Shriver Center Studies Actively Pursue Childhood Obesity in Developmental Disabilities

It is well known that obesity has emerged as a serious public health problem in the U.S., one that is increasing both in prevalence and severity. In 2006, 17 percent of U.S. children and adolescents were reported to be overweight, and over a third of adults obese. Despite a flood of articles across all media outlets and the release of scientific reports on the obesity “epidemic,” shifting American behaviors in the direction of healthy lifestyles is a challenge for all. While a solid foundation of research exists for children in the general population, in fact, very little attention has been given to understanding and treating childhood obesity in children with developmental disabilities. Adding them to the fight to promote good health for all children is only just beginning; research is still needed to understand, prevent and treat this mounting health problem for this unique population.

Understanding the Problem

While obesity is generally understood to result from a long-term pattern of taking in more calories than one’s body expends, understood as “energy imbalance,” the factors that give rise to such imbalances are varied and complex. Contemporary research supports the notion that body weight is a complex combination of genetic, metabolic, behavioral, environmental, cultural and socioeconomic factors. The fact that obesity rates have doubled over the last two decades has led many to conclude that because we live in a social environment that actively promotes food over-consumption and sedentary lifestyles, it has become increasingly difficult for individuals to strike a balance between getting enough exercise/physical activity and modulating their caloric intake.

Obesity, defined as excess body fatness, can be determined in several ways. Because body fatness is difficult to measure, body mass index (BMI), which is weight divided by height squared, is highly correlated with body fatness and is used to identify persons who are overweight or obese. For children and teens, BMI is age- and sex-specific. For example, females naturally carry a higher percentage of body fat than males. After a child’s BMI is calculated, it is plotted on BMI-for-age growth charts (for girls or boys) that have been developed by the Centers for Disease Control and Prevention. This produces a percentile ranking, which is most commonly used in assessing children’s growth, and indicates how the child’s BMI compares to children of the same sex and age.

Two important factors contributing to the likelihood that childhood obesity will persist into adulthood are severity and age of onset. The greater the severity of obesity, the more likely it is to persist; furthermore, the probability of an overweight child becoming an overweight adult increases with age. Of greatest concern are the negative consequences of childhood obesity. It is associated with an increased risk for type 2 diabetes, orthopedic problems, sleep apnea, elevated cardiovascular risk factor levels, menstrual irregularities and social problems.

Research on overweight in children with developmental disabilities has been limited, with most of our knowledge coming from clinical observations and studies with small sample sizes. High prevalence rates of overweight among children with genetically-related disabilities such as Prader-Willi syndrome and Down syndrome, and obesity in children with other disabilities, such as spina bifida and cerebral palsy, have been documented, but little work has been done on children with other types of disabilities. Likewise, scant attention has been paid to identifying effective means for preventing and treating obesity in persons with developmental disabilities.

continued on page 2
Three Shriver Center Studies on Childhood Obesity  

Shriver childhood obesity research initiatives  

In response to this lack of research, the Shriver Center’s Healthy People Healthy Communities (HPHC) division has developed a comprehensive research program designed to better understand, treat and prevent the problem of obesity in children with developmental disabilities. Three NIH-funded childhood obesity research studies are currently underway.

Linda Bandini, PhD, RD, a nutritionist and established obesity researcher and Director of Nutrition in Shriver’s Leadership Education in Neurodevelopmental Disorders (LEND) program, is conducting a study on diet and physical activity in children with autism, funded by the National Institute of Child Health and Human Development (NICHD). The study, called the Children’s Activity and Meal Patterns Study (CHAMPS), has several aims. One is to determine whether children with autism demonstrate more food selectivity than typically developing peers. According to Dr. Bandini, parents often report that their children restrict their intake to a few foods, but research on this has been limited.

“We are examining the food patterns of children with autism to determine if they differ from those of typically developing children,” said Bandini. Another aim of CHAMPS is to test the hypothesis that children with autism take part in less physical activity than typically developing children. “Parents report that their children are often not included in games, or on sport teams that their peers are involved in, said Bandini. “We will examine children’s physical activity levels and participation in different activities to determine how they differ from typically developing children. The data obtained on both dietary intake and physical activity will help us determine the need for specific interventions to increase physical activity and improve nutritional intake among children with autism.”

A second study, the Physical Activity in Children (PAC) study is directed by Sharon Cermak, EdD, an occupational therapist on the faculty of the UMMS Department of Family Medicine and Community Health/Shriver Center and the Boston University Sargent College of Health and Rehabilitation Sciences, Department of Occupational Therapy, and the director of Occupational Therapy in Shriver’s LEND program. Dr. Cermak’s study, also funded by NICHD, focuses primarily on children with difficulty in motor coordination who may have received diagnoses of dyspraxia, motor planning problems, Developmental Coordination Disorder (DCD) or may simply be described as clumsy children. The PAC study seeks to determine whether children with poor motor coordination engage in less physical activity, have lower levels of fitness and/or poorer self-perceptions than their peers.

“Children develop fitness through physical activity. Because movement is harder for children with DCD, they are less likely to be physically active,” said Cermak. “Low physical activity is a risk factor for low fitness and related obesity. Thus, children with DCD are at risk for low levels of physical fitness. It becomes cyclical.”

“It may be tempting for people to ask ‘so what if a child’s coordination is affected?’ But such problems can lead to issues like exclusion from sports or activities with peers, resulting in low self-esteem or a desire to withdraw from physical activity,” Cermak continued.

The net result may be that children with poor motor competence may perceive themselves as less physically attractive, have fewer friends and have difficulty with social acceptance. For many children with compromised motor skills, their quality of life suffers in the end.

Finally, a third Shriver University Center of Excellence in Developmental Disabilities (UCEDD) project studies on weight loss for overweight adolescents with Down syndrome. Funded by the National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK), the “Health U.” program teaches adolescents and their families about good nutrition and daily physical activity. The study is a randomized controlled trial in which participants are assigned to one of two conditions: an educational condition and a behavioral intervention condition.

“Our hypothesis is that when you teach families to change their lifestyles at home, that allows a greater chance of long-term positive change. This study will help us learn if adolescents with Down syndrome, with their family’s support, can better manage their health habits and control their weight...”

continued on next page
“Obesity is a highly stigmatized condition that can lead to discrimination of overweight people. Our main focus here is on improving health, not labeling food and behavior as good or bad. We live in an environment where food is available readily and cheaply, and we are not required to move frequently or vigorously. We have to find ways to support people to make concerted efforts to eat healthily and to take time out of each day to get physical activity, because it is no longer built into our daily lives to do so.”

HPHC’s approach to the problem of obesity in children with special health care needs and developmental disabilities accounts for the psychosocial dimensions of obesity.

“Obesity is a highly stigmatized condition that leads to the discrimination of overweight people,” said HPHC Director Carol Curtin, MSW, “Our main focus here is on improving health, not labeling food and behavior as good or bad. We live in an environment where food is available readily and cheaply, and we are not required to move frequently or vigorously. We have to find ways to support people to make concerted efforts to eat healthily and to take time out of each day to get physical activity, because it is no longer built into our daily lives to do so.”

HPHC has other projects in the planning stages, including examining the problem of obesity in children and adults with attention deficit hyperactivity disorder; determining the correlates of physical activity in adolescents with intellectual/developmental disabilities; and developing community-based physical activity programming for adolescents with autism spectrum disorders.
CDDER’s Health and Wellness Promotion Initiatives

Enhancing health, safety and the quality of life for people with developmental disabilities is the vision of the Center for Developmental Disabilities Evaluation and Research (CDDER) located at the E.K. Shriver Center. Established in 2000, CDDER is a University of Massachusetts Medical School (UMMS) Center of Distinction within UMMS’ Commonwealth Medicine Division as part of its Center for Health Policy and Research.

CDDER’s mission is to promote and conduct applied research, evaluation, quality improvement, education and training aimed at informing policy decisions and advancing practice to improve the health and well-being of people served by public agencies. To fulfill its mission, CDDER partners with public agencies to customize solutions through the research and analysis of programs serving people with developmental disabilities. The Massachusetts Department of Mental Retardation (DMR) is one of the largest and most active partners; smaller partnerships exist in other states such as Connecticut.

The multidisciplinary faculty and staff at CDDER include Charles Hamad, PhD, Director; Alexandre Bonardi, MHA, OTR/L, Assistant Director; Steven Staugitis, PhD, Assistant Professor, UMMS; Bob Baldor, MD, Medical Director, Vice Chair, Department of Family and Community Medicine, UMMS; Joan Beasley, PhD, Senior Project Director; and Emily Lauer, consultant.

Health and wellness promotion is a major emphasis of CDDER’s work, which conducts best practices research and provides development support for its partners. For example, DMR started its Health Promotion and Coordination Initiative in partnership with CDDER to develop a body of work meant to ensure that the health of the people in its care is addressed. “The first product was developed in recognition that annual physicals were often not conducted adequately for people with developmental disabilities. They were more like school and camp physicals where clinicians simply check off boxes, rather than comprehensive examinations,” said Bonardi.

In an effort to address this disparity in the delivery of health care to people with intellectual disabilities, CDDER worked with a multidisciplinary team of expert clinicians to develop a set of guidelines, entitled Preventive Health Recommendations for Adults with Mental Retardation, through the National Guidelines Clearinghouse. The guidelines, based on findings that the population with intellectual and developmental disabilities has unique health screening needs, recommends a schedule of health maintenance and specialized health care visits (i.e., exams for cancer prevention, hypertension, diabetes, vision and hearing screening, dementia, depression, etc.), general counseling and guidance, preparation for exams and communication guidelines for practitioners.

CDDER also collaborated with DMR clinicians and staff to develop the DMR Training and Resource Manual in December 2003, which includes the Preventive Health Recommendations and provides recommended standards, physician tools, fact sheets, and other field-tested forms and systems. Its purpose is to promote rigorous preventive screening programs and provide recommendations for practice including a two-stage process comprising an outcome evaluation and a process evaluation targeted to measure the success of screening initiatives and report compliance. The full manual can be downloaded at: www.mass.gov/Eeohhs2/docs/dmr/hpci_training_manual.pdf.

In 2004, CDDER convened the DMR Health Advisory Committee, an external body of advisors, to assist the agency on setting its health priorities. A subcommittee, the Healthy Lifestyles Workgroup, comprises staff members, clinical experts from the Shriver Center UCEDD, the Institute for Community Inclusion, the Massachusetts Department of Public Health and the DMR; an early task was to identify innovative practices that may serve as models for health promotion strategies for families and other providers. CDDER developed a survey of Massachusetts provider agencies known as the Healthy Lifestyles Survey. The report, published in November 2006, summarized findings from 55 respondents representing 44 agencies evenly distributed across Massachusetts. The survey questions focused on healthy lifestyle issues, such as physical fitness, nutrition and weight management for adult consumers with intellectual disabilities. Its purpose was to learn about “pockets of excellence” among current local initiatives, to seek information about what useful or “best” practices in programs exist as well as what barriers exist, and to gather information about innovation and strategies to share with families and providers.

The survey findings revealed the following:

- Interest exists in the provider community to promote healthy lifestyles
- Providers are looking for more information and models of best practice
- Funding is a primary need to introduce, sustain and maintain health promotion
- Physical activity initiatives presently have used mostly informal supports, though formal supports are needed and would improve programs
- Nutrition training is needed for staff and consumers
- Information is needed on movement activity and limited mobility
- Individuals’ resistance to activity arose as a prominent survey theme

Members of the subcommittee are currently developing a basic nutrition and activity recommendations guide specific to the DMR population.

CDDER work on preventive care and healthy lifestyles is an important start to changing practice and to understanding what is needed to enhance the health, safety and quality of life for people with intellectual disabilities. “Getting good health care is an essential part of a good healthy lifestyle,” said Bonardi. “Our work lays a foundation of supports for health promotion, since you can’t get to the gym if you’re not well.”

3 Ibid.
In October 2007, University Center of Excellence in Developmental Disabilities UCEDD Associate Director Jim Gleason, MS, PT, worked with the Special Olympics Healthy Athletes® program to train new clinical directors, and to administer physical therapy screenings at the 2007 Special Olympics World Summer Games in Shanghai, China. The Healthy Athletes program provides free health screenings for vision, hearing, oral health, podiatry, physical therapy and other aspects of health promotion. The physical therapy screening, known as FUNfitness, includes evaluation of flexibility, balance, strength and cardiovascular endurance. These screenings help Special Olympics athletes perform better in sports and their chosen field of athletic competition, and provides much needed health services and identification of health needs for people with intellectual disabilities. Athletes and coaches are taught exercises, and referrals for needed health care are provided.

In Shanghai, more than 7,000 athletes from 164 countries competed in athletic competitions. Nearly 19,000 health screenings were provided in the two weeks of the Games reaching 4,900 athletes. In the area of FUNfitness, physical therapists screened 2,576 athletes.

Gleason is the Education and Research Coordinator for the FUNfitness program and works with a team of experts to provide training so that these health screenings can be implemented around the world. Physical therapists, sports professionals and exercise experts learn to administer the FUNfitness screenings, then return to their home countries or states to implement screening programs.

In Shanghai, there was continuous media coverage of Special Olympics events highlighting the capabilities and accomplishments of people with intellectual disabilities. Thousands of volunteers assisted Special Olympics athletes, learning first hand about the capabilities of people with disabilities. In addition, Chinese officials made strong statements of commitment to expanding opportunities for people with disabilities in their country.

Pictured here: a Brazilian Special Olympics Athlete and his coach have just finished a FUNfitness screening with therapists from Namibia and Brunei and several Chinese volunteers.
Health U. Teens and Parents Exercise Healthy Eating and Activity Choices

In today’s fast-paced world, busy consumers continually face challenges in choosing healthy foods amid an array of temptations. Food is seemingly available around every corner; inexpensive choices lure consumers to buy now and buy often. Conflicting reports and advertisements about the nutritional value of various foods, leave most people confused about what they should be eating. While healthy eating guidelines such as the Food Guide Pyramid (www.MyPyramid.gov) are available, this information can be unwieldy and difficult to understand especially for people with intellectual disabilities and their families, who need information presented in an easily accessible way to facilitate understanding and appreciation of the long-term benefits of healthy foods and daily exercise.

Last year, the Shriver Center took an important step toward this goal by launching the Health U. program. With funding from the Deborah Munroe Noonan Memorial Fund and the John Alden Trust, researchers developed a pilot weight-loss intervention study to educate and provide behavioral support to overweight adolescents with intellectual disabilities and their parents on how healthy eating and regular physical activity leads to gradual, moderate weight loss. Five adolescents and their parents participated in a 14-session program featuring an interactive nutrition and physical activity curriculum and supportive behavioral intervention strategies. A larger Health U. study is currently underway, supported by funding from the National Institute of Diabetes, Digestive and Kidney Disorders (NIDDK) and led by Richard Fleming, PhD, a behavioral psychologist at the Shriver Center. “This endeavor is important because there is a lack of national focus on health promotion among children and adolescents with intellectual disabilities. It is clear that there is a struggle with obesity in both the U.S. and in the world, and we need to find ways to support people with disabilities to make healthy choices and engage in regular physical activity,” said Shriver faculty member Carol Curtin, MSW, principal investigator of the Health U. pilot program. “Engaging kids and parents in an interactive program designed to provide information and support in a way that the kids themselves could understand and use is at the heart of our approach.”

Parents of participants praised Health U. for creating positive changes in their children. “My daughter Sara looks at physical activity and eating in a whole new way. She has a foundation to build on now, everything from portion sizes and understanding healthy foods better to taking part in track and field,” said Robin.

“There was a real sense of camaraderie among the staff people. My son Patrick began wanting to improve his habits and do well. Positive reinforcement played a big role, and that definitely helped,” said another parent.

Kelly saw nutritional improvements in her daughter Abby. “Her awareness is better than before, and she can definitely make better choices now. She might choose yogurt over a cookie, for example. We haven’t always been healthy eaters, so that’s definitely a good thing,” said Kelly.

As with any eating or exercise program, drastic changes are seldom the answer. Therefore, Health U. did not promote stopping snacks, but instead focused on identifying healthier snacks and increasing nutrition awareness, a strategy that particularly pleased Elaine, mother to 15-year-old Brian. “Many times people with intellectual disabilities hear information, but have trouble processing what it means or why it should matter. That can be very hard when trying to help with nutrition. Without understanding what that means, it can be very difficult for them to relate to things,” Elaine said.

For the general population of children:
- Excess energy intake (soda and fast food consumption)
- Skipped breakfasts, low intake of fruits and vegetables
- Low levels of physical activity
- Sedentary behavior (watching television, viewing videos, using a computer)

For children with special health care needs, add:
- Medication-induced weight gain
- Difficulty chewing or swallowing
- Unusual responses to sensory stimuli and abnormalities in eating
- Mobility limitations
- Coordination issues
- Energy management
- Family stressors
- Limitations in family resources
- Struggles with peer interactions

All parents involved in the program pointed to the need for structure and routine as reasons why proper nutrition can be difficult, especially when images from other sources compete for their attention.

“The media doesn’t help much, particularly by constantly running ads showing fast-food places to be fun and exciting. A lot of times, those are the main things people latch on to,” said Patty.

Despite these potential pitfalls, everyone expressed confidence in their child’s newfound ability to stay on top of these issues.

“Past nutritionists would always talk to me about what should be done and never to my daughter,” Robin commented. “I was always saying, ‘Why are you talking to me?’”

“Kids with disabilities aren’t usually given ownership of issues in their lives,” Elaine added. “I feel like Brian has that now and it is a tremendous help.”

The current Health U. study is focusing on adolescents and young adults with Down syndrome. It will be completed at the end of 2008, at which point Dr. Fleming, Curtin and their colleagues will be publishing their results and planning ways to expand the program and develop curricula for members of the community,

**spotlight on Health Promotion Resources**

We all deserve to have a high quality of life, both physically and mentally; a healthy lifestyle is the cornerstone of this goal. The benefits of physical activity and good nutrition are within reach of all individuals, from the very young to the oldest among us, with and without disabilities.

The following resources stress this core concept; helping children and adolescents with disabilities lead healthy lives has been the focus for the efforts listed below. Visit these sources for information and tips related to nutrition, physical activity and more.

**Publications**

**AAP Policy Statement: Prevention of Pediatric Overweight and Obesity**

Published by the American Academy of Pediatrics Committee on Nutrition, the policy statement proposes strategies for early identification of excessive weight gain, dietary and physical activity interventions, and advocacy and research.

http://aapolicy.aappublications.org/cgi/reprint/pediatrics;112/2/424.pdf

**CLOSING THE GAP: A National Blueprint to Improve the Health of Persons with Mental Retardation: Report of the Surgeon General’s Conference on Health Disparities and Mental Retardation.**

Published by the Office of the U.S. Surgeon General, Closing the Gap is essential reading for understanding the critical importance of health promotion for people with intellectual disabilities and the health disparity challenges that exist. PDF version, U.S. Department of Health and Human Services, Public Health Service, Office of the Surgeon General, 2002

www.surgeongeneral.gov/topics/mentalretardation

**Children With Special Health Care Needs:**

**Nutrition Care Handbook**

This resource, published by the American Dietetic Association, provides a ready reference for health care professionals monitoring the nutritional care of children with special health care needs, including Down syndrome, autism, cerebral palsy and other disorders. Softbound, 180 pages, 2005.

www.eatright.org/cps/rde/xchg/ada/hs.xsl/shop_1292_ENU.HTML.htm

**KidsHealth**

Provides physician-approved health information for children and adolescents. Created by The Nemours Foundation’s Center for Children’s Health Media, KidsHealth provides families with accurate, up-to-date and easy-to-understand health information.

www.kidshealth.org/kid

**Kid’s Quest on Disability and Health**

Early adolescents with and without disabilities can go on a guided "Quest" to learn about life with disabilities and some of the issues related to daily activities, health and accessibility. Hosted by the CDC’s National Birth Defects and Developmental Disabilities Center, Kid’s Quest asks questions such as, “Can a Kid in a Wheelchair be an Athlete?" Which can be used in lessons about health, social studies and tolerance in society.

www.cdc.gov/ncbddd/kids/kidhome.htm

**Zigawhat?**

A Web site for “learning, connecting, growing, coping and fun for young people with disabilities and their peers.” Maintained by the National Dissemination Center for Children with Disabilities (NICHCY).

www.nichcy.org/kids/index.htm

**Web sites for all ages interested in health promotion for people with disabilities**

The National Center on Physical Activity and Disability (NCPAD) is an information center concerned with physical activity and disability. Being active is an important part of getting and staying healthy. The Web site clears up the common confusion people have about the relationship between having a disability and being healthy. The main message there is that “the important thing is not what you do, but that you do something.”

www.ncpad.org

**Special Olympics**

Special Olympics is a leading name in health promotion for people of all ages with intellectual disabilities. Through sports training and competition, children and adults with intellectual disabilities are empowered to become “physically fit, productive and respected members of society.”

www.specialolympics.org
Research Interests

Dr. Bandini’s interests in nutrition and metabolism drive her ongoing research at the Shriver Center. Her research lies in understanding energy expenditure, energy intake and meal patterns among children with and without developmental disabilities. Bandini also has an interest in developing health promotion programs for children and adults with developmental disabilities. She serves as a principal investigator and co-investigator on several ongoing studies at the Shriver Center, all of which focus on nutrition and physical activity factors in children and adolescents with developmental disabilities including Down syndrome, autism and developmental coordination disorder. Bandini has been instrumental in creating the UCEDD research program devoted to health promotion for people with developmental disabilities and has provided scientific leadership in conceiving of and carrying out the Center’s ambitious health promotion research agenda.

Activities

Bandini has authored nearly 60 journal articles, chapters and monographs. She has been a reviewer for national and international journals of nutrition, obesity and pediatrics including American Journal of Clinical Nutrition, British Journal of Nutrition, Pediatrics, Journal of the American Dietetic Association, Journal of Pediatrics, Acta Paediatrica, International Journal of Obesity, Obesity Research and Journal of Pediatric Gastroenterology and Nutrition. In addition, Bandini has served on a number of NIH and CDC scientific review panels focused on clinical nutrition, obesity and health promotion. She presents at major national professional conferences regularly and is a member of the American Dietetic Association, the North American Association for the Study of Obesity, the American Society of Nutrition and the Boston Obesity Nutrition Research Center.

Career Influences and Vision for the Future

Bandini credits her early years spent as a dietitian for the Fernald School in Waltham as her motivation to pursue research in the developmental disabilities field, particularly because it was extremely difficult to assess nutritional status and monitor nutritional needs of the residents there. Her unique combination of hands-on field experience and dedication to continuing this important field of research is still evident today. She envisions her research being instrumental in the future development of effective health promotion programs for children and adults with developmental disabilities.

Research Support

Bandini’s research is presently supported by funding from the Maternal and Child Health Bureau (MCHB), the Health Resources and Services Administration/ Administration on Developmental Disabilities (HRSA/ ADD), and the National Institute of Child Health and Human Development (NICHD).

- Principal Investigator, Diet, Activity & Obesity in Children with Autism, NICHD, 5/1/06-4/30/08
- Co-investigator, Physical Activity, Physical Fitness and Obesity in Children with Developmental Coordination Disorders, NICHD, 5/1/06-4/30/08
- Co-investigator, A Parent-Supported Weight Reduction Program in Down Syndrome, NIDDK, 7/1/06-6/30/08.

Selected Peer Reviewed Articles


E.K. Shriver Center
LEND Fellows for 2007-2008

The Shriver Center UCEDD Leadership Education in Neurodevelopmental and Related Disorders (LEND) program is an intensive 10-month fellowship 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. Each year, the LEND program admits 10 interdisciplinary professionals from the field of neurodevelopmental disabilities as well as family members of individuals with neurodevelopmental disabilities to the program. 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 efforts, and working as effective change agents at the program, institutional, community, regional and national levels.

We are pleased that the following individuals are participating as our 2007-2008 LEND Fellows:

**Tamara Armstrong, PsyD**
Behavioral Science/Primary Care Psychologist
Studies as a post-doctoral fellow in Primary Care Psychology at UMass Medical School.

**Meredith Bolden, MSW**
Social Worker
Works with children and adolescents with Asperger syndrome and high functioning autism at CNS/Pathways Academy at McLean Hospital in Belmont.

**Maura Buckley**
Parent, Health Care Manager
Full-time mother of three children, of whom two have autism and mitochondrial disorders. Advocates to build awareness of these disorders.

**Dianne Coscia, MD**
Physician
Studies as a pediatric fellow in Developmental and Behavioral Pediatrics at Boston Medical Center.

**Deborah Finn, MEd**
Educator
Educates children within Boston Public Schools who are medically fragile and have developmental disabilities.

**Carmen Pimentel**
Program Coordinator
Coordinates HIV & AIDS client advocacy program at the Latin American Health Institute (LHI) in Boston.

**Sally Savelle, MEd**
Special Educator, Consultant
Trains parents and school personnel to implement the DIR®/Floortime™ approach with children with autism spectrum disorders.

**Julie Savoyski, MS, OTR-L**
Occupational Therapist
Works in a number of therapeutic settings with children and adolescents from a variety of backgrounds at the Home for Little Wanderers in Boston. Coach for Special Olympics of Massachusetts Alpine Ski Team.

**Sue Wolf-Fordham, JD**
Jewish Agency Community Liaison, Lawyer, Parent
Co-founded The Special Needs Initiative, an international special education, family support and humanitarian aid program. Founding director of Yesodot, a support program for Boston Jewish families challenged by disability. Mother of two teens with disabilities.
Peer Reviewed Publications


Conference Abstracts, Papers, and Invited Presentations

questionnaire to assess child mealtime behavior within the context of families. Obesity Research. 155:A228.


Serna, R. W. (October, 2007). Aprendizagem de discriminação auditiva em indivíduos com falta de habilidades intelectuais: onde estamos e aonde precisamos ir. (Auditory discrimination in individuals with intellectual disabilities: Where are we and where do we need to go.) XXXVII Reunião Anual de Psicologia Sociedade Brasileira de Psicologia Florianópolis, Brazil.

Faculty Appointments & Activities

Robert Bass, PhD, Director, New England INDEX and LEND Faculty, served as the technical lead to establish the Massachusetts Aging and Disabilities Information Locator (MADIL), a project under the Massachusetts Executive Office of Health and Human Services. It can be accessed from http://mass.gov/eohh or directly at www.madil.org. Additionally, New England INDEX and the Massachusetts Network of Information Providers for People with Disabilities (MNIP) held their annual meeting on November 2, 2007, which featured newly appointed Massachusetts Assistant Secretary of Health and Human Services Jean McGuire as the key-note speaker.

Kathleen Braden, MD, Director, LEND Program, chaired the development of a statement of principles for the Association of University Centers on Disability (AUCD) on “Medical Interventions for People with Severe Disabilities” in response to the “Ashley treatment.”

William Dube, Ph.D., Associate Professor of Psychiatry, Shriver Center Research Faculty, was appointed to the Board of Editors for the Journal of the Experimental Analysis of Behavior and the Journal of Applied Behavior Analysis in 2007. He was also appointed to be Elected Member at Large on the Division 25 Executive Committee of the American Psychological Association.

Richard W. Serna, Ph.D., Associate Professor of Psychiatry, Shriver Center Research Faculty, was appointed to the Board of Editors for The Psychological Record in 2007. He was also appointed as Director of Research for the University Center for Excellence in Developmental Disabilities at the Shriver Center.


Lee Vorderer, MA, LEND Faculty, was instrumental developing and launching the undergraduate Minor in Disability Studies that began in Fall 2007 at the University of Massachusetts-Lowell. One of the first courses in this process was Introduction to Developmental Disability, a course designed by Ms. Vorderer, and taught by Ms. Vorderer and former LEND fellow Katherine Fox.
Translational Studies of Neurobehavioral Effects of Mercury Exposure in Brazil

William McIlvane, PhD, E.K. Shriver Center Director, was recently awarded a planning grant from the National Institute of Environmental Health Sciences to conduct a translational research and research training project to investigate mercury poisoning in Brazil. The project, which will use a similar test battery to examine the neurobehavioral effects of mercury exposure in both children and nonhuman primates (Cebus apella monkeys), was deemed highly innovative by NIH. The Shriver Center’s neurocognitive test battery will be re-tuned for use in neurobehavioral testing of Cebus apella, and will examine the constructs of motivation, attention, memory and executive functioning. The use of such a similar mercury-sensitive test battery for human and nonhuman primates has the potential to move the field of neurotoxicology beyond its current research findings on the effects of mercury exposure.

The project is a collaborative international effort in which basic and clinical researchers from the United States and Brazil will develop an interdisciplinary program of translational biobehavioral research and research training focusing initially on the neurotoxic effects of mercury exposure. The research training will involve primarily doctoral students from Brazil and the U.S., as well as undergraduate students. The project will validate novel methods for evaluating neurobehavioral functioning in nonhuman primates, apply the methods to study effects of mercury exposure on behavior, and extend the methods to evaluate sensory and neurocognitive function of mercury exposure in children living near gold-mining operations in Brazil. The project scientists include Drs. McIlvane and Leo H. Buchanan from the University of Massachusetts Medical School UMMS–E.K. Shriver Center, Dr. S. Allen Counter of the Harvard Medical School, Dr. M. Christopher Newland of Auburn University in Auburn, Alabama, and Drs. Maria Elena Crepo Lopez, Domingos Diniz, Olavo de Faria Galvão and Luis Carlos de Lima Silveira of the Universidade Federal do Pará in Brazil.

Dr. William J. McIlvane, Director, UMMS/E.K. Shriver Center