disabilities. Thanks to a recent grant award from the National Institute on Deafness and other Communication Disorders (NIDCD), Dr. McIlvane and other Shriver colleagues are currently developing instructional software that represents a new attempt to improve communication outcomes for individuals with disabilities via a Picture-Aided Communication Systems Manager (PACSMAn).

Dr. McIlvane describes PACSMAn as “...a computer-managed instructional procedure for teaching relations between symbols (e.g. pictures or line drawings) and their corresponding items. PACSMAn is intended to guide teachers trying to teach symbolic relations to students with minimal or no skills in this area. PACSMAn is best used in an environment where some type of AAC platform is already in place.”

Communicating through pictures has long been recognized as a viable alternative for some individuals with disabilities. Many widely known and distributed products also try to fill this gap, among them the Picture Exchange Communication System (PECS), a six-stage program that starts with initiation of communication through the exchange of a single picture for a child's favorite item and then gradually teaches functional communication using picture cards that represent “I see” or “I want” to build sentences and answer questions.

According to Dr. McIlvane, PACSMAn aims to address gaps in currently available products

continued on page 2
PACSMAn Software Project

continued from page 1

to support instruction at critical junctures in PECS and similar programs that sometimes prove hard to teach to many AAC candidates. “For example, until they reach Phase III of the PECS program, individuals do not actually have to discriminate between pictures on the PECS cards. Some fail at this phase and the PECS curriculum has very limited guidance on how to address the failures. PACSMAn is designed to support teachers in establishing the skills in Phase III and other component skills of nonverbal communication,” he elaborates.

Dr. McIlvane believes PACSMAn would be most effective if begun early in a child’s attempts at communication, but could be used by any age group. Likewise, he believes using computers to manage PACSMAn gives it a unique niche, integrating technology that makes the necessary teaching procedures more effective and easier to use.

“A primary goal of PACSMAn involves displaying sequences of items and allowing the child to point at what they want or need, for example, pointing at individual symbols for “I” “want” “chocolate” “milk” to request that particular drink. The algorithms of PACSMAn structure teaching to contrast a given request with other similar requests to build confidence that the individual understands the request being made and thus is capable of expressing his/her actual desires rather than merely responding to available pictures in sequences learned by rote.”

Christophe Gerard, PhD, Director of Disability Technology Development, agrees. He notes that sequencing is a key part of PACSMAn. It aims to assist with identifying items with similarities; a sugar cookie versus a chocolate cookie, for example. Doing so not only offers the individual greater choices, but assures that the individual’s choice is based on the specific characteristics of the item chosen.

PACSMAn’s capabilities also extend to the individual working with the child, offering the ability to record a child’s response electronically and determine if that response matches up with the want or need s/he is trying to establish. Furthermore, an accompanying database will allow multiple results and test dates to be recorded and stored. PACSMAn will allow teachers to make automated queries of the database in order to make decisions concerning the teaching sequences (e.g., when to add new items, when to accelerate teaching, when to remediate, etc.). By doing so, the program assists the teacher in assessing whether appropriate learning is taking place and generally supports an ongoing process of optimizing individualized instruction in picture-aided communication.

Since the grant is intended to develop pilot software for PACSMAn, there is no definitive timetable on its availability for public use. If each stage goes as expected, however, Dr. McIlvane believes it could be commercially available by the end of 2014.

When asked what eventual users of PACSMAn may see as its greatest benefit, McIlvane pointed to its universality. “PACSMAn can be used anywhere; at school, a child’s home, in clinical settings, and other places. This inclusive approach allows us to not only see fewer failures in programs like PECS, but also helps give a voice to children who might otherwise be unable to communicate.”

Did you know?

Over two million people with significant expressive language disabilities use augmentative or alternative communication (AAC) to communicate. These conditions include but are not limited to autism, cerebral palsy, dual sensory impairments, genetic syndromes, intellectual disability, multiple disabilities, hearing impairment, disease, stroke, and head injury.\(^1\)

AAC uses every means possible to communicate. A person’s ability to use AAC devices may change over time, thus, the AAC system that works best for someone today may not be the best system tomorrow.\(^2\)

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1 American Speech and Hearing Association (ASHA)
2 American Speech and Hearing Association (ASHA)
Using computers to manage PACSMan gives it a unique niche, integrating technology that makes the necessary teaching procedures more effective and easier to use.

CAMEL Mobile Laboratory Assists in Growing Recruitment for Research Studies

Thanks to the recent acquisition of a mobile laboratory, Shriver Center researchers now have the ability to take their studies “on the road” to cities and towns throughout Massachusetts and include individuals who fit study participation criteria but face travel constraints.

Joint funding for the Community Access Mobile Evaluation Laboratory (CAMEL) was awarded to Shriver Center Executive Director William McIlvane PhD from the federal Health Resources and Services Administration (HRSA) of the U.S. Department of Health and Human Services (HHS), and National Institute for Child Health and Human Development (NICHD). A longtime supporter of the idea, Teresa Mitchell PhD was also instrumental in the acquisition and refurbishment of the mobile laboratory.

“In my experience, families often want to participate in our research, but the most frequent obstacle is travel and scheduling. The CAMEL allows us and our equipment to come to them, making it much easier and less stressful for everyone,” Mitchell elaborated.

The CAMEL comfortably holds up to five people including a driver, and offers several potential uses, according to Dr. Mitchell. “We already use the CAMEL for eye-tracking sessions and EEG monitoring. In the future, it could also host behavioral studies, participant characterization and interviews, among other possible uses. Primarily, the CAMEL allows us to take our research out of the laboratory and visit more homes, schools and non-traditional sites. These are places where participants can be tested easily, but have traditionally been difficult to visit.”

CAMEL van will allow Shriver Center researchers to take their studies into the community.

CDDER Co-Hosts Be Aware–Take Care Training with Massachusetts DDS

On October 24, 2012, over 380 direct support professionals, house managers, provider agency and DDS staff, nurses and other caregivers gathered in Devens, Massachusetts for a training entitled Be Aware–Take Care: Prevention, Risk and Safety at the Front Line of Services to Individuals with Intellectual Disability.

Organized by the Massachusetts Department of Developmental Services (DDS) and the Shriver Center’s Center for Developmental Disabilities Evaluation and Research (CDDER), the training brought together experienced professionals from a variety of backgrounds to encourage a culture of safety when caring for individuals with intellectual disability. Topics included:

- Using DDS data to improve care for individuals with intellectual disabilities
- Recognizing behavioral challenges and understanding that changes in behavior may be associated with health related or aging issues; creating a unified plan of care
- The “Fatal Four”: Understanding that dehydration, aspiration, constipation, and seizures in people with intellectual disability can contribute to serious health conditions and may go unnoticed since symptoms are subtle and individuals affected may be unable to communicate discomfort.

Barbara Pilarcik, RN, Executive Director of The Association for Community Living gave the keynote address, discussing the importance of a culture of safety and the “dignity of risk”; allowing individuals with intellectual disabilities to make their own decisions concerning risk. Massachusetts DDS Commissioner Elin Howe welcomed participants and underscored the importance of these topics.

Several individuals with connections to the UMass Medical School-Shriver Center also presented or served as panel discussants: Emily Lauer, MPH, CDDER; Lauren Charlot, PhD, Director, ID/MH Clinical Services, UMass Memorial Medical Center; Julie Moran, DO, Director, Aging and Developmental Disabilities Clinic, Beth Israel Deaconess Medical Center (Shriver Center LEND alum, 2006); Robert Baldor, MD, CDDER Medical Director, UMMS Vice Chair, Department of Family Medicine and Community Health.
Communication Through Facial Expression Focus of Two Studies

For Ruth Grossman, PhD, CCC-SLP, communication is a broadly defined term that goes far beyond spoken language. “I’m really interested in facial expression, tone of voice, body language, the social signals that we use to start a conversation, everything beyond actual words,” she explains.

An adjunct assistant professor at the UMass Medical School-Shriver Center and Assistant Professor at Emerson College, Dr. Grossman has spearheaded two studies designed to examine the interaction of verbal and non-verbal communication in children and adolescents with ASD. Her research interests in facial expression and social communication are reflected within this population since children with ASD often have difficulty mastering these types of communication.

Dr. Grossman’s first study is known as “Look Who’s Talking” and encompasses children and adolescents from the ages of eight to 17, both with and without ASD. Individuals with ASDs who participate in the study present as high functioning. In other words, they are verbal and often perform well academically, but still experience social setbacks because of a marked difficulty in understanding social cues. One way that typically developing individuals understand social cues is by matching up tone of voice with expression. To that end, a key component of “Look Who’s Talking” involves playing back the same sentence using a different tone of voice each time to simulate a different emotion, such as anger, joy, or sadness. Then, a participant is shown side-by-side pictures of different facial expressions, and asked to identify which expression matches the audio sample.

“ ‘Look Who’s Talking’ isn’t just focused on picking out the ‘right’ expression, but also on how someone picks which expression to focus on,” Dr. Grossman says. “Eye tracking lets us look at that, and see where in the face kids look to get information on where they need to focus. If we can help teach them where on the face to focus, it may help eliminate social barriers.”

Dr. Grossman’s second study, “Express Yourself” attempts to trace the facial expressions being made by youth with ASD and those who are typically developing, ages 10 to 17. She is particularly interested in what types of facial expressions appear during conversations, telling stories, or other socially expressive activities. To assist in this endeavor, Dr. Grossman attaches 32 reflective markers to a participant’s face that allow the six infra-red motion capture cameras to observe and record any change in expression instantaneously. Motion capture is often used in computer animated films or ones with highly complex special effects for the same purpose. Using such technology has been largely accepted by all the participants.

“While conducting phone screenings, we ask if participants will mind having their faces touched. There isn’t much resistance to the procedure. It has actually been more challenging to make sure all the markers stay on during the test,” Dr. Grossman says.

Through “Express Yourself,” she hopes to move beyond the question of simply whether facial expressions are different among teens with ASD, but what makes them different or unusual when compared to others. Dr. Grossman believes answering this question will help increase opportunities for individuals with ASD in a variety of ways.

“Autism is a disorder of social communication. These social communication deficits can hold individuals with autism back in a variety of areas; they may be qualified for a specific job, but unable to get past the interview, for example. Children and adolescents with high-functioning autism are the people that truly have the ability to succeed in life. Focusing on these intervention-based approaches offers a chance to help them do that,” Dr. Grossman concludes.
Face Processing Study Examines the Whole Picture

The “Foundations of Learning” study is an ongoing, five year project funded by a grant from the National Institute of Child Health and Human Development (NICHD) and overseen by William McIlvane, PhD, Shriver Center Executive Director. The Foundations project encompasses four smaller studies, each with the goal of spotlighting differences between individuals with autism spectrum disorder (ASD) and individuals with other intellectual disabilities.

One of the Foundations studies being conducted by Teresa Mitchell, PhD involves face processing in children with ASD and Down syndrome compared to typically developing children. As the name suggests, “face processing” refers in part to someone’s ability to process emotional information in faces, thereby helping them to discern moods or determine appropriate reactions in specific situations. This is an ability that most people perform automatically. Examples include curling a lip in to signify anger or raising an eyebrow to indicate doubt. Individuals with ASD and Down syndrome, however, often have significant difficulties establishing these connections.

“Face processing is a terrific subject to study, because depending on the question you ask in your research, the faces will either be very similar and therefore very difficult to discriminate, or will be wildly different and indicative of very different emotions,” Dr. Mitchell elaborates, adding that individuals with ASD and Down syndrome, as Dr. Mitchell puts it, “Are we seeing the expected response? The right side of a typically developing individual’s brain usually processes faces much quicker than the left. Is that happening? Regardless of the answer, what does that tell us? Is it something we can use to learn more about autism?”

Although rhetorical, Dr. Mitchell’s last question illustrates another overarching theme of all research done at the Shriver Center. Along with testing hypotheses and recording results, the work done could make a difference in daily life for an individual with a disability.

“I believe that face processing is something typically developing individuals do every day, virtually subconsciously, like widening our eyes in surprise,” Dr. Mitchell says. “Knowing that my research has the potential to help someone with ASD is truly an amazing feeling.”

Dr. Mitchell breaks down the testing involved in the face processing study into three primary levels, using the following criteria:

**Level 1: Baseline testing for attributes such as IQ or language comprehension.** These tests are unrelated to the study’s primary purpose, but help to ascertain needed reference points for each subject in the study. “Autism is a heterogeneous disorder without a known cause, so these tests are ways to describe your study participants when writing papers or publishing results. They can also be used to make correlations easier; how did people with specific IQs perform on study tasks, for example?” Dr. Mitchell explains.

**Level 2: Behavioral testing such as matching to sample tasks and facial discrimination.** This level can illustrate whether subjects can detect major or minor differences between pictures. Pictures may illustrate the same expression (varying degrees of a smile, for example) and the goal is to see if the participant can identify it. Pictures may also show entirely different expressions, such as happiness in one picture and anger in another and see if the participant can identify them. “The key at level 2 is to observe what a participant does; once they are shown these images, what happens next?” Dr. Mitchell explains.

**Level 3: Testing unique to the study itself, eye-tracking and EEG scans of brain activity.** For face-processing, this level does not necessarily select a specific answer or characteristic. Instead, the important idea is choosing one object to present to participants, and then have them look at it and record all possible data. “What someone focuses on, how long someone maintains focus, even the order they focus on things, can all be useful points of study,” Dr. Mitchell says.

Likewise, the EEG, or brainwave, portion of the study applies the same principle studying brainwaves: How is the individual’s brain responding to the image being looked at? Or,
Foundations Study Family Reflects on Their Experience

Research studies can often shed light on questions that families may have about their children’s challenges and needs. Recently, Carole Slipowitz and husband Dan Halbert spoke with us about enrolling their son Jesse in Shriver Center research studies and what they learned by doing so. Jesse is 15 years old with an Autism Spectrum Disorder (ASD).

Q: You’ve enrolled Jesse in several research studies, both here and at other institutions. Why do you feel they are important?

Carole: Jesse is an outgoing person who likes to interact socially with others and go to new places. Participating in research studies is fun for him, and the staff make it easy for us. It also makes us feel good that through our family’s participation we may be helping other kids like Jesse in the future.

Q: Which studies has Jesse participated in at the Shriver Center?

Carole: Two parts of the Foundations of Learning study, “Face Processing in Individuals with Autism and Down syndrome” and “Focus of Attention.” Jesse is still having sessions with the Focus of Attention study. He also participated in the Teen Recreation and Activity Choices (TRAC) study.

Q: Did you observe Jesse during any of the Face Processing study?

Carole: Yes. The research was very interesting to me as a psychologist. I was particularly impressed with the level of detail involved in the study such as the number of facial expressions used, and the differences in each. I would have trouble telling them apart! It appealed to Jesse also. He is very good with computers and likes to demonstrate mastery of things. The study offered many opportunities for that.

Q: As a parent, did the research study confirm anything you observed about Jesse?

Carole: Yes. I suspected that Jesse had difficulty looking at things for long enough to really take them in. One of the tests they performed for the study involved eye-tracking; that is, noticing where Jesse’s gaze went. He had to focus on something for 15 seconds for the reading to “count.” Jesse was able to, but only for two seconds. I was glad to finally have concrete information about that.

Q: What will you remember most about involving Jesse in research at the Shriver Center?

Daniel: From a personal standpoint, it is clear that researchers at Shriver Center are well-versed in working and interacting with individuals with autism; they do not overreact if Jesse is distracted by objects that interest him, such as a telephone. Also, the testing environment itself is professional and well-maintained and also quiet and relaxing.

Q: Would you recommend other families take part in research studies at the Shriver Center?

Carole: Absolutely. It’s been a wonderful experience.

spotlight on Resources for AAC

Websites

ASHA Special Interest Group on Augmentative and Alternative Communication

The American Speech and Hearing Association’s SIG on Augmentative and Alternative Communication is “dedicated to improving the quality and availability of AAC services to consumers throughout the life span, to promote clinically relevant research, educate and mentor current and future professionals, and to identify and address the needs of service providers in the professions of speech-language pathology and audiology.”

http://www.asha.org/SIG/12/default/

United States Society for Augmentative and Alternative Communication (USSAAC)

This site provides information and support on AAC issues, technology, tools and advancements. Their primary mission is to support individuals who use nonverbal communication and all those who serve them, including therapists, families, educators, researchers, and others.

http://www.ussaac.org/

Center for Applied Special Technologies, (CAST, Inc.)

CAST is a nonprofit research and development organization that works to expand learning opportunities for all individuals, especially those with disabilities, through Universal Design for Learning. CAST offers free multimedia learning tools to the public on their web site.

http://www.cast.org

AAC Institute

A not-for-profit, charitable organization dedicated to people who rely on augmentative and alternative communication (AAC). The Institute states that the two most important values expressed by people who rely on AAC are: “1) saying exactly what they want to say, and 2) saying it as fast as they can.” Achieving the goal of AAC is best accomplished by using the principles of evidence-based practice and performance measurement.

www.aacinstitute.org
DAC Communication an Essential Tool for Consumer Advisory Council Member

Written expression is a key component of many commonplace tasks: composing e-mails, answering medical questionnaires, and note taking, just to name a few. Individuals with mobility disabilities may often have difficulty in such areas. Knowing what they want to say and being physically able to express it may be two entirely different things for some. Andrea Strumpf, M.Ed., a long-time member of the Shriver Center’s Consumer Advisory Council, understands those difficulties well. Due to a diagnosis of cerebral palsy, fine motor issues make writing particularly difficult for her. As a result, Strumpf knows the importance of alternative and augmentative communication (AAC) in both her academic and professional life.

“Dictation is my primary form of AAC, although the method is different for me these days. Back in school, I spoke papers aloud and someone else typed them on a computer. It was very challenging, but the most effective way available at the time. Today, I primarily use ‘Dragon’ speech recognition software, which is much more convenient,” Strumpf says.

After completing an undergraduate degree in Spanish from Wellesley College, Strumpf received a Master’s degree in Education from Boston University in 2008. Despite these advanced credentials, she later would encounter barriers when pursuing employment in the public schools. “Most schools I’ve seen have difficulty meeting the needs of a teacher with a disability,” Strumpf continues, citing personal examples of being unable to hang decorations on her classroom wall due to its height and being unable to reach the copier from her wheelchair.

While not directly related to AAC, these experiences serve as motivation for Strumpf in her current job: privately tutoring students with disabilities. “AAC is extremely important in my role as a tutor. Many of the students I work with have dyslexia; people often equate that with misreading words in a text, but it also affects completing mathematical word problems, understanding comments on an essay, and even affects non-academic areas like obeying road signs,” she elaborates.

Strumpf sees speech recognition software as invaluable for her students, but her reasoning goes beyond ease of use. “Dyslexia affects people by making them see words out of order and causing confusion. Speech recognition software not only puts the words on a screen, but also helps ensure they can be grammatically understood by others,” she says. “The look on a student’s face when their words appear for the first time is priceless.”

Despite its success, Strumpf admits she has received some concerns from educators on the use of AAC in the classroom. “First, speech recognition software is only useful if it hears one voice at a time; otherwise, it won’t know what to display. Some teachers feel the necessity for quiet makes the software impractical, since that isn’t always feasible in a classroom. Second, someone using speech recognition software to take an exam cannot do so in the classroom, since their answers will be overheard. This leads some instructors to question test results, believing someone else did the work, particularly if the student has a PCA with them.”

Despite the unresolved issues, Strumpf remains a strong supporter of AAC communication and speech recognition software. “These methods are essentially the only way I can use a computer. Without them, my life today would be drastically different.”

“Most schools I’ve seen have difficulty meeting the needs of a teacher with a disability.”

Shriver Center spotlight

SHRIVER CENTER SPOTLIGHT is published twice per year by the Eunice Kennedy Shriver University Center at UMASS Medical School.

The Shriver Center is dedicated to advancing local, national, and international efforts to improve the quality of life for individuals with intellectual and developmental disabilities (IDD) and their families. To that end, we carry out research to understand environmental and biological processes that influence behavioral development. In parallel and in collaboration, we carry out IDD-relevant programs of technology and information dissemination, education and training, technical assistance, and clinical service.

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Teresa V. Mitchell, PhD

Research Interests
Dr. Mitchell’s research combines a lifelong love of psychology with observing differences in behavioral and brain development between typically developing individuals and those with disabilities, including deafness and autism. More than just observational analysis, Dr. Mitchell’s work attempts to translate what those differences reveal about how individuals with disabilities perceive and attend to the world around them. For example, how do individuals who are deaf use their vision to compensate for their inability to hear? How do individuals with autism process the faces and expressions of others so they can recognize emotions and quickly adapt to new environments? As the founder and principal investigator of the Perceptual Development Lab (PDL), Dr. Mitchell, along with two laboratory assistants and occasional summer staffers, uses the PDL to integrate traditional behavioral measurements of reaction time and accuracy with advanced technology that includes eye-tracking (measuring where and for how long someone’s gaze lingers), event-related potentials or ERPs (recording variations of electrical activity evoked by specific input), and functional MRI (measuring oxygenated blood flow to the brain in response to stimuli or tasks). By combining these methods, the results generated are both reliable and complementary, qualities that make them uniquely informative. The PDL marks Dr. Mitchell’s latest full-scale exploration of brain development, but not her first. While pursuing her PhD in Developmental Psychology at Indiana University, Dr. Mitchell began to expand her ideas outside a traditional classroom setting, serving as a research assistant in IU’s Cognitive Development Lab. After completing her degree, Dr. Mitchell completed postdoctoral training at the University of Oregon and the Duke-UNC Brain Imaging and Analysis Center before arriving at the Shriver Center in 2002.

Dr. Mitchell’s efforts to broaden and translate her research into practice do not stop at the laboratory door, however. Thanks to a wide variety of college-level teaching experiences, she maintains an active role in shaping the minds of future researchers, both in her specialties and the overall field of psychology. Past courses include: Behavioral Disorders of Childhood and Adolescence, Personality Psychology, and lectures on the biology and culture of deafness.

Activities
Dr. Mitchell currently serves as review editor for the journal Frontiers in Developmental Psychology, and as a reviewer for 12 other journals including the International Journal of Disability Development and Education, Journal of Cognitive Neuroscience, and Brain and Language. She has also authored 25 peer-reviewed journal articles. Audiences for her national and international presentations include the Jean Piaget Society, the Society for Research in Childhood Development, and the Cognitive Neuroscience Society. Additionally, Dr. Mitchell serves as a member of the NIH Fellowship Study Section Review Group on Sensory and Motor Neuroscience, Cognition and Perception. Dr. Mitchell is also a recipient of the Postdoctoral National Research Service Award (1996-1999) funded by the National Institute for Deafness and Other Communication Disorders (NIDCD).

Career Influences and Vision for the Future
Dr. Mitchell’s first job after completing her undergraduate degree took her to the Eastern North Carolina School for the Deaf. As a behavioral programming specialist, she quickly became immersed in the deaf community despite having no prior experience with this population. While learning on the job, Dr. Mitchell credits much of her early understanding in the field to a deaf colleague who tutored her in American Sign Language (ASL) and its importance to the community. A self-described “fierce defender” of ASL today, Dr. Mitchell later expanded on those early lessons by pursuing a Master’s in Counseling and Deafness Rehabilitation from New York University, which supplemented a traditional counseling degree with courses in understanding the deaf culture and language while also assisting deaf individuals with life skills such as finding employment, job training and education in the hearing world. As a result of these pursuits, it should come as no surprise that Dr. Mitchell uses her research to look beyond the limitations of a disability, and instead attempts to understand how to maximize people’s potential. This perspective echoes a common theme stressed by all of Dr. Mitchell’s professional and academic mentors. “We are agents of our own development. It doesn’t just happen to us – we make it happen through all of our own experiences.”

Current Research Support
- Co-Investigator with William McIlvane, PhD, Program Project #3—Multimodal Analyses of Face Processing in Autism and Down Syndrome, NIH, 2007-2013.

Selected Book Chapters

Selected Peer-Reviewed Articles


The following individuals completed Shriver Center LEND fellowships for the 2012-2013 academic year. We congratulate them for their scholarly efforts, and are pleased to share their backgrounds.

Salimata (Sali) Bangoura, BS, MPH
Specialty: International Health, Maternal and Child Health
As a native of Mali, West Africa, Sali has long been interested in international health issues, particularly relating to individuals with disabilities and their families. Her experiences include serving as regional director of an educational program to integrate computers from the One Laptop Per Child Foundation into the Mali school system, and also as a medical coordinator for families of children with special health care needs, helping them receive lifesaving medical care from the Medical Missions Foundation in that country. Sali is a 2007 graduate of Hunter College, and currently enrolled as a Master's Degree candidate at the Boston University School of Public Health.

Ginny Brennan, M.Ed.
Specialty: Psychology, Special Education Advocate, Parent
Combining an extensive background in psychology and personal experience raising children with various disabilities, Ginny has extensive training in educational advocacy. After successfully advocating for students and families in over 45 school districts and private schools, her primary focus is on the design and implementation of her vision for the Rising Hope Farm, a multi-faceted learning center for children and adults with both learning and living components. The learning component plans to offer a wide range of equestrian, recreational, agricultural, culinary, arts-related, therapeutic, wellness and social opportunities. The living component will offer a range of accessible and supported housing. Ginny hopes to establish a pilot program this summer.

Juliana Brody-Fialkin, MSW, LCSW
Specialty: Social Work/Public Health
A Boston native with a lifelong passion for social work, Julianna currently serves as a case manager and parent educator for Boston Medical Center, working with families that include children recently diagnosed with ADHD. Julianna brings valuable experience in understanding oversight and policy review through a previous position at the Massachusetts Office of the Child Advocate. Julianna also values a sense of community awareness, and is collaborating with several state agencies and organizations to bring affordable housing and hospital-level medical care to her neighborhood.

Ivys Fernández, JD
Specialty: Law, Family Support
In her role as a family navigator at Boston Medical Center, Ivys assists families whose children have been diagnosed with autism receive needed services by helping them “navigate” the health care and school systems. Her long-term goals include developing accessible resources for Hispanic immigrants targeting health, education, and entitlements of individuals with disabilities. Originally from Puerto Rico, Ivys primarily serves individuals from Hispanic backgrounds.

Charles (Charlie) LeFevre, BA
Specialty: Psychology, Adult Services
Charlie comes to the LEND Program by way of Buffalo, NY, from a non-profit human services agency primarily serving children and young adults with autism. Through his previous roles as a Medicaid service coordinator, a case manager, and a supported employment specialist, Charlie is quite familiar with the various challenges faced by individuals with autism and their families. His current interests involve advocating for underserved families, and furthering opportunities for individuals with autism. Additionally, as a coach for the Asperger’s Association of New England’s Life Management Assistance Program (LIFEMAP), Charlie assists individuals with Asperger’s Syndrome in overcoming barriers and maximizing their independence.

Jennifer O’Leary, MBA
Specialty: Business Administration, Parent
A mother of three (two of whom have ASD), Jennifer acutely understands the challenging road faced by individuals with disabilities and their families. Her service in key professional roles transfers that knowledge to others. These roles include a current position as Chair of the Maynard Special Education Parents Advisory Council, and as a trainer for the Early Intervention Training Center in Massachusetts. In her training, Jennifer offers new service providers the perspective of a family receiving services. Jennifer’s primary focus lies in educating families and professionals on the needs of individuals with disabilities, their siblings and families, and emphasizing the need for family-centered and family-directed care.

Hemaluck (Lynn) Suwatanapongched, MD
Specialty: Developmental Behavioral Pediatrics
As a post-doctoral fellow at Boston University Medical Center, Lynn assists individuals with disabilities and their families in finding the best care and resources available. Her current research focus examines the role of parental language in the school system, specifically its relationship to parents’ success in advocating for their children in the special education system.

Joanne (Jodie) Vasily-Cioffi, JD
Specialty: Law, Parent
After a career in corporate law, Jodie’s current focus lies in educational policy. As the mother of two young daughters with special needs, she is particularly interested in ensuring the K-12 public educational system offers the same learning opportunities to individuals with disabilities as typically developing children. Jodie has previously completed an advocacy training course offered by the Federation for Children with Special Needs, and currently serves on the board of her local Special Education Parent Advisory Council. She also volunteers at a non-profit that brings disability-related educational content to local classrooms.

Helen Waldron, BS
Specialty: Family Professional Partnerships, Parent
Helen’s long-term focus involves bridging the gap of disparities among vulnerable populations through education and health policy reform. As mother to a ten-year-old son with multiple disabilities, Helen understands the challenges parents face as advocates. With a background in clinical research and data management, Helen currently holds a position as a program assistant at the National Center for Family/Professional Partnerships of Family Voices. The NCFPP provides technical assistance to Family-to-Family Health Information Centers, other family leaders, families, and professionals nationwide. It promotes families as partners in the decision-making of healthcare for children and youth with special health care needs (CYSHCN) at all levels of care.

The Shriver Center Leadership Education in Neurodevelopmental and Related Disorders (LEND) program is an intensive 10-month program designed to enhance the knowledge and skills of future leaders, clinicians, and family members in interdisciplinary, family-centered, and culturally competent care of children with neurodevelopmental disabilities and their families. The program focuses on policy, legislation, leadership, and management skills; graduates are committed to improving the lives of children with developmental disabilities and their families by demonstrating excellence in clinical, scholarly, and professional disability efforts, and working as effective change agents at the program, institutional, community, regional and national levels.
Editor’s Note: We are pleased to debut a new regular feature beginning with this issue. “Snapshot” will provide brief, periodic updates designed to detail new and ongoing projects, announce changes, or highlight achievements among the various departments here at the Shriver Center.

Autism Insurance Resource Center (AIRC)

AIRC Receives Prestigious 2012 “Organizational Hero Among Us” Award from AAIDD

The Autism Insurance Resource Center and its director Amy Weinstock were recently honored with the very prestigious “2012 Organizational Hero Among Us” award by the American Association on Intellectual Disability (AAIDD). The “Hero Among Us” Awards are presented annually in several categories and serve as an acknowledgement of excellence in the field of intellectual and developmental disabilities. 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/

Emergency Preparedness/UCEDD

Active Planning Project Assists First Responders in Ensuring Safety of Individuals with Disabilities

Individuals with disabilities are at high risk of losing independence, sustaining serious injury, and dying from the effects of emergencies and disasters. Therefore, first responders must understand how to best ensure the safety of individuals with disabilities during emergencies. The Active Planning Project addresses this need by training emergency management personnel to identify gaps in MA local emergency plans. To date, 62 towns and over 560 first responders and disability community members have participated. The training focuses on disability demographics, appropriate interaction with individuals with disabilities, and inclusive emergency planning for the whole community, via group discussion and lecture.

Participating towns later complete a workbook developed by the Shriver Center. Workbook tools help towns highlight strengths and gaps in local emergency plans. To date, all towns completing the workbook have identified gaps and developed remediation plans.

Center for Developmental Disabilities Evaluation and Research (CDDER)

Online Training Course Launches in Preventative Health Care for Adults with Intellectual Disabilities

CDDER announces a free online training course in conjunction with the MA Department of Developmental Services (DDS) entitled “Preventive Health Care for Adults with Intellectual Disabilities.” This computer based course aims to educate DDS staff, providers, and others who support adults with ID about the importance of preventive health care, the need for regular preventive health screenings, and how to advocate for adults with ID at medical appointments. Course topics include:

- Introduction to preventive health care and preventive health screenings for adults with Intellectual Disabilities
- Overview of DDS health tools for communication
- Advocacy for the annual health visit

The course can be completed from any computer, anytime, and takes approximately 40 minutes. Certificates of completion are available.

To register for and begin the course, visit http://onlinetraining.umassmed.edu/healthscreen-reg/event/registration.html.

Questions? E-mail CDDER@umassmed.edu
The Active Planning Project is a Shriver Center UCEDD activity. Key project members include:

• Sue Wolf-Fordham, JD, Project Manager
• Nancy Shea, JD, MPA, Project Coordinator
• Patrick Gleason, MA, Active Planning Trainer
• Jennifer Brooks, Recruitment Coordinator
• David Stowe, M.E.M., Consultant, Active Planning Trainer
• Charles Hamad, PhD, UCEDD Director

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INDEX

Website Redesign Allows for Cleaner and Easier Navigation in Locating Disability Resources

INDEX collects and maintains information on a wide variety of programs, agencies, and individual providers in Massachusetts that have something to offer to people with disabilities. The information available is almost limitless: information about accessible housing centers, assistive technology, disability specific information, even recreational opportunities, depending on an interest.

In its latest attempt to better serve individuals with disabilities, INDEX staff has redesigned its website to make navigation easier and more intuitive for individuals whose disability may interfere with their ability to fully use the Internet. A partial list of new or updated features includes:

• Multiple search options
• More accessibility (additional screen reader compatibility; easy, pale, high contrast and single column versions of web pages; guided searches to help visitors locate a provider, and more)
• Social media links on the home page, including a disability blog with new topics every month
• Adding or updating available services online (providers only).

Check out the new website for yourself, and see what INDEX has to offer. Visit http://www.disabilityinfo.org.

Massachusetts Act Early

Gabovitch reappointed CDC Ambassador; Governor’s Commission Recommends State Effort

The Association of Maternal & Child Health Programs (AMCHP) has reappointed Elaine Gabovitch to serve as the CDC “Learn the Signs. Act Early” (LTSEA) Ambassador for Massachusetts. During her 15-month commitment period, Gabovitch will: (1) promote the goals and objectives of LTSEA to improve early identification of autism and other developmental disabilities; (2) serve as a state point-of-contact for the national program; (3) support the work of the MA Act Early Coalition; and (4) promote the CDC “Autism Case Training: A Developmental Behavioral Pediatrics Curriculum.” She has served as team leader for the statewide coalition since June 2010.

The Massachusetts Governor’s Autism Commission has cited MA Act Early in three of its recent recommendations related to improving screening and detection in the state. The Commission issued its final report in late March to the state legislature after two years of ongoing research and deliberation. The full report may be downloaded at: http://www.mass.gov/hhs/autismcommission.

More information on MA Act Early, including free downloadable campaign materials on early childhood development, is available at: www.maactearly.org.
opportunities
Participation in Local, State and National Initiatives

Shriver Center Faculty “Light It Up Blue” for Autism Awareness Month

This year’s Light It Up Blue event at the UMass Medical School (UMMS) to promote World Autism Awareness Day was held on April 2, 2013 at the Worcester campus. Hosted by the Child and Adolescent Neurodevelopmental Initiative (CANDI) team at UMMS the event was cosponsored by Massachusetts Act Early, Autism Resource Center of Central MA, and the new Center for Autism and Neurodevelopmental Disorders (CANDo) at UMMS. In addition to a Provider Fair and a movie, the schedule included a short program of speakers:

- Elaine Gabovitch, MPA, Director of Family and Community Partnerships at the Shriver Center and State Team Leader/ CDC Ambassador for the MA Act Early state effort, shared information about what the “Learn the Signs. Act Early.” campaign offers to families, educators and clinicians through outreach, training and early identification efforts.
- Sue Loring, Director of the Autism Resource Center of Central Massachusetts, who served on the Massachusetts Autism Commission, gave the highlights of the 13 priority areas in the commission report released last month.
- Jean Frazier, MD, Vice Chair of Psychiatry and the Siff Chair in Autism, announced the exciting launch of the CANDo clinic this summer. She highlighted the great need that the CANDo will fill in the central and western parts of Massachusetts, and the interdisciplinary approach the clinic will use in meeting the needs of children, adolescents and families.

The community event culminated in the lighting of the medical school building in dramatic blue light, along with buildings around the world, to help shine a light on autism.

Massachusetts Autism Commission Issues Report with Help of UMMS Shriver Center Expert

With the prevalence of autism increasing at an alarming rate, the Massachusetts Autism Commission issued a report on March 28, 2013 calling for the Commonwealth to take “broad and ambitious” steps to improve services and supports for the estimated 75,000 people in Massachusetts with autism. Amy Weinstock, the director of the Autism Insurance Resource Center located at the UMass Medical School’s Eunice Kennedy Shriver Center, served on the Commission and said the report’s comprehensive recommendations will serve an important purpose.

“The Commission’s charge was very expansive and we really wanted to take a holistic approach at evaluating current services, identifying gaps and making recommendations for improvement,” Ms. Weinstock said. “I think the recommendations in this report represent a real blueprint for Massachusetts and, when adopted, will extend the state’s status as a national leader in addressing the needs of residents and families affected by autism.”

Among the many findings of the report, several critical needs were identified, including:

- The need for a single entity to provide comprehensive information on services and supports available to autistic residents;
- The need to improve access to mental health services, and to tailor those services to the diverse needs of residents on the autism spectrum;
- The need to change eligibility standards for adult services, focusing on functional ability rather than the current IQ standards;
- The need to improve employment, housing and case management services for adult residents with autism; and
- The need to establish and maintain consistent, statewide data collection on the number of people with autism in Massachusetts.

Established in April 2010 as the Governor’s Special Commission Relative to Autism, the goal of the Commission was to examine the needs of residents with ASD, both children and adults, and to make recommendations for a comprehensive, statewide approach to improve services. The full report can be found at: http://www.mass.gov/eohhs/gov/commissions-and-initiatives/autism/the-massachusetts-autism-commission-final-report.html
“I think the recommendations in this report represent a real blueprint for Massachusetts and, when adopted, will extend the state’s status as a national leader in addressing the needs of residents and families affected by autism.”

Health U.: A Nutrition Curriculum for Teenagers with Intellectual and Developmental Disabilities

Linda G. Bandini, PhD, RD; Carol Curtin, MSW; Richard K. Fleming, PhD; Melissa Maslin, MEd; and Renee Scampini, MS, RD

Shriver Center health promotion team faculty and staff have published a nutrition education curriculum for adolescents with intellectual disabilities (ID). The curriculum is based on research that the team has done for youth with ID as part of a weight loss program and has been refined further through its implementation in educational programs with students at several area special needs schools.

The goal of the curriculum is to provide youth with relevant knowledge about eating healthy and the importance of physical activity. Despite an abundance of nutrition education materials for typically developing adolescents, there is a lack of nutrition education materials geared specifically toward adolescents with ID. Nutrition education programs designed to address this population’s cognitive and communicative needs are likely to be more effective than attempts to modify existing curricula.

This curriculum provides age-appropriate nutrition education materials for adolescents and young adults with mild to moderate ID. It includes 10 lessons, each of which provides a short discussion where new concepts are introduced, an activity that includes hands-on learning, time to engage in movement/physical activity, and a “taste test.” The curriculum includes both basic and more advanced activities to accommodate a wide variety of abilities. Instructors can mix and match these activities according to the needs of their students. Each lesson includes a “Take Home Ideas” sheet for students to share what they learned with their parents/guardians. The curriculum also includes a large online appendix of lesson materials and resources that can be downloaded for each lesson.

The curriculum can be purchased at Amazon.com at: http://www.amazon.com/Health-Curriculum-Intellectual-Developmental-Disabilities/dp/1482351692/ref=sr_1_6?ie=UTF8&qid=1368044019&sr=8-6&keywords

LEND Alumni Present at the MCH Annual Making Lifelong Connections Conference

Five Shriver Center Leadership Education in Neurodevelopmental and Related Disabilities (LEND) alumni were invited to participate in a two-day interdisciplinary leadership meeting entitled “Making Lifelong Connections: Leadership, Networking and Career Development for MCHB Trainees” on April 4-5, 2013 co-hosted by the University of Wisconsin Pediatric Pulmonary Center (PPC) and the Wisconsin LEND along with the University of Alabama at Birmingham PPC. The meeting provided a forum for current and former maternal and child health (MCH) trainees to work together to enhance their leadership skills, network, and develop professional connections. All five alumni were accepted to present current or past projects related to MCH. Jonathan Jenkins, MS (2012) presented a case study entitled “Power in Prayer: The Power of Religion and Spirituality for Children with Developmental Challenges and Their Families.” Eve Wilder, MPH (2011) presented her policy paper “The Turning 22 Puzzle: Recommendations to Increase State Capacity for Serving High Functioning Adults on the Autism Spectrum.” Amy Weinstock, MA (2005) shared insights about the passage of the Massachusetts autism insurance bill on the Leadership panel, while Elaine Gabovitch, MPA (Class of 2006) and Linda Helmig-Bram, PhD (2012) spoke personally and professionally on the Family panel about the impact of family involvement in MCH and the boundaries that may get blurred for family members.

Two Additional Grants for Shriver Health Promotion Team

Linda Bandini, PhD and Carol Curtin, MSW received funding from the Ruderman Family Foundation to develop and implement an inclusive, community-based program benefitting pairs of Jewish adolescents with developmental disabilities and their typically developing peers. The *The Healthy Activity and Recreation for Teens (HEARTS)* program features physical fitness training, social skill development, peer support, and nutrition awareness in order to support teens to live healthy, active lives.

In addition, Linda Bandini, PhD, RD, was recently awarded a two-year grant by the Maternal and Child Health Bureau (HRSA/ MCHB) entitled *Diet, Feeding Practices, and Obesity in Children with Intellectual Disabilities*. The project will examine the eating patterns, mealtime behaviors, and parenting feeding styles and practices in children with intellectual disabilities compared to typically developing children ages 3-8 years. The relationship of these to children’s weight status will be explored. Carol Curtin, MSW, and Aviva Must, PhD (Tufts University) will also serve as co-investigators on the project.

**Grant Awards**

**Linda Bandini, PhD.** *Diet, Feeding Practices and Obesity in Children with Intellectual Disabilities*. Health Resources and Service Administration (HRSA/MCHB) entitled *Diet, Feeding Practices, and Obesity in Children with Intellectual Disabilities*. The project will examine the eating patterns, mealtime behaviors, and parenting feeding styles and practices in children with intellectual disabilities compared to typically developing children ages 3-8 years. The relationship of these to children’s weight status will be explored. Carol Curtin, MSW, and Aviva Must, PhD (Tufts University) will also serve as co-investigators on the project.

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**Linda Bandini, PhD.** *UAB Obesity Research Project on Prevalence Adaptations and Knowledge Translations.* University of Alabama. (Period: January 2012- September 2013).


**Carol Curtin, MSW.** *Healthy Activity and Recreation for Teens. Ruderman Family Foundation.* (Period: December 2012- December 2013).

**Curt Deutsch, PhD.** *Genomics of Neuropsychiatric Research. University of California San Diego.* (Period: September 2012- August 2013).

**Charles Hamad, PhD.** *University Center of Excellence on Developmental Disabilities. Association on Intellectual and Developmental Disabilities.* (Period: July 2012- June 2017).


**Janet Twyman, PhD.** *Set2Read: Center on Innovations in Learning. (National center center supported by the U.S. Department of Education, Office of Elementary and Secondary Education. Awarded to Temple University: Marilyn Murphy, PI).* (Period: September 2012- June 2018)


**Linda Bandini, PhD.** *Diet, Feeding Practices and Obesity in Children with Intellectual Disabilities*. Health Resources and Service Administration (HRSA/MCHB) entitled *Diet, Feeding Practices, and Obesity in Children with Intellectual Disabilities*. The project will examine the eating patterns, mealtime behaviors, and parenting feeding styles and practices in children with intellectual disabilities compared to typically developing children ages 3-8 years. The relationship of these to children’s weight status will be explored. Carol Curtin, MSW, and Aviva Must, PhD (Tufts University) will also serve as co-investigators on the project.


**McIlvaine, W. J., & Kledaras, J. B.** (2012). *Some things we learned from Sidman and some we did not (We think). European Journal of Behavior Analysis, 13(1), 97-109.*


**Books & Book Chapters**


“Health U” educates adolescents making healthy food choices and engaging in regular physical activity. The initial “Health U” pilot that eventually led to the current project was the subject of an article in our premiere issue of this newsletter.

Twyman to Direct Innovation and Technology for National Center on Innovations in Learning

Janet Twyman, PhD, BCBA, Associate Professor of Pediatrics at UMass Medical School, has recently been named Director of Innovation and Technology for the Center on Innovations in Learning (CIL) housed at Temple University. Her appointment follows a five year grant award from the United States Department of Education to develop CIL into one of only seven model centers in the country. CIL aims to increase learning opportunities and improve outcomes for students by assisting state education agencies in developing and implementing programs designed to promote innovation at the local education agency level. As Director of Innovation and Technology, Dr. Twyman’s responsibilities include identifying educational innovations and future best practices in the field, and offering assistance to states on technology selection, including tools to assist in managing, sustaining, and implementing learning innovations.

Former “Health U” Participants

The Shriver Center, in collaboration with UMass-Boston, will be carrying out a full trial of its “Health U” program, a weight loss intervention for overweight adolescents with intellectual disabilities (ID) using a family-based behavioral intervention approach. “Health U” educates adolescents making healthy food choices and engaging in regular physical activity. The program also teaches parents how to use supportive behavioral techniques to encourage their adolescent sons or daughters to adopt and maintain healthy eating and activity behaviors. The program is designed to promote gradual, consistent weight loss. The “Health U” study will compare weight loss outcomes between two groups of adolescents and their families – those who receive the core Health U. sessions and those who also receive additional maintenance sessions. The project is a newly funded R01 grant from the National Institute of Child Health and Human Development (NICHD) and will be led by Richard Fleming, PhD, Associate Professor of Exercise & Health Sciences at UMass-Boston and Adjunct Associate Professor of Psychiatry at UUMS. The Health U program was designed by Dr. Fleming and Shriver Center colleagues Linda Bandini, PhD, Carol Curtin, MSW, James Gleason, MS, PT, and Melissa Maslin, MEd. The initial “Health U” pilot that eventually led to the current project was the subject of an article in our premiere issue of this newsletter (See http://tinyurl.com/2de93lr).
On April 2, 2013, UMass Medical School’s Shriver Center marked the launch of a new online course for parents of children with autism spectrum disorder (ASD) entitled Discovering Behavioral Intervention: A Parent’s Interactive Guide to Applied Behavior Analysis, or ABA. The 10-module online learning guide was created by an interdisciplinary Shriver Center course development team dedicated to helping families of children with autism spectrum disorder. Scientists, course developers, graphic designers, instructional designers, and parent advisors all contributed to this evidence-based, educational tool.

The learning modules offer rich content about ABA in a self-paced format supported by family-friendly videos, interactive graphics, and immersion exercises. Throughout the series, Discovering Behavioral Intervention introduces the language and principles of ABA, and features parents of six children on the spectrum as trusted guides. Their real-life stories will help parents navigate the complex world of autism and behavioral intervention. Parents will learn how to advocate for their child’s education and health care, secure high-quality behavioral services, and actively monitor and evaluate their child’s program.

The UMMS-Shriver Center Discovering Behavioral Intervention development team was led by principal investigator Richard Fleming, PhD, and included Maura Buckley, MPA (who now serves as its product manager through UDiscovering, a program of UMMS affiliate UHealth Solutions), Elaine Gabovitch, MPA, Cheryl Gray, Melissa Maslin, PhD, and Elise Stokes, MS. In the future, UDiscovering will offer Discovering Behavioral Intervention and many more new online training tools, products, and services developed by the UMMS-Shriver Center to help families and professionals touched by or working in the field of intellectual and developmental disabilities. More information about Discovering Behavioral Intervention may be found at: http://www.udiscovering.org/.

As parents become more familiar with the foundation and concepts of ABA, the doors open to greater learning. DBI demonstrates the power of reinforcement, the principles of behavior, and how to motivate children with ASD.