



The Massachusetts Sibling Support Network: Supporting Siblings of People with Disabilities

Growing up with a brother or sister with a disability—whether the disability is emotional or physical, visible or hidden—is a unique, often challenging, and potentially rewarding experience. Nationwide, adult siblings of people with disabilities report that the sibling experience profoundly influences their childhood and adolescence, and shapes the type of individuals they become.

“Sibling involvement has been expanding among families of people with disabilities for several reasons,” explains Emily Rubin, Director of Sibling Support at the Eunice Kennedy Shriver Center. First, people with disabilities today have significantly longer life spans due to medical advances and overall improved health, often outliving parents who serve as primary caregivers. Second, since deinstitutionalization in the 1970s, people with disabilities are living at home longer, creating stronger sibling relationships. Third, state and federal funding options are decreasing, and sibling involvement is a natural outgrowth of cost-saving measures.

The Massachusetts Sibling Support Network (MSSN), of which Rubin is co-founder and president, emerged from concerns about the impact of disability on siblings, especially adult siblings who serve as primary caregivers, but also young siblings who are growing up alongside brothers and sisters with different abilities and needs.

Origins of the MSSN trace back to 2009, when an exploratory committee investigated the needs of siblings of people with disabilities across Massachusetts and the types of supports that existed to meet those needs. The committee soon expanded into a diverse network of adult siblings, parents of young siblings, mental health professionals, and

sibling service providers, all connected to sibling issues on a personal or professional level. In 2010, the committee evolved into the MSSN. Its mission is to support siblings of people with disabilities across the siblings’ lifespans by providing education, creating welcoming communities, and improving the range and availability of sibling support services in Massachusetts.

The MSSN actively provides education about the sibling experience to communities through “No Sibling Left Behind” presentations, which have been well-received at state and national conferences, as well as at Parent Advisory Council (PAC) meetings across the state. These presentations emphasize the importance of siblings voicing their own ideas about the roles they want to play within the family. From an early age, siblings should be taught that there is no “right” role for a sibling to play and it often changes over time. As siblings approach young adulthood, the MSSN advises that families should create a working plan that identifies each sibling’s interest in involvement, so that siblings are prepared to assume agreed-upon responsibilities when they reach adulthood.

In addition to sponsoring ongoing social events for adult siblings and young siblings, the MSSN is currently planning several larger events focused on educating the public and providing networking opportunities. This fall,



Emily Rubin, Director of Sibling Support at the E.K. Shriver Center, and President of the Massachusetts Sibling Support Network.

the MSSN will host a screening of “Cowboy Song,” a recently released independent film about an adult sibling and his brother with a disability, created by Brooklyn-based filmmaker Marie Regan. Early next year, the MSSN has plans for a state-wide sibling services conference, with the goal of bringing together service providers interested in offering sibling services. Looking ahead to 2014, the MSSN intends to cosponsor an educational workshop showcasing the work of Don Meyer, founder of the National Sibling Support Project and his Sibshop model of recreational peer support. The MSSN website, www.masiblingsupport.org, provides a wealth of resources for siblings, including sibling research, listings of sibling services offered across the state, and announcements of upcoming events for siblings.

continued on page 2



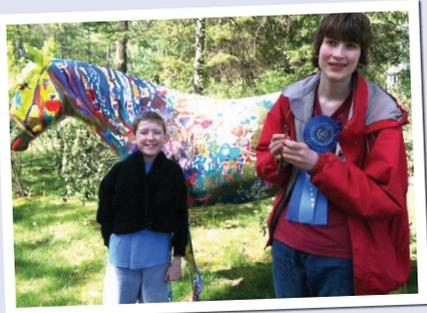
IN THIS ISSUE

MA Sibling Support Network	1	Initiatives: Mental Health Project Supports Siblings.....	8
Theme: On Siblings of Individuals with Disabilities.....	2	Did you Know?.....	8
EKS Sibling Support Group Shape LABBB Director.....	3	LEND Alumni Speak at Haitian Health Conference.....	9
Perspective: Faculty Reflect on Sibling Career Impact....	4	Illuminati: Jean A. Frazier, MD	10
Perspective: LEND Fellows Discuss Parenting Sibs.....	6	Focus on Faculty.....	11
Shriver Center 2011-2012 LEND Fellows	7	Spotlight on Sibling Support Resources.....	12

Eunice Kennedy Shriver Center
 University of Massachusetts Medical School
 200 Trapelo Road
 Waltham, MA 02452
 781.642.0001
www.umassmed.edu/shriver

Massachusetts Sibling Support Network

continued from page 1



Theme: On Siblings of Individuals with Disabilities

This issue of the *Shriver Center Spotlight* focuses on siblings of individuals with disabilities. In the following pages, we explore a number of challenging questions. What is it like for siblings to grow up alongside brothers and sisters with disabilities? How does the sibling experience influence and shape individuals as they grow into adulthood? What types of career choices do siblings make? What lessons do siblings learn from their brothers and sisters with disabilities? What types of resources are available for siblings? Why is sibling support important?



We approach our topic from multiple perspectives representing the voices of adult siblings, parents of young siblings, and researchers and professionals working in the field. We feature the Massachusetts Sibling Support Network, a new organization whose mission is to provide support, education, and community for siblings at all stages of life.



It is clear to us that growing up with a brother or sister with disabilities can be a profound and transformative experience. We invite you to read on and discover for yourself.

Rubin explains that the sibling experience is influenced by many factors including parental attitudes toward the child with a disability. In general, the more



Massachusetts Sibling Support Network

accepting parents are of the child's disability, the more accepting the siblings will be; likewise, if parents are angry or in denial about the disability, those sentiments tend to trickle down to the siblings as well. Other factors that affect the sibling experience include the severity and type of disability, characteristics like birth order, sibling gender, and family size. Family culture also plays a large role; "culture" refers not only to ethnicity and race, but also independence, interdependence, caregiving expectations, and communication styles.

Rubin adds that sibling issues change in scope as siblings age. Young siblings may struggle to understand the impact of their sibling's disability on their family, while adult siblings may find themselves navigating complex healthcare, housing, employment and benefit systems previously managed by parents.

Don Meyer, soon-to-be guest speaker for the MSSN, outlines the unusual challenges and opportunities many siblings experience in his book, *SibShops: Workshops for Siblings of Children with Special Needs*, co-authored by Patricia Vadasy. These challenges include: embarrassment, guilt, isolation, loneliness, loss, resentment, pressure to achieve, and increased responsibilities. Opportunities include increased maturity, increased sense of self, independence, tolerance, pride, vocational opportunities, and advocacy skills.

Rubin reports that early research on siblings generally carried a pessimistic view. Throughout the 1960s, 1970s, and 1980s,

most literature suggested that siblings were at greater risk for negative outcomes and could be expected to demonstrate poor adjustment. A more recent shift in research acknowledges that positive outcomes can

result from having a sibling with a disability. Sibling literature includes both clinical research and empirical studies and tends to focus on children, but an increasing body of knowledge now exists about adults. Key findings include:

- Sibling attitudes about disability mirror parent attitudes
- Siblings are not at significantly greater risk for emotional problems than the general population, though siblings of people with mental illness tend to have more difficulty coping
- Same gender siblings are more likely to support each other, and the most involved siblings tend to be sisters
- The behavior of the person with a disability can impact the sibling relationship
- Shared activities among siblings increase when adults with disabilities move out of the family home and into the community.

Rubin attributes the success of the MSSN to the fact that its mission resonates with family members. "Siblings of people with disabilities share a profound and recognizable experience; though every sibling is unique, there are striking situational parallels. The MSSN understands that siblings identify with other sibs, and they want to be part of a larger community. By providing community and education, and increasing the availability of sibling services, we are simultaneously affirming the sibling experience and helping siblings in Massachusetts lead more fulfilling lives."

The MSSN is a state chapter of the national Sibling Leadership Network and collaborates with key stakeholders in the disability field including the Eunice Kennedy Shriver Center, the Massachusetts Developmental Disabilities Council, the Institute for Community Inclusion, The Arc, and the Federation for Children with Special Needs.

SIBLING LEADERSHIP NETWORK

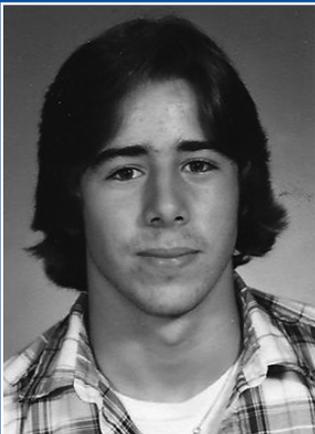
“By providing community and education, and increasing the availability of sibling services, we are simultaneously affirming the sibling experience and helping siblings in Massachusetts lead more fulfilling lives.”

Early Sibling Support Groups at the Shriver Center Helped Shape LABBB Executive Director

Since its inception over 40 years ago, the Shriver Center has strived to improve the lives of individuals with disabilities and their families through education, research, and service. Patric Barbieri, MBA, M.Ed., has had the unique opportunity to see that mission in action on both professional and personal levels.

Professionally, Barbieri currently serves as the Executive Director of the LABBB Collaborative special education program. An acronym of the five Massachusetts towns it serves (Lexington, Arlington, Burlington, Belmont and Bedford), LABBB draws students with disabilities from all grade levels and helps them achieve their highest potential—academically, socially, vocationally, and recreationally. Barbieri’s overall affiliation with LABBB spans 22 years, starting as a classroom teacher. “LABBB is very different from my bachelor’s degree in business management, but I love getting involved at every level and that is why I pursued a degree in special education,” he says.

On a personal level, Barbieri’s passion for the disability community is partially due to his younger sister Michele, diagnosed with Down syndrome at an early age and currently living independently in Lexington. One of four children raised in the 1960’s and 70’s, Barbieri explains his parents’ decision to include Michele as much as possible in local community activities at a time when disabilities were not well understood.



Patric Barbieri as a teenager in 1978 when he attended a sibling support group at the Shriver Center.

“They simply would not tolerate anything less. It reflected the attitude of our community, friends, and family. I was on the hockey team and very active in town sports, but more people knew Michele than me,” Barbieri remembers. Michele pursued her own interests as well, taking part in ice shows, swimming lessons, and later, working in retail stores. Michele’s success in these areas has led Barbieri to re-examine one key aspect of assisting individuals with disabilities.

“When I look at what Michele learned in school, and some of her current struggles, I think emphasizing practical topics like money management would have been a great help, especially now that she is living on her own. We need to examine what individuals with disabilities should learn to succeed in life, not just in a classroom,” he elaborates.

Michele’s diagnosis also led to Barbieri’s initial connection to the Shriver Center, as he joined a sibling support group there in 1978 while a teenager. In small groups split by age, siblings discussed the positive and negative impact of disability on their lives. “One really cool aspect came when siblings brought their brother or sister to our end-of-year party. We finally met people we heard so much about.” Barbieri credits those sibling groups with not only providing a much-needed emotional outlet, but also serving as a valuable asset in his current role.

“I can speak to parents, families, and school systems, and empathize with them. My experience allows me to see things differently . . . and helps prevent others from seeing me as an outsider,” he adds.

That sense of connection also pays other dividends. LABBB enjoys partnerships with nationally respected disability organizations like Best Buddies, while also creating volunteer and mentoring opportunities for typically developing students to assist individuals with intellectual disabilities. Additionally, LABBB recently established professional ties with the Shriver Center by becoming a new, school-based research partner site as part of the Shriver Center’s Foundations study related to autism.

Perhaps most importantly, Barbieri believes his current situation is an ideal fit. “I truly enjoy working as part of the LABBB Collaborative and making a positive difference for students with disabilities. I’m very excited to see what our next steps will be.”



Patric Barbieri in his current role as LABBB Executive Director

“I can speak to parents, families, and school systems, and empathize with them. My experience allows me to see things differently . . . and helps prevent others from seeing me as an outsider.”



Kass Braden, MD of the E.K. Shriver Center

"I chose a field where virtually every project I work on reminds me of my brother."

Faculty Reflect on their Siblings' Impact On their Professional Careers

Whatever our paths in life, some questions are nearly universal. "What do you want to be when you grow up?" is one of the most common. Choosing a profession is often motivated by personal factors such as individual interests, academic strengths, and family backgrounds. Faculty members Jean Frazier, MD and Kathleen "Kass" Braden, MD, both of whom grew up with a sibling with a disability, recently discussed the reasons they pursued careers in medicine.

Dr. Jean Frazier currently serves as the Robert M. and Shirley S. Siff Chair, Professor of Psychiatry and Pediatrics at the University of Massachusetts Medical School (UMMS). In addition, she is a faculty member in two programs of the UMMS Graduate School of Biomedical Sciences. These noteworthy accomplishments are the latest in a prestigious 20 year career marked by a desire to improve the lives of individuals with disabilities.

Frazier's connection to disability-related issues is also personal, however. As one of five children growing up in Ohio, her sister Carol was diagnosed with Down syndrome. Dr. Frazier and her sister are close in age and their sibling relationship deepened over the years as they shared a bedroom until Frazier attended Wellesley College in the late 1970's. They have experienced many humorous and challenging moments together.

"I liked having a neat and clean room growing up; Carol didn't," Dr. Frazier remembers. "That could be frustrating. Carol adapted very quickly after I left for college; it didn't take long before more of her things found their way on to my side of the room," she laughs. More serious challenges arose for both women when others made fun of Carol.

"Our neighborhood growing up was generally very welcoming. Still, teasing happened often enough to upset me," Frazier says. "As Carol's older sister, I felt like something of a protector and did not want to see her hurt."

Still, Frazier's peers and friends largely accepted Carol's joining them during activities and outings. Carol made the most of her active nature, becoming a Special Olympics athlete who also took part in swimming and track and field. One notable difference Frazier remembers during Carol's school-age years is that her education occurred in a separate school and

workshop-type environment, since inclusion for individuals with disabilities did not yet exist. Carol's success continues, and she now lives semi-independently in California.

"It's wonderful seeing Carol take charge of her life. We are continually impressed with how far she has come," Frazier elaborates, adding that the two often talk about work-related concerns, maintaining personal relationships, and staying healthy. Frazier describes herself as an "advocate from a distance" since she and Carol live on opposite coasts.

Frazier is also acutely aware of Carol's impact on her professional career. "Growing up with Carol has given me a fuller appreciation of the inherent potential every person has, while also reminding me to stop and see the beauty in everything and everyone. My time in med school has enabled me to help people live better lives, and I am so grateful for the role that Carol has in my life."

Dr. Kass Braden's specialty in developmental and behavioral pediatrics spans her 34 year career, and includes running developmental pediatric clinics, lecturing to pediatric and family medicine residents, supervising fellows in developmental pediatrics, and a previous post as Medical Director of the Tufts Medical Center for Children with Special Needs. Currently Director of the Shriver Center's LEND Program, Braden is again impacting the disability field for families and parents statewide.

Braden also experienced the pull of a sibling's disability in her career choice. Her late older brother David was born in Peru but raised in Grosse Ile, a small island south of Detroit, Michigan during the 1950s. Early on it was clear David had a developmental disability. Though undiagnosed by doctors during his life, Braden now believes David had Angelman's syndrome, as he exhibited many signs and symptoms of that disorder: extremely pale skin, white hair, pale blue eyes, short stature, an inability to speak, and a very happy demeanor.

As David's self-described "translator" growing up, Braden vividly recalls his mischievous nature and surprising strength, including once climbing and flipping over an eight-foot fence their father built. "David often ran because it was fun when people chased him. He was loved by all who knew him," Braden says.

continued on next page

“Growing up with Carol has given me a fuller appreciation of the inherent potential every person has, while also reminding me to stop and see the beauty in everything and everyone.”

When David turned seven, doctors advised he be put in a state institution. After being told the state would assume no care responsibilities for David otherwise, the family hesitantly agreed. Despite regular visits, soon after arriving David cried more often, withdrew from others, and either forgot or purposely ignored acquired skills like dressing himself. These memories led Braden to refuse to work anywhere affiliated with a state institution during her fellowship in developmental and behavioral pediatrics.

Her choice of specialty itself illustrates differences between Braden and her parents. “My father was an OB/GYN, but both parents viewed working with children with disabilities as nothing but continued sadness, largely from David’s experiences. They never understood my perspective that it could also bring happiness and good news to people with disabilities and their families,” Braden explains.

A year after David was placed in a state institution, he moved to a residential

community for children and adults with disabilities. This setting included a special arrangement where families paid communally for ongoing housing and care to ensure coverage if a resident became orphaned. Here David began to blossom, again bringing happiness to those around him. He passed away there at the age of 22. “Staff and residents from the community came and wept at his funeral,” Braden recalls.

Braden’s mother channeled her anger over David’s poor experiences in a state-run institution into advocacy, becoming a leading voice for the creation of Michigan’s Arc, an organization dedicated to helping people with disabilities fully participate and contribute to their communities. Braden only discovered this late in her mother’s life.

As for herself, Braden celebrates David’s role through her career path. “I chose a field where virtually every project I work on reminds me of my brother. I love what I do, and wouldn’t have it any other way.”

“As Carol’s older sister, I felt like something of a protector and did not want to see her hurt.”



Jean Frazier, MD and her sister Carol Frazier

Shriver Center spotlight

SHRIVER CENTER SPOTLIGHT is published twice per year by the **Eunice Kennedy Shriver 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.

SHRIVER CENTER SPOTLIGHT

Editorial Staff

Associate Director: Charles Hamad, PhD

Editor-in-Chief: Carol Curtin, MSW

Managing Editor: Elaine Gabovitch, MPA

Content Editor: Emily Rubin, MA

Writer: Patrick Gleason, MA

Photography: Richard Caira

Layout & Design: Susan Sutherland Designs

Feedback

We appreciate your feedback. Please send your comments and suggestions to:

Elaine Gabovitch, Managing Editor

SHRIVER CENTER SPOTLIGHT

UMMS/Shriver Center

200 Trapelo Road

Waltham, MA 02452

Phone: 781.642.0052

Email: Elaine.Gabovitch@umassmed.edu

Publication and copyright information:

SHRIVER CENTER SPOTLIGHT and its content are copyrighted by the E. K. Shriver Center; some materials may carry other copyrights (noted where appropriate). Permission is granted to quote from us at length, while giving credit to the SHRIVER CENTER SPOTLIGHT, a publication of the Eunice Kennedy Shriver Center (and original author, if appropriate).

SHRIVER CENTER SPOTLIGHT is supported by Grant #ADD90DD062501 from the U.S. Administration on Developmental Disabilities. Opinions expressed may not reflect those of the E. K. Shriver Center, UMASS Medical School or their funding sources. The Shriver Center is an equal opportunity employer and educator.

Visit us on the Web at www.umassmed.edu/shriver

©2012 Eunice Kennedy Shriver Center,
University of Massachusetts Medical School

LEND Fellows Share Perspectives on Siblings

We recently sat down with LEND alumni Amanda Rossetti (2010) and Linda Helmig Bram (2012), to hear their views on sibling issues. Both are mothers, raising a typically developing child and a child with a disability. Here is what they had to say about sibling dynamics and their LEND Capstone projects.

What was/is the nature of your LEND project?

Linda: Developing a website to provide information and support for families who have a child in residential care or are considering such a move.

Amanda: The LiveAutism Project, an online community that would enable parents and professionals opportunities to inform, interact and share ideas about how to successfully navigate services and options available for people with ASDs and their families.

Identify the connections between your LEND project and your interest in sibling issues.

Linda: I have a 10 year-old daughter with autism and an intellectual disability, and a 7 year-old son who is developing typically. I have observed firsthand the ways in which my son struggles to understand the reasons for his sister's placement in a residential facility. Sometimes his sister's symptom severity and

out-of-home placement does not feel fair to him, and certainly often feels overwhelmingly sad. The entire family is impacted by a child's transition to residential care, and siblings are affected in a powerful way.

Amanda: I have two daughters, aged 11 and 14. My older daughter has an autism spectrum disorder, and my younger daughter does not have disabilities. Part of the vision for the LiveAutism community is offering user-generated content devoted specifically to the needs of the sibling community. I hope to launch the site in the near future; my goal is to provide siblings the opportunity to access information and find support with others facing similar challenges.

In your experience, what are the biggest challenges faced by siblings of people with disabilities?

Linda: One of my son's challenges is his realization that the majority of kids he knows at school, cub scouts and other activities have siblings who live at home, and are capable of relating to and playing with them in typical ways. My son so wishes to share his interests with his sister, but her capacity for this is limited. Also, not having her there to attend special family occasions, holidays, and vacations reminds us of how sad it is that she can't be with us for these significant childhood events that her brother is experiencing.



2010 LEND alum Amanda Rossetti with her daughters

Amanda: Parentification of the typically developing sibling is the biggest challenge for my younger daughter. Sometimes we expect that she should/can "help" us with her sister's daily living needs, or we expect her to act more mature when her sister is acting out in public. We try to offset this by providing my younger daughter with access to a monthly sibling group, and we set aside one-on-one time doing "typical" things. We also talk openly with her about how difficult it is to grow up with a sibling with autism. Another challenge is how tough it is to find support groups and other offerings throughout a sibling's lifespan. Siblings have unique needs dependent on one's age and life stage, and the specific diagnosis of the brother or sister.

What types of supports or interventions do you think siblings benefit most from?

Linda: Sibling groups are terrific. My son attends one monthly group in our home community, and a second group that is held at his sister's school. The personal connection of attending a group at her school seems important to him.

Amanda: Support groups focused on specific ages and diagnoses, where discussion topics include coping techniques and sibling self-care.



2012 LEND fellow Linda Helmig Bram with her husband Tony, and her son and daughter.

“We also talk openly with her about how difficult it is to grow up with a sibling with autism. Another challenge is how tough it is to find support groups and other offerings throughout a sibling’s lifespan.”

E.K. Shriver Center LEND Fellows for 2011-2012

The following individuals completed Shriver Center LEND fellowships for the 2011-2012 academic year. We congratulate them for their scholarly efforts, and are pleased to share their backgrounds and the themes of their yearlong leadership projects.



Jean Batty, BS, BA

Specialties: Disability Advocacy/Interior Design/Family

As a community access monitor, Jean established a Disability Access Commission (DAC) to address accessibility issues in her town. With the support of Congressman Edward Markey and Representative Jason Lewis, she obtained a \$2 million dollar federal stimulus grant to make the local train station accessible. True to her ideal of “equal opportunity for individuals with disabilities,” Jean’s LEND project was entitled “The Thanksgiving Bill: A Plan to Build Inclusive Homes.” Jean’s inspiration for her advocacy efforts is her young son who has spina bifida



James Clark, BS

Specialties: Business Economics/Independent Living Advocacy

An active self-advocate with a physical disability since age five, James currently serves as the coordinator of the Statewide Independent Living Council of Massachusetts and is also treasurer for a local independent living center. He previously worked in the Accounting & Financial Reporting section of the Massachusetts Department of Transportation. James is a strong advocate for increased employment and advancement of persons with disabilities, understanding the history of the independent living movement, and youth disability leadership initiatives.



Holly S. Boker, MSW

Specialties: Social Work/Family

Holly works as a social worker for the integrated community preschool in Billerica, MA. Her previous experience includes working in Israel and Rochester, NY as an outpatient mental health therapist for children and adolescents. Holly’s LEND project entitled “Identifying Quality Picture Books That Include Characters with Disabilities: A Blog Project” uses her background as a children’s book writer to explore and evaluate how children’s literature portrays characters with disabilities. Holly is a mother of three, including teenage twins with learning disabilities.



Laura Hajar, MPH

Specialties: Public Health/Freelance Photography

Laura’s extensive background in photography led to a 12-year career focusing on pediatric health care that included time as a staff photographer for St. Jude’s Children’s Research Hospital. Currently, Laura works as a health outreach educator for Boston Medical Center. Laura’s LEND project was entitled “Snapdragons: A Photography Program for Children with Autism Spectrum Disorders.” The program will use photography as a social development tool at a one-week camp in West Chester, PA serving campers with autism spectrum disorders.



Linda Helmig Bram, PhD

Specialties: Clinical Psychology/Family

Linda is the parent of a daughter with severe autism and cognitive delays who is served in a residential setting, a clinical psychologist at the Boston Institute for Psychotherapy, and a clinical instructor at the Cambridge Health Alliance. Linda’s LEND project, entitled “Development of a Website for Families with Children who have Developmental and Intellectual Disabilities and Need Residential Services” will fill a critical void for families who currently have or are considering a residential placement for their child with a disability, as well as for the professionals who serve them. Linda also holds a strong special interest in sibling issues (see article on page 6).



Wilhelmina Hernandez, MD

Specialty: Developmental-Behavioral Pediatrics

Originally from the Dominican Republic, Wilhelmina recently completed a post-doctoral fellowship in Developmental Behavioral Pediatrics at Boston University Medical School. Effective June 2012, she began a clinical research fellowship at Bellevue Hospital/New York University Langone Medical Center. Wilhelmina’s LEND project, “Working on Reciprocal Dialogue in Spanish (WORDS) Curriculum,” seeks to increase Early Intervention provider awareness of Hispanic culture and how it impacts the promotion of early literacy in Hispanic children from birth-to-three years.



Kate Taube Brewer, BS

Specialties: Management/Advocacy/Family

Kate is a special education information specialist at the Federation for Children with Special Needs in Boston and mother of three daughters with special needs. She has served on the MA Department of Developmental Services Citizen Advisory Board (CAB), Children’s Hospital CAB, the Duxbury Special Education Parent Advisory Council, and local interfaith councils. Kate has also served as an educational surrogate parent for the Massachusetts Department of Child and Family Services. Indicative of her deep interest in mental health issues for youth, Kate’s LEND project explored this topic in “A Review Article: The Role of Schools in the Lives of Adolescents with Depression.”



Jonathan Jenkins, MA

Specialty: Clinical Psychology

Jonathan was recently accepted as a predoctoral psychology intern at the Cambridge Health Alliance as he prepares for his doctoral degree in August 2013 from the University of Denver in clinical psychology with a focus on pediatric neurodevelopment. Jonathan’s LEND project “Real Healing through Virtual Athletics: How Video Games Can Aid in Healing Both Mind and Body in Pediatric Rehabilitation Settings” envisions a gaming technology program to address psychological concerns and treatment compliance of pediatric patients with traumatic physical injuries in rehabilitative settings.



Suzanne Casey, BA

Specialty: Human Services

Suzanne acts as the Development Officer for Delta Projects, a nonprofit that provides residential supports for individuals with intellectual and developmental disabilities. In 2011, Suzanne was accepted into the University of Delaware’s Leadership Institute and brought back several innovative ideas to her work, such as starting up a self-advocacy program, and emphasizing person-centered planning and self-determination. Suzanne’s LEND project answers the question “How Massachusetts Can Move from the Residential Living Model to Independent Self Directed Living.”



Kristie Usher, RD

Specialty: Nutrition

A current doctoral candidate at the Friedman School of Nutrition Science and Policy at Tufts University, Kristie’s dissertation focuses on designing and implementing a nutrition intervention at a Massachusetts school serving children with I/DD. As an extension of her dissertation work, Kristie’s LEND project was entitled “Federal and State School-based Nutrition Policies: Opportunities for Obesity Prevention for Children with Intellectual and Developmental Disabilities in Residential Care.” The policy paper uses a residential school case study to point out nutrition policy implications for students, families, school practice and legislation.

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.

Sibling Support Demonstration Project Promotes Family-Centered Mental Health Care

Most people know at least one or two individuals who have struggled with mental health issues. Ever wonder what it was like for their siblings, many of whom grew up in families often marked by the stigma of mental illness and the misunderstanding of well-intentioned friends, teachers, and relatives?

Emily Rubin, Director of Sibling Support at the Eunice Kennedy Shriver Center, has spent the last two years planning, developing, and implementing a project to address the complicated and often overlooked needs of siblings of children with mental health challenges. Rubin explains, “Mental illness affects every community, yet there is a widely recognized lack of support for siblings of children and adolescents struggling with mental health needs. Many of these siblings live in a world of unpredictability, are subjected to shifting moods and inappropriate behaviors, and never know when their brother or sister will lash out or withdraw.” Rubin adds that while most mental health services focus on the child with mental health issues, it’s essential to address the needs of siblings, many of whom grow up “walking on eggshells”; siblings are often the target of verbal and physical aggression, and are at risk for developing maladaptive behaviors themselves.

Rubin’s Sibling Support Demonstration Project (SSDP) fills a critical service gap for these siblings and their parents in crisis. This family-centered, mental health care initiative provides interventions and supports during and after a child’s psychiatric hospitalization. The goals of the project are: 1) to increase sibling resiliency and mitigate the trauma commonly experienced by siblings of children and adolescents admitted for psychiatric hospitalization; 2) to build skills, competency, and confidence among parents; 3) to help restore family stability once the patient returns home, minimizing chances of future psychiatric hospitalizations; and 4) to build capacity among medical practitioners, thereby influencing the delivery of mental health care in hospital settings.



Dr. Ernesto Gonzalez, Dr. Adele Pressman, Emily Rubin, MA and Theresa Cary, LCSW, represent the Sibling Support Demonstration Project at Cambridge Health Alliance. Missing from the photo are team members Dr. Jacob Venter, Dr. Mardoche Sidor and Heidi Katz, MA, DMT

Rubin is partnering with the Cambridge Health Alliance (CHA), where the project was launched at the end of 2011. The first phase of the pilot includes sibling support groups facilitated by CHA medical residents, fellows and social workers, supervised by CHA psychiatrist Dr. Adele Pressman. Concurrent parent education groups are led by a parent mentor who brings the experience of raising a child with mental health needs.

Pressman reports, “Our partnership with Emily has added tremendous value to the mental health services we offer CHA families. Emily brings a wealth of knowledge about sibling issues, wonderful project management abilities, and a unique skill set that enables her to enlist the trust of families and educate them about the sibling experience. An added bonus is the way the project provides sibling education to CHA medical trainees.”

The second phase of the pilot is currently in development and includes post-hospitalization services to ensure that families do not return home in a state of isolation, have support to recover from the psychiatric crisis, and have access to resources to decrease rates of future hospitalization.

Dr. Pressman goes on to explain, “When a family is trying to manage the multiple demands and strains brought by a child’s mental illness, siblings find themselves bewildered by what they see happening to their brother or sister, are unable to get the attention they wish for from their parents, and feel like they are inexplicably different from their peers.” Pressman describes the SSDP as

continued on next page

Did you know?

Nearly one third of families nationwide (representing over 20 million families total) have at least one member with a disability.¹

Siblings of people with disabilities have identified their own issues of importance which include one-on-one time with a parent, the right to maintain their own lives, opportunities to meet other siblings of individuals with disabilities, and accurate information about their sibling’s disability and its consequences.²

The number of adults with intellectual or developmental disabilities aged 60 or over who live in the community is expected to double its current rate and reach 1.2 million by 2030.³

In small groups, children aged 5-13 learn about their sibling’s illness, learn to develop coping skills, and participate in fun activities alongside peers who also have a brother or sister with mental health issues. In a nearby room, the parent mentor educates parents and caregivers on strategies to support siblings, connects them with community resources, and facilitates discussions based on specific questions raised by parents.

“My hope is for children and adolescents to speak openly about having a sibling with mental health needs, and through that experience, become better prepared as adults to transition into a caregiving role.”

“Many of these siblings live in a world of unpredictability, are subjected to shifting moods and inappropriate behaviors, and never know when their brother or sister will lash out or withdraw.”

“a safe place where the siblings of psychiatrically troubled children and adolescents are given the opportunity to discover that they are not, in fact, alone with their experience. They learn that their feelings of anger, sadness, loss, and even guilt and shame, are also shared by others. This serves to be enormously liberating for sibs who have internally worried that there must be something wrong with them if there is so much wrong in their world.”

Rubin adds that as they age, siblings—especially sisters—tend to become primary caregivers to brothers and sisters with disabilities, so it’s especially important for siblings to receive proper support and information early on. This will enable them to advocate effectively, alongside the affected sibling in the future, with awareness and compassion.

When CHA social worker Theresa Cary, who works with seniors in the Geriatric Psychiatry Unit, joined the project, she brought a life span perspective. Cary says, “I work with adult sibling caregivers whose brothers and sisters have struggled with mental health issues their entire lives. They recall during childhood not knowing exactly what was wrong with their brother or sister, but knowing clearly that something wasn’t right. They express how difficult it has been to be placed in the role as caregiver, and they seem desperate for support and direction. My hope is for children and adolescents to speak openly about having a sibling with mental health needs, and through that experience, become better prepared as adults to transition into a caregiving role.”

Positive response among CHA families and clinicians fuels Rubin’s plans to expand the Sibling Support Demonstration Project to additional pediatric and adolescent psychiatric units in the Boston area.

¹ Disability Funders Network Website (2009), Disability Stats & Facts.

² What Siblings Would Like Parents and Service Providers to Know, Sibling Support Project Website

³ Coyle, C.E., Mutchler, J. & Kramer, J. Fact Sheet: Sibling Caregivers of Aging Adults with Intellectual Disabilities, UMASS Boston

Shriver Center LEND Alumni Speak at 2012 Haitian Health Conference

On April 7, 2012, the 11th Annual Haitian Health Conference held at the Boston University School of Medicine explored the theme of *Understanding and Serving People with Developmental Disabilities in Haiti and the United States*—a first for the Greater Boston Haitian community. Several Shriver Center LEND alumni took part, several of whom are originally from Haiti, including the conference’s course director Nicole Prudent, MD, MPH, a 2011 LEND graduate. Dr. Prudent and her colleagues from the Haitian Health Institute emphasized the devastating 2010 earthquake in Haiti as a springboard to address both natural and acquired disability topics for Haitian people. Over 150 attendees represented educational, clinical, research and other professional disciplines, along with many family members of children with disabilities and senior citizens living with disability in the Greater Boston Haitian community.

Featured prominently throughout the day were LEND alumni known as “LEND Fellows for Haiti” from both LEND programs in Massachusetts: the Eunice Kennedy Shriver Center (EKS) and the Institute for Community Inclusion (ICI). Jennifer Williams, BS and Elizabeth Zwick, MBA (EKS LEND 2011) delivered the presentation “Americans with Disabilities Act: Twenty-Two Years of Progress.” Evelyne Milorin, BA (EKS LEND 2010, from Haiti, Course Director, LEND Fellows for Haiti) and Elaine Gabovitch, MPA (EKS LEND 2006, current LEND family faculty) presented a workshop on “Learn the Signs. Act Early—A Program to Raise Awareness about Autism and Other Developmental Concerns.” Renald Raphael, MD (ICI LEND 2006) moderated “Sibling Issues in Families with Children with Developmental Disabilities.” Jessie Charles, MPA (EKS LEND 2011, from Haiti) participated on a panel

addressing “Emergency Preparedness for Individuals with Developmental Disability.” Eve Wilder, MPH (EKS LEND 2011) and Carline Balthazar-Louizia, MD (EKS LEND 2005, from Haiti) led the conference attendees through final “Reflections and Suggestions.” Shey Jaboin (ICI LEND 2010) provided support throughout the event.

The former Secretary of State for the Inclusion of Persons with Disabilities of Haiti and current National Coordinator, Haitian Society for the Blind, Michel A. Pean, PhD delivered the keynote address based on the overarching conference theme. Other notables included Jean Ford Figaro, MD who presented “Living with Disability in Haiti in 2012” and Marilyn Augustyn, MD who shared “Defining Developmental Disability.” Parent members of the Haitian Family Support Center were recognized for their contributions and effectiveness in advocacy. Closing remarks and a call to action were made by Marie St. Fleur, Esq., in her role as the Chief of Advocacy and Strategic Investment for the City of Boston.

For the organizers, the most striking outcome was how the language used by presenters and participants changed from beginning to end; people began to use more inclusive terms such as “differently-abled” instead of “disabled.” According to one attendee, “After attending the “Sibling Issues in Families” and the “Learn the Signs” workshops, I learned more about the inside experience of living close to disability. I have a newfound empathy and appreciation for the differently-abled and their loved ones who support them.” Another attendee stated, “This conference is important for our communities!” One attendee summed it up, “An awesome day! Thank you for everything, for the work, leadership, care and love you have put into the day. Keep it up!”



LEND alumni speakers join with HHI guest speakers and event staff. Pictured above from left to right are Jessie Charles (3rd), Eve Wilder (4th), Beth Zwick (5th), guest speaker Dr. Jean Ford Figaro (7th), Keynote Dr. Michael Pean (8th), Dr. Nicole Prudent (9th), Elaine Gabovitch (11th), Evelyne Milorin (12th), and Jennifer Williams (13th).



Jean A. Frazier, MD

Specialties	Child and Adolescent Psychiatry, Psychopharmacology, Neuroimaging, Autism, Early Onset Bipolar Disorder, Schizophrenia
Faculty Since	2008
Titles	Co-Director, Clinical & Translational Research Support Core, Intellectual & Developmental Disabilities Research Center (IDDR), E.K. Shriver Center Robert M. and Shirley S. Siff Chair, Professor of Psychiatry and Pediatrics, UMASS Medical School Vice Chair & Director, Child and Adolescent Psychiatry Division, UMASS Memorial Medical Center Co-Director, Child and Adolescent Neurodevelopment Initiative (CANDI), UMASS Memorial Medical Center Medical Director, Massachusetts Child Psychiatry Access Project (MCPAP), UMASS Memorial Medical Center Faculty, Graduate School of Biomedical Sciences in Clinical and Population Health Research Program, UMASS Medical School Faculty, Graduate School of Biomedical Sciences in Neuroscience, UMASS Medical School
Education	1982, BA, Wellesley College, Wellesley, MA, Music 1987, MD, Dartmouth Medical School, Hanover NH
Board Memberships and Advisory Roles	Advisory Committee on Psychoactive Medication for Children and Adolescents, Massachusetts Department of Mental Health Scientific Advisory Board, Autism Speaks Autism Clinical Trials Network Professional Advisory Council, Child and Adolescent Bipolar Foundation Advisory Board, New England Center for Autism

Jean A. Frazier, MD

Research Interests

Dr. Frazier stresses two important pieces of advice to new medical school graduates interested in child mental health and just starting out: keep the patient at the center of everything they do, and never lose their quest for knowledge to improve the lives of children and their families. It seems only natural therefore, that one of Frazier's prime research interests should combine both ideas. As Co-Director of the Child and Adolescent Neurodevelopmental Initiative Laboratory (CANDI) at UMASS Medical School, Dr. Frazier, her co-director Dr. David Kennedy, and a staff of approximately 19 others engage in research into the neurobiology and treatment of autism, bipolar disorder, and schizophrenia in children and adolescents. Frazier estimates about 11 projects are currently ongoing. CANDI represents the newest iteration of similar programs Frazier instituted during her time in the Harvard system and at McLean Hospital before she arrived at UMASS Medical School in 2008.

One driving force behind Frazier's interest in autism, bipolar disorder, and schizophrenia stems from the overlap of symptoms seen in all three disorders. For example, children with autism may also experience mood reactivity in response to changes in their environment, and some may have mood changes attributable to depressive or bipolar disorder, whether previously diagnosed or not. Frazier and her colleagues hope to eventually find "biomarkers" or uniquely identifiable characteristics linked more closely to domains of dysfunction, such as mood reactivity or social withdrawal, which can be common to these three disorders, and possibly neurodevelopmental disorders as a whole. In addition, Frazier looks forward to continuing her work in clinical trials and expanding these efforts into more novel treatment interventions for these populations. A logical next step, this allows for potentially new funding sources and an increased presence in the field while also embracing Frazier's quest for knowledge.

Activities

Dr. Frazier currently serves as field editor for the Harvard Review of Psychiatry, and associate editor for *Psychotic Disorders: Journal of Child and Adolescent Psychopharmacology*. She is also an ad hoc reviewer for 16 additional journals with over 100 academic peer-reviewed publications and book chapters to her credit. Audiences for her nearly 70 presentations over the last decade include the National Institute of Mental Health (NIMH), the American Academy of Child and Adolescent Psychiatry, and the Chilean Congress of the Society of Psychiatry and Neurology of Infancy & Adolescence. Frazier also has extensive experience as a professional mentor, and is a two-time honoree as one of the *Best Doctors In America*. Additionally, she raises funds for disability-related research through participation in national bicycling events.

Career Influences & Vision for the Future

Dr. Frazier credits several colleagues for helping to shape her ultimate career path. Each offered different types of support: encouraging pursuit of child psychiatry, obtaining research fellowships, serving as a professional and research mentor to others, focusing her work on the disability community,

modeling successful interactions with patients, and managing multiple professional responsibilities. Each skill plays a vital role in Frazier's self-described "most rewarding aspect of her work": assisting individuals with disabilities and their families, and knowing that help is real and tangible. When asked about changes in her field since the advent of her career, Frazier describes the growth of managed care, and how it forces creative thinking to solve medically-related issues in a world increasingly focused on financial costs. To that end, she strongly advocates using a collaborative, team-based approach that allows for multiple points of view without sacrificing limited resources. Frazier believes that such an approach increases the likelihood of positive outcomes.

Current Research Support

Dr. Frazier's current research projects are funded with support from the National Institute of Child Health and Human Development (NICHD), the National Institute on Mental Health (NIMH), the National Institute on Drug Abuse (NIDA) and the National Institute of Neurological Disorders and Stroke (NINDS), as well as private donors and outside companies:

- Site Principal Investigator with Dr. Karl Kuban, *Neonatal Biomarkers in Extremely Preterm Babies Predict Childhood Brain Disorders: The Elgan-2 Study (Extremely low gestational age newborns)*, NINDS, 2011-2016
- Co-Director, Clinical & Translational Research Support Core, *Interdisciplinary Research in Intellectual Disabilities*, NICHD, 2010-2015
- Co-Principal Investigator with Dr. Robert Findling, *Best Pharmaceuticals for Children Act Pediatric Off-Patent Drug Study (PODS): Lithium for the Treatment of Pediatric Mania*, NICHD 2010-2013
- Co-Principal Investigator with Dr. David Kennedy, *A Knowledge Environment for Neuroimaging in Child Psychiatry*, NIMH, 2009-2012
- Principal Investigator, *Hormonal Influences on Frontolimbic Neuromaturation in Girls with Bipolar Illness*, private donor, 2009-2012
- Site Principal Investigator, *A Randomized, Double-Blind, Placebo-Controlled Study of the Efficacy, Safety, and Tolerability of STX209 (Arbaclofen) Administered for the Treatment of Social Withdrawal in Adolescents and Adults with Autism Spectrum Disorder*, Seaside Therapeutics, 2011-Present
- Site Principal Investigator, *A Randomized, Double-Blind, Placebo-Controlled Study of the Efficacy, Safety, and Tolerability of STX209 (Arbaclofen) Administered for the Treatment of Social Withdrawal in Adolescents and Adults with Fragile X Syndrome*, Seaside Therapeutics, 2011-Present
- Site Principal Investigator, *A Randomized, Double-Blind, Placebo-Controlled, Fixed-Dose Study of the Efficacy, Safety, and Tolerability of STX209 (Arbaclofen) Administered for the Treatment of Social Withdrawal in Children with Fragile X Syndrome*, Seaside Therapeutics, 2011-Present
- Site Principal Investigator, *The Evaluation of LAMICTAL as an Add-On Treatment for Bipolar I Disorder in Children and Adolescents 10 to 17 Years of Age*, Glaxo Smith-Kline, 2008-Present
- Site Principal Investigator with Dr. Terry L. Jennigan, *Creating a Pediatric Imaging-Genomics Data Resource*, NIDA, (no cost extension), 2009-2011

focus on faculty

Grant Awards, Publications, Presentations and Activities

Selected Peer-Reviewed Articles

Chen, Y., Norton, D.H., McBain, R., Gold, J., **Frazier J.A.**, & Coyle, J.T. (In press). Enhanced local processing of dynamic visual information in autism: Evidence from speed discrimination. *Neuropsychologia*.

Frazier J.A., Giuliano, A., Johnson, J.L., Yakuitis, L., Youngstrom, E.A., Breiger, D., et al. (In press). Neurocognitive Outcomes in the Treatment of Early-Onset Schizophrenia Spectrum Disorders Study. *Journal of the American Academy of Child and Adolescent Psychiatry*.

Hodge, S.M., Makris, N., Kennedy, D.N., Caviness, V.S., Howard, J., McGrath, L., Steele, S., **Frazier J.A.**, Tager-Flusberg, H., & Harris, G.J. (2010). Cerebellum, Language, and Cognition in Autism and Specific Language Impairment. *Journal of Autism and Developmental Disorders*, 40, 300-16.

Shen, Y., Dies, K.A., Holm, I.A., Bridgemohan, C., Sobeih, M.M., Caronna, E.B., Miller, K.J., **Frazier J.A.**, et al. on behalf of the Autism Consortium Clinical Genetics/DNA Diagnostics Collaboration. (2010). Clinical Genetic Testing for Patients with Autism Spectrum Disorders. *Pediatrics*, 125, 727-35.

Sikich, L., **Frazier J.A.**, McClellan, J., Findling, R., Vitiello, B., Ritz, L., et al. (2008). Double-blind Comparison of Antipsychotics in Early Onset Schizophrenia and Schizoaffective Disorder. *American Journal of Psychiatry*, 165, 1420-31.

Frazier J.A., Hodge, S., Breeze, J., Giuliano, A., Terry, J., Kennedy, D., et al. (2008). Diagnostic and Sex Effects on Limbic Volumes in Early-Onset Bipolar Disorder and Schizophrenia. *Schizophrenia Bulletin*, 34, 37-46.

Frazier J.A., McClellan, J., Findling, R.L., Vitiello, B., Anderson, R., Zablotzky, B., et al. (2007). Treatment of early-onset schizophrenia spectrum disorders: demographic and clinical characteristics. *Journal of the American Academy of Child and Adolescent Psychiatry*, 46, 979-88.

Moore, C., **Frazier J.A.**, Glod, C.A., Finn, C., Breeze, J., Dieterich, M., Lyoo, I.K., & Renshaw, P.F. (2007). Anterior cingulate cortex glutamate and glutamine levels in children and adolescents with bipolar disorder. *Journal of the American Academy of Child and Adolescent Psychiatry*, 46, 524-34.

Frazier J.A., Chiu, S., Breeze, J.L., Makris, N., Lange, N., Kennedy, D.K., et al. (2005). Structural brain magnetic resonance imaging of limbic and thalamic volumes in pediatric bipolar disorder. *American Journal of Psychiatry*, 162, 1256-65.

De Fossé, L., Hodge, S.M., Makris, N., Kennedy, D.N., Caviness, V.S., McGrath, L., Steele, S., Ziegler, D.A., Herbert, M.R., **Frazier J.A.**, Tager-Flusberg, H., & Harris, G. (2004). Language association cortex asymmetry in autism and specific language impairment. *Annals of Neurology*, 56, 757-66.

Frazier J.A., Cohen, L.G., Jacobsen, L., Grothe, D., Flood, J., Baldessarini, R.J., Piscitelli, S., Kim, G., & Rapoport, J.L. (2003). Clozapine serum concentrations in children and adolescents with childhood-onset schizophrenia. *Journal of Clinical Psychopharmacology*, 23, 87-91.

Frazier J.A., Biederman, J., Bellordre, C.A., Garfield, S.B., Geller, D.A., Coffey, B.J., & Faraone, S.V. (2001). Should the diagnosis of Attention Deficit Hyperactivity Disorder be considered in children with pervasive developmental disorder? *Journal of Attention Disorders*, 4, 203-11.

Bush, G., **Frazier J.A.**, Rauch, S.L., Seidman, L.J., Whalen, P.J., Jenike, M.A., Rosen, B.R., & Biederman, J. (1999). Anterior cingulate dysfunction in attention-deficit/hyperactivity disorder revealed by fMRI and the counting Stroop. *Biological Psychiatry*, 45, 1542-52.

Kumra, S., **Frazier J.A.**, Jacobsen, L.K., McKenna, K., Gordon, C.T., Hamburger, S., et al. (1996). Childhood-onset schizophrenia: a double blind clozapine trial. *Archives of General Psychiatry*, 53, 1090-7.

Frazier J.A., Giedd, J., Hamburger, S.D., Albus, K., Kaysen, D., Vaituzis, C., et al. (1996). Brain anatomic magnetic resonance imaging in childhood onset schizophrenia. *Archives of General Psychiatry*, 53, 617-24.

Grant Awards

Linda Bandini, PhD.

Cushing Opportunities for Meals Eaten Together at School (COMETS). Deborah Monroe Noonan Memorial Research Fund. (Period: September 2011-August 2012).

Robert Bass, PhD.

Grant Support for Autism Insurance Resource Center (Initial). Massachusetts Developmental Disabilities Council. (Period: June 2011-November 2011).

Robert Bass, PhD.

Grant Support for Autism Insurance Resource Center (Follow-Up). Massachusetts Developmental Disabilities Council. (Period: December 2011-June 2012).

Robert Bass, PhD.

Outreach Program at the Autism Insurance Resource Center. Doug Flutie Jr. Foundation for Autism. (Period: January 2012-December 2012).

Alexandra Bonardi, MHA.

Pilot Project for Health Surveillance of People with Intellectual Disabilities. AUCD & CDC/NCBDDD, Subcontract. (Period: September 2011-September 2013).

William Dube, PhD.

Behavioral Persistence: Basic, Translational and Clinical Studies. University of New Hampshire, Subcontract. (Period: April 2011-January 2012).

Karen Lionello-Denolf, PhD.

Contingency Manipulation in Discrete Trial Interventions for Children with Developmental Disabilities. NIH. (Period: January 2012-July 2012).

William Mcllvane, PhD.

Optimizing Initial Communication for Children with Autism. NIH. (Period: September 2011-May 2014).

Peer-Reviewed Publications

Bandini, L.G., Gleason, J.G., Curtin, C., Lividini, K., Anderson, S.E., Cermak, S.A., Maslin, M. & Must, A. (In press). Comparison of physical activity between children with autism

spectrum disorders and typically developing children. *Autism: International Journal of Research and Practice*.

Deutsch, C.K., & Mcllvane, W.J. (In press). Non-mendelian etiologic factors in neuropsychiatric illness: Pleiotropy, epigenetics, and convergence. *Behavioral and Brain Science*.

Grisante, P.C., Galesi, F.L., Sabino, N.M., Debert, P., Arntzen, E., & **Mcllvane, W.J.** (in press). Go/no-go procedure with compound stimuli: Effects of training structure on the emergence of equivalence classes. *The Psychological Record*.

Conference Abstracts, Papers, & Invited Presentations

Cataldo, M. & **Mcllvane, W.J.** (2012). Translational Analysis and Treatment of Chronic Aberrant Behavior-Transition States, Behavioral Economics, and Idiosyncratic Functions. *Symposium Conducted at the 45th Annual Gatlinburg Conference on Research and Theory in Intellectual and Developmental Disabilities*, Annapolis, MD.

De Souza, D., de Rose, J., Hanna, E. & **Mcllvane, W.J.** (2012). Generalized syllable recombination in reading of Portuguese words by Brazilian children with and without intellectual and developmental disabilities. *Paper Presented at the 45th Annual Gatlinburg Conference on Research and Theory in Intellectual and Developmental Disabilities*, Annapolis, MD.

Detrich, R. & **Twyman, J. S.** (Eds.). (In press). Evidence-based practice, scientifically based instruction, and educational effectiveness. *Proceedings of the 2010 Association for Behavior Analysis Education Conference*. Oakland, CA: The Wing Institute.

Dube, W., Schlichenmeyer, K., Grant, E. & Roscoe, E. (2012). Functional analysis of problem behavior: a systematic approach to the identification of idiosyncratic variables. *Proceedings of*

the 45th Annual Gatlinburg Conference on Research and Theory in Intellectual and Developmental Disabilities, Annapolis, MD.

Gabovitch, E. & Choueiri, R. (May 29, 2012). MA Act Early's *Considering Culture in Autism Screening Project*. *Considering Culture in the Screening and Assessment of Young Children with Developmental Concerns Conference*. Burlington, VT: Department of Health & University of Vermont LEND Program.

Gabovitch, E. & Osbahr, T. (May 10, 2012). *Learn the Signs. Act Early!* Massachusetts Early Intervention Consortium (MEIC) Annual Conference, Marlborough, MA.

Grossman, R., Schmid, A., Steinhart, E. & Mitchell, T. (2012). Visual fixation patterns during emotional face-voice matching. *Proceedings of the 45th Annual Gatlinburg Conference on Research and Theory in Intellectual and Developmental Disabilities*, Annapolis, MD.

Mcllvane, W.J. (2012). Basic and applied research in reading of children with intellectual and developmental disabilities (IDD). *Proceedings of the 45th Annual Gatlinburg Conference on Research and Theory in Intellectual and Developmental Disabilities*, Annapolis, MD.

Mitchell, T., Meyer, S., Monk, K., & Mcllvane, W.J. (2012). Eye gaze behaviors during face processing in Down syndrome. *Proceedings of the 45th Annual Gatlinburg Conference on Research and Theory in Intellectual and Developmental Disabilities*, Annapolis, MD.

Serna, R., Preston, M. & Mitchell, T. (2012). Pitch discrimination in children with autism spectrum disorders and intellectual disabilities. *Proceedings of the 45th Annual Gatlinburg Conference on Research and Theory in Intellectual and*

Developmental Disabilities, Annapolis, MD.

Twyman, J.S. (2012). Basic and applied research in reading of children with intellectual and developmental disabilities (IDD). Symposium discussant at the *Proceedings of the 45th Annual Gatlinburg Conference on Research and Theory in Intellectual and Developmental Disabilities*, Annapolis, MD.

Wilkinson, K., O'Neill, T., Nauss, J., Thistle, J. & Mcllvane, W.J. (2012). Eye tracking helps reveal mechanisms underlying facilitation of responses to visual communication displays by individuals with and without intellectual disabilities. *Proceedings of the 45th Annual Gatlinburg Conference on Research and Theory in Intellectual and Developmental Disabilities*, Annapolis, MD.

Wilkinson, K. & Dube, W. (2012). Uses of eye tracking/pupillometry to enrich understanding of information and sensory processing in individuals with intellectual disabilities. *Proceedings of the 45th Annual Gatlinburg Conference on Research and Theory in Intellectual and Developmental Disabilities*, Annapolis, MD.

Faculty Appointments & Awards

Alixé Bonardi, MHA was promoted to Clinical Assistant Professor, Family Medicine and Community Health, University of Massachusetts Medical School, 2011.

Rupal Patel, PhD was appointed Adjunct Associate Professor of Psychiatry, University of Massachusetts Medical School, 2011.

Rachel Thompson, PhD was appointed Adjunct Associate Professor of Psychiatry, University of Massachusetts Medical School, 2011.

Janet Twyman, PhD, BCBA was appointed Associate Professor of Pediatrics, University of Massachusetts Medical School, 2011.



Being the Other One: Growing Up with a Brother or Sister Who Has Special Needs

The author of this book is a counselor and health educator, as well as the adult sibling of a sister with cerebral palsy. Based on extensive interviews with siblings of all ages, the author takes a life span perspective and focuses on the experiences of siblings from childhood through adulthood. Sections of the book highlight strategies, the need for support, exercises for personal development, and resources.

Strohm, K. (2005). *Being the Other One:*

Growing Up with a Brother or Sister Who Has Special Needs. Boston, MA: Shambhala Publications, Inc.

The Sibling Slam Book: What It's Really Like To Have A Brother Or Sister With Special Needs

This book reflects the complex and insightful views of 80 teenagers who have brothers and sisters with disabilities; the book includes responses to such questions as "Got any good stories about your sib?" and "What is the hardest thing to do as a sibling?" Though the voices are sometimes funny and/or painful, they are always honest and authentic.

Meyer, D.(Ed.) (2005). *The Sibling Slam Book: What It's Really Like To Have A Brother Or Sister With Special Needs.* Bethesda, MD: Woodbine House, Inc.

Brotherly Feelings: Me, My Emotions, and My Brother with Asperger's Syndrome

This book explores the range of emotions that an eight-year-old child experiences in response to his brother's disability. Though the book focuses on Asperger's Syndrome, the emotions that are addressed are relevant for siblings of children with all types of disabilities. Using age-appropriate language, the authors define a range of emotions including feeling doomed, doubtful, proud, responsible and optimistic. The chapter entitled "What I Do When I Can't Take It Anymore!" addresses coping skills geared specifically to young siblings.

Freder, S. and Schiffmiller, R. (2007). *Brotherly Feelings: Me, My Emotions, and My Brother with Asperger's Syndrome.* Philadelphia, PA: Jessica Kingsley Publishers.

Websites

Massachusetts Sibling Support Network

The MSSN is the only organization in Massachusetts focused on supporting siblings of people with disabilities across the siblings' life span. The network is made up of adult siblings, parents of young siblings, service providers, educators, mental health and medical professionals. The MSSN provides information and education on sibling issues, referrals to sibling services across the state, and social connections for siblings of all ages.

www.masiblingsupport.org

Sibling Support Project

The Sibling Support Project is a national organization committed to supporting siblings of individuals with special health, developmental, or mental health concerns. The Sibling Support Project trains local service providers to deliver Sibshops, which are recreational peer support groups for young siblings. The Sibling Support Project also hosts online communities for young siblings, teen siblings, and adult siblings.

www.siblingsupport.org

Sibling Leadership Network

The SLN is a national organization committed to providing tools, information and support to help siblings advocate alongside their brothers/sisters with disabilities. The SLN encourages siblings to take on leadership roles within the field of developmental disabilities at the local, state and federal level.

www.siblingleadership.org

The Arc

Aware of the unique needs of siblings of people with disabilities, The Arc recently created the National Sibling Council. The Council's goal is to help siblings network, access support and resources, and get involved with advocacy and programming at The Arc.

www.thearc.org

Books

All About My Brother

In this charming picture book, then-eight-year-old sibling Sarah Peralta demystifies autism by giving us insights into the world of her younger brother, who is nonverbal. Through her simple depictions of her brother's everyday behavior, Sarah encourages others to approach autism without fear or pity. Copies of this book have been donated to school libraries across the United States to help children (and especially siblings) learn about autism spectrum disorders.

Peralta, S. (2002). *All About My Brother: An Eight-Year-Old Sister's Introduction to Her Brother Who Has Autism.* Shawnee Mission, KS: Autism Asperger Publishing Co.



University of Massachusetts Medical School
Eunice Kennedy Shriver Center
200 Trapelo Road
Waltham, MA 02452-6319