The Vanderbilt Kennedy Center works on the premise that we make the fastest progress when laboratory research is tied to insights from clinical care. In today’s world of advanced technologies and specialists, it can be difficult for one person to span these domains. Vanderbilt and this Center have invested in recruiting and nurturing faculty able to bridge between laboratory and clinic. Jeremy Veenstra-VanderWeele, M.D., exemplifies this new generation of translational researchers whose aim is to speed discovery to improve lives—in his case, the lives of individuals affected by autism and related disorders.

Veenstra-VanderWeele is assistant professor of Psychiatry, Pediatrics, and Pharmacology. He is director of Child and Adolescent Psychiatry, medical director of the Treatment and Research Institute for Autism Spectrum Disorders (TRIAD), and director of the Fragile X Treatment Research Program.

The Veenstra-VanderWeele research group works to translate genetic and biomarker discoveries to better understand and treat autism spectrum disorder (ASD) and pediatric obsessive compulsive disorder (OCD). In the molecular lab, his team uses mouse models to understand the underlying neurobiology of social impairment and rigid-compulsive behavior. In partnership with Kevin Sanders, M.D., Cassandra Newsom, Psy.D., and Zachary Warren, Ph.D., he is studying new medication treatments based upon mouse models related to autism.

The Story Begins

Veenstra-VanderWeele started on the road to research with a summer job in a University of Chicago lab led by Edwin Cook, M.D., renowned for his studies of the molecular genetics and neurochemistry of ASD, ADHD, and OCD.

“I caught the bug for research in that experience,” said Veenstra-VanderWeele. He recalls a late-night conversation almost 20 years ago when he asked what could come out

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Saving Lives Through Literacy

BY JAN ROSEMERGY

If you're a parent or grandparent and your child or grandchild is unable to read, you know that your child's future is at stake. A scholarship to the VKC Reading Clinic has made it possible for Jane Morgan's grandson Christian to learn to read. "It's his life," she said.

This Fall, the Dollar General Literacy Foundation provided a $50,000 grant so that students can receive high-quality tutoring at the Reading Clinic and tutors can receive state-of-the-art training. Over 5 years, Dollar General has donated $250,000. Christian is only one of many students receiving scholarships. The Dollar General Literacy Foundation is saving lives.

One Family's Determination

Christian began 1st grade in a private school, but his teacher recognized that he had learning differences that required more support services than the school could provide and recommended enrollment in their county's public school system. Morgan describes this as the beginning of their “nightmare.” Christian was not assessed until the last full day of school in his 2nd grade year. In 3rd grade, he was still not learning to read and the extra 30-minute sessions he received twice a week with other students with reading delays were not helping.

"Every day when I took him to school, I felt like I was sending him into the lion's den," Morgan said. “He wasn’t getting help there and was suffering.”

Through their pediatrician, the family was referred to the Center for Dyslexia at Middle Tennessee State University, where Christian was found to have “a textbook case of dyslexia.” “That was the very saddest thing,” Morgan said, “how long it took to diagnose.”

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of this work. Dr. Cook talked about a newly published paper on the first mouse model of fragile X syndrome and the possibilities this provided for understanding what’s happening in the brain and new treatments based upon that understanding.

Fast forward through college, a predoctoral fellowship in molecular genetics, medical school, residency, and a child psychiatry fellowship. Veenstra-VanderWeele came to Vanderbilt in 2006 as a postdoctoral fellow in the lab of Randy Blakely, Ph.D., Allan D. Bass Professor of Pharmacology and director of the Vanderbilt/NIMH Silvio Conte Center for Basic Neuroscience Research. Since genetic findings were finally beginning to emerge, he came to study how genetic variants lead to changes in brain and behavior.

Outside of science, people are often mystified how mice can give us insight into humans. Veenstra-VanderWeele explains that mice provide a useful animal model because of similarities between the mouse and human brain.

“Mice also have observable social behavior, sometimes even observable repetitive behavior,” said Veenstra-VanderWeele. “They give us a window into what is actually happening in the brain related to genetic and environmental risk factors in humans.”

In addition to launching his own molecular laboratory in 2009, Veenstra-VanderWeele started a clinical research program studying new treatments based upon the insights gained from genetic mouse models of autism, including the model of fragile X syndrome.

Veenstra-VanderWeele estimates that he and his colleagues have initiated more than 20 different clinical trials to date, most related to fragile X syndrome. Often the number of participants is quite small, but when results are promising, clinical trials can be scaled up.

“We’re starting to believe that it is really going to be the story that we’ve been hoping for over the last 20 years, beginning with the identification of the fragile X gene in the early 90s, the articulation of a theory in the early 2000s, and now clinical research with the hope of developing treatments to transform the lives of individuals with fragile X syndrome. That’s what we want to do, not only for fragile X syndrome but also for risk factors for autism.”

Chasing Biomarkers

“Since I was in Ed Cook’s lab, I’ve been chasing a biomarker in autism that I think is one of our best clues in a broader autism population, and that’s elevated blood serotonin levels,” Veenstra-VanderWeele said.

Serotonin is a brain chemical that carries signals across the synapse, or gap, between nerve cells. The serotonin transporter (SERT) regulates serotonin levels in the synapse by taking serotonin back up into the neuron. In 2005, VKC investigators Blakely and James Stuchlif, Ph.D., identified rare genetic variations in children with autism that disrupt SERT function. Subsequently, Veenstra-VanderWeele and Blakely created a mouse model that expressed the most common of these variations.

“The mice showed changes in social behavior and communication from early life that may parallel aspects of autism,” Veenstra-VanderWeele said, theorizing that atypical levels of serotonin during development may lead to longstanding changes in the way the brain functions.

Despite his optimism about new treatments arising from an understanding of how the brain is altered in ASD, Veenstra-VanderWeele thinks that it is unlikely that a medication alone will reverse a developmental disorder. An ideal outcome would be finding biological treatments that will put the brain in a state to benefit more from effective behavioral treatments.

Pathways to Discovery

Veenstra-VanderWeele has been following two related paths to uncovering the causes of autism. The first is working to identify rare gene variants or genetic mutations that add substantial risk. A related path is identifying biological markers that may lead to a treatment that would benefit larger numbers of children with ASD. A third path is basic research into how the social brain works across species.

Much of the research exploring the social brain, including work by VKC investigator Elizabeth Hammock, Ph.D., points to the oxytocin system as being critically important for shaping social behavior. To date, the evidence is not strong that oxytocin is specifically involved in autism, but intranasal oxytocin has been shown to change certain aspects of social behavior in the general population, as well as in young people with autism.

“The hope is that we may harness this universal social hormone to change the way that an individual with autism may respond to other people,” Veenstra-VanderWeele said.

An NIH multisite national clinical trial for the Study of Oxytocin in Autism to Improve Reciprocal Social Behaviors (SOARS-B) is expected to be underway soon, with Nashville as one of five sites.

Veenstra-VanderWeele believes that we are entering the most exciting time for developmental disabilities research: “We have quite a lot of knowledge about behavioral treatments, and we are on the cusp of seeing initial medication treatments emerge. The rapidly expanding knowledge of genetic and other risk factors related to autism and other developmental disorders suggests that high-impact, potentially transformative treatments may be possible.”

Clinical Consultation

For Veenstra-VanderWeele, what he does in his lab and what he does in clinic are intertwined: “I couldn’t give up seeing children with autism because that’s what motivates everything we do in the lab.”

In his Treatment Resistant Autism Consultation Clinic, Veenstra-VanderWeele typically sees a child and family for two visits. He focuses on understanding a child’s strengths and challenges, what has been tried, and what is most likely to lead to improvement. Often that is a behavioral treatment, including treatments based upon Applied Behavior Analysis or Cognitive Behavioral Therapy.

Veenstra-VanderWeele points out that available medications do not treat the core problems of autism but rather associated problems such as hyperactivity, impulsivity, or anxiety, conditions that can be treated regardless of whether an individual has autism.

“Sometimes the most meaningful thing I can do in clinic is to assure a family that they’re doing all that they possibly can do. We need to do our best to help those things that can be helped and then support a child and family in making the best of the life that they have.”

Jeremy Veenstra-VanderWeele
Director's Message

Unless you're a scientist, you may never have heard of the term "translational research." But understanding it—even taking part in it—matters, because over time such research may improve or even save our own lives, or the life of someone we love. Although the term wasn't popular back in 1965 when our Center was founded, it is striking that our founders' vision foretold today's excitement for translational research.

The goal of translational research is to speed up discoveries that improve lives by bridging basic and clinical and community research.

Basic researchers seek answers to fundamental questions about how things work. VKC basic research labs test theories about biological processes involved in the development of cells or how genes are expressed in the brain.

Clinical, medical, or behavioral researchers aim to solve health or behavioral problems in the people with whom they work. These VKC researchers are devising more effective interventions for children with autism, language delays, Down syndrome, or reading disabilities.

At the helpful suggestion of a parent in our VKC Community Advisory Council, we developed a graphic depicting translational research. The graphic highlights a two-way connection between basic and clinical research. In translational research, basic scientists think about the clinical applications of their work. Clinical researchers consider basic studies that would help them produce better treatments or interventions.

Similarly, a translational relationship exists with the community. One of our key roles at the VKC is to help translate what we learn in basic, clinical, and behavioral research into practice—in early intervention programs, schools, and medical or psychological practices. In turn, issues encountered in the community can feed back and prompt studies that will help improve outcomes, community practices, and public policies.

Translational research is the center stone of biomedical research. We need this rigorous approach to unravel the complexities of autism, Down syndrome, learning disability, and other developmental disabilities. Translational research is different from yesterday's segregated research silos within disciplines. Instead it requires partnerships among basic and clinical scientists, families, and communities. The good news is that from our beginnings in 1965 onward to today, these translational partnerships also have been the center stone of the VKC. Our collaborative, translational research approaches propel us into new discoveries that make positive differences in the lives of people with disabilities and the families who love them.

ResearchMatch Maker

“Matchmaker, Matchmaker, make me a match,” go the lyrics from Fiddler on the Roof. A quite different but vitally important match is the aim of ResearchMatch: matching persons who are willing to take part in research with researchers who need study participants in order to advance knowledge. Now, through a partnership with the Vanderbilt Kennedy Center (VKC), the ResearchMatch website has added a sub-registry to match families who have a family member with an intellectual or developmental disability with researchers who are seeking such participants.

“One of the challenges in conducting research in developmental disabilities is difficulty in connecting to individuals affected and their families,” said Elisabeth Dykens, Ph.D., VKC director. “Researchers communicate through disability organizations at the local, state, and national levels, which is quite helpful, but many families are not members of such organizations. ResearchMatch’s sub-registry for intellectual and developmental disabilities offers researchers across the country a new way to connect with families nationwide.”

Launched in late 2009, ResearchMatch is the country’s first nationwide, nonprofit, volunteer research recruitment platform for all health conditions. It is a free and secure way for volunteers to connect with researchers who are studying a wide range of conditions to match them with studies that may be a good fit. The site is a product of a Consortium of research institutions, including Vanderbilt University and Meharry Medical College. The Consortium received federal funding through the Clinical and Translational Science Awards (CTSAs) to speed translation of discoveries from “bench to bedside.”

The Consortium is led by the National Center for Advancing Translational Sciences.

ResearchMatch, which is hosted by Vanderbilt, was designed by Gordon Bernard, M.D., principal investigator for Vanderbilt’s CTSA and associate vice chancellor for Research, and Paul Harris, Ph.D., associate professor of Biomedical Informatics and Biomedical Engineering. Harris and Dykens have collaborated on the development of the Intellectual Disabilities Sub-Registry, which was launched this summer.

“The feedback provided by the Kennedy Center’s Community Advisory Council was invaluable for creating this sub-registry,” said Kathleen Edson, ResearchMatch program manager. “We begin with a set of questions that researchers regard as the most important for matching with study participants. The next and most important step is to test and review the questions within the community. This ‘Community Review’ is crucial in helping us build a prescreening tool that will not only aid researchers but also select questions that we know volunteers will answer. Your Advisory Council gave us such a great perspective.”

How It Works for Families

It’s simple. You go to the Web site (www.researchmatch.org). First, you fill out a few basic questions about yourself or the person you wish to register. Second, you create a unique username and password that only you will know. Third, if you wish, you provide a bit more about your health background; these responses are optional. Finally, you submit your profile to ResearchMatch and wait to be contacted by researchers who think you’ll be a good match for their study.

If you identify yourself or a family member you’re registering as having an intellectual disability, the site offers five additional sub-registry questions. Where does the person with intellectual disabilities currently live? Which of the following best describes what the person with intellectual disabilities does most of the time on a typical day? Continued on page 7
An International Perspective

Maria Paula Mello

KC UCEDD trainee Maria Paula Mello has had longstanding interest in doing comparative research in international special education. Last year, she applied for a Fulbright Scholarship to investigate the current state of special education in rural Brazil. She proposed the implementation of a needs assessment, outlined a series of technical assistance activities for training educators, and suggested the development of a website for sharing tools and information to better equip educators to support students with disabilities in the classroom.

“I wanted to return to Brazil to explore school systems and to share some of what I was learning through my program,” said Mello, whose family emigrated from Brazil to New York when she was 7 years old. “I had been working on a research project with the Tennessee Autism Summit Team to assess services for people with autism in rural and nonrural counties in Tennessee. Then I focused my thesis on disability service availability in rural areas. I designed the proposal to extend what I was learning about rural communities and to put some of what I had been doing here into practice there.”

Mello says her faculty advisor, Bob Hodapp, Ph.D., VKC UCEDD Research director and professor of Special Education, provided assistance throughout the proposal process. In addition to reviewing, editing, and encouraging Mello to think intentionally about the sustainability of the project, he also organized a group of faculty, staff, and students to provide Mello with two rounds of mock interviews. Though she received enthusiastic feedback from reviewers, she did not receive the Fulbright Scholarship.

“I think we were all a little surprised that the Fulbright Program didn’t fund the project,” said Hodapp. “The proposal was well thought through with some substantial outcomes. I was impressed with Maria’s ability to combine her own personal experiences with her interests and coursework and then devise a way to share her knowledge in a geographic area she knew would benefit. I was also impressed that she decided she would do some of the work anyway. She’s bright and determined.”

Over the summer following graduation, after she was accepted into the Special Education Doctorate Program at Vanderbilt’s Peabody College, Mello scaled down her proposal to outline goals that could be accomplished in a 2-week visit to Fortaleza, Brazil. Originally spanning 10 months, her shortened trip and project would now focus more on conversations and consultations with educators and school psychologists and on the development of a resource-heavy website. Mello currently is developing a website for families and school educators in Brazil.

“I learned so much,” said Mello. “I was able to connect with a school psychologist who taught me a lot about how Brazil’s fairly new classroom inclusion laws [2008] have played out in the school systems. I learned that not enough professionals are available to support the growing needs of the families, especially in rural areas. Though I needed more time, I take away an affirmed sense of purpose in the work I could do there. I know I will return to this work in the future.”

A Theological Perspective

Yesterday afternoon I was sitting in my professor’s office discussing an upcoming project in the Divinity School. “But is it a theological conversation?” I asked, worried I may be off topic. “Of course it is!” he responded. “Theology deals with what it means to be deeply human.” He’s right, and my involvement with Next Steps and the Kennedy Center have been invaluable in shaping my theological worldview.

When I arrived at Vanderbilt last August, I was worried about how the next two years would look financially. I needed a job. I took up two Work-Study positions, one working in communications at the Kennedy Center and another as a job coach with Next Steps.

As a job coach, I walked with students as they navigated new work environments, watching them rediscover what it meant to be confident and believe in themselves over and over again. Tammy Day, Next Steps director, was eager to capture the voices of our students on film. We got a camera, started filming, and then I got out of the way. The students loved being involved in the movie project. After watching it all come together over several months, it dawned on me that I was a part of something special. I was documenting incredible stories of hope.

My positions within these two organizations have changed dramatically over the past year. I’m a job coach, teacher, videographer, and job developer. The Kennedy Center has allowed me to continue making videos where I get to tell some great stories with a camera. The best part is that working with Next Steps has given me the chance to actually be a part of these stories.

The most valuable takeaway for me has been watching how faculty and staff at both Next Steps and the VKC approach and relate to people with disabilities in intentional ways. From individualized Person-Centered-Planning meetings to a simple conversation in the hall, these organizations hinge on connecting with individuals on a deeply personal level. I think this interaction should be a model for how we encounter people in general. This is deeply theological to me because it resists a formula to human interaction. It requires me to listen before speaking.

I’m not sure what kind of job I’ll get when I graduate. Teaching? Filming? Writing? Wherever I end up, I’m grateful to have a concrete example of what it looks like when an organization is person-centered rather than profit-centered.

Kyle Jonas is a Master of Theological Studies candidate, Vanderbilt Divinity School and Graduate Department of Religion.
Laying a Strong Preschool Foundation

BY JAN ROSEMERGY

“All I really need to know, I learned in kindergarten” is the truism of the Robert Fulghum book by that title—but before kindergarten, there’s preschool. Young children with and without disabilities learn a lot there that will help make them successful in kindergarten and beyond. That’s why the Preschool Division of the Tennessee Department of Education has partnered with TRIAD not only to provide training for early childhood educators and special educators but also to develop a model preschool classroom in each of the State’s three grand regions.

The Preschool Division selects the school system and school for the model classroom. Their Preschool Consultants look for a blended classroom with an even number of typically developing children and children with disabilities who are 3 to 5 years old.

Middle Tennessee Model Classroom

Two pre-K classrooms, located in Cookeville High School in Putnam County, are the first model classrooms. “We are helping the teachers make over their classrooms to help not just kids with autism but typically developing kids and kids with other disabilities,” said LaTamara Garrett, TRIAD Early Childhood Training coordinator.

Training began in July. TRIAD staff had 5 full-day visits with teachers to provide coaching, mentoring, and guidance on use of evidence-based practices. The next step was a 3-day TRIAD training workshop in September hosted by Cookeville High School Pre-K. Because the Department of Education funds the training, the workshop was provided at no cost to schools. The workshop combined lecture, small group discussion, video footage, and demonstrations of evidence-based interventions by early childhood teachers. A unique feature of the workshop was giving participants hands-on practice with students with disabilities in a Cookeville model pre-K classroom. Workshop participants were preschool teachers, teaching assistants, and behavioral consultants. Jenny Thomas, Manchester City Schools director of special education said, “We got to visit two pre-K classrooms that were absolutely equipped to meet the needs of not just students with autism but all students. In my experience, TRIAD has the best training and support for educators.”

Six to 8 weeks following the training, TRIAD staff make half-day visits to schools of teachers who received the training. During the workshop, the teachers developed goals to address in their classrooms. The follow-up visits focus on goal progress, next steps, and ways that TRIAD staff can help teachers be successful.

Evidence-Based Strategies

TRIAD early childhood training emphasizes classroom use of multiple evidence-based strategies. Primary focus is on the following four strategies: (a) use of visual schedules and supports, so that all the children know what to expect and when; (b) use of naturalistic teaching of communication and social skills; (c) use of discrete trial teaching with prompts; and (d) reinforcement to teach academic and behavior skills.

“Our goal is to help teachers find positive ways to increase their students’ independence,” Garrett said.

“We are very thankful to have had TRIAD come in and help us get these things in place,” said Abby Grigsby, a teacher in a model pre-K class. “It has taken some time to get in place, but it is definitely valuable.”

Although the initial training for the model pre-K classrooms is completed, TRIAD staff will make two follow-up visits this academic year and three follow-up visits next year.

Partnering to Create a Welcoming Community

BY ELIZABETH TURNER

As part of its efforts to extend community outreach, several TRIAD staff members recently conducted autism training for 78 site directors of the YMCA Fun Company after-school care program. These YMCA staffers have taken the tools and lessons learned from this training to the more than 70 Fun Company sites in elementary and middle schools throughout Middle Tennessee.

“We’re excited to be able to provide quality training opportunities to community service providers, especially those who work directly with children and other individuals with autism spectrum disorder,” said Lauren Weaver, TRIAD behavioral/educational consultant. “Creating an understanding and awareness across the community is important for all families.”

Weaver, TRIAD’s Sarah Blumberg and Jon Staubitz, and graduate student Maria Lemler conducted the training in August.

During the 3-hour training, site directors received an overview of autism spectrum disorder, and strategies to support children on the spectrum and to include them in group activities. Information on strategies included ways to provide one-to-one support for children when needed. They also worked together during educational activities and were given materials such as schedules and visual supports to use in their activities.

Other Community Outreach

This training is one of several that TRIAD is providing. TRIAD hosted a 6-hour training session for educational staff at the Nashville Zoo in September and held a similar training session at Cheekwood Botanical Gardens in October. Similar training will be provided for staff of the Learning Center of the Frist Center for the Visual Arts and Nashville Wishing Chair Productions of Nashville Public Library.

“These trainings will provide foundational information to better support and address the needs of children with autism spectrum disorder,” said Weaver, “so that families can be welcomed and supported within community programs.”
SAVING LIVES THROUGH LITERACY  
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Their pediatrician’s second referral was to the Reading Clinic. Before then, the family “had no hope,” Morgan said. Morgan recalls the day when Christian rejoined her in the Clinic waiting room, and read the sign, “Please turn off your cell phone.” He began reading billboards as they drove, showing by his questions that he not only was reading but comprehending. “I had never heard him read, like some words together,” she said. “It was big.”

The scholarship support made possible by Dollar General’s gift is essential for this family. The family’s home was destroyed in the Nashville flood. Four days after they bought a new home, not yet insured, a fire destroyed it. The grandparents, both retired, now provide a three-generation home for Christian and his mother.

“You have no idea the burden this [scholarship] lifts off our family, because we couldn’t afford the services.”

Christian is now in a private school for children with learning differences. His grandmother drives long distances daily to take him to and from school and the Reading Clinic. In response to a friend who seemed to imply her efforts were excessive, Morgan said, “Would you not drive 1,000 miles a week for your child to receive cancer treatment if you thought you could save his life? It’s the same thing. It’s his life.”

Scholarship Program
The Dollar General Literacy Foundation grant makes tutoring possible for students whose families otherwise could not afford such services. Scholarship support is on a sliding scale related to family income.

“Around 75% to 80% of students enrolled receive some scholarship support” said Elise McMillan, J.D., VKC UCEDD co-director. “A scholarship can be continued for up to six consecutive sessions, providing a great foundation for students to become readers.”

Tutoring
The Reading Clinic uses an evidence-based, direct, systematic, multisensory approach in the one-to-one tutoring sessions. The Clinic serves students from kindergarten through 8th grade, including students with developmental disabilities. The Clinic can be contacted at (615) 936-5118, readingclinic@vanderbilt.edu.

“It is because of the Dollar General Literacy Foundation that the Reading Clinic is able to continue providing such an amazing resource to the community,” said McMillan.

Research Interests
Investigate how genes predispose us to certain neurological or psychiatric disorders and what changes in the brain are responsible for these changes in our experience or behavior. In the Neuroimaging Genetics Lab, we use noninvasive magnetic resonance imaging (MRI) to look for brain patterns that are related to a particular disorder, and then we search for genes that are associated with those brain patterns. The long-term goal is to enable the early identification of people at risk for these disorders, so that they can benefit from personalized therapeutic strategies as they become available.

Principal Investigator
• Novel MRI biomarkers for the early detection of Alzheimer pathology in Down syndrome (VKC Hobbs Discovery Grant)
• MRI biomarkers and genetic risk factors for chemotherapy-related cognitive impairment (Vanderbilt Brain Institute & VICTR)
• Validation of MRI biomarkers for Alzheimer’s disease (VICTR)

Clinical Interests
My clinical interests include understanding the biological mechanisms that underlie disorders of cognitive impairment, such as Alzheimer’s disease, which is highly prevalent in individuals with Down syndrome, as well as cognitive dysfunction associated with cancer treatment. I also am interested in understanding how genes predispose some people to anxiety or depression, and our studies in Williams syndrome are helping us understand the brain basis of anxiety in this rare genetic condition.

Honors and Awards
• NIMH Neuroscience Training Grant Fellowship, 2001-2002
• NLM Informatics Training Grant Fellowship, 2002-2006
• NIH Roadmap for Medical Research Postdoctoral Fellowship, Biobehavioral Intervention Training Program, 2006-2008
• Review Editor, Frontiers in Statistical Genetics and Epidemiology, 2011-Present
• Editorial Board Member, Academic Editor, PLoS ONE, 2011-Present
• Genome Technology Magazine, Young Investigator Award, 2010
• Steering Committee Member, Down Syndrome Biomarker Initiative (DSBI), 2013-Present

Education
• B.A., 1995, Philosophy, Vanderbilt University
• M.S., 2005, Biomedical Informatics, Vanderbilt University
• Ph.D., 2006, Neuroscience, Vanderbilt University

Attraction to Developmental Disabilities Research
For as long as I can remember, I have been fascinated with learning about how the brain works and what can go wrong in the brain to cause problems with cognition, mood, and personality. I am interested in understanding the relationship between cognitive function, consciousness, and self-determination and how a person’s self-identity is altered in neurocognitive disorders. My interest in neurodevelopmental disorders began when I was pregnant with my first child and I started to experience all the hopes and fears that we have as parents about our children’s health and well-being. In my research program, I now study cognitive disorders across the lifespan, from neurodevelopment (e.g., in Down syndrome or Williams syndrome) to mid-life neurocognitive dysfunction (e.g., chemotherapy-related cognitive impairment), to neurodegeneration (e.g., in Alzheimer’s disease).

Reasons for VKC Membership
The Vanderbilt Kennedy Center is exceptional in its commitment to the people it serves and also the people it trains and employs. The positive energy and enthusiasm that is projected by its leadership is inspiring, and the collaborations that I have developed with investigators through the Kennedy Center have been among the most productive and enjoyable. I am eager to discover new areas where I can bring my skills and experience to bear. I am proud to be associated with such an amazing group of scientists, educators, and clinicians.

Selected Publications
• Koran, M. E., Holman, T. J., & Thornton-Wells, T. A., for ADNI. (in press). Genetic interactions between calcium channel genes modulate amyloid load measured by positron emission tomography. Human Genetics. PMID: 24026422
**Accolades**

**BY ELIZABETH TURNER**


A trio of VKC staff members—Tennessee Disability Pathfinder’s **Tracy Beard,** assistant director, and **Carolina Meyerson,** Spanish Services coordinator, and **Carol Rabideau,** LCSW, UCEDD social worker—presented a national webinar organized by the Association of University Centers on Disabilities titled "Multicultural Organizations and Developing Culturally Competent Parent Support Groups.”

**Matt Brock,** Special Education doctoral student and UCEDD trainee, was recently selected to receive the 2013 Alice H. Hayden Emerging Leader Award from TASH, the international organization dedicated to equity, opportunity, and inclusion for people with disabilities. Brock’s award will be presented in Chicago this December at the annual TASH Conference.

A team of TennesseeWorks Partnership members and staff members, led by TennesseeWorks team members **Sarah Harvey** and **Rachael Jenkins,** staffed a booth at the Governor’s 60th Annual Economic Community Development Conference at the Music City Center. Staff presented TennesseeWorks’ goals to hundreds of attendees, including state senators, mayors, city councilmen, and representatives for large businesses in Tennessee. The aim of TennesseeWorks, a 5-year project, is to improve the employment landscape for Tennesseans with disabilities.

**Carolyn Hughes,** Ph.D., professor emerita of Special Education, and **Erik Carter, Ph.D.,** associate professor of Special Education, recently published *The New Transition Handbook: Strategies High School Teachers Use That Work!* The text is available for purchase on Amazon and in other retail outlets.

**Pablo Juárez, M.Ed.,** BCBA, has been appointed as associate director of the Treatment and Research Institute for Autism Spectrum Disorders (TRIAD). Most recently, he has served as administrative director of TRIAD Professional Development and Training.

**René Marois,** Ph.D., professor of Psychology, was one of two Vanderbilt professors featured in the PBS series “Brains on Trial.” The series, which aired in September, explored how the growing ability to separate truth from lies may affect the way criminal trials are conducted in the future.

Next Steps at Vanderbilt Class of 2013 graduate **Will McMillan** was honored with the Down Syndrome Association of Middle Tennessee’s 2013 Self-Advocate Award. McMillan received his award at DSAMT’s annual Buddy Walk festivities in October.

**Alexander Santana,** Multicultural Program coordinator, Tennessee Disability Pathfinder, recently graduated from the second session of MyCity Academy. MyCity empowers new Americans to receive an intellectual disability shown over the last year? What types of studies would you be interested in learning more about for the individual with intellectual disabilities, yourself, or others in the family? All questions can be answered by checking multiple choices.

Your information is stored securely and is kept confidential. Once you have registered, you may receive by email information from ResearchMatch about studies that have been approved by Institutional Review Boards (IRBs) at the researchers’ home institution. IRBs protect the rights and welfare of research participants. You are not obligated to take part in any study; you can edit your profile at any time, and you can withdraw from ResearchMatch if you no longer wish to be in the registry.

**How It Works for Researchers**

For researchers, ResearchMatch provides a convenient, easily accessible, and effective way to access study participants. The ability to recruit participants based on specific demographic information makes the system highly effective.

Currently, ResearchMatch partners with universities in the CTSA network. Each university enters into a contract with ResearchMatch, which includes designating an institutional liaison to facilitate participation in ResearchMatch by their institution’s researchers. Within the next year, ResearchMatch will begin enrolling institutions outside the CTSA network.

Nearly 1,800 researchers among 84 participating academic and medical institutions have registered to use ResearchMatch and are currently recruiting ResearchMatch volunteers, numbering over 44,000, for 350 active studies.

“Our ResearchMatch team is looking forward to continued partnerships with researchers, volunteers, and stakeholders as we work together to make a difference in today’s patient-centered research,” Harris said.”

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**Matt Brock**  
**Carol Rabideau, LCSW**  
**René Marois, Ph.D.**  
**Will McMillan**  
**Alexander Santana**
**Growing Together: Murray House Fellows and SGS Buddies**  
**BY ELIZABETH TURNER**

Murray House Fellows and Susan Gray School students have some similarities—both are trying to learn their way around a new school, make friends, and adjust to new schedules. What is pretty remarkable about this pairing is that they’re roughly 17 years apart in age.

Freshmen living in the Murray House of the Vanderbilt Commons have a special opportunity in service learning. Selected students are matched with students at Susan Gray School (SGS), an inclusive learning environment for children as young as 1 year old. Murray House Fellows schedule time (usually an hour a week) for one-to-one play with their SGS “buddies.” By the time the VU student is ready to graduate with a bachelor’s degree, the buddy also is preparing to graduate from SGS and enter the wild world of kindergarten.

The Murray House Fellowship Program was the brainchild of former Murray Head of House Sharon Shields, Ph.D., Peabody College associate dean for Professional Education and professor of the Practice of Education and Human Development.

“I’ve been a friend of the Susan Gray School for a long time. I was actually a friend of Susan Gray’s,” Shields said. “I wanted to do something that was sustained service, not just a one-time thing. I serve Next Steps at Vanderbilt as a faculty member, and I thought this would be a great way to connect the postsecondary experience with the beginning of education. It’s sustained advocacy and impact, which is something we need to be teaching at Vanderbilt.”

“The Fellows support the School as a whole with events during the year, such as the Lil Pumpkin Parade,” said Kiersten Kinder, Ph.D., Susan Gray School site director, referring to the annual event during which SGS students dress up for Halloween and circle Peabody Quad. “It’s a great way for them to become potential student workers.”

Roger Cone, Ph.D., is currently serving as Murray Head of House and is continuing the Fellowship Program that Shields started, although Shields emphasizes that the students are what keeps the program alive.

“It’s a student-formed student organization. They are our ‘boots on the ground,’ and they run the program,” she said. “It’s completely a volunteer service, and it’s all about a reciprocal relationship.”

Ryan McKenney maintains a relationship with SGS that began when he was a freshman. Now a junior, he serves as SGS event planner.

“I would highly encourage curious freshmen to join the program,” McKenney said. “It allows college students to grow with their buddy, to form a relationship with the family, and to make a profound difference in the School and in the lives of their buddy and classmates.”

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**First Lipscomb Pharmacy Trainee Welcomed**  
**BY ELIZABETH TURNER**

The Vanderbilt LEND Program has seen a bit of change in the past 2 years: the retirement of LEND director Terri Urbano, Ph.D., M.P.H., R.N., the welcoming of new LEND director Tyler Reimschisel, M.D., and assistant director Evon Lee, Ph.D., as well as the addition of the program’s first Psychiatry trainee, Danica Denton, D.O. This academic year, LEND has seen even more growth with the addition of the first Pharmacy trainee, Katie McLaughlin, who also is LEND’s first trainee from Lipscomb University.

McLaughlin has a background in biology, having graduated from Morehead State University in Kentucky. Pharmacy drew her interests in undergraduate studies, so she is continuing her education as a second-year pharmacy student in Lipscomb University’s College of Pharmacy. McLaughlin works part-time as a pharmacy intern in the Vanderbilt Medical Center. She also serves as vice president of membership for Lipscomb’s chapter of the American Pharmacists Association Academy of Student Pharmacists (APhA-ASP).

“Dr. Reimschisel actually piqued my interest in the LEND program,” said McLaughlin. “I also am involved with the Vanderbilt Program in Interprofessional Learning [VPIL]. I am in Dr. Reimschisel’s Pediatric Neurogenetics and Metabolism Clinic every Wednesday afternoon along with a Nurse Practitioner student and a student in Medicine. We stay in the Clinic for 2 to 3 years as a part of the VPIL program. All three of us chose to participate in the LEND program together because of our experience with the patient population we have interacted with in the Clinic over the past year.

“I think that pharmacy has mixed well with the other areas of study that have classically been a part of the LEND program,” she continued. “I feel that any time you add a new perspective or outlook, it enriches the ability of the group to learn from each other. Pharmacy is also a relatively recent inclusion to the approach of interprofessional patient care, so I feel it’s appropriate to incorporate this aspect in the LEND program.”

Since the beginning of the semester, McLaughlin has had opportunities to work with other LEND trainees and to gain perspective on the fields that improve the lives of individuals with disabilities.

“I have learned so much from the other LEND trainees already. I had no idea all the different specialists it sometimes requires to care for a child with neurodevelopmental disabilities, particularly outside of the clinic setting,” McLaughlin said. “I feel my pharmacy background has brought a different aspect to the other trainees. Putting children on medication can be very frightening, especially for parents. Even when medications are necessary, such as seizure medications, parents often are concerned about the possible dangers and associated side effects. That is exactly the type of training that pharmacists receive and can bring to the table.”

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**Growing Together: Murray House Fellows and SGS Buddies**  
**BY ELIZABETH TURNER**

Murray House Fellows and Susan Gray School students have some similarities—both are trying to learn their way around a new school, make friends, and adjust to new schedules. What is pretty remarkable about this pairing is that they’re roughly 17 years apart in age.

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“...
Training Advocates
On November 25, the latest cohort of trainees enrolled in the Volunteer Advocacy Project (VAP) will graduate, marking the project’s 5th year of training interested individuals to become special education advocates. The project has graduated more than 300 advocates who have gone on to support more than 450 families in special education meetings across the state.

Much of the core content, such as overviews of the Individuals with Disabilities Education Act, individualized education plans, behavior intervention plans, non-adversarial advocacy techniques, and legislative change, carries over through each session. However, VAP coordinator Lynise Parisien says one of the more exciting aspects of the program is the commitment to adding timely and relevant content when appropriate.

“This session, we had the opportunity to provide training on the Response to Instruction and Intervention (RTI2) model,” said Parisien. “Starting July 1, 2014, all school districts in Tennessee will be required to use this method to determine eligibility of students to receive Special Education services in the category of Specific Learning Disability. Parents are going to have a lot of questions. It was important for us to provide information to our advocates so they can better support families they serve through this transition.”

Parisien also expressed excitement about the November graduation speaker, Jerry Bush, who is deputy assistant commissioner of Special Populations, Tennessee Department of Education. Having a speaker from the Department of Education speaks well about the shifting perceptions of advocates, Parisien said. Once stereotyped as adversarial, advocates are now more aptly viewed as assets. Their role in educating parents on their rights and serving as a bridge to collaboration between parents and the school system are invaluable.

For more on the VAP, email lynise.parisien@vanderbilt.edu.

Raising Awareness Through Multicultural Outreach
The VKC Multicultural Outreach Program continues to expand its activities, which focus on alleviating barriers to accessing disability resources and providing cultural awareness training, information, and assistance to families with different cultural backgrounds. Program staff have worked directly with more than 300 refugees and immigrants from 34 countries of origin now living in 22 counties across the state. Staff continue to forge new partnerships and to provide technical assistance, ensuring that more agencies and organizations are better able to support these families.

Multicultural Outreach staff provide administrative leadership to coordinate the Multicultural Alliance on Disability. This year, the Alliance partnered with the VKC UCEDD to collect stories highlighting the challenges that families with diverse cultural backgrounds experience. Their stories have been shared in statewide trainings and are used to raise awareness nationally.

Staff also provided national technical assistance by presenting a webinar, Multicultural Organizations and Developing Culturally Competent Parent Support Groups sponsored by the Association of University Centers on Disability. The webinar focused on the development of culturally and linguistically competent support groups and programs for diverse populations.

For more on the Kindred Stories booklet, visit kc.vanderbilt.edu/kindredstories. For more on the AUCD webinar, email tracy.beard@vanderbilt.edu.

Working to Improve Employment Options
Convened by the Tennessee Department of Intellectual and Developmental Disabilities (DIDD), the Employment First Task Force began meeting in August to focus on increasing employment opportunities for people with disabilities in Tennessee. Elise McMillan, J.D., UCEDD co-director, has been appointed to the Task Force, which was organized as a result of an Executive Order issued by Tennessee Gov. Bill Haslam on June 19.

The Executive Order establishes state support for the Employment First initiative, which involves a coalition of state agencies and key stakeholders. It includes representatives of DIDD; VKC UCEDD; Departments of Labor and Workforce Development, Mental Health and Substance Abuse Services, Education, and Human Services; Bureau of TennCare; Tennessee Council on Developmental Disabilities; Disability Law & Advocacy Center of Tennessee; and University of Tennessee Center for Literacy, Education and Employment.

The Order directs dedicated parties to develop programming, training, and best practice strategies designed to meet the goal of increasing integrated employment opportunities compensated at a competitive wage for persons with disabilities who desire to work. To read the Executive Order, visit www.state.tn.us/sos/pub/execorders/exec-orders-haslam28.pdf.

Collaboration With Center of Excellence
The VKC is co-sponsoring a series of lectures coordinated through the Vanderbilt Center of Excellence for Children in State Custody (VU COE), a program based in Vanderbilt Psychiatry. The series focuses on the care and well-being of children and adolescents in State custody, and is intended for clinicians, social workers, state employees, and other stakeholders. The VU COE is directed by Richard Epstein, Ph.D., M.P.H., a member of the Psychiatry faculty and VKC member.

To improve the quality and visibility of the series, the VKC assists with publicity, and records the presentations, which allows the VU COE to archive the lectures for future availability. The collaboration has enabled the VU COE to reach a wider audience and has provided greater access to VKC members who can benefit from the series content.

For more on the VU COE, visit https://medschool.vanderbilt.edu/coe.

VVKC UCEDD Reaching Out  BY COURTNEY TAYLOR
Giving as an “Eternal Gift” Bob Henderson

Bob Henderson’s energetic and compassionate spirit has led him in a number of adventurous personal and professional directions. His spirit and his strong sense of leadership have been motivated by his relationship with his brother Britt, who passed away in 1994.

“I think growing up with a brother with a disability influenced me to more accepting of differences,” said Henderson. “Britt was an integral part of our family. He taught me a lot about appreciating people and about empathy. I don’t even remember feeling embarrassed or resentful of him, which you sometimes hear from people who have a brother or a sister with a disability. Britt had a very positive influence on my life.”

As a graduate of Belmont University with a degree in business management, Henderson currently works as a regional manager with The Sisk Company, which supplies financial institutions with products such as identity theft protection devices. He also is the owner of Athens-South, an internet and mobile media marketing firm he established in 2011. In addition to his business ventures, Henderson served as a Lieutenant Naval Flight Officer with the United States Navy.

“I signed up with the Navy right before I finished at Belmont,” said Henderson. “After I graduated, I went to Aviation Officer Candidate School and had a really good experience. I left the Navy early to work for my father, but eventually I returned and transferred to the Tennessee International Guard right before Desert Storm. I was in Bosnia in 1994, which was at the height of that terrible conflict. It was important work and I feel very proud of what I did there.”

Henderson is committed to bettering his community through service. As past president of the Nashville Preservation Society, he lobbied for restoration of Fort Negley and conversion of Kelly’s Point Battlefield to the Metro Greenways Park system. He volunteers with his faith community’s construction team, and was recently appointed to the Belmont University Alumni Board. He just completed a 136-mile bicycle ride to raise money for multiple sclerosis. He credits his father with instilling a commitment to service.

The generosity of the Henderson family is inspirational. The family has been a longtime supporter of Vanderbilt Kennedy Center activities, especially in education. They endowed the Britt Henderson Training Series for Educators in 1994, which has provided training in evidence-based practices for hundreds of teachers. The family also made a 4-year financial commitment to Next Steps at Vanderbilt.

“I applaud the work the Vanderbilt Kennedy Center is doing with programs like Next Steps,” said Henderson. “Getting people employed in the community is really where the rubber meets the road. Looking back at Brit’s life, he didn’t have anything structured after high school. Nobody did back then. I am also impressed with what has been done with the Britt Henderson Training Series. It’s really amazing that my parents were able to make Brit’s life an eternal gift for thousands of people to benefit from.”

Pilot Program of ACM Lifting Lives Series a Success

After several exciting months of seeing the country music business up close, the inaugural ACM Lifting Lives Series is officially on the books.

Since March, participants with various disabilities visited businesses on Music Row and observed the many facets of the music business. As directed by ACM CEO Bob Romeo, the ACM Lifting Lives Series was modeled after the Leadership Music Program, during which music industry members visit a different side of the music business each month in an effort to understand all that goes into creating a hit country song, from the songwriter to the studio manager to the radio producer.

The ACM Lifting Lives Series was created through a partnership between the Vanderbilt Kennedy Center and the Academy of Country Music. Each summer, they work together to create the ACM Lifting Lives Music Camp, a week-long experience for campers with Williams syndrome. The campers are immersed in songwriting, recording, and performing at the Grand Ole Opry, while also participating in research to better understand the syndrome. The Music Camp has been a valuable learning experience for participants, and the Lifting Lives Series was a way of extending the experience beyond one week in summer.

“The ACM did a spectacular job getting artists and professionals to work with our group,” said Sheryl Rogers, ACM Lifting Lives Series project manager. “The participants wrote their own song with hit country songwriters Hillary Lindsey and Blair Daly. Then the Academy lined up people to help with the writing, as well as the recording, video, and marketing. It was a great behind-the-scenes look at the music industry. The participants even had a chance to sit with reigning ACM Group of the year Little Big Town at Universal Music Group in Nashville.”

Participants in the Lifting Lives Series closed out the 2013 project with a night of glitz and glamour at ACM Honors at Ryman Auditorium, Sept. 10, an evening dedicated to honoring special recipients of this year’s Academy of Country Music Awards. They even took the stage to sing with reigning ACM Duo of the Year Thompson Square to sing The Judds’ classic song “Love Can Build a Bridge.”

“The students did great. They were very nervous and sort of ‘deer in the headlights’ during rehearsals, but when show time came about, they were all naturals,” Rogers said.

Because of the success of the ACM Lifting Lives Series’ pilot session, another session is planned for 2014.
Linda Dupré is retiring in January 2013 after 42 years of commitment to the mission of the Vanderbilt Kennedy Center. It is not only what she has done but the quality with which she has done it that have made her a linchpin within our Center and among the most valued support staff for Center directors and investigators.

Dupré began in 1971 as a research assistant for cognition research led by Penny Brooks, Ph.D., now professor of Psychology, Emerita. Brooks was directing the predoctoral and postdoctoral training program in intellectual/developmental disabilities research, which was supported for over 50 years by NICHD. In 1974 Dupré began coordinating this program and later other VKC-affiliated research training programs, as well.

“I loved working on the training grants because of interacting with the graduate students and postdocs,” Dupré said. “Knowing all these people, seeing them graduate and go on professionally to do great things, has been wonderful.”

Amy Michelle Casey, a former trainee, wrote, “Linda is amazing. She is always willing to share her expertise. On top of being highly efficient and organized, Linda cares so much about you personally.”

In 1988 Dupré transitioned to become coordinator and then director of Grants Development Services. One of this Center’s strengths as a national Eunice Kennedy Shriver Intellectual and Developmental Disabilities Research Center (IDDRC) is the expertise of “core staff”—the scientific and administrative staff who provide ongoing research support to Center investigators.

“Because of her knowledge of the NIH grants application process, Linda’s work has been invaluable to Center researchers,” said VKC director Elisabeth Dykens, Ph.D. “Just as critical has been her ability to manage large, multisite grant applications, and the large infrastructure grants for the IDDRC, UCEDD, and LEND. The personal and professional strength that she brings to carrying out this role has enabled many VKC investigators to stay competitive and to obtain grant funding, even during the most difficult of times in the extramural world. Our Center is a university-wide research institute, and Linda is the epitome of this very special charge that we hold.”

Dupré recalls that in 1988, grants were still written on typewriters, copied, and mailed, often on the brink of deadlines. She was an artist with correction and cover-up tape. Then there’s the true story of her chasing down a mail delivery truck after midnight.

In some years, Dupré has managed the grant submission process for over 80 external applications, as well as intramural applications and Center continuation applications with biosketches and project abstracts from 70 or more investigators.

“This year, Linda has exemplified the VKC mission in ways that few people outside of the Center see, but that all of us within the Center recognize,” said Tim Stafford, VKC director of Administrative Services. “She has enabled our researchers to improve lives by doing everything necessary to ensure that their grants were submitted on time, in the right format, and with all the pieces required to become the next important discovery. She has been a mentor to students, a foundation for faculty and staff, and a friend to all.”

Stephen Camarata, Ph.D., professor of Hearing & Speech Sciences, has worked with Linda over many years in multiple roles. “Linda personally embodies the spirit of the Kennedy Center: selfless service,” he said. “She has always put supporting the Kennedy Center family at the top of her priorities. All of us owe Linda our deepest thanks for the sacrifices she has made on our behalf and for the amazingly high quality of her work for more than three decades. She is truly irreplaceable, but her good nature has no doubt been infused into the very bricks of the Kennedy Center, so she will always be with us.”

Dupré deserves the final word: “I worked so hard all these years because of the people. The Kennedy Center appreciated everything I’ve done. It’s been great working here.”

Community Advisory Council Transitions

Since 2005, Doria Panvini has chaired the VKC UCEDD Community Advisory Council (CAC) with a strong commitment to the development of meaningful supports and services for individuals with disabilities and their families. While she stepped down from her position in September, her influence and exceptional leadership over the years has laid the foundation for an ongoing and integral partnership between the CAC and VKC faculty and staff.

Panvini led the charge in encouraging the Center to add employment as an area of emphasis. Under her watch, the CAC received the Association of University Centers on Disabilities’ Council on Community Advocacy Award. Her influence is seen in much of what the Center does, and UCEDD leadership and CAC members are pleased Panvini will remain an active member and that she will continue on the Center’s Public Policy Team.

“My time as chair has been so enjoyable,” said Panvini. “I have been impressed with how receptive leadership is to CAC input. They listen. To be heard is a true gift.”

Panvini’s successor is Christine Sartain, who has been serving as CAC vice-chair. She is a parent advocate and was a 2011 Family Trainee in the Vanderbilt LEND Training Program. Her professional background includes teaching, organizing, and policy advocacy, and she has leadership experience in both emerging and established volunteer organizations. She is co-director of Organization and Policy for the Special Education Advocacy Center.

“Christine will do a wonderful job,” said Panvini. “She understands disability systems and is the parent of a young child with Down syndrome. I have great confidence in her insights and abilities. Our new vice-chair is John Shouse, who also is a parent advocate committed to improving the quality of life for people with disabilities. Together they make a powerful team.”

“We move forward with new leadership,” said Elise McMillan, J.D., VKC UCEDD co-director. “We have a remarkable partnership with our Community Advisory Council. These dedicated self-advocates, parents, and community members encourage us in ways that align us with best practices. It is an honor to work with them.”

BY COURTNEY TAYLOR
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Unless otherwise noted, events are free and open to the public. Events are subject to change. Please check the website calendar at kc.vanderbilt.edu or contact (615) 322-8240 or toll-free (1-866) 936-VUKC [8852].

Please keep this calendar and check the Event Calendar on the VKC website for updates. If you wish to receive event announcements by email, send your email address to kc@vanderbilt.edu.

For disability-related training and other events statewide and nationally, see the searchable Pathfinder Disability Calendar www.familypathfinder.org.

*Event will be held in Room 241 Vanderbilt Kennedy Center/One Magnolia Circle Bldg (110 Magnolia Circle).

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