienced by individuals and families.”

Gabovitch matches fellows with mentor families or adults with disabilities based on their self-defined learning needs and specific fields of interest. The fellow’s response not only helps locate individual mentors and/or mentor families, but may also influence the academic focus Gabovitch provides in the course that covers topics such as adults with disabilities, the experience of fathers, sibling perspectives, family-to-family networks, parent-professional partnerships, community-based participatory research, collective impact and other themes.

“Essentially, the FCP course begins at a person-centered and family-centered level and then progressively expands outward to the systems level over the semester.”

Several Former LEND Fellows Join the Shriver Center Faculty and Staff

Several LEND fellowship graduates have stayed on at the Shriver Center to develop and support programs that expand the Center’s mission. They are listed alphabetically by last name below.

Alexandra “Alixe” Bonardi, MS, MHA, OTR/L (Class of 2001)
Alixie is currently a LEND faculty member and is a Research Assistant Professor of Family Medicine and Community Health at UMass Medical School, and former Director of Center for Developmental Disabilities Education and Research (CDDR) at the Shriver Center. Additionally, Alixe is a Senior Policy Specialist at the Human Services Research Institute (HSRI) directing their National Core Indicators program. Alixe says of her experience, “The LEND fellowship at the Shriver Center was at the beginning of a new professional path for me. It allowed me to build on my clinical experience and move into doing work at the systems level that aims to improve the quality of supports and services for people with intellectual and developmental disability.”

Elaine Gabovitch, MPA (Class of 2006)
Elaine serves as the Shriver Center LEND’s Family Faculty and as an Instructor in the Department of Family Medicine and Community Health at UMass Medical School. She is also the Center for Disease Control and Prevention’s (CDC) Ambassador to Massachusetts for the national “Learn the Signs: Act Early” program and the Massachusetts Act Early State Team Leader. Elaine says of her LEND experience, “As a fellow, the work was hard but so engaging on issues that I care deeply about. She goes on, “Now, my role as Family Faculty has allowed me to teach almost 100 students to date, mentor Family fellows, manage several projects, engage with the community, and do more than I ever imagined possible.”

Nancy Shea, JD, MPA (Class of 2009)
Nancy is the Project Coordinator for the Shriver Center’s Emergency Preparedness and Response Initiative. She also teaches an online course through UMass Lowell entitled Disability and the Law. Nancy says of her experience with LEND, “I enjoyed becoming a part of a close knit group of friends who were working on a common goal. I was instantly made to feel valuable and capable of making a contribution to the field of disability studies by faculty and peers.” She continued, “The LEND teachers, peers in my class, and fellows from other classes served as a source of support and inspiration for my current work.”

Susan Swanson, MS, CCC-SLP (Class of 2000)
Sue is an Instructor in the Department of Psychiatry at UMass Medical School and coordinates the clinical training program at the UMass Medical School main campus. A speech-language pathologist by training, Sue conducts clinical evaluations and provides clinical training in the Center for Autism and Neurodevelopmental Disorders (CANDO) at UMass Medical School. Sue says of her experience, “Completing the LEND fellowship was an extraordinary and life changing experience for me.”

Amy Weinstock, MA (Class of 2003)
Amy serves as the founding Director of the Autism Insurance Resource Center within the Shriver Center’s INDEX Program. She conceived of the Massachusetts’ landmark ARICA legislation for insurance coverage related to autism services, an effort that was incubated during her LEND fellowship. Amy says, “LEND has been transformational to my work, by providing me with the knowledge, training, and resources to help me make a major impact on the lives of people affected by autism in Massachusetts.”

Sue Wolf-Fordham, JD (Class of 2008)
Sue is the Senior Project Manager for the Shriver Center’s Emergency Preparedness and Response Initiative. She is particularly interested in inclusive emergency planning for individuals with disabilities. Sue says of her experience with LEND, “I loved every minute of it and found it exciting and transformational. I’ve never experienced such a supportive academic environment where the faculty seemed interested in my personal and professional development and where ‘outside the box’ thinking was nurtured to such an extent.”
“Parents, families, and adults will always be the best teachers of how to succeed in their own lives.”

**spotlight on LEND Alumni in Print**

The written work of several Shriver Center LEND alumni has been published in professional journals and books, children’s literature, and even in state legislation. The following is a limited, selected sampling and does not include training curricula, videos, web sites, and myriad other post-LEND efforts by our alumni network:

**Professional Publications**


**Did you know?**

There are 43 LEND programs in the US and territories.


**Did you know?**

The Shriver Center LEND program has graduated 157 alumni since 2000, including:

- 59 graduates from the Suffolk University Sawyer School of Business with 31 Masters in Health Administration (MHA) degrees and 28 Masters in Public Administration (MPA) degrees awarded; and
- 24 post-doc fellows from Boston University Medical School, Tufts University Medical School, and UMass Medical School’s Center for Integrated Primary Care,
- 5 Maternal & Child Health concentrators from Boston University School of Public Health;
- 32 family fellows; and
- 20 foreign-born fellows from around the world.

**Did you know?**

Shriver Center LEND alumni represent the following disciplines: advocacy, applied behavioral analysis, architecture & interior design, audiology, banking, business management, developmental-behavioral pediatrics, early intervention, education, family, geriatrics, health administration, human services, law, music therapy, nursing, nutrition, occupational therapy, osteopathic medicine, pediatrics, philanthropy, physical therapy, photography, psychology, public administration, public health, research, self-advocacy, social work, speech & language pathology, and others.


**Children’s Literature**

**Jonathan Haywood Jenkins, PhD (Class of 2012), & Jennings, L. (illust.). (2014).** *Wednesday Afternoons with Dr. J.*, “a whimsical illustrated children’s narrative that serves to add to the rich history of therapeutic literature by exposing children to basic principles of psychotherapy and the discussion of emotions.” CreateSpace Publishing.

**Legislation**

Kathleen Braden, MD

Research Interests
Dr. Kathleen Braden, known to friends and colleagues as “Kass,” views her career as spanning three main areas: advocacy (both on clinical and systems levels), teaching, and providing clinical care from a family-centered, interdisciplinary perspective. Dr. Braden completed her residency in General Pediatrics at a city hospital in the Bronx, New York. She then went on to specialize in developmental and behavioral pediatrics (DBP), a field that examines behavioral and cognitive factors related to disabilities. This interest came later in her training as a physician, since from the beginning of medical school she had always envisioned becoming an internist. However, when it came time for her Internal Medicine rotation, she became disillusioned by what she saw as lack of emotional involvement by many doctors about their patients. While trying to figure out a new path, Pediatrics came up as her last rotation and Braden “fell in love” with the field. She brought a vast array of experiences when she joined the Shriver Center in 1997, having worked in the learning disability clinic at Boston Children’s Hospital and as the Medical Director at the Center for Children with Special Needs (CCSN), at Tufts Medical Center.

Braden served as the Director of the Shriver Center LEND program from 1999 until her retirement in October 2014. Her many responsibilities as LEND Director included supervision of and teaching in the Advanced Leadership Fellowship Program, developing the developmental-behavioral pediatrics (DBP) rotation schedule for family medicine residents at UMass Medical School (UMMS), teaching pediatric and psychiatry residents about child development at both CCSN and UMMS, and attending meetings to advocate for disability-related content in the UMMS curriculum, among others. Braden’s valued leadership has been a vital part of the program’s continued success.

Activities
Braden served on several statewide and national committees and advisory boards. A partial list includes the Steering Committee for the Massachusetts Act Early Program, the National Center for Children’s Vision and Eye Health, the Advocacy Committee for the Society for Developmental and Behavioral Pediatrics, and the International Committee for the Society of Developmental Pediatrics. In addition, Braden’s past positions included a three-year term as a board member for the national New England Genetics Consortium located at the Fogarty Center in Washington DC, while serving on several statewide and national meetings to advocate for disability-related content in developmental at both CCSN and UMMS, and attending development at both CCSN and UMMS, and attending meetings to advocate for disability-related content in the UMMS curriculum, among others. Braden’s valued leadership has been a vital part of the program’s continued success.

Publications, Presentations, and Courses


Board Memberships and Advisory Roles
Steering Committee, Massachusetts Act Early Program
Advocacy Committee, Coalition for Developmental and Behavioral Pediatrics
International Committee, Society for Developmental and Behavioral Pediatrics
Massachusetts Early Intervention Interagency Coordinating Council
Advisory Board, National Center for Children’s Vision and Eye Health
Mal-Ed Scientific Advisory Board, Fogarty Center, NIH
Advisory Board, HRSA Healthy People 2020 Autism Roadmap
New England Genetics Consortium

Career Influences & Vision for the Future
Braden knew she enjoyed medicine at an early age, as she loved to spend time on the weekends making hospital rounds with her father, also a physician. In addition to her father, she also credits her late older brother David who had an intellectual disability for influencing her choice to pursue developmental pediatrics. During her Pediatrics rotation in medical school, she remembers feeling very comfortable with many nonverbal patients because of her experiences as a sibling. (An article on Dr. Braden and her brother previously appeared in the 2012 Spotlight issue on Siblings of People with Disabilities.)

Despite these early connections, Braden wasn’t initially sure she would become a doctor. Drawing on a lifelong love of the outdoors, she decided to pursue her bachelor’s degree in ecology, seeing a reciprocal connection between human beings and the natural environment. After graduating from Barnard College at Columbia University in 1971, she entered the Columbia School of General Studies where she completed her science pre-requisites for medical school and pursued her career in medicine.

Braden’s career took her beyond the United States. Her father did volunteer work in other countries during her childhood and the entire family often accompanied him. She remembers spending a year in Malaysia at the age of 14, along with an earlier stay in British Guyana. These experiences helped shape her perspective and eventually led to her joining a research project in the Congo in 1987 with her husband to study the HIV virus in Africa. Dr. Braden credits this experience with allowing her to use and develop an entirely different skillset that would allow her to make a difference in the US. She later continued her international work receiving pilot grant funding from the Ford Foundation to reduce the frequency of unwanted pregnancy and HIV infection in adolescent girls in KwaZulu-Natal, South Africa.

As Braden reflected back on her career, she emphasized the notion that medicine cannot be separated from one’s life; it must be integrated into it, remembering how her young daughter Alana would often go to the hospital with her when she was called in. Judging by the varied and diverse interests and accomplishments throughout her career, it’s safe to say Dr. Braden has done just that.

Kathleen Braden pictured here with husband Gerald Keusch and daughter Alana.
E.K. Shriver Center
LEND Fellows for 2014-2015

We are pleased to present the following individuals as Shriver LEND Fellows for the 2014-2015 academic year. We congratulate them on their efforts and wish them well in the future:

**Stacie Colwell, MD, PhD**
Specialty: Developmental-Behavioral Pediatrics

Stacie is completing the second year of a three year developmental-behavioral pediatrics (DBP) fellowship at Tufts Medical Center. Prior to beginning the fellowship, Stacie worked for ten years at a non-profit community hospital in Vermont where patients often included a wide range of individuals with disabilities, mental health issues, or who had been placed in foster care a system in which Stacie saw the parent of a son who has a neurodevelopmental disability. Guided by the goal of providing the same level of care she would expect for her family, Stacie has strove to gain skills in advocacy and collaboration to better assist her family and community in the future.

**Shawn McCurley, BA, MS**
Specialty: Psychology/Human Services

Shawn currently serves as Director of Human Resources for Delta Projects, Inc., a non-profit that offers supports to children and adults diagnosed with intellectual and developmental disabilities. Shawn aims to consistently improve systems and services throughout the Human Service industry to strategically remove industry barriers through the use of policy and change leadership. Shawn attributes much of his interest in leadership to time spent in the US Marine Corps and the skills developed through his service. He currently holds an MS in Organizational Leadership from Roger Williams University, a Graduate Certificate in Non-Profit Management from Suffolk University, and is also enrolled in the Suffolk University MPA Program as a LEND fellow.

**Amy Till, BS**
Specialty: Computer Science/Non-Profit/Parent

Amy has held several senior consultant and project manager positions throughout over her 15 year career as a Computer Software Specialist. Amy applied those same leadership skills during a four-year stint as Christian Education Director for St. Paul’s Episcopal Church in North Carolina where she supported 13 volunteer youth leaders and 20 church school teachers. Currently, Amy serves as Project Coordinator of the Natick Together for Youth Coalition working with community members to promote a safe, healthy, and drug-free environment. The mother of two, one with a neurodevelopmental disability, Amy is motivated to help families with fewer resources to have more options in the future. Amy is also currently enrolled in the Suffolk University MPA Program.

**Meredith Pizzi, BS, MT-CP**
Specialty: Music Therapy

Meredith has been a Board Certified Music Therapist for over 10 years. Her clinical work focuses primarily on children and young adults with disabilities, as well as early childhood development. Meredith is the founder and owner of two separate businesses: Roman Music Therapy Services, LLC, an independent, community based music therapy agency and Raising Harmony, a resource that provides music therapists, educators, families with information, training, and resources on all aspects of music and its relationship to early childhood. Meredith has also created Sprouting Melodies, a music therapy-based program that supports young children and their families and caregivers using music to support overall healthy growth and development. Meredith is also currently enrolled in the Suffolk University MPA Program.

**Jennifer Stewart, BA, MPP**

Specialty: Public Health

As the past transition specialist for EMARC and newly hired transition specialist at the Federation for Children with Special Needs, Jennifer works collaboratively with families and stakeholders such as schools, state agencies, adult services, and family support organizations to increase awareness and planning for transition age students (14-24). Jennifer’s goal is to increase collaboration between support systems while also increasing information accessibility. Previously, Jennifer served as a Program Coordinator for Americorp VISTA, where she created a volunteer mentoring program to assist clients with disabilities in job seeking and placement. Additionally, while at UMass Boston, Jennifer managed the national evaluation of a school-based social inclusion program run by the Special Olympics called Project Unity. She holds a Master’s in Public Policy from The Heller School of Management at Brandeis University.

**Kelley Devlin, RD, LDN**
Specialty: Public Health/Nutrition

Originally from Connecticut, Kelley recently received her MPH from the BU School of Public Health’s Master & Child Health program. A long-time interest in the field of community nutrition led her to work with underserved children and families, both as a dietician and later through her work with the Women, Infants & Children Supplemental Nutrition Program (WIC) in Waterbury. These experiences helped shape Kelley’s long-term interests of social justice and eliminating health disparities after she witnessed many families unable to access needed nutrition. Kelley believes participating in the LEND program has expanded her awareness of disability policy and given her the tools to prevent health disparities and marginalization of individuals with disabilities.

**Terri Farrell, BA, MBA**
Specialty: Business/Marketing/Parent

Terri serves as project director for the Autism Insurance Resource Center (AIRC). The AIRC is based out of the Shriver Center’s Worcester campus, and assists families in obtaining medically necessary treatments under the AIRC law. Terri is also the mother of two, including a teenager with autism spectrum disorder (ASD). Her work with the AIRC is just one way Terri assists the disability community. She also reviews family service grants for Autism Speaks, and chairs the SEPAC in her hometown of Lynfield, MA. Terri holds an MBA from Northwestern University.

**Shirley Huang, MS, CCC-SLP**
Specialty: Speech-Language Pathology

Bilingual in English and Cantonese, Shirley understands the unifying bond that language can bring to families and cultures. As a speech language pathologist, her professional interests primarily focus on pre-school and school-age language, bilingual language development, and developmental disorders (Autism, Cerebral Palsy, ADD/ADHD). While a graduate intern at the Center for Children with Special Needs at Tufts Medical Center, Shirley developed an alternative/augmentative communication book designed to help a four-year old girl speak Cantonese and be better understood by her family. As a result, she now aims to develop accessible, culturally sensitive resources that can educate and support multicultural families. Shirley has a Master’s Degree from the Sargent College of Health and Rehabilitation Sciences at Boston University.

**Elizabeth Jassee, M.Ed**
Specialty: Special Education

For over 20 years, Elizabeth has staunchly advocated for individuals with disabilities to have the most appropriate educational, medical, therapeutic, and recreational services possible. As a mother of two children with ASD and co-occurring learning and mental health disorders, she knows just how important advocacy is, and also realizes how effective supports (or the lack of them) can impact someone’s quality of life. Through the LEND program, Elizabeth has worked to improve the quality of life for those with disabilities by broadening and changing disability policy so that societal perceptions about individuals with disabilities can change.

**Carl Richardson, BS**
Specialty: Communications

Carl currently holds the position of ADA Coordinator for the Massachusetts State House. In this role, Carl ensures that all activities, programs and services provided through the State House are free of barriers so truly anyone can participate. This includes all aspects of accessibility: universal design, signage, interpretative services, and website layout, among others. Diagnosed with blindness and deafness himself, Carl aims to continue giving a voice to the employees and constituents of the Commonwealth regardless of their ability. A graduate of Emerson College in Boston with a degree in Communications, Carl is now pursuing an MPA degree through the LEND partnership with Suffolk University MPA.

**Shawn McCurley, BA, MS**
Specialty: Psychology/Human Services

Shawn currently serves as Director of Human Resources for Delta Projects, Inc., a non-profit that offers supports to children and adults diagnosed with intellectual and developmental disabilities. Shawn aims to consistently improve systems and services throughout the Human Service industry to strategically remove industry barriers through the use of policy and change leadership. Sean attributes much of his interest in leadership to time spent in the US Marine Corps and the skills developed through his service. He currently holds an MS in Organizational Leadership from Roger Williams University, a Graduate Certificate in Non-Profit Management from Suffolk University, and is also enrolled in the Suffolk University MPA Program as a LEND fellow.

**Meredith Pizzi, BS, MT-CP**
Specialty: Music Therapy

Meredith has been a Board Certified Music Therapist for over 10 years. Her clinical work focuses primarily on children and young adults with disabilities, as well as early childhood development. Meredith is the founder and owner of two separate businesses: Roman Music Therapy Services, LLC, an independent, community based music therapy agency and Raising Harmony, a resource that provides music therapists, educators, families with information, training, and resources on all aspects of music and its relationship to early childhood. Meredith has also created Sprouting Melodies, a music therapy-based program that supports young children and their families and caregivers using music to support overall healthy growth and development. Meredith is also currently enrolled in the Suffolk University MPA Program.

**Jennifer Stewart, BA, MPP**

Specialty: Public Policy

As the past transition specialist for EMARC and newly hired transition specialist at the Federation for Children with Special Needs, Jennifer works collaboratively with families and stakeholders such as schools, state agencies, adult services, and family support organizations to increase awareness and planning for transition age students (14-24). Jennifer’s goal is to increase collaboration between support systems while also increasing information accessibility. Previously, Jennifer served as a Program Coordinator for Americorp VISTA, where she created a volunteer mentoring program to assist clients with disabilities in job seeking and placement. Additionally, while at UMass Boston, Jennifer managed the national evaluation of a school-based social inclusion program run by the Special Olympics called Project Unity. She holds a Master’s in Public Policy from The Heller School of Management at Brandeis University.

**Amy Till, BS**
Specialty: Computer Science/Non-Profit/Parent

Amy has held several senior consultant and project manager positions throughout over her 15 year career as a Computer Software Specialist. Amy applied those same leadership skills during a four-year stint as Christian Education Director for St. Paul’s Episcopal Church in North Carolina where she supported 13 volunteer youth leaders and 20 church school teachers. Currently, Amy serves as Project Coordinator of the Natick Together for Youth Coalition working with community members to promote a safe, healthy, and drug-free environment. The mother of two, one with a neurodevelopmental disability, Amy is motivated to help families with fewer resources to have more options in the future. Amy is also currently enrolled in the Suffolk University MPA Program.

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 inter-disciplinary, 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.
Shriver Center Debuts New Website

The Shriver Center is pleased to announce its new and improved website with a new URL: http://shriver.umassmed.edu. The new site features a simplified navigation so that all web site visitors (e.g., individuals with disabilities, family members, researchers or service providers) can quickly and easily access the information they need. Additionally, it was created with the ability to scale automatically depending on what a visitor uses to view the site (e.g., computer, tablet, or other mobile devices).

The updated website allows visitors to:

• Explore the wide range of programs that align with its mission
• Find out about community resources such as disability information, emergency preparedness, and health promotion
• Discover areas of IDD research such as behavioral analysis, neurobehavioral science and neurogenetics, learning technologies, and population health
• Become aware of technical assistance opportunities from accessible web design and development, to quality improvement and risk management, and more
• Learn about its educational and training opportunities, including our Leadership Education in Neurodevelopmental and Related Disorders (LEND) program

The Shriver Center welcomes your feedback as it continues to update the web site and share information to improve the lives of those with I/DD and autism spectrum disorder.

Pictured is the home page of the newly updated Shriver Center Web Site http://shriver.umassmed.edu.
**“LEND helped me become a successful principal investigator on developmental-behavioral pediatrics (DBP) and LEND training grants. It was a great training program.” — D.V. (Class of 2009)**


Wolf-Fordham, S., Twyman, J. S., & Hamad, C. D. Educating first responders to provide emergency services to individuals with disabilities. *Disaster Medicine and Public Health Preparedness, 8*(6), 533-540.

**Books & Book Chapters**


**Conference Presentations, Posters, & Abstracts**


Bandini, L. G., Curtis, C., Must, A., & et al. (2014) Healthy Weight Research Network for children with ASD/DD. *The CAAI virtual poster symposium, sponsored by the Association of University Centers on Disabilities (AUCD).*


Dube, W. V. (2014). Research in stimulus overselectivity: Populations and interventions. *Invited Address at the 35th Annual Berkshire Association for Behavior Analysis and Therapy Conference, Amherst, MA.*


Charles Hamad, PhD, who has been the Interim Executive Director of the Shriver Center and was also the Shriver Center’s Associate Director and UCEDD Director for 15 years, retired from his administrative responsibilities effective January 15th, 2015. Hamad does not plan to leave UMass Medical School or the Shriver Center, and will remain a part-time retired faculty member. He will focus his efforts on his grant-funded research and project portfolio. Carol Curtin, MSW will assume the role of Interim Executive Director, and will have administrative responsibility and authority for the Shriver Center until a permanent Executive Director is named (more information on page 24). She also assumed the UCEDD Directorship at the end of 2014.

Hamad’s many years of service to the Shriver Center and UMass Medical School and his many contributions to the field of Intellectual and Developmental Disabilities were profiled in the last *Spotlight* issue, Spring 2014. We hope readers will revisit this special issue on the Shriver Center’s online curriculum led by Hamad to see the full body of his work and legacy. We wish to thank Hamad for his many contributions to the UCEDD and Shriver Center as a whole and are pleased that he will remain on the faculty to continue his innovative and visionary work.
“Federal Funding Trends and Diversification of Funding Strategies” UCEDD Technical Assistance Institute, Bethesda, MD.


Mackay, H. A. (2014). Conditional stimulus control and the acquisition of and emergence of pre-academic skills. Presented at Experimental Analysis of Human Behavior SIG Career Award: Celebrating the Contributions of Dr. Harry Mackay at the 40th Annual Convention of the Association for Behavior Analysis International, Chicago, IL.


McIvane, W. J. (2014). The behavior analyst's utility belt in 2025: What shall we do with these wonderful toys? Invited Presentation at the 2014 Meeting of the Southeastern Association for Behavior Analysis, Wilmington, NC.


Twyman, J. S. (2014). Blending behavior science and digital technology: Are we ready for "Educaton 3.0"? Keynote Presentation at the Cambridge Center for Behavioral Studies Annual Meeting of the Trustees, Atlanta, GA.


“Team Shriver” Continues Fundraising Efforts in Annual UMMS Walk To Cure Cancer

“Having a significantly greater understanding of the service constellation for individuals with developmental disabilities who live in my state has dramatically improved the quality of the services I provide.”
— J.S. (Class of 2008)

Since 2007, Shriver Center faculty, staff, family members, and friends have proudly joined together to form “Team Shriver” and participate in the “Walk to Cure Cancer.” The annual fundraiser serves to support ongoing research at the Cancer Center of Excellence, located at UMass Memorial Health Care/UMass Medical School in Worcester, Massachusetts. The mission of the Cancer Center is to deliver state-of-the-art cancer prevention, diagnosis, and therapy while providing the most advanced research, clinical trials, and patient support resources.

The 2014 event took place on September 28, 2014 under clear blue skies on the campus of UMass Medical School. It also marked the first “Walk” since the Shriver Center moved into new dual locations in Charlestown and Worcester. Despite the change in geography, Team Shriver continues to embody the spirit of community, camaraderie, and fun that makes the event successful. In addition, Team Shriver’s fundraising efforts over the years have made a meaningful, sustainable contribution to cancer research as a whole.

Typically, Team Shriver generates funds from year-round events such as luncheons and indoor yard sales, as well as establishing individual fundraising pages where anyone interested may donate online. Team Shriver raised approximately $2,800 for this event, with donations permitted to the end of 2014.

Shriver Center Administrative Assistant Donna Caira has walked every year since Team Shriver began and spoke very highly of the experience. “This event is very important. Besides raising funds, it also allows people to do something specific and active in the fight against cancer. Feeling that connection often motivates people to become more involved,” Caira said.

Emergency Preparedness Project Coordinator Nancy Shea agreed. Shea is a second year participant who won the 2013 award for the top single fundraiser throughout UMMS. “Cancer is so universal; virtually everybody knows at least one person who has been diagnosed. Likewise, the cost of treatment can be exorbitantly high. It’s very important people do as much as they can to raise funds and help continue the fight,” Shea said.
Carol Curtin, MSW, Assumes Position as LEND Director

Shriver Center faculty and staff would like to congratulate Carol Curtin on several recent appointments. In keeping with the theme of this issue, her promotion to the position of LEND Director is timely and significant. The appointment is the latest in a series of administrative promotions for Curtin; she also currently serves as acting Executive Director of the Shriver Center in addition to her roles of IDDRC Core Director and UCEDD Director.

As LEND Director, Curtin oversees the nationally recognized program and is focused on both the clinical and advanced leadership tracks. At the same time, Curtin is developing several new initiatives within the LEND program, including continued expansion of clinical training efforts on the main campus of the UMass Medical School in Worcester, a focus on transition issues for individuals with disabilities and their families, and with Linda Bandini, PhD, establishing partnerships with special education programs in public schools as clinical training sites for graduate students in nutrition, physical activity, and other disciplines to work with youth with disabilities on healthy lifestyles and wellness.

Curtin’s primary research interests reside in the area of health promotion for individuals with disabilities; specifically, identifying unique modifiable risk factors for obesity and other adverse health outcomes, and devising targeted, tailored interventions to reduce risk factors. The most recent example of this work came as her role as Co-Director with Linda Bandini, PhD on the Healthy Weight Research Network (HWRN), a national research network funded by the Maternal Child Health Bureau. The HWRN brings together a nation-wide interdisciplinary group of researchers who work to advance the understanding of obesity risk factors in children with ASD and other developmental disabilities, to promote the development of evidence-based solutions to achieve healthy weight in this population, and to disseminate research findings to broad and diverse audiences.

The appointment as LEND Director marks Curtin’s latest role in assisting individuals with disabilities, but it is hardly her first. Before coming to the Shriver Center in 2002, Curtin served for six years as Clinical Director at the Center for Children with Special Needs (CCSN) at Tufts Medical Center, a key training partner of the LEND program. Prior to her appointment as the Clinical Director, she worked for six years at the CCSN as a clinical social worker and clinical coordinator, and was a Senior Social Worker within the Department of Social Work Services at Tufts Medical Center. Prior to her work at Tufts; Curtin was the Admissions and Pupil Services Director at the Riverview School in Sandwich, MA, a residential school for adolescents with neurodevelopmental disabilities. She also held previous positions in community mental health and vocational rehabilitation settings where she delivered clinical services to people with developmental and behavioral health conditions across the lifespan. Curtin also maintained a private psychotherapy and clinical consultation practice for nearly 20 years.

Curtin has published 30 peer-reviewed journal articles to date, in addition to several book chapters and numerous conference presentations. She has served as an invited reviewer for over 18 different national and international journals, and has participated as a grant reviewer for the Maternal Child Health Bureau and Administration on Intellectual and Developmental Disabilities.

Throughout her career, Curtin has kept the needs of individuals with disabilities and special health care needs as a top priority. The Shriver Center LEND program will continue to thrive under her steady leadership.