Research participants are asked to make judgments about the relative timing and number of visual and auditory events that they perceive.

Sight and Sound Separation in Autism  
BY CRAIG BOERNER

Like watching a foreign movie that was badly dubbed, children with autism spectrum disorders (ASD) have trouble integrating simultaneous information from their eyes and ears, according to a Vanderbilt study in *The Journal of Neuroscience* (January). The study, led by Mark Wallace, Ph.D., is the first to illustrate the link and strongly suggests that deficits in the sensory building blocks for language and communication can ultimately hamper social and communication skills in children with autism. Wallace is professor of Hearing & Speech Sciences, Psychiatry, and Psychology, director of the Vanderbilt Brain Institute, and associate director of the Vanderbilt Conte Center for Neuroscience Research.

“There is a huge amount of effort and energy going into the treatment of children with autism. Virtually none of it is based on a strong empirical foundation tied to sensory function,” Wallace said. “If we can fix this deficit in early sensory function then maybe we can see benefits in language and communication and social interactions.”

The findings could have much broader applications because sensory functioning is also changed in developmental disabilities such as dyslexia and schizophrenia, Wallace said.

In the study, Vanderbilt researchers compared 32 typically developing children ages 6-18 years old with 32 high-functioning children with autism, matching the groups in virtually every possible way including IQ.

Study participants worked through a battery of different tasks, largely all computer generated. Researchers used different types of audiovisual stimuli such as simple flashes and beeps, more complex environmental stimuli like a hammer hitting a nail, and speech stimuli, and asked the participants to tell them whether the visual and auditory events happened at the same time.

The study found that children with autism have an enlargement in something known as the temporal binding window (TBW), meaning the brain has trouble associating visual and auditory events that happen within a certain period of time.

“Children with autism have difficulty processing simultaneous input from audio and visual channels,” said co-author Stephen Camarata, Ph.D., professor of Hearing & Speech Sciences and Psychiatry. “The auditory and visual signals do not match in their brains.”

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Team William—One Decade of Giving Back  
BY COURTNEY TAYLOR

Dear Students, We are looking for a tutor for our son, William, who is 7 years old and has Down syndrome. William is a healthy, active, engaging boy who would love to play and learn with you. We would love your input in designing a curriculum to structure your time with William and will be delighted to brainstorm how this work may apply to your graduate coursework or thesis. Sincerely, The Spickards. (September 13, 2004)

When Andrea McDermott Sanders applied to tutor William Spickard in reading in 2004, she did so in an effort to generate additional income and to extend her education experience while at Peabody. Shortly after starting, Sanders realized that she was forging personal and professional bonds with the 7-year-old and his family that would go beyond a paycheck or even a supplementary educational experience. Her time with the family would eventually empower her to become an advocate, urging her down a 10-year road of combined passions and good will.

“The family took a leap of faith when they hired me,” said Sanders. “I was fairly new to special education, had never tutored a child with Down syndrome, nor had I taught reading. So, it was pretty clear they looked beyond my immediate skill set. I think they, too, sensed a connection between William and me. Our sessions had structure, literacy building, and always culminated with a sports activity. It just so happened that, during the same time, I took up long-distance running. I can

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Andrea Sanders with William Spickard, inspiration for Team William
11,795 copies of LEND guides on autism and other developmental disabilities given to families and service providers

Families First workshops serve 262 families who have children with autism

TRIAD workshops serve 305 families with children with autism

1,533 Vanderbilt Autism Resource Line calls

85+ research/educational events

76 Vanderbilt student Ambassadores in circles of support for 14 Next Steps at Vanderbilt students

506 community members statewide generated 1,300 ideas in 6 TennesseeWorks Community Conversations

48 educators focus on “High Expectations in Competitive Work” in Britt Henderson Training Series

Trainees of 6 universities in 13 disciplines make up the Vanderbilt LEND

Children and adults with disabilities exhibit 110 art works

3 Reading Clinic sessions provided 97 students with 2,328 hours of tutoring

1,300 ideas in 6 TennesseeWorks Community Conversations
My message takes stock of our last year with some fun numbers, both large and small, that offer a sense of the breadth of work at the VKC and its impact across the state and nation. Yet these numbers tell only part of our story. The rest lies in the creative, brilliant contributions of Center members. I am in awe of all that they accomplish and am deeply grateful for their insights day after day, year after year.

As I’ve reflected on all that our Center’s faculty, trainees, and staff have accomplished in the last year, the image that comes to mind is of a many-faceted diamond—a gem of great value, sparkling with light, and strong.

For a diamond to show its brilliance, it needs to be shaped, its facets created and sharpened. With the support of Vanderbilt, National Institutes of Health, foundations, State agencies, and donors, we provide the vision, resources, and infrastructure that shape this diamond of a Center. Yet it is the creativity of everyone who is a part of this Center that makes it truly shine, shedding new light on some of the toughest challenges faced by individuals and their families.

Ironically, one of the biggest challenges in the field of developmental disabilities is development itself—the fact that children with developmental disabilities grow up and become adults. All too often, families describe this transition into adulthood as “falling off a cliff,” with services that are fragmented or simply not available. More than ever, the Center is working across the life span in ways that promote and showcase the strengths and gifts that adults with developmental disabilities bring to their families and communities.

TennesseeWorks is transforming the employment landscape for young people with developmental disabilities across the state. “Meaningful work. Real pay. Opportunities for every Tennessean with a disability.” This UCEDD project is an extraordinary collaboration of state agencies and organizations that target the chronic unemployment faced by adults with intellectual and developmental disabilities.

As well, too many adults with developmental disabilities receive inadequate health and mental health care. A new UCEDD project targeted these disparities, Health Care for Adults with Intellectual and Developmental Disabilities, a Toolkit for Primary Care Providers (iddtoolkit.org). A product created with many talented collaborators, the Toolkit is now providing physicians and other health care providers electronic access to specific communication and best practice tools needed to care for adults who often have multiple medical or mental health needs.

Continued on page 8
More independent work environments may lead to reductions in autism symptoms and improve daily living in adults with the disorder, according to a new study released in the Journal of Autism and Developmental Disorders.

Researchers at Vanderbilt University and the University of Wisconsin-Madison examined 153 adults with autism and found that greater vocational independence and engagement led to improvements in core features of autism, other problem behaviors, and ability to take care of oneself. “We found that if you put the person with autism in a more independent vocational placement, this led to measurable improvements in their behaviors and daily living skills overall,” said lead author Julie Lounds Taylor, Ph.D., assistant professor of Pediatrics and Special Education. “One core value in the disability community and at the Vanderbilt Kennedy Center is placing people with disabilities in the most inclusive environments possible. In addition, this study gives us evidence that increasing the level of independence in an employment or vocational setting can lead to improvements in autism symptoms and other associated behaviors.”

Participants averaged 30 years of age and were part of a larger longitudinal study on adolescents and adults with autism. Data were collected at two time points separated by 5.5 years.

Taylor and her colleagues looked at such autism symptoms as restricted interests, repetitive behaviors, communication impairments, and difficulties with social interactions. They found that the degree of independence in vocational activities was uniquely related to subsequent changes in autism symptoms, other problem behaviors, and activities of daily living.

The results provide preliminary evidence that employment may be therapeutic in the development of adults with autism. Similar to typically developing adults, vocational activities may serve as a mechanism for providing cognitive and social stimulation and for enhancing well-being and quality of life.

Underemployment is a common phenomenon among adults with autism, the authors noted, with around 50 percent of adults with autism primarily spending their days with little community contact and in segregated work or activity settings.

Taylor says this research highlights the importance of intervention and employment programs for adults with autism.

Research supported by Autism Speaks, NIA (R01 AG08768) and NIMH (K01 MH92598), with core support provided by EKS NICHD (P30 HD15052; P30 HD03352) and National Center for Research Resources (1 UL1 RR024975). Reprinted from ResearchNews@Vanderbilt. Findings have been widely reported by national media.

Bullies—No! Kindness—Yes! Nashville Opera and TRIAD Partner for Inclusion

“I was a bully. I did not think about how you feel inside,” sings Billy Goat Gruff, when Lucy, the littlest goat, has shown the bully kindness by asking him if he’s OK when he falls off the bridge. By the time her friends return to help, she and the ex-bully have become friends. “You must be kind to each and everyone,” they sing.

The power of kindness is the lesson of John Davies’ Billy Goats Gruff, an opera for children produced by the Nashville Opera for an audience that often is not included—children with autism and their families. Many children with autism are unusually sensitive to light and sound, which makes it difficult for them and their families to experience community events like seeing a play or going to the zoo.

TRIAD partnered with the Nashville Opera on this special performance, Feb. 15, of Billy Goats Gruff at the Noah Liff Opera Center. The partnership is part of TRIAD’s Community Outreach to help organizations adapt their programs so that children with autism and their families can be included. For this performance, TRIAD collaborated with the Nashville Opera to make modifications and developed family supports.

TRIAD supports included a tip sheet for parents; a tip sheet explaining how to use a Social Story™; three versions, at varied language levels, of a Social Story™ about attending the performance and a great gift to the community. Thank you!” and “The thought and love that went into making this performance accessible to children with autism was obvious.

"Bravi!" TRIAD and the Nashville Opera look forward to future collaborations. For information on TRIAD’s Community Outreach, email autismsresources@vanderbilt.edu.
inevitably, it’s on one of those days when the schedule is full and you’re already falling behind that you hear that the next patient is “special.” You don’t want “special,” you want “simple.” “Simple” means catching up and easing the stress of a full waiting room. “Special” means extra time you don’t have. You resign yourself to a 20-minute slot being stretched to 40 minutes, and you take the chart from the door as you familiarize yourself with the case, suppressing your frustration.

On the other side of that door, with her mother, is a young woman. She is nervous, rocking back and forth in her wheelchair and mumbling softly. This is her first visit to a family physician. “Her” doctor, a pediatrician, isn’t seeing her anymore. She knew him well, since he followed her since birth. His office was cheerful, and his staff knew her by name. They always put her into the same exam room and offered her a favorite toy from the waiting room. The nurses had stethoscope covers in animal prints that she liked to touch. No one here knows her, and nothing is special about this sterile room. She wonders if they will hurt her. This is a scary situation and place.

Her mother is anxious, too. She got up at 5 a.m. to get herself and the patient ready, make the long drive, and arrive at 8:30 a.m. to complete paperwork for the 9 a.m. appointment. Thick hallway carpet made the wheelchair hard to push. The nurse was unable to weigh the patient, and her daughter resisted the attempt at getting her blood pressure. They have been here for over an hour and her daughter is restless. The mother is wondering if this practice will be able to provide adequate care for her child who has been the center of her world for the past 18 years.

It isn’t just the concern for time that makes us dread these encounters. We realize that it’s frequently the patients who take the most time who need us the most and are the ones who help us expand our skills. Yet we may be afraid of not being able to meet the needs of our “special” patients. We think, “Someone else must be better qualified than I am,” but often that is not the case. We also hate to look ignorant. “Your son has Prader-Willi syndrome. What’s that?” might not be the best icebreaker. We are responsible for providing all our patients with the care they need, but we may not know how to quickly find the tools to equip ourselves for accomplishing this.

The CDC estimates that 1 in 6 children during 2006-2008 had a developmental disability, and the numbers were increasing. Still, many family physicians have had little experience in long-term management of patients with developmental disorders, and some disabilities hinder communication and mobility and may lead to problematic behaviors. In addition to treatment of any acute problems, many require monitoring for syndrome-specific medical problems, which are sometimes overlooked. They may require modifications to enhance communication and comfort, assistive devices for mobility, and help in finding community resources. It can be difficult to build rapport, address immediate needs, and familiarize yourself quickly with accurate information about the disorder that will facilitate the optimum outcome for the patient, caregivers, and your practice. Thankfully, the first Electronic Toolkit for Care of Adults with Developmental Disabilities is now available, which can make the process a bit easier. This toolkit is an adaptation for U.S. use of Tools for the Primary Care of People with DD (Surrey Place Centre, 2011), which was based on Canadian consensus guidelines and was peer-reviewed and evidence-based. In 2013, with a grant from the Special Hope Foundation, the Toolkit was adapted for U.S. use as a website, also accessible by smartphones and tablets. The project was led by the Vanderbilt Kennedy Center UCEDD and LEND (Elise McMillan, J.D., P.T.; Janet Shouse, Project Manager), in collaboration with the UT Boling Center for Developmental Disabilities UCEDD and LEND, and the TN Department of Intellectual and Developmental Disabilities, in consultation with a multidisciplinary Advisory Committee, on which I served.

The Toolkit is aimed at primary care providers but also is useful for other health care professionals, as well as adults with disabilities and their caregivers. Features include:

• Tips on preparing your office and staff, e.g., offering a casual “welcome to our practice” with a brief tour, scheduling the first formal visit, and completing release of information forms.
• A downloadable, fillable form for each office visit, which could be completed by a patient or caregiver before or upon arrival.
• A “cumulative patient profile,” an expanded history form which better explores issues pertinent to a patient with a developmental disability than standard medical and social history templates.

• “Health Watch Tables,” information and suggestions for monitoring intervals for conditions pertinent to specific disorders, with references and resources; these include pediatric information, which is helpful for family physicians who may assume primary care for these individuals at birth or during childhood.

• “Behavioral and Mental Health Issues,” which includes suggestions for handling behavioral crises.

• “Resources,” with links to educational and advocacy sites. I found the link to “Americans with Disabilities Act Guidelines for Physicians’ Offices” to be particularly enlightening, since the expectations for equal accessibility are more extensive than one might think.

The Toolkit has limitations. It does not interface with EHR systems, although forms can be printed and scanned into the record. It does not cover all developmental disorders or all possible scenarios. However, it is a one-stop, informative resource that can serve as a valuable starting point from which we can work to reduce health care disparities for a large group of people. Potentially, it can help to bridge the gap when these children transition to adulthood and whenever other reasons force them to switch providers.

Your feedback is invited, so that this site will reach its fullest potential for addressing the needs on both sides of that exam room door. ■

Sherry L. Robbins, M.D., is a Family Practice Physician, Kingsport; part-time Clinical Assistant Professor, James H. Quillen College of Medicine, East Tennessee State University, Johnson City; Co-Editor, Tennessee Family Physician; and Director, Board of the Tennessee Academy of Family Physicians. Her editorial (edited here for space constraints) is reprinted with permission from Tennessee Family Physician Journal (March 2014), Tennessee Academy of Family Physicians.
Putting Faith To Work
The Vanderbilt Kennedy Center is the lead site for Putting Faith To Work, a project directed by Erik Carter, Ph.D., and Courtney Taylor, M.Div. A collaboration of four University Centers for Excellence in Developmental Disabilities (UCEDDs) were awarded a nearly half-million-dollar Signature Employment Grant from the Kessler Foundation focused on building the capacity of faith communities to support employment for members with disabilities.

Putting Faith To Work is focusing its efforts to connect people with disabilities to quality employment opportunities through the natural networks represented by congregational members, and will provide, or make linkages to, other individualized supports.

An overarching goal is to develop an accessible, step-by-step manual that details key elements of the approach, which could be drawn upon by any of the more than 335,000 congregations nationwide.

“Our model carefully integrates discovery approaches, natural supports, and customized employment features and delivers them through faith networks,” said Carter, associate professor of Special Education.

“But it also builds upon scriptural understandings of the dignity of work, stewardship of one’s talents or gifts, and the responsibility of the community to support those ‘on the margins.’ We are convinced that we must work both within and beyond the formal service system if we’re going to fundamentally change the employment landscape for Americans with disabilities,” said Carter, associate professor of Special Education.

The day concluded with a panel of speakers charged with making recommendations on how to move forward with strategies and planning in Tennessee. Among the panelists was Paul Newhouse, M.D., Jim Turner Professor of Cognitive Disorders, professor of Psychiatry, Pharmacology, and Medicine, and director of the Vanderbilt Center for Cognitive Medicine, who is leading the Memory Treatment Research Study for Adults with Down Syndrome.

Co-sponsors of the Forum included the National Task Group on Intellectual Disabilities and Dementia, The Arc Tennessee, Down Syndrome Association of Middle Tennessee, Tennessee Council on Developmental Disabilities, Vanderbilt Kennedy Center, Tennessee Community Organizations, and TNCO ACTS.

VKC at Tennessee Disability Day on the Hill
Staff, faculty, students, and families involved in the VKC programs TennesseeWorks, Tennessee Disability Pathfinder, Next Steps at Vanderbilt, and Tennessee Kindred Stories of Disability contributed to ensure the voices of Tennesseans with disabilities were heard during Disability Day on the Hill, January 29.

Members of the Tennessee Parent Coalition through the TennesseeWorks Partnership discussed the importance of competitive and integrated employment for persons with intellectual and developmental disabilities with their representatives. Self-advocates and parents with Tennessee Disability Pathfinder’s Multicultural Outreach Program spoke to legislators about the need for access to resources such as Family Support and multicultural awareness.

Next Steps at Vanderbilt students, alumni, and student Ambassadors (peer mentors) thanked legislators for the Step Up Scholarship and shared how the education they are receiving is ensuring a path to employment and independence as adults.

A collection of stories relaying the employment experiences of Tennesseans with disabilities were heard during Disability Day on the Hill, January 29.

Partners included the Human Development Institute (KY UCEDD, Milt Tyree, Harold Kleinert), the Texas Center for Disability Studies (TX UCEDD, Penny Seay, Bill Gaventa), and the Institute on Community Integration (MN UCEDD, Angela Amado, Derek Nord, Joe Timmons). All are members of the recently launched National Collaborative on Faith and Disability.

Aging, Dementia, and Developmental Disabilities
According to the World Health Organization, the number of people with dementia worldwide is estimated at 35.6 million and has been projected to nearly double every 20 years. Older adults with intellectual and developmental disabilities are among those who are at risk of or who are experiencing Alzheimer’s disease and related dementia, and numbers of those affected are on the rise.

On February 7, a State and Community Forum on Aging, Dementia, and Developmental Disabilities was held to provide information to individuals with developmental disabilities and families, direct support providers, clinicians, program staff, administrators, and public policy makers.

Presenters included National Task Group on Intellectual Disabilities and Dementia member Matthew P. Janicki (co-chair), who provided an overview of aging and dementia and outlined program options. Rick Rader addressed treatment options. Neuropsychologist Lucy Erald discussed screening, assessment, and diagnosis. VKC social worker Carol Rabideau, L.C.S.W., provided information on social care issues and strategies.
Leading the Vanguard of Discovery
Paul A. Harris, Ph.D.
Director of Office of Research Informatics • Associate Professor of Biomedical Informatics and Biomedical Engineering • Vanderbilt Kennedy Center Investigator • Joined Vanderbilt Kennedy Center in 2013

Research Interests
My focal area is clinical research informatics, a subdomain of informatics concerned with applying informatics theory and methods to design, to conduct, and to improve clinical and translational research. As director of Research Informatics, I have an opportunity and obligation to consider all medical areas of specialty and to devise generalizable informatics-based solutions that enable discovery and facilitate efficient conduct of studies. I have a strong passion for (1) building software platforms and organizational models that enable researchers to change the world through innovative research; (2) creating opportunities through informatics-based solutions to help individuals and families affected by medical conditions; and (3) developing and supporting consortium-based models for widespread collaboration and software solutions dissemination.

Principal Investigator
• eMERGE Coordinating Center (NIH/NHGRI)
• Mid-South Clinical Data Research Network (PCORI)
• National Children’s Study – REDCap Informatics Management Systems Hub (NIH/NICHD)

Clinical Interests
It is my hope and expectation that the systems and processes invented and operationalized by my team are relevant across all clinical domains. Several examples of our work include the Vanderbilt Syn-Derivative and Research Derivative (research data warehousing platforms), ResearchMatch and SubjectLocator (national and local participant recruitment), ROCKET (information sharing), IRBshare (streamlining implementation for multi-center studies), and REDCap (data planning, collection, and management).

Honors and Awards
• Research Enhancement Award for Outstanding Contributions to Research, Vanderbilt University Medical Center Faculty Award (2011)
• Outstanding Researcher Award, Vanderbilt Department of Biomedical Informatics (2011)
• Fellow, American College of Medical Informatics (2013)

Education
• B.S., 1987, Mechanical Engineering, Tennessee Technological University
• M.S., 1993, Biomedical Engineering, Vanderbilt University
• Ph.D., 1996, Biomedical Engineering, Vanderbilt University

Attraction to Developmental Disabilities Research
One of the reasons I love working in academia, especially within the field of clinical research informatics, is the opportunity to see real-world examples of impact from our work on a regular basis. It is most rewarding to think that the work our teams are doing today might literally provide service or contribute to research that will make a difference in the lives of people we strive to help tomorrow. My mother has worked for many years with individuals and families affected by developmental disabilities, and I have seen through her efforts the incredible impact even one individual can have in serving the needs of others. I believe that, by focusing energy and attention on rare disease and developmental disabilities research, we have the potential to help communities that are most deserving and in great need of assistance.

Reasons for VKC Membership
The Vanderbilt Kennedy Center is an exceptional organization with an important mission: improving the quality of life of persons with disabilities and disorders caused by the disruption of typical development. I began collaborating with Kennedy Center teams several years ago and quickly grew to appreciate the culture and professionalism of faculty, staff, and volunteers. Working with the Kennedy Center has been transformative. I am honored to be a member and highly value my affiliation.

Selected Publications

Donors Make 2014 Hobbs Discovery Grants Possible
Thanks to the wonderful generosity of members of the VKC Nicholas Hobbs Donor Society and the many others who give to the Vanderbilt Kennedy Center, the Center was able to fund four Hobbs Discovery Grants for 2014, announced VKC Director Elisabeth Dykens.

This grant competition is open to VKC investigators or members. The grants support multidisciplinary, innovative preclinical or clinical pilot studies in preparation for submitting competitive grant applications to federal agencies or private foundations. Awards were:

• Quantitative cry acoustics for measurement of pain in neonates: Correlations with cortical nociceptive processing and neurodevelopment
Stephen Bruel, PI (Anesthesiology), Dan France (Anesthesiology), Nathalie Maitre (Pediatrics/Neonatology), Carrie Menser (Anesthesiology)

• Using novel MRI techniques to provide further biological specificity in reading disabilities
Laurie Cutting, PI (Special Education), Seth Smith (Biomedical Engineering), and Sheryl Rimrodt (Pediatrics)

• Neuronal basis of auditory behaviors after hearing impairment
Ramnaranay Ramachandran, PI (Hearing & Speech Sciences), Troy Hackert (Hearing & Speech Sciences), Jon Kaas (Psychology)

• Down syndrome behavioral phenotype
Christopher Lemons, PI (Special Education), Seth King (Special Education)

“We are enormously grateful to all our Nicholas Hobbs Society members and other donors for their generosity, which makes these innovative pilot grants possible,” Dykens said.
We have a spot opening up on our Board of Directors,” she said. “Would you have any interest in serving?” The question came as a surprise, since I’d never served on a Board of Directors and wasn’t even sure what the job entailed. Still, I pondered the question, took a deep breath, and said “Yes.”

Here’s what I’ve come to know. For families affected by autism, positive changes come most often as a result of family-to-family, person-to-person local connection, and through the passion and dedication of local volunteers, local organizations, and local professionals.

Though “the work” can often be frustrating and sap our energies, we also know that it is incredibly, amazingly, and unexpectedly fulfilling. What we know in our heart of hearts, beyond any doubt whatsoever, is that the best organizations, whether small or large, don’t measure success by how much money they raise, nor by how many “members” they have, how many conferences they organize, work-groups or task-forces they are appointed to, or how many “position papers” they author. It’s not measured by how much research they fund, how many legislative initiatives they support, how many walks they organize, or by how often they’re in the media. Those things are a part of the work, and I’m proud that our local autism organization has been involved in all these arenas. But they’re not the work. They’re not why we exist or how we measure our success. We know that success can only be counted by how many lives you see changed as a result of the caring communities you create. And truly changed lives always and by necessity come about one at a time.

There is certainly a need for and a valid purpose for the large national autism advocacy organizations…. But the biggest “hidden secret” in the autism world lies in the day-to-day work of one-on-one support, education, and advocacy that goes on in local communities every day across the country, and around the world. It lies in the knowing glances and smiles we share with one another and powerfully helping to change the life of one individual and one family at a time. When they share their stories with you, and you share yours with them, it’s a sacred trust. Our responsibility is to honor that trust, first by loving the people you encounter in “the work” as completely and genuinely as possible. And then, we further honor that trust by using those stories to bring about even more changed lives.

That is the work that matters.

Above all, I know this one thing to be true: if you want to impact your community, it’s going to come from the hard work and dedication of local folks just like you. Get involved. Volunteer. Worthy nonprofit organizations abound in the disability community, right in your town, who could surely use people with a passion for their cause. You don’t have to be a board member. Maybe your strength is helping organize events. Or talking to new families. Or helping someone strategize for an IEP meeting. Maybe it’s simply sitting at a table and signing people in for a workshop or handing out information packets at a community fair. Maybe your calling lies in being that voice on the other end of the phone when someone new to your community just needs to talk.

Whatever your passion or your particular strength, just volunteer, even if you’re not sure what you have to contribute. And don’t be surprised when you find that giving of yourself in this way will also change your life forever for the better.

I had no idea of that truth back then. But because I’ve seen it over and over, I now know it is true. I know it because it has changed mine. We are not here to see through each other. We are here to see each other through. 

John Shouse is the father of 3 children, including a teenage son with autism, and is Vice Chair of the VKC UCEDD Community Advisory Council.
and social skills aimed at improving their potential for working or volunteering in the music industry.

Our diamond of a Center also shines with a cadre of bright, committed students and trainees. Trainees provide the ideal win-win scenario: They learn from us, we learn from them, and their energy and new ideas help Center programs flourish even in these tight fiscal times.

**UCEDD and LEND trainees** in Special Education, Social Work, and Divinity assisted with Next Steps at Vanderbilt. They designed and taught classes to Next Steps students. They were job coaches in internships, co-led Next Chapter Book Clubs, assisted with research, and were counselors in the Next Steps Summer Institute.

Trainees have also helped with the development of a Down Syndrome Biobank, analyzed surveys on services needs for children on the autism spectrum, and led and evaluated the impact of the Volunteer Advocacy Project, a program that trains volunteers in special education laws and policies, who then assist families who need help working with their children's schools. Trainees take part in Tennessee Kindred Stories of Disability, an enlightening service learning experience for students as they interview families and write their stories. The 2013 theme-focused editions—The Tennessee Waiting List and Families with Diverse Cultural Backgrounds—are helping inform Tennessee legislators and public policy makers.

**Research** is at the heart of all that we do. It is the force that keeps the diamond together. In our Fall Discovery issue, I shared our vision of translational science—discoveries from labs to clinics to communities and back again. See also (p.2) a summary of new discoveries through basic research. In the last year, I have seen the UCEDD, LEND, and TRIAD coming into their own in basic, behavioral, and clinical science within our almost 50-year-old IDDRC. Increasingly, these research discoveries are leading to exciting, long-awaited new treatments and interventions in many types of disabilities—learning disabilities, Down syndrome, rare conditions, and young children with autism.

So what then makes our diamond of a Center shine? A stream of countless "ah-ha" moments. When parents learn a new skill that helps them and their children. Something finally clicks for a struggling reader. A drug trial shows unexpected life-changing effects. A professional musician is touched beyond words by the overwhelming passion for music in our campers with Williams syndrome. A high school student from USN sings in a theater production with children with autism. An undergraduate gets "turned on" to the field by working in a lab or in Next Steps. A research discovery in autism is featured in news media across the country. A colleague excitedly shares new data that change his thinking. An adult with Down syndrome realizes that practicing Mindfulness relaxation can change her outlook on the world. Together, these small, powerful moments lead to fun numbers and create a sparkling, thriving Center that will shine on for years to come.

**TennesseeWorks.org Has a Fresh New Look!**

TennesseeWorks unveiled a new website last month, which promises to be the state’s “go-to” resource for professionals, families, employers, and others committed to helping young people with intellectual and development disabilities find and maintain meaningful employment. While developed and administered through the Vanderbilt Kennedy Center, the website is the fruit of the collective efforts of more than 50 partners working to improve employment outcomes across the state.

In exploring the new website, visitors will find user-friendly navigation tools leading to a searchable database of employment-related resources, video success stories, a calendar of events, and employment news from around the state.

The informative section “Getting to Work” highlights evidence-based recommendations that families and educators can follow to better ensure young people with disabilities are connected with employment.

“The ‘Getting to Work’ section should be very helpful for our visitors,” said TennesseeWorks dissemination coordinator Rachael Jenkins. “It outlines nine practices that have promise in making an impact for families. Each practice is described and explanations are shared about why they are important, how to make them happen, and then where to find out more information. Another useful feature of the new website is the Resources section. Having both local and national resources, subscribe to a monthly newsletter, and connect through social media.

Still under development are sections for youth, which will address topics such as how to find a job, how to impress employers, and how to develop friendships at work. Another section under development is “By the Numbers,” which will focus on data reporting.

“There is much we know as a field about how to equip young people with the skills, supports, and experiences that lead to a good job in the community,” said Erik Carter, Ph.D., associate professor of Special Education and principal investigator on the Tennessee-Works grant. “With this website, our goal is to ensure that the best of what we know really works penetrates the practices of schools, agencies, and communities in every corner of our state.”

TennesseeWorks was formed in 2011 with the goal of strengthening state policies and systems to promote the employment of young people with intellectual and developmental disabilities. It is made possible through funding from a Projects of National Significance: Partnerships in Employment Systems Change grant from the Administration on Intellectual and Developmental Disabilities.
Running for Research

In 2011, in an effort to expand its reach beyond scholarships, Team William began concentrating its fundraising efforts on funding for a Hobbs Discovery Grant focused on literacy and Down syndrome. Discovery grants, supported by philanthropy, are competitive grant opportunities for Vanderbilt Kennedy Center members and investigators for conducting pilot research.

In January, the Down Syndrome Behavioral Phenotype Project, led by Christopher Lemons, Ph.D. (Special Education), received the Team William Discovery Grant. Lemons’ project focuses on improving the current understanding of the behavioral phenotype (a set of shared characteristics) in individuals with Down syndrome, and its relationship to the academic outcomes. This information can then be used to adapt, modify, and/or tailor reading and math interventions for individuals with Down syndrome.

Lemons’ team will recruit 90 children with Down syndrome and 90 children with intellectual disabilities other than Down syndrome. The project will document patterns of difference related to the behavioral phenotype between the two groups, and will explore performance on academic measures. They will collect data through direct assessment, parent interviews, surveys of parents and teachers, and collection of school records. Part of what the team will be able to document is a better idea of what parents think schools could be doing to better support their children’s academic development. The project will inevitably produce data to support a need for higher expectations—brining the mission of Team William full circle.

“If you stop and think about what Andrea and to the Spickard family for the opportunity to further our research in this area,” said Lemons. “Funding like this is critical, especially to junior faculty members. I’m also grateful on another level. Earlier in my career, I worked as a classroom teacher and often what I tried in regard to reading didn’t work or was extremely challenging to implement. To further our work on this topic and to witness how appreciative the classroom teachers are who receive our intervention or participate in our projects is an incredible gift. Seeing positive outcomes and having teachers realize we can push this group of students a lot further than we ever thought we could—this is what continues to motivate me.”

The Finish Line

April 26, 2014, marks the 10th and final run for Team William. Though the team is retiring its sneakers, its efforts are not complete. The legacy of Team William lives on in the lives of students who are now reading on levels their families and teachers may have never thought possible. It lives on in the work of teachers who will receive training in evidence-based reading instruction for students with Down syndrome and for all of the students they instruct. It lives on in a shifting societal perspective of raised expectations and a belief in the potential of students with disabilities.

“There are not appropriate words to describe how grateful our family is for the scholarship our son received to the Vanderbilt Kennedy Reading Clinic,” said mother Kelly Clippinger. “Brian

Continued on page 11
Barbara Bovender is a founding member of the VKC Leadership Council. When asked what led to her decision to join, she promptly replied, “Because Annette Eskind asked me, of course!” Besides being close friends to the Center’s Leadership Council founding chair, Bovender is a perfect match for the Center’s mission of improving the lives of children and adults with developmental disabilities and their families.

A Registered Nurse who practiced for 15 years, Bovender said, “I’ve always been a caretaker. I told my mom when I was 5 years old that I was going to be a nurse.” Her nursing career was in ground-breaking settings of psychiatric care in community and academic medical center hospitals and later in public health and school nursing. The Bovenders established the Eva W., Barbara T., and Sara M. Bovender Scholarship in Vanderbilt’s School of Nursing. As a former nurse, she understands the hurdles that families face when their children have disabilities. “I found that you spend half your life learning the service system and the other half helping families learn to navigate it. It was like hand-to-hand combat, helping families deal with disability.”

When she joined the Leadership Council, Bovender appreciated that the Vanderbilt Kennedy Center was within a stellar university environment, where “there is so much you can learn. I love to learn.”

One of the aspects of the Center that she most appreciated—then and now—was that the Center links “basic research to community practice. You go into outreach,” she said. She joined the Leadership Council because she felt, “I want to be on this team. I want to learn what’s to be learned, and I want to contribute whatever I can to helping to unlock the mysteries of the mind. It just resonated with me, to be an ambassador to the community, to help people navigate the system and cope.”

Bovender and her husband Jack grew up 5 miles apart in a small North Carolina town where they attended school together, like their mothers before them. After she completed her RN and was working in a community hospital, she persuaded her to continue her career at Duke Medical Center, since he was attending Duke. Now married for 47 years, his career with HCA led them to Nashville. “Bovender has a son, Richard, and are grandparents to 15-month-old twin boys. Richard’s interest in the arts led Bovender into the Nashville arts community. She serves on the Tennessee Performing Arts Center Board, is a life-time member of the Nashville Opera Board, and is on the Board of the Cheekwood Art Museum and Botanical Gardens. Bovender is appreciative of this Center’s Disability and the Arts Program and research and intervention programs incorporating the arts like SENSE Theatre for autism and the ACM Lifting Lives Music Camp for Williams syndrome.

“Performing arts touch the soul,” Bovender said. “You can touch so many people through music, the performing arts, and the visual arts. When they’re exposed to the arts, no matter what level they’re performing on, they learn better.”

Bovender is not only a Nashville philanthropist, but she is also an international philanthropist. She is involved locally, nationally, and internationally with the Red Cross. She is a founding member of the American Red Cross Tiffany Circle, a women’s philanthropic society, which also has Tiffany Circles in Canada, England, France, the Netherlands, and Australia. She is a member of the American Red Cross Tiffany Circle National Council, serves on the Tiffany Circle International Committee, and is American Tiffany Circle liaison to Great Britain and Japan. Additionally, she serves as a Board Trustee of the American Museum in Britain, is a World Fellowship Benefactor to The Duke of Edinburgh’s International Award World Fellowship, and is a member of the Churchill Society. Bovender summarized, “I’d rather be doing than talking.”

Despite international travel, work, and friendships, Bovender’s love of Nashville is clear. “It’s just invigorating to be part of this vibrant, happening city.”

Bovender’s service is extensive, but whether it’s the VKC Leadership Council or one of many other organizations and causes to which she contributes, it adds up to the same thing. As Bovender said, “When you establish friendships and you network in a common cause, you can have a greater impact.”

Research supported by NIH grants DC10927 and DC011993, Simons Foundation Explorer Award, VKC MARI/Hobbs Award, and the Vanderbilt Brain Institute. Reprinted from ResearchNews@Vanderbilt (includes video).

Findings have been widely reported by national and international media.

A second part of the study found that children with autism also showed weaknesses in how strongly they “bound” or associated audiovisual speech stimuli.

“One of the classic pictures of children with autism is they have their hands over their ears,” Wallace said. “One reason for this may be that they are trying to compensate for their changes in sensory function by looking at one sense at a time. This may be a strategy to minimize the confusion between the senses.”

Wallace noted that the recently released Diagnostic and Statistical Manual of Mental Disorders, 5th Edition (DSM-5), which serves as a universal authority for psychiatric diagnosis, now acknowledges sensory processing as a core deficit in autism.
Neuroscience and Education: The Connection

A Summer Symposium hosted by Annette Eskind Institute of Learning at Currey Ingram Academy and Vanderbilt Kennedy Center for Excellence in Developmental Disabilities

June 5-6, 2014 (Th-Fri)
Currey Ingram Academy, Brentwood TN

For educators and other professionals. Topics include ADHD, sensory integration, technology, anxiety, reading, sleep, and executive functioning. Nationally renowned Plenary Speakers Robert Brooks, Ph.D., and Laurie Cutting, Ph.D. Additional co-sponsors—Vanderbilt Brain Institute and Vanderbilt Peabody College. Register ($175) before May 1 at kc.vanderbilt.edu/registration

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CALENDAR OF EVENTS | MAY 2014–JULY 2014

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 TN Disability Pathfinder Calendar www.familypathfinder.org.

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

**VKC Member or Investigator

- **MAY 5**, Britt Henderson Training Series Partnering with Paraprofessionals Info jennifer.l.rowan@vanderbilt.edu. Held in Vanderbilt Commons Room 237. Monday 4:30-7 p.m.

- **MAY 16**, Next Steps at Vanderbilt Open House Register at kc.vanderbilt.edu/ registration. Info (615) 343-0822 Fri. 2-3:30 p.m.

- **MAY 29-30**, 12th Annual Tennessee Disability MegaConference Change! World-class speakers, interactive workshops, educational sessions, exhibits. $130 one day (Thursday or Friday), $245 2-day (Thursday & Friday). Info at www.tndisabilitymegaconference.org. Nashville Airport Marriott Hotel, 600 Marriott Dr (615-889-9300)

- **JUNE 4**, Neuroscience Graduate Seminar Series Neurobiology of Brain Injury in the Premature Brain Vittorio Gallo, Ph.D., Director, Children’s Research Institute, Children’s National Medical Center Wednesday 4:10 p.m.

- **JUNE 5-6**, Neuroscience and Education: The Connection A one-stop symposium for educators, professionals to hear about the latest brain research as it relates to education. Held at Currey Ingram Academy, Brentwood. Info at kc.vanderbilt.edu/registration

- **JUNE 22-28**, ACM Lifting Lives Children’s Research Institute, Music Camp* Children’s National Medical Center Residential camp for individuals with Williams syndrome (16 yrs+)

- **JULY 13-18**, Next Steps at Vanderbilt Summer Institute Residential college transition program for rising high school juniors, seniors, and young adults with developmental disabilities up to age 24

- **VFK SUMMER PROGRAMS** Info Laura McLeod@vanderbilt.edu Contact TN Disability Pathfinder for information on TN summer activities. *Registration is closed.
  - **JUNE 2-13**, SENSE Theatre* For youth, 7-18 years of age, with and without autism. Performances Friday, June 13 and Saturday, June 14, 7 p.m., Fondren Hall, Scarritt Bennett Campus, Nashville. Tickets free but advance reservation required (limited seating) at kc.vanderbilt/registration
  - **NOW THROUGH MAY**, Healing Arts Project, Inc. (HAPI) If you would like to receive an email announcement of VKC art exhibits, please email ucedd@vanderbilt.edu

DISCOVERY | Winter/Spring 2014
AUTISM TRAININGS FOR K-12 PERSONNEL
With the TN Dept of Education, TRIAD offers free autism-specific workshops for school personnel, parents, and the community in locations across TN. For dates/locations, see kc.vanderbilt.edu/TRIAD/events

READING CLINIC
Tutoring students with reading challenges through middle school. Space limited. Info (615) 936-5118 or readingclinic@vanderbilt.edu

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 or LAC@vanderbilt.edu.

NEXT STEPS AT VANDERBILT
A 2-year certificate postsecondary education program for students with intellectual disabilities providing individualized Programs of Study in education, social skills, and vocational training. Info (615) 343-0822 or NextSteps@vanderbilt.edu

VIEW LISTS OF STUDIES, CRITERIA, AND CONTACT INFORMATION
Research Match
www.researchmatch.org

REGISTER AND BE NOTIFIED OF RESEARCH STUDIES
See also VUMC Clinical Trials
www.vanderbilthealth.com/clinicaltrials

TENNESSEE DISABILITY PATHFINDER
Web hub for information related to employment of people with disabilities. Info (615) 322-4999 TennesseeWorks.org

AUTISM TENNESSEE EVENTS
Autism Tennessee
www.autismtn.org
Event information (615) 385-2077 Registration is requested for all events. Vanderbilt Kennedy Center/One Magnolia Circle Bldg.

DSAMT EVENTS
Down Syndrome Association of Middle Tennessee
www.somethingextra.org (615) 386-9002

Hannah Martin of ACM Lifting Lives joins Rondal Richardson and songwriter Tammy Vice at the kick-off of the 2014 ACM Lifting Lives Career Exploration Series, which helps young adults with intellectual and developmental disabilities develop vocational and social skills aimed at improving their potential for employment in the music industry.

Sarah Jennings, a third-year master’s student at Vanderbilt Divinity School, won the Vanderbilt STAR songwriting competition on March 14 with her winning song “Addicted to You.” Her prize is a single-song recording contract and/or publishing agreement from Nashville indie label Lamon Records. The event benefited Next Steps at Vanderbilt.