Is More Better?
Down Syndrome Language Intervention by Paul Yoder, Ph.D.

Education has only just begun to study how often treatment sessions should occur to maximize benefit to students. We conducted a study to find out whether daily treatment sessions were more helpful than weekly sessions for improving spoken vocabulary in children with Down syndrome and in children whose intellectual disability has other causes.

Past research has shown that children with Down syndrome tend to have more trouble learning to speak than children whose intellectual disability has other causes. We hoped that daily therapy, an unusually high rate of therapy, might provide the extra help that children with Down syndrome need to make the difficult transition to spoken language.

The Language Treatment
Our treatment method was Milieu Communication Teaching (MCT), which has 3 parts.

The first part teaches children to use gestures, nonword vocalizations, and eye contact to ask for things/actions, to communicate liking something, or to take turns. This follows the principles of Prelinguistic Milieu Teaching. Research has shown that children communicating in these ways predicts later language growth and provides a rich opportunity for parents to respond in ways that teach spoken words.

The second part teaches parents to notice their children's nonverbal communication and then to respond in ways that are thought to teach children to use and understand words. We followed the curriculum Hanen It Takes Two to Talk.

Key Findings
The researchers systematically screened more than 4,500 studies and reviewed the 32 studies published from January 1980 to December 2011 on therapies for people ages 13 to... Continued on page 3

Autism Therapies for Adolescents
More Evidence Needed by Jennifer Wetzel

Vanderbilt Kennedy Center researchers studying interventions for adolescents and young adults with autism, in an August report, found that evidence is insufficient to support findings, good or bad, for therapies currently used.

Although the prevalence of autism is on the rise, much remains to be discovered when it comes to interventions for this population, the researchers concluded.

"Overall, there is very little evidence in all areas of care for adolescents and young adults with autism, and it is urgent that more rigorous studies be developed and conducted," said Melissa McPheeters, Ph.D., M.P.H., director of Vanderbilt's Evidence-Based Practice Center and senior author of the report, a systematic review of therapies published by the Department of Health and Human Services' Agency for Healthcare Research and Quality (AHRQ).

Zachary Warren, Ph.D., director of the Vanderbilt Kennedy Center's Treatment and Research Institute for Autism Spectrum Disorders, said, “There are growing numbers of adolescents and adults with autism in need of substantial support. Without a stronger evidence base, it is very hard to know which interventions will yield the most meaningful outcomes for individuals with autism and their families.”

Key Findings
The researchers systematically screened more than 4,500 studies and reviewed the 32 studies published from January 1980 to December 2011 on therapies for people ages 13 to... Continued on page 2
Director’s Message Travel the Road to Discovery

Your gifts and dedication are making a positive impact on science, scientists, and individuals with disabilities. Collectively, we thank you.

Now more than ever, annual gifts remain critically important to the basic and clinical research mission of the Vanderbilt Kennedy Center. Every dollar you invest in our talented researchers returns many more dollars in larger grants from the National Institutes of Health (NIH) or other agencies. Your support allows us to collect the critical preliminary data needed to successfully compete for increasingly precious NIH grants.

Nicholas Hobbs Discovery Grants are supported by your annual gifts. As I write, we are reviewing a dozen applications submitted by talented multidisciplinary research teams proposing innovative research.

With Hobbs Discovery Grants, VKC investigators are gathering data to address pressing needs. Our center is a hub for talented scientists who tackle other tough questions on the causes and best possible outcomes for individuals with autism, learning disabilities, Down syndrome, and other disabilities.

As a way to continue to recognize our dedicated supporters, Vanderbilt recently launched the Oak Leaf Society, which focuses on giving loyalty as measured by consecutive years of giving rather than the amount of the contribution.

Join with us on the road to discovery.

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AUTISM THERAPIES FOR ADOLESCENTS from page 1

30 with autism spectrum disorders. They focused on the outcomes, including harms and adverse effects, of interventions, including behavioral, educational, vocational, and medical.

Behavioral and educational therapies. Some evidence revealed that treatments could improve social skills and educational outcomes such as vocabulary or reading, but the studies were generally small and had limited follow-up.

Vocational therapies. Only five articles tested vocational interventions, all of which suggested that certain vocational interventions may be effective for certain individuals, but each study had significant flaws that limited the researchers’ confidence in their conclusions. The researchers’ findings on vocational interventions were featured in the Aug. 27 issue of Pediatrics.

“We need more research to be able to understand how to treat core symptoms of autism in this population, as well as common symptoms such as anxiety, compulsive behaviors, and agitation,” said Jeremy Veenstra-VanderWeele, M.D., assistant professor of Psychiatry, Pediatrics, and Pharmacology.

“Individuals, families, and clinicians currently have to make decisions together, often in a state of desperation, without clear guidance on what might make things better and what might make things worse, and, too often, people with autism spectrum disorders end up on one or more medications without a clear sense of whether the medicine is helping.”

The most consistent findings were identified for the effects of antipsychotic medications on reducing problem behaviors that tend to occur with autism, such as irritability and aggression. Harms associated with medications included sedation and weight gain.

The Review

As recently as the 1970s, autism was believed to affect just one in 2,000 children, but newly released data from the Centers for Disease Control and Prevention indicate that 1 in 88 children has an autism spectrum disorder. Boys with autism outnumber girls 5 to 1, which estimates that 1 in 54 boys in the United States have autism.

Additional investigators on this report included Dwayne Dove, M.D., Ph.D., fellow in Developmental-Behavioral Pediatrics; Nila Sathe, M.S., M.L.I.S., program manager, Institute for Medicine and Public Health; and Rebecca Jerome, M.L.I.S., M.P.H., assistant director, Eskind Biomedical Library.

Their research, published in the report, Interventions for Adolescents and Young Adults with Autism Spectrum Disorders, was funded by the Agency for Healthcare Research and Quality’s Effective Health Care Program and conducted through Vanderbilt’s Evidence-Based Practice Center.
The third part starts when children begin to use words in treatment sessions. It teaches children to use words to express what they have been trying to communicate without words. We used a sequence of prompts to encourage children to produce words and immediate rewards for talking at moments when children are thought to learn best. This part follows Milieu Language Teaching principles.

Study's Questions
Our study aimed to answer three questions. Do children with Down syndrome acquire spoken words at a slower rate than children with other intellectual disabilities of the same age and the same intelligence level? Within each subgroup (Down syndrome vs. other intellectual disability), do children receiving daily MCT sessions learn to use more spoken words than children receiving weekly MCT? Is receiving daily MCT associated with more family stress than receiving weekly MCT?

Who Took Part
Sixty-four families took part. Children were 18 to 27 months at entry. All had intellectual disabilities and spoke little before entering the study. On average, the children had cognitive levels on the 12.5-month level. Among the children, 35 had Down syndrome, and 29 had intellectual disabilities from other causes, most of which were unknown. Almost all treatment sessions occurred in the home.

Study Design
The research design was strong in several ways. First, families assigned to the weekly group were similar to the families assigned to the daily group on 39 different aspects that can affect language development. This occurred because families were randomly assigned to daily vs. weekly treatment. Second, frequent assessment of the number of words that parents reported their children said allowed us to visualize well each child's spoken vocabulary development. Our primary measure of growth in spoken vocabulary came from the checklist of words that parents had heard their children use in the last month. By using parents' knowledge of what their child said, we could track each child's use of words, not just in our clinic visits, but everywhere and at any time parents heard their child talk. Parents completed this checklist every 3 months.

Third, children received the planned quality and quantity of treatment. At least 98% of the sessions lasted our target of at least 45 minutes a session. Even young children could tolerate (and usually enjoy) sessions that lasted longer than we had tried in the past. The average treatment duration was a little under 9 months. Our staff treatment providers also met our goal of providing an average of at least one correctly implemented teaching episode per minute.

Findings
All children grew in their spoken vocabulary. Regardless of the number of times per week children received the treatment or whether they had Down syndrome, on average, children learned to use 16 new words in 9 months. However, regardless of how often they received treatment, children with Down syndrome learned 10 new words, while children with intellectual disabilities for other reasons learned 28 new words. Parents reported the same amount of stress regardless of whether their child received treatment daily or weekly.

If we do not consider whether or not children had Down syndrome, receiving MCT daily did not appear to have a clearly better effect than receiving it weekly. However, within the Down syndrome group, once cognitive level was controlled, children receiving daily MCT gained more words (mean = 17 words) than children receiving weekly MCT (mean = 5 words).

It may be discouraging to hear that having Down syndrome can place a child at greater disadvantage for learning to use new words than a child already experiences from having an intellectual disability. The good news is that more frequent sessions per week can help make up for some of this disadvantage. Additionally, adding more sessions a week did not cause parents to feel more stress.

It has long been argued that toddlers with autism need more hours of treatment per week than is provided by many states through early intervention programs. This study provides data to argue that toddlers with Down syndrome also need more hours of treatment per week.

Paul Yoder, Ph.D., is professor of Special Education and VKC investigator.

Autism Online Training for Tennessee Educators

TRIAD and the Tennessee Department of Education have partnered to provide Basic Online Training Sessions. They are available for viewing by Tennessee school personnel now through May 31, 2013.

Autism Spectrum Disorders and Principles of Behavior and Learning. This 2-hour workshop provides a basic understanding of the characteristics of ASD and how they impact learning and behavior. The emphasis is on understanding the function of behavior and basic strategies for teaching students appropriate behaviors to replace challenging behaviors.

Improving Communication in Students with ASD. This 2-hour workshop provides information on developing functional and measurable communication goals, and using evidence-based strategies, including incidental teaching, discrete trial training, and visual supports to improve students’ communication throughout the day.

Registration is required. Contact Linda Copas, Director of Behavior & Autism Services, TN Dept. of Education, linda.copas@tn.gov.
Pay It Forward  BY MEGAN HART

Hart is Coordinator of Education and Training Services, Tennessee Disability Pathfinder. The following are excerpts from her remarks to students with developmental disabilities attending the 2012 VKC Next Steps Summer Institute. She is an Arc Tennessee Board member and is chairing Tennessee Allies in Self-Advocacy (TASA) (tnselfadvocacy.org).

As a person with a disability, I can relate to some of the lessons you have learned [at the Summer Institute] because they are similar to some of mine.

I was born a little person, but I was a typical child until I became paralyzed at age 5. After mistakes made during surgery on my spinal cord, I woke up able to move only my head. Like anyone growing up, I had to learn independent living, social, and self-advocacy skills, but my disability has had a major effect on learning them.

I have supportive family, friends, and professionals who have always expected me to learn these skills and have created learning opportunities. We often don’t realize that these expectations contribute to our developing essential skills. My parents had the same expectations for me to develop these skills as they did for my siblings without disabilities. It wasn’t always easy.

Children with disabilities sometimes experience difficulties developing social skills because they don’t have opportunities to interact with their peers in the same way as children without disabilities. After I became paralyzed, I could no longer play on the playground, so I had to find other opportunities to socialize with my peers. I drew pictures and had races with them as they took turns pushing my wheelchair during recess.

Sometimes having a disability can make it seem difficult to develop friendships because of others’ perceptions. A disability can be seen by others without disabilities as a major difference that makes them hesitant to interact. It takes social skills to make them realize that despite having a disability, we have shared interests and abilities to develop friendships.

Even though I had great friends, at times I felt left out. Perhaps I wasn’t invited to a party, or I was the odd girl out in a group of friends. I could have assumed it was because I have a disability, but everyone has these experiences growing up. It is part of developing social skills.

Growing up, we are learning self-advocacy skills. Although self-advocacy applies to anyone, it has significant meaning for individuals with disabilities. Since we often rely on others for assistance, it takes effort to make sure we communicate for ourselves without allowing others to communicate for us.

A child who says “wa-wa” or points to water to communicate wanting to drink is using a self-advocacy skill. As we grow up, our needs and desires become more complicated, but we can communicate for ourselves. Until we learn what all of our needs and desires are, other people advocate for us, and we learn from them. I didn’t know how to communicate all of my needs for school accommodations when I was young, so my mom was a great advocate for me. As I became older, I was able to communicate those needs for myself.

You will continue to have many experiences throughout your lives that require self-advocacy. Take advantage of postsecondary education programs, which help us continue to develop skills. Through my postsecondary education, I developed more independent living skills and learned to navigate a new environment. I developed more social skills when developing new friendships, which was difficult at first because I didn’t know anyone. The challenges I experienced were well worth it because I made friends who will be a special part of my life forever.

My self-advocacy skills continued to develop when I had to communicate my accessibility needs at college. The campus was not yet wheelchair-friendly, but the school administration and my classmates helped make sure I could get to where I wanted to be. Despite the challenges it created, it also created opportunities. I couldn’t complain when a cute group of guys offered to carry my wheelchair up the dorm steps. The college became more accessible during my four years there. Campus life played an important part in my ability to develop skills and obtain a valuable education.

Looking to the future, you will continue to face challenges that are not necessarily created by the disability you have but are affected by the disability. You will face challenges when trying to find a job. You will likely change your mind several times when deciding what to do and where to work. That’s okay. It’s part of the process. You will need to advocate for yourself to let others know about the skills and talents you have to do a job. With every new challenge comes an opportunity to learn more about yourself.

I have one more piece of advice: Pay it forward. Give back what you have learned to others. Share your experiences and knowledge. Teach others how to become more independent. Make others feel more comfortable in social situations by sharing your skills with them. Support others in advocating for themselves.
**Oxytocin Nasal Spray Clinical Trial**  
**BY JAN ROSEMERGY**

Recent reviews of the research literature on autism therapies (see cover story) indicate the urgent need for large-scale, well-designed studies to provide evidence that guides effective treatment. Now, a large clinical trial is beginning to test the safety and effectiveness of oxytocin to improve sociability and communication in children and teens with autism.

Oxytocin is a naturally occurring hormone that plays a critical role in sociability and bonding. “Data from single-dose administration of oxytocin suggest some improvement in aspects of social functioning. This has led to its use by some physicians and families, but without solid evidence of safety or effectiveness,” said Jeremy Veenstra-VanderWeele, M.D., assistant professor of Psychiatry, Pediatrics, and Pharmacology, TRIAD medical director, and principal investigator (PI) for the Vanderbilt site clinical trial.

The trial is called SOARS-B for the Study of Oxytocin in Autism to Improve Reciprocal Social Behaviors. It will include 300 children with autism, ages 3 to 17, at five sites in Boston, New York, Seattle, Nashville, and Chapel Hill, North Carolina. During the first 6 months, half of the children will receive the oxytocin spray. The other half will receive an inactive spray. Neither researchers nor participants will know who is taking the active drug. During the second 6 months, all participants will receive the oxytocin spray. “Half the children taking part will have an IQ in the broad typical range and intact verbal function, and half will have intellectual disability and some degree of language impairment. We want to know if oxytocin helps a particular subset,” Veenstra-VanderWeele said.

The researchers will measure social skills and communication over the study’s course. In addition, they will collect blood samples to conduct gene-based studies to evaluate whether genetic variation in the oxytocin receptor affects response to treatment.

“If this medication increases social interest, then it could be connected to a social skills training intervention. Such a combination could have greater impact than either medicine or behavioral treatment alone,” said Veenstra-VanderWeele.

Based in part upon preliminary data from an Autism Speaks study, the National Institutes of Health awarded $12.6 million to fund this national clinical trial. “This study will be the largest planned clinical trial in autism conducted to date,” said Zachary Warren, Ph.D., TRIAD director and Vanderbilt site co-PI. “TRIAD and Vanderbilt are contributing to creative ways of combining cutting-edge pharmacology with exceptional data collection in a drive for answers.”

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**Baby Sibs—A Window Into Autism**  
**BY JAN ROSEMERGY**

For the past decade, TRIAD researchers have been part of the Baby Siblings Research Consortium, a national network of researchers studying younger siblings of children with an autism diagnosis. Since “baby sibs” are at higher risk for autism than younger siblings of typically developing children, researchers track their development in order to identify early biological or behavioral markers. TRIAD has three ongoing baby sibs studies.

TRIAD’s first study is a multi-site effort to track development through early infancy. “We’re looking at very early skills related to attention and emotion to see if we can chart differences that will help us identify autism earlier,” said Zachary Warren, Ph.D., associate professor of Pediatrics and Psychiatry and TRIAD director.

The second large study is aimed at improving measures for early detection. Currently, pediatricians typically ask parents to complete the Modified Checklist for Autism in Toddlers (M-CHAT) at well-child visits around 2 years of age. TRIAD is testing a revised M-CHAT version for younger siblings to see if it might be a better way to screen for early warning signs of autism. This study is open to families who have an older child with autism and an infant sibling, 16 to 30 months old. Families receive an evaluation of their baby sib at study entry and a re-evaluation at 36 months.

In the newest study, TRIAD is partnering with researchers at 6 other universities to create the High Risk Baby Siblings Research Consortium Biorepository, funded by Autism Speaks and the Simons Foundation. Biological samples and clinical information on families with one or more children on the autism spectrum are being collected. The goal is to support research on the genetic and environmental factors that increase or decrease risk for autism.

“Family participation in research is contributing not just to one idea, but to many ideas of value to their own and other families as well as to scientists across the country,” Warren said. “We have families who have graciously afforded us the ability to check in on their baby’s development at 6, 9, 12, and 18 months. Now we have this ability to link that information to differences in neurogenetic pathways.”

“Families are worried about younger siblings being on the spectrum,” said Amy Nicholson, TRIAD psychological examiner. “We can help families track development. If concerns need to be discussed, we’re there with families for that discussion. We also can provide reassurance about the positive aspects of their child’s development. Families can let us hold some of the worry so that they can enjoy their child.”

For TRIAD studies, contact (615) 322-7565, toll-free (877) 273-8862, or autismresources@vanderbilt.edu.
Research Interests
My research is focused on the cognitive and social/environmental factors that affect children’s ability to learn to read. I am co-investigator on a study that explores the cognitive and neurobiological profile associated with children who exhibit late-emerging reading disability, and how it is similar or different than early reading failure. I conduct large-scale studies in the areas of reading intervention and assessment. My research involves modeling individual differences in the development of children’s reading skills.

Principal Investigator
• Predictors and Subtypes of Reading Disabilities: Implications for Instruction of “Late-Emergers,” Institute of Education Sciences (IES)
• Response-to-Intervention as an Approach to Preventing and Identifying Learning Disabilities in Reading, IES
• Evaluating a Multicomponent Reading Comprehension Program Designed to Address the Diverse Needs of Struggling Readers in Late Elementary School, IES

Honors and Awards
• President, Society for the Scientific Study of Reading (2012-present)
• Co-Editor, Annals of Dyslexia (2006-present)
• Co-Editor, National Reading Conference Yearbook (2006-present)

Education
• B.S., 1983, Chemical Engineering, University of Michigan
• M.S., 1986, Chemical Engineering, Northwestern University
• Ph.D., 1993, Learning Disabilities, Northwestern University
• Postdoctoral Research Fellowship, 1999-2000, Institute for Behavioral Genetics and Department of Psychology, University of Colorado Boulder

Selected Publications

Attraction to Developmental Disabilities Research
My interests in studying reading disabilities first began when I got a job out of college working at the Landmark School in Beverly, MA, for children with dyslexia. The year I spent teaching raised so many questions for me that I decided to go back to school and get a Ph.D. in Communications Disorders and Learning Disabilities from Northwestern University.

Reasons for VKC Membership
My research interests revolve around helping to improve the long-term literacy outcomes of children who struggle to develop reading skills. This focus fits well within the core mission of the Kennedy Center. Being a VKC investigator has provided me with opportunities to extend my research that would not have been possible without the relationship. I value the multidisciplinary research opportunities afforded by being a VKC member.

New Stories of Hope video
The Vanderbilt Kennedy Center has recently released “Stories of Hope,” a video that showcases just a few of the families affected by the work of VKC investigators, researchers, Next Steps ambassadors, and more. To view, visit kc.vanderbilt.edu (see “View Stories of Hope Video” on homepage).
Treatment Window for Genetic Disorder  

BY MELISSA MARINO AND LEIGH MACMILLAN

Tuberous sclerosis complex (TSC) is a relatively common genetic disorder that causes benign tumors to form in different organs, including the brain. These brain lesions can lead to seizures, autism, and cognitive or behavioral disorders. Although it is known that mutations in two genes (TSC1 or TSC2) cause the disorder, specific abnormalities that cause neurologic features are not clear.

In Neurobiology of Disease (January 2012), Kevin Ess, M.D., Ph.D., and colleagues showed that mice genetically engineered to lack TSC1 in the brain die prematurely, have increased brain size, and have anatomical and cellular abnormalities in both neurons and glia (the brain’s supporting cells). Additionally, activity of the “mammalian target of rapamycin complex” (mTORC1 and mTORC2) pathways was altered in brain cells. Treatment with rapamycin (a drug commonly used to combat organ rejection) prevented premature death and reversed glial abnormalities. The results suggest that a postrnatal treatment window may exist for combating some of TSC’s neurological and cognitive effects.

Kevin Ess is assistant professor of Neurology, Pediatrics, and Cell & Developmental Biology, and a VKC member. This research was supported by the NINDS, the Tuberous Sclerosis Alliance, American Epilepsy Society/Milken Family, and VKC.
The toddlers and preschoolers of the Susan Gray School (SGS) are settling into their inclusive classrooms, which have dynamic new names like Soaring Eagles and Rising Monarchs. With the new year have also come changes in leadership, the addition of graduate students and more master’s level teachers, and plans for refurbishing space.

“The School is embarking upon dramatic and exciting transformations,” said Ann Kaiser, Ph.D., Susan Gray Chair in Education and Human Development and professor of Special Education and Psychology. Kaiser and Mary Louise Hemmeter, Ph.D., associate professor of Special Education, are SGS faculty co-directors.

“Our first goal was to get the Susan Gray Teaching Fellows program up and running. This exciting program, funded by Rodes Hart and the Peabody Administration, puts an early childhood special education master’s student in every classroom. This improves teacher/student ratios and provides excellent training for our students. Second, we are more than halfway to having a master’s certified early childhood special education teacher in each classroom. That’s a huge quality change. Third, we hired an accomplished new site director, who is also an educator, to be present every day providing leadership. Finally, we plan to improve our before- and after-care programs to make the entire day a high-quality learning experience.”

The new site director, Kiersten Kinder, received her doctorate in Special Education in 2010 from Peabody, where her research was focused on the professional development and coaching of teachers.

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“Working at the Susan Gray School really is the job of my career,” said Kinder. “I was a classroom teacher for 10 years in inclusive early childhood classrooms in Chicago. After focusing so heavily on research during my graduate studies, I realized that I really missed being part of a school. I love working with teachers and hope to create a risk-free environment for them to grow professionally.”

“We are thrilled that we were able to recruit Kiersten,” said Hemmeter. “She is such a thoughtful mentor for the teachers, and she loves being around children and families every day. That’s a great plus.”

The new year will bring refurbishment of classrooms with paint, improved child-sized bathroom fixtures, and space redesigned to accommodate a new “art studio” and “science lab.” In addition to a new after-care program, Hemmeter, Kaiser, and Kinder will be developing new community programs and extending the programs available to SGS families of infants and toddlers served in collaboration with Tennessee Early Intervention Services.

“We’re already a model for how early childhood inclusive education can happen well,” said Kinder. “We have a strong, dedicated staff and excellent support through the Special Education Department, the Vanderbilt Kennedy Center, and the Peabody Dean’s Office. With so many people working together to make it even better, it’s really an exciting time.”

Elizabeth “Liz” Graves came to Vanderbilt after working for a brief time in the speech and language department of a rural school district. Fascinated by the advantages provided to children who are deaf through advances in cochlear implant technology, she was anxious to learn more about how she could combine her love of education and audiology to improve infant and child outcomes. She eagerly embraced the interdisciplinary approach to the provision of family services emphasized in LEND training—Leadership Education in Neurodevelopmental Disabilities.

“I wanted the opportunity to work with students who were deaf and hard of hearing in rural areas, where services can be sparse,” Graves said. “My background as a deaf educator and now as an audiologist allows me to combine both roles effectively—especially in rural areas where knowledge of cochlear implants is still in its infancy.”

Today Graves works as a pediatric audiologist for the Mama Lere Hearing School at Vanderbilt, a program of the Vanderbilt Bill Wilkerson Center, and she travels to several school districts as part of an outreach program providing audiologic services for children in rural Middle Tennessee.

Funded by the Maternal and Child Health Bureau, the LEND mission is to improve the health of infants, children, and adolescents with disabilities through graduate education across a diverse range of professional disciplines. LEND training prepares students for leadership roles in their respective disciplines. There are 43 LEND programs in 37 states. In 2008, the number of pediatric audiology trainees funded through the LEND network was expanded because of the shortage of highly qualified pediatric audiologists. The Vanderbilt LEND has a Pediatric Audiology sub-award.

For the 2012-13 academic year, the LEND has 20 trainees in pediatric audiology, deaf education, developmental/behavioral pediatrics, nursing, occupational therapy, physical therapy, psychiatry, psychology, social work, and speech-language pathology, and a family trainee.
Changing the Employment Landscape

Virtual every state-level indicator confirms that relatively few Tennesseans with significant disabilities have the opportunities and supports to access and maintain competitive, integrated employment. The employment rate for Americans without disabilities is 79.7%. The employment rate for Tennesseans with developmental disabilities is 17%. The goal is to close that gap by improving the employment rate to 44% within 5 years.

Now that goal is more achievable, thanks to the Vanderbilt Kennedy Center (VKC) and the Tennessee Collaborative for Meaningful Work receiving a Projects of National Significance: Partnerships in Employment Systems Change grant from the Administration on Intellectual and Developmental Disabilities.

“The Collaborative is an impressive group of 28 agencies and organizations that have been working together for over a year to improve employment outcomes,” said Elise McMillan, VKC UCEDD co-director. “While the Vanderbilt Kennedy Center is the administrative lead, this grant allows a valuable partnership to grow in its statewide efforts.”

In addition to parent support organizations, disability nonprofits, and employment-related agencies, State partners include Intellectual and Developmental Disabilities, Education, Human Services Division of Rehabilitation Services, Labor and Workforce Development, and the Tennessee Council on Developmental Disabilities and the Tennessee Higher Education Commission.

“Research and experience are clear,” said Erik Carter, Ph.D., associate professor of Special Education and the project’s principal investigator. “Meaningful work can make a real difference in the lives of young people with intellectual and other developmental disabilities. This grant will enable us to make compelling changes in policies and practices across Tennessee to ensure that every youth with a significant disability has the aspirations, opportunities, and supports to access a good job during and after high school.”

The project will focus on establishing compelling and sustainable employment partnerships; stimulating and advancing systems/policy change statewide; raising the aspirations and capacities of people with intellectual and developmental disabilities (IDD), their families, service systems, employers, and communities regarding competitive work as the first choice; and increasing access to meaningful work while youth with IDD are still in high school and to multiple pathways to future careers after school.

For information on the Collaborative, visit www.tennesseeworks.org.

Reading Clinic’s New Leadership

The Reading Clinic has begun its 2012 Fall session with the new leadership of associate director Nicole Davis, Ph.D., research assistant professor of Radiology and Radiological Sciences. The position was created to provide day-to-day leadership.

“Nikki comes to us with a wealth of knowledge about child development and Vanderbilt,” said Laurie Cutting, Ph.D., Patricia and Rodes Hart Associate Professor of Special Education and associate professor of Psychology, Radiology, and Pediatrics. “Specializing in reading abilities and disabilities, she has worked with me both as the associate director of our Education and Brain Sciences Research Laboratory, and she has assisted me in my role as faculty director of the Reading Clinic, providing reading consultation and tutor training in our evidence-based reading intervention programs. Her passion, combined with her clinical and educational background, provides her with the knowledge necessary to ensure that the Clinic will continue to grow in capabilities and services to our community.”

For Davis, her work both in reading research and in reading intervention has been a natural and deeply personal progression.

“Many individuals in my family, including my dad and older brother, have dyslexia,” said Davis. “I loved to read. I grew up thinking that reading was something magical. Eventually, I entered graduate school and enrolled in any reading-related course or training program that I could find. I also worked in reading-related research labs. However, I wanted to return to working with families. I am thrilled to contribute to the field of reading intervention in this way.”

The Reading Clinic provides individualized reading tutoring for children in grades K-8 who are behind in reading or who have disabilities. For information, call (615) 936-5118.

Access Nashville Expands Its Reach

The Tennessee Disability Coalition and Access Nashville are collaborating to coordinate training on replication of Access Nashville for Tennessee ADA affiliates, partner agencies, and other interested entities. The training is funded by a grant to the Coalition from the Southeast ADA Center, a project of the Burton Blatt Institute of Syracuse University.

Access Nashville is a VKC UCEDD project led by Carole Moore-Slater, Tennessee Disability Pathfinder director. Through this hands-on service learning project at Vanderbilt and other local colleges, students are trained to assess the accessibility-friendliness of restaurants, entertainment attractions, hotels, and transportation services.

“We are thrilled to see the interest in Access Nashville and the recognition of the power it has as a service-learning project,” said Moore-Slater. “We have trained close to 800 college students who have identified barriers that individuals with physical disabilities face when trying to do something that many of us might take for granted, like eat in a restaurant. We have a saying at Access Nashville that accessibility is good business. It’s a win-win situation for the patrons with disabilities and the businesses widening their customer base by being accessible.”

For information, contact carole.moore-slater@vanderbilt.edu.
The Dollar General Literacy Foundation awarded a Youth Literacy grant of $50,000 to the VKC Reading Clinic.

“The Dollar General Literacy Foundation is pleased to support the literacy efforts of the Vanderbilt Kennedy Center Reading Clinic,” said Rick Dreiling, Dollar General’s chairman and CEO. “The Youth Literacy grants are awarded annually at the start of the school year so that the funds are in place to have an impact on reading education and support.”

In August, the Dollar General Literacy Foundation awarded grants totaling more than $2 million to 564 non-profit organizations, community groups, schools, and libraries throughout the United States. It is estimated that approximately 315,000 youth will be served as a result of these grants.

Since its founding, Dollar General has been committed to supporting literacy and education. To further this support, the Dollar General Literacy Foundation was established in 1993 to improve the functional literacy of adults and families by providing grants to nonprofit organizations dedicated to the advancement of literacy.

For more information about the Dollar General Literacy Foundation or for a complete list of grant recipients, visit www.dgliteracy.org.

The VKC Reading Clinic provides intensive, individualized, one-to-one tutoring using assessment and instructional methods proven by research to promote reading. It serves students in grades K-8 who are behind in reading or have learning disabilities, developmental disabilities, or intellectual disabilities. For information, contact (615) 936-5118.

Realizing Potential: Mary Layne Van Cleave

At age 19, Mary Layne Van Cleave began student teaching in a high school math classroom. She had studied for 3 years, with a major in math and a minor in education, in the teaching program at Middle Tennessee State University. She was eager to get into the classroom and gain teaching experience. It turns out she hated it.

“It was the worst experience of my life,” said Van Cleave. “I realized quickly that I was not going to be able to do that for the rest of my life. I didn’t have a clue what I wanted to do. I stayed in school for another year and got a master’s degree in math. Right before graduation, the head of the department called to tell me there was a program at Vanderbilt in Biostatistics looking for students and he thought I might be interested. I really didn’t know what else I was going to do so—I was!”

Van Cleave went on to receive her second master’s degree in Biostatistics. After graduation, she began to work for the State Department of Health in the Office of Health Statistics, and eventually was asked to build a data program for the Tennessee Hospital Association. Five years ago, she became the executive vice president and chief operating officer of the Hospital Association. She beams when she talks about her work.

Van Cleave is married and has two children. She met her husband John while at Vanderbilt. He was studying law and is now an attorney with Watkins McNeilly. Their son Andrew is 24 and their daughter Lindsey is 23. Lindsey graduated from Southern Methodist University a year ago and now works for an insurance company. Andrew graduated in 2011 with the first cohort of students enrolled in Next Steps at Vanderbilt, a 2-year certificate program for students with intellectual disabilities.

“Next Steps wasn’t the first contact we had with the Vanderbilt Kennedy Center,” said Van Cleave. “Andrew always had trouble reading, so we enrolled him at the Reading Clinic when he was about 10 years old. I don’t know what they did or how they did it, but it clicked and he started to read. At that point, the program was only for kids up to age 12, but I begged them to continue working with him and they let him stay until he was 20. He worked so hard and learned so much. I feel like the Reading Clinic probably gets much of the credit for Andrew graduating with a regular diploma and for what he’s been able to do since then.”

Van Cleave’s introduction to the VKC Leadership Council was 2 years ago, when she was invited to speak about the transformations she had seen in Andrew during his participation in Next Steps at Vanderbilt. Soon after she delivered that passionate speech, she was invited to join the Council. She also chairs the Next Steps Advisory Board and considers it a personal goal to raise awareness about this postsecondary program.

“More people need to know the invaluable resource we have in the Kennedy Center,” said Van Cleave. “I especially would like to see more awareness of the Next Steps program. Andrew blossomed in that program. I watched his attitudes about himself change. I watched him go from being painfully introverted to holding his own in a group of college kids. I watched him begin to take pride in the way he dresses, travel without me on out-of-state spring break trips, and begin a job that he really enjoys. Next Steps changed his whole life and his whole potential for a future. I have a great love for the Kennedy Center.”
Donna Eskind, VKC Leadership Council Chair, and Shirley Speyer, Nicholas Hobbs Society Chair, welcomed members to the Fall Leadership Council Meeting in September.

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Community Leadership—New CAC Members

Leadership by individuals with disabilities and family members is a hallmark of the national network of University Centers for Excellence on Developmental Disabilities (UCEDDs) and their funding agency, the Administration on Intellectual and Developmental Disabilities. Such leadership helps ensure that UCEDDs are meeting the real, most important concerns within their states. The VKC UCEDD has an energetic and committed Community Advisory Council (CAC). The CAC advises the UCEDD leadership and is a full partner in planning, implementing, and evaluating activities. At its September meeting, the CAC welcomed several new members for 3-year terms.

Ron Butler is the parent of an adult son with an intellectual disability and cerebral palsy. Butler is a past president of The Arc Tennessee, where he is also a board member, and he is on the board of Mid-TN Supported Living, Inc. He is retired from Ford Motor Company.

Belinda Martinez has two children, one with autism. A parent volunteer, she works with the Spanish-speaking community of Montgomery County to provide advocacy support, resources, and information for children, teens, and adults with autism and other disabilities.

Christine Sartain is a parent advocate and was the 2011-12 Vanderbilt LEND Family Trainee. Her professional background includes teaching, organizing, and policy advocacy. Most recently, she has been involved in the Disability Coalition on Education, the VKC Volunteer Advocacy Project, and the Special Education Advocacy Center. She has a daughter, Lake, who has Down syndrome and attends the Susan Gray School. Sartain is CAC Vice Chair.

Erin Thompson facilitates a family support group for Tennessee Voices for Children and is the founder of the Maryville Autism Coalition. She has served on the Board of the Autism Society of East Tennessee. When she is not spending time with her three children and husband, Thompson is devoted to helping children and families who have special needs get connected in their community. She has helped form a strong faith-based resource for families to help them feel comfortable in a church setting with their children.

Karen Weigle, Ph.D., is a clinical psychologist with 20 years of experience working with people with autism and other developmental disabilities and their families. She is co-director of Psych Asses, a comprehensive, multispecialty evaluation clinic, and is a technical assistant and trainer for the Center for START Services at University of New Hampshire, a national program designed to develop local crisis prevention and intervention services for persons with intellectual and developmental disabilities and mental health concerns.

Erin Richardson has been a disability advocate since 2001, when her middle son was diagnosed with a chromosomal abnormality. Formerly a practicing attorney, she has been an educational advocate for Middle Tennessee families since 2005. In 2011, she started the Special Education Advocacy Center, dedicated to advocating for families and students with disabilities in education settings. Richardson has served since 2008 on the Mayor’s Advisory Council for Special Education.

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Find Us on Facebook
Find us on Facebook for frequent updates and discussions on news, events, and research going on at the Center.
tinyurl.com/vkcfacebook

Giving
kc.vanderbilt.edu/giving

Alyne Queener Massey
—Remembering a Friend

Vanderbilt Kennedy Center Leadership Council member and our good friend Alyne Queener Massey passed away on September 11, 2012. She was a generous leader and philanthropist who had a deep devotion to Vanderbilt and its mission. In addition to serving on the Vanderbilt Kennedy Center Leadership Council, she served on the Vanderbilt Board of Trust and on the Board of the Monroe Carell Jr. Children’s Hospital at Vanderbilt. She was a founding member of the Vanderbilt Heart Advisory Council. She will be missed greatly.
NOVEMBER 26*
Special Lecture
Social Attention and the Cognitive Phenotype of Autism Spectrum Disorders
Peter Mundy, Ph.D.
Director of Educational Research, MIND Institute; Professor and Lisa Capps Chair for Neurodevelopmental Disorders and Education, University of California Davis
Co-sponsor: Postdoctoral Intervention Research Training Program in Special Education
Monday 4:10 p.m.

DECEMBER 5*
Developmental Disabilities Grand Rounds
A Potential Role for the Thalamus in Developmental Disorders Involving Inattention and Neglect
**Vivien Casagrande, Ph.D.
Professor of Cell & Developmental Biology and Ophthalmology & Visual Sciences. Register at: kc.vanderbilt.edu/registration Wednesday 12 p.m.

DECEMBER 7*
Community Advisory Council Meeting
VU Student Life Center, 310 25th Ave. South, Nashville. Register at: kc.vanderbilt.edu/registration Tuesday 11 a.m.-4 p.m.

DECEMBER 8*
TRIAD Families First Workshops
Safety Saturday
Register at: kc.vanderbilt.edu/registration Info (615) 322-6027 or families.first@vanderbilt.edu
Saturday 9 a.m.-12 p.m.
See website for Spring workshops

DECEMBER 12-14*
Autism Diagnostic Observation Schedule (ADOS-2) Research Training
TRIAD-led course for psychologists, pediatricians, behavioral specialists, SLPs, and research assistants who have completed ADOS-2 clinical training and regularly assess individuals with ASD. Fee $1500/person.
Info (615) 322-6533 or amy.r.swanson@vanderbilt.edu

DECEMBER 13*
Lectures on Development and Developmental Disabilities
Order and Disorder in the Developing Emotional Brain: Prospects for Cultivating Healthy Minds
Richard J. Davidson, Ph.D.
Professor of Psychology and Psychiatry, University of Wisconsin
Thursday 4:10 p.m.

JANUARY 21*
Spring 2013 Volunteer Advocacy Program
12-week training program covering special education law and advocacy strategies. Registration and application materials due by Jan. 15.
$30 for materials. Register at: kc.vanderbilt.edu/registration
Info (615) 414-4579 or lynise.parisen@vanderbilt.edu
Mondays 5-8 p.m. (6-9 p.m. East TN sites)

JANUARY 23*
You and Your Legislators: Disability Advocacy for 2013
TN issues, federal issues, communicating with legislators
Carrie Guiden, Arc TN; Carol Westlake, TN Disability Coalition; David Mills, VU Community, Neighborhood, & Government Relations. Lunch provided. Register at: kc.vanderbilt.edu/registration Wednesday 11:30 a.m.-1 p.m

JANUARY 24*
Lectures on Development & Developmental Disabilities
Martin Luther King, Jr. Commemorative Lecture
Creating Inclusive Communities–One Dream At a Time
Lucille Zeph, Ed.D.
Director of Center for Inclusion & Disabilities, University of Maine
Thursday 4:10 p.m.

JANUARY 30*
Statistics and Methodology Core Training Seminar
Multilevel SEM with Applications to Mediation
Kristopher Preacher, Ph.D.
Assistant Professor of Psychology & Human Development. Register at: kc.vanderbilt.edu/registration Wednesday 12:30 p.m.

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

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].

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

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.

Susan Gray School children are mini-Vandy Commodores! The School received the 2012 Education Award of the Mayor’s Advisory Committee for People With Disabilities.
CAALENDAR OF EVENTS | NOVEMBER 2012-MARCH 2013

■ FEBRUARY 6*
    Developmental Disabilities
    Grand Rounds
    The Control and Limitations of Attention in the Human Brain
    **René Marois, Ph.D.
    Associate Professor of Psychology and Radiology & Radiological Sciences.
    Register at:
    kc.vanderbilt.edu/registration
    Wednesday 12 p.m.

■ FEBRUARY 7*
    Lectures on Development & Developmental Disabilities
    Emotion and Survival: What’s the Relation?
    Joseph LeDoux, Ph.D.
    Professor of Neural Science & Psychology.
    New York University
    Thursday 4:10 p.m.

■ FEBRUARY 11*
    Lectures on Development & Developmental Disabilities
    Engaging Autism: Developmental Implications for Interventions
    Connie Kasari, Ph.D.
    Professor of Psychological Studies
    University of California Los Angeles
    Monday 4:10 p.m.

■ FEBRUARY 20
    Neuroscience Graduate Program Seminar Series
    TBA
    Susan G. Amara, Ph.D.
    Thomas Detre Professor and Chair of Neurobiology, University of Pittsburgh; Co-Director, Center for Neuroscience.
    Co-sponsor
    Vanderbilt Brain Institute Room 1220 MRB III Lecture Hall
    Wednesday 4:10 p.m.

■ FEBRUARY 27*
    Intervention 2.0 Lecture Series
    New Approaches to Developing Reading and Math Programs for Students with Serious Learning Problems
    **Doug Fuchs, Ph.D., Nicholas Hobbs Chair in Special Education & Human Development, Professor of Special Education; **Lynn Fuchs, Ph.D., Nicholas Hobbs Chair in Special Education & Human Development, Professor of Special Education; **Donald Compton, Ph.D., Professor and Chair of Special Education
    Wednesday 4:10 p.m.

■ MARCH 8*
    Community Advisory Council Meeting
    Info (615) 936-8852
    Friday 9 a.m.-2 p.m.

■ MARCH 13*
    Developmental Disabilities Grand Rounds
    Rewiring the Brain in Children With Disabilities: A Multidisciplinary Approach
    **Nathalie Maître, M.D., Ph.D.
    Assistant Professor of Pediatrics, Division of Neonatology.
    Register at:
    kc.vanderbilt.edu/registration
    Wednesday 12 p.m.

■ MARCH 20*
    Intervention 2.0 Lecture Series
    Including Students With Severe Disabilities in Secondary Schools: Peer Support Strategies to Foster Relationships and Learning
    **Erik Carter, Ph.D., Associate Professor of Special Education
    Wednesday 4:10 p.m.

■ MARCH 28*
    Lectures on Development & Developmental Disabilities
    Brainstorm Lecture, TBA
    Helen Neville, Ph.D.
    Professor of Psychology, Institute of Neuroscience, University of Oregon
    Thursday 4:10 p.m.

■ ARTS AND DISABILITIES EXHIBIT
    Monday-Friday 7:30 a.m.-5:30 p.m.
    Lobby VKC/One Magnolia Circle
    Info (615) 936-8852
    • SEPT. 1 THROUGH DEC. 31
    • Creative Expressions XVIII
    Jointly sponsored by the VKC and the Nashville Mayor’s Advisory Committee for People with Disabilities, this annual exhibit features work by artists with a wide range of abilities/disabilities and ages.
    • JAN. THROUGH MARCH
    Art created by students in the VKC Reading Clinic Summer 2012 programs.

■ AUTISM TRAININGS FOR K-12 SCHOOL PERSONNEL
    With the Tennessee Department of Education, TRIAD offers free autism-specific workshops for school personnel, parents, and the community in locations across the state. Dates/locations TBA; see
    kc.vanderbilt.edu/TRIAD/events.

■ TENNESSEE DISABILITY PATHFINDER • MULTI-CULTURAL OUTREACH
    Helpline; Web site with Searchable Database, Calendar, and Resource Library; Print Resources
    www.familypathfinder.org
    English (615) 322-8529
    Español (615) 479-9568
    Toll-free (1-800) 640-INFO [4636] tpapathfinder@vanderbilt.edu
    Project of VKC UCEDD and TN Council on Developmental Disabilities

■ NEXT STEPS AT VANDERBILT
    A 2-year certification postsecondary education program for students with intellectual disabilities providing individualized Programs of Study in education, social skills, and vocational training. Open Houses:
    • JAN. 18
    • MARCH 15
    • MAY 17
    Info (615) 343-0822
    NextSteps@vanderbilt.edu

■ READING CLINIC
    Assessment and tutoring for students through middle school
    Info (615) 936-5118
    nicole.davis@vanderbilt.edu

■ TAKE PART IN RESEARCH
    VKC Research Studies
    For children and adults, with and without disabilities
    Lynnette Henderson (615) 936-0448
    Toll-free (1-866) 936-VUKC [8852]
    • Research Family Partners
    kc.vanderbilt.edu/rfp
    Register and be notified of research studies
    • StudyFinder
    kc.vanderbilt.edu/studyfinder
    View lists of studies, criteria, and contact information
    • See also VUMC Clinical Trials
    www.vanderbilthealth.com/ clinicaltrials

■ LEARNING ASSESSMENT CLINIC
    Multidisciplinary academic assessments of students, 5-25 years, to identify learning strengths and challenges and to recommend strategies to improve academic learning.
    Info (615) 936-5118

Vanderbilt Kennedy Center

Vanderbilt autism clinical, educational, and research activities were the focus of a study tour by disability professionals from CREAH! Champagne-Ardenne, a regional disability center in France.