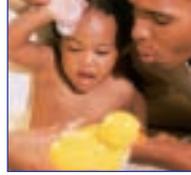
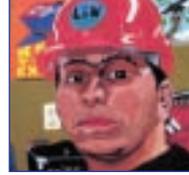




4 University Center for Excellence  
Emergency Preparedness and Disabilities



5 TRIAD—Autism Research  
National Early Intervention Clinical Trial



9 Autism Exhibit and Autism and the Arts Workshop



11 Listening to Community Voices

## Discovery

### Sorting Out Reading Instruction, LD & IQ

By Jan Rosemergy



Researchers who are dedicated to finding the best ways to teach struggling students to read know that “First you learn to read. Then you read to learn.”

One in five children has difficulty learning to read. Reading failure begins early and is difficult to remediate beyond the primary grades. When children fail at early literacy experiences, they begin to dislike reading, read less than competent classmates, and as a consequence lose an important means for gaining vocabulary, background knowledge, and information about text structure. In short, the word-rich get richer, while the word-poor get poorer, known as “The Matthew Effect.”

Doug Fuchs, Ph.D., and Lynn Fuchs, Ph.D., have dedicated their research careers to developing the most effective methods for teaching reading and math to diverse learners in elementary schools—methods that also are feasible for teachers in typical classrooms. Together they hold the Nicholas Hobbs Chair in Special Education and Human Development and are professors of special education. They founded and direct the Vanderbilt Kennedy Reading Clinic, coordinated by Caresa Young. Doug Fuchs is co-director of the National Research Center on Learning Disabilities.

#### Defining Learning Disabilities

Students with learning disabilities (LD) make up the majority of school-age individuals with disabilities. The number of students with LD has increased from 1.2 million in 1979-1980 to 2.9 million in 2003-2004. *Continued on page 2*

### Video Wasted on Toddlers, Unless Interactive

By Melanie Moran

Your toddler can sing along with The Wiggles and knows Big Bird’s face as well as she knows her own, but are those hours spent watching children’s videos really helping her learn? Research indicates that parents should choose videos with high interactive content if they want their children to be educated as well as entertained by their time in front of the tube.



GEORGINE TROSETH

Toddlers who had been given instructions in person about how to find a stuffed toy hidden in a room usually found the toy, unlike children who had been given instruction through video.

Georgene Troseth, Ph.D., Megan Saylor, Ph.D., and research assistant Allison Archer conducted two experiments to better *Continued on page 3*

### Director’s Message

### Are We Asking the Right Questions?



MELANIE MORAN

Pat Levitt, Ph.D.

At the Vanderbilt Kennedy Center, we place upon ourselves the responsibility of developing meaningful programs and making the essential community and professional links to bring the best and newest information and services to people with developmental disabilities and their families. This issue of *Discovery* provides some wonderful examples of this in the clinical arena.

Treatments in 2007 are decidedly different than even just a few years ago, thanks in large part to information obtained from research. I have written often about the unique nature of our efforts at the Vanderbilt Kennedy Center in the context of weaving *Continued on page 3*

## Sorting Out Reading Instruction from page 1

Roughly 70 to 80% of students with specific learning disabilities in special education have deficits in reading.

The usual method for identifying LD has relied on a discrepancy between IQ and achievement, because of the paradox that students with learning disabilities often show normal or above average intelligence on IQ tests but fail to achieve in specific academic areas.

Research now shows that this identification method has many problems. For example, children who read poorly have similar characteristics, regardless of whether they have a discrepancy between IQ and achievement. Also, the size of the discrepancy does not indicate the severity of the LD. Moreover, the data obtained through an assessment of the IQ-achievement discrepancy does not usually inform instruction in useful ways.

“Perhaps the most significant criticism is that defining LD as a discrepancy between IQ and performance results in what is viewed as a ‘wait to fail’ model,” Doug Fuchs explained. “Students are not identified until their academic performance falls significantly behind their peers.”

When a learning disability is defined as a discrepancy between IQ and performance, students typically are not identified until about 10 or 11 years of age. Yet research shows that performance problems become more difficult to address the longer they persist, with students falling further and further behind their peers. Often these students develop negative views of themselves as competent learners.

“Educators and researchers alike recognize that we need to identify students with LD earlier and intervene earlier,” Fuchs said. “Responsiveness to Intervention (RTI) has emerged as an alternate or supplemental way of identifying learning disabilities.”

With RTI, a learning disability is identified when a student fails to respond to teaching methods that research has shown to work well for most students. The movement to adopt RTI is fueled by longstanding dissatisfaction with the IQ-achievement discrepancy method, as well as dissatisfaction with IQ measures generally.

“With RTI, a learning disability comes to be defined as severe low achievement, and intelligence as such is not a part of the construct,” Fuchs said. “The field is grappling with how learning disabilities are defined and identified, which led us, as researchers, to ask what role, if any, intelligence should play in understanding this group of learners.”

### Relevance of Intelligence?

Fuchs and Caresa Young undertook a review of the research literature directed at the question:

What is the relevance of intelligence to learning among children at risk for school



EYEWIRE

failure? They reviewed 13 studies involving 1,542 students who were at risk for school failure or who had reading disabilities to determine whether IQ predicted responsiveness to reading intervention. Their findings, summarized here, were reported in an article “On the Irrelevance of Intelligence in Predicting Responsiveness to Reading Instruction” published in *Exceptional Children* (Vol. 73, No. 1, Fall 2006).

Fuchs and Young used the following five criteria to select studies. Their authors (a) published them in peer-reviewed journals; (b) administered intelligence tests, or, in a few cases, proxies for an intelligence test, to each participating child; (c) applied well-defined, intensive reading interventions; (d) used reading or reading-related measures to index effects of the interventions; and (e) included children at risk for reading failure or students who had already been identified as having a reading disability.

Fuchs and Young organized the studies by type of intervention implemented, contrasting phonological awareness training versus more comprehensive reading instruction, defined as interventions that also include, for example, decoding, fluency building, or comprehension components. They also organized studies by children’s age: early primary (preschool to first grade) versus late primary (second through sixth grades).

“Our hypothesis was that as a reading intervention becomes more comprehensive, IQ may become a more important predictor of responsiveness,” Fuchs explained. “Plus, as students get older, the demands and expectations for reading increase, moving beyond mastery of simple phonological awareness and decoding skills to text analysis and comprehension.”

Findings were mixed on the question of whether IQ scores of students who were at risk or had a reading disability predicted responsiveness to reading instruction. Nevertheless, in a majority of studies (8 of 13, or 65%), IQ explained at least a modest degree of unique variance in children’s responsiveness.

“Specific features of the studies, including the nature of the instructional interventions, were related to why IQ was an important predictor,”

Fuchs explained. “IQ often predicted responsiveness to reading instruction—especially when instruction is relatively comprehensive, when reading comprehension is a measure of student performance, when investigators indicate fidelity-of-treatment information was collected, and when IQ is assessed with a valid measure.”

“To put this another way,” Fuchs continued, “IQ often mediates or influences the effectiveness of reading instruction such that it is more or less effective for children with higher versus lower IQ scores. By extension, children’s more specific cognitive, linguistic, and perceptual characteristics, as well as their attentiveness and behavior in school, may help predict instructional responsiveness.”

“Schools should set ambitious goals and provide rigorous instruction for all children,” Fuchs continued. “But there isn’t a single route to closing the achievement gap. Our review suggested that specific child characteristics like IQ may help teachers provide differentiated instruction. And if student characteristics like intelligence have implications for instructional methods, then they should be assessed regularly during the instructional-development process, as well as when determining eligibility for special education supports.”

With regard to defining and identifying learning disabilities, the findings of Fuchs and Young provide some support for those who understand LD partly in terms of individual intelligence.

“But this argues,” Fuchs said, “for taking a broad approach to intelligence not as a single global IQ score but as an array of specific cognitive, perceptual, and linguistic processes that are important to how we think about learning disabilities, how we identify students, and how we instruct them.” ●

### Internet Resources

#### Center on Instruction

[www.centeroninstruction.org](http://www.centeroninstruction.org)

#### Learning Disabilities Association of America

[www.ldanatl.org](http://www.ldanatl.org)

#### National Center on Student Progress Monitoring

[www.studentprogress.org](http://www.studentprogress.org)

#### National Dissemination Center for Children with Disabilities

[www.nichcy.org/resources/LD1.asp](http://www.nichcy.org/resources/LD1.asp)

#### National Research Center on Learning Disabilities

[nrld.org](http://nrld.org)

#### Responsiveness-to-Intervention Evaluation, Technical Assistance, and Dissemination Activities

[nrld.org/research/rti.shtml](http://nrld.org/research/rti.shtml)

#### Vanderbilt Kennedy Center Resources

#### Vanderbilt Kennedy Reading Clinic

[kc.vanderbilt.edu/kennedy/community/reading.html](http://kc.vanderbilt.edu/kennedy/community/reading.html)

## Video Wasted on Toddlers

from page 1

understand which type of video best engaged toddlers. Troseth and Saylor are assistant professors of psychology at Peabody College and Vanderbilt Kennedy Center researchers.

In the first experiment, they tested differences in learning from video and from face-to-face interactions among 24 2-year-olds. A woman on a TV screen told the children where to find a stuffed animal hidden in another room. She then gave a second group of children the same information in person. The first group of toddlers rarely found the stuffed animal, suggesting they just didn't believe or listen to the woman on the screen. The children given the instructions in person usually found the toy.

In the second experiment, the researchers used a closed-circuit video system to make the video interactive. The woman on the screen could see, hear and respond to the children through conversation and games. After five minutes of interacting with the woman on the TV, children used the information she provided to find the hidden object.

Troseth and her colleagues believe the results indicate that because toddlers understand the difference between their "real" environment and what they see on videos, they are likely to dismiss information offered by someone on television unless that person is clearly interacting with them. This interaction can include tactics such as asking children questions, using their name, or referring to something the child can see and touch in their real environment.

"There is good evidence from other research that watching shows such as *Dora the Explorer* and *Blue's Clues* in which characters speak directly into the camera and wait for responses can positively impact children's mental and

language development," Troseth said. "Our new findings have implications for educational television aimed at toddlers, as well as for the use of video images in research with this age group."

Troseth also offered some advice for parents feeling guilty about turning their kids over to the electronic babysitter.

"As long as video exposure is a small part of infants' and toddlers' daily activities, and those activities include lots of time interacting with family members, parents should stop feeling guilty,"

Troseth said. "What's bad is if the television is always on in the background. This disrupts parent-child interaction and the quality of children's play."

Troseth served as a consultant for Sesame Workshop on their new DVD series, which uses Muppet babies and caregivers to encourage and model good social interaction. She is a member of the Vanderbilt Learning Sciences Institute.

The research was supported by Vanderbilt's Peabody College and the National Institute of Child Health and Human Development. These findings were published in the May 17, 2006, issue of *Child Development*.

Troseth and Saylor are continuing this line of research. Working with psychology graduate student Gabrielle Strouse, they have found that toddlers more readily learn a new word or skill from a person who is present, compared to learning from a person on video. In this study, the skill involved was assembling a toy.

Compared to the "finding game" used in the



COURTESY OF GEORGINE TROSETH

Researchers used a closed-circuit video system to create an interactive video learning situation, which was contrasted with toddlers learning directly from the same adult.

earlier research, these tasks are more like what a child might experience from watching television.

"People on TV don't tell you where to find hidden toys," Troseth explained, "but they might teach vocabulary words or demonstrate new skills like how to tie shoes."

Additionally, the more recent research used recorded videos, which is more similar to television than the "live interaction" video used in the earlier study.

Troseth and Saylor found, with these prerecorded videos, that repetition helped toddlers learn the new skill. Children who saw three demonstrations of how to assemble the toy learned just as well from a person on video as from a person who was present. So, even if toddlers are not as efficient at learning from video as from real social interaction (which only requires one repetition), they may learn from video if they get more repetitions.

"Fortunately, as parents know, most toddlers are willing to see the same video over and over," Troseth said. ●

## Director's Message from page 1

research throughout our outreach programs and professional training series. It would be far easier to simply provide a few key services, efforts that at most other centers are separate from the main research agenda.

Why do we make life so complicated? In part, the rationale is that our integrated efforts provide us with better opportunities to obtain more meaningful data from carefully planned studies that undergo scrutiny. In my opinion, there is no better way to inform us about the best means to improve the quality of interventions and training initiatives that address some of the most difficult problems we face in behavior, education and medicine related to developmental disabilities.

Our various summer camps for individuals with Down syndrome, autism, Williams syndrome, and other cognitive impairments perhaps best highlight what is so unique about our research-service interface: We utilize every opportunity to gather information that will make outreach and programmatic efforts better and more responsive each year.

Every research study must begin with a hypothesis that hopefully poses an answerable question. Yet how do we know that we are even asking the right questions? It may come as no great surprise that the relationship that develops between investigator and participant and their family is among our most valuable resources for keeping us on the right track.

While we initially pose questions that we believe our experiments will answer, the art of scientific inquiry provides the best opportunities to continue

to fine-tune those questions, based on invaluable information gathered through interactions with our research partners and their families who participate in clinical studies. We just never know how a tidbit of information about some unique aspect of that individual's experience with a developmental disability will translate into a new perspective from which our scientists can revise and refine questions.

From someone who has spent most of his career studying animal models of brain disorders, in which gathering such insights from the "participants" is far more challenging, I am sometimes jealous of my clinical research colleagues. For they learn, through the process of inquiry that is linked to outreach and training, far better than I, that the questions they pose are not only on the right track, but that the answers truly will be meaningful to all of you. ●

# Vanderbilt Kennedy Center for Excellence in Developmental Disabilities

## Being Prepared for Emergencies By Jan Rosemergy



Terri Urbano, Ph.D., M.P.H., R.N.

**G**overnment is responsible—but so are you. This is the “take-home” message for individuals and families, for service providers and agencies, as states and counties plan for emergencies. In the wake of Hurricane Katrina, all are concerned—but no one more so than individuals with disabilities,

who may be especially vulnerable in an emergency and whose unique needs are too often overlooked or not well understood by emergency planners and responders.

Emergency planning is happening at the federal, state, and local levels. It is a priority of Tennessee State agencies and the Tennessee Developmental Disabilities Network, as well as the Association of University Centers on Disabilities.

The Vanderbilt Kennedy Center for Excellence is helping to provide leadership through the expertise of Terri Urbano, Ph.D., M.P.H., R.N. Urbano, professor of clinical pediatrics, is the Center’s director of training and of health. Urbano was involved in supporting persons with disabilities through hurricanes during her years of service at the Mailman Center for Child Development UCEDD in Miami. She is the author of *The Complete Bioterrorism Survival Guide* (2006, Sentient).

### National Action

National action was spurred by the aftermath of Hurricane Katrina. Pat Morrissey, Commissioner of the Administration on Developmental Disabilities, U.S. Health and Human Services, personally visited sites in Louisiana and Mississippi in September 2005. She returned to Washington, determined to mobilize for improved emergency planning for individuals with disabilities. Morrissey gained the collaboration of leaders of other federal agencies.

In June 2006, a national 3-day “Working Conference on Emergency Management: Individuals and Disabilities and the Elderly” was held in Washington, D.C. Each governor appointed a delegation of their key state officials responsible for emergency planning. Governor Bredesen appointed representatives of the Tennessee Emergency Management Agency (TEMA), Health, Homeland Security; Council on Aging and Disability; and Disability Law and Advocacy Center. Urbano

attended as a recorder and was later invited to join the group officially.

National leaders updated state delegations about emergency planning for people with disabilities, including the need to include individuals with disabilities as participants in the planning process. Delegations also worked together on preparation and recovery issues. Each state is now providing quarterly progress reports to the National Council on Disability.

### Tennessee Action

The Tennessee delegation formed an Executive Committee, initially chaired by Judy Eads, assistant commissioner of health. Eads, Urbano, and the Executive Committee organized the first “Tennessee Emergency Preparedness Stakeholders Meeting for Individuals with Disabilities and the Elderly,” Nov. 16. Individuals with disabilities and family members, service providers, and advocates were invited. The outcome was establishing five working committees: Training and Education (which Urbano chairs), Long-Term Recovery, Planning, Public Awareness, and Resources.

Populations with functional needs in a mass casualty event include, but may not be limited to: children, persons with physical or cognitive disabilities, persons with pre-existing mental health and/or substance abuse problems, frail or immunocompromised persons, non-English speakers, persons with dementia or reduced activities of daily living, and homeless and transient populations.

Instead of setting up ‘special needs shelters’ or trying to make shelters accessible in all the ways necessary, Tennessee’s plan for the first line of response is to relocate individuals with functional needs to vacant beds in licensed health care facilities, other than hospitals, because they already have accessible facilities and staff trained to meet functional needs. Once placed, needs would be assessed and plans for subsequent care would be made and implemented.

“I think this is a very innovative model,” Urbano said. “It offers immediate support during a crisis and a structured plan for returning individuals to their natural environment as rapidly as possible.”

Urbano and others will be presenting on emergency preparedness for persons with disabilities at the Tennessee Disability Mega Conference.

### Be Prepared

The need for individual plans is particularly important when considering persons with disabilities.



BIG STOCK PHOTO

“Be prepared, not scared,” Urbano emphasized. “The steps are easy and do-able. Just as we take care of our health or take our medication daily, we need to plan for emergency events. Knowledge is power.” ●

### Internet Resources

#### Assisting People with Disabilities in a Disaster (United Cerebral Palsy)

[www.ucp.org/ucp\\_channel.doc.cfm/1/11/10427/10427-10427/2450](http://www.ucp.org/ucp_channel.doc.cfm/1/11/10427/10427-10427/2450)

#### Disaster Preparedness for People with Disabilities

[www.disabilityresources.org/DISASTER.html](http://www.disabilityresources.org/DISASTER.html)

#### Emergency Evacuation Preparedness Guide (Center for Disability Issues and the Health Professions)

[www.cdihp.org/products.html#evac\\_guide](http://www.cdihp.org/products.html#evac_guide)

#### Emergency Preparedness for Children with Special Health Care Needs (American Academy of Pediatrics and the American College of Emergency Physicians, Emergency Information Form)

[www.aap.org/advocacy/epcparent.htm](http://www.aap.org/advocacy/epcparent.htm)

#### Preparedness Information for Seniors & People with Disabilities (American Red Cross and Department of Homeland Security, FEMA)

[www.redcross.org/services/disaster/0,1082,0\\_603\\_,00.html](http://www.redcross.org/services/disaster/0,1082,0_603_,00.html)

#### Tennessee Disability Pathfinder-Emergency Preparedness

[kc.vanderbilt.edu/tnpathfinder/disaster.html](http://kc.vanderbilt.edu/tnpathfinder/disaster.html)

#### Tennessee Emergency Management Agency

<http://www.tnema.org/>

#### Transportation and Emergency Preparedness Checklist (National Consortium on Human Service Transportation Coordination)

[www.dotcr.ost.dot.gov/asp/emergencyprep.asp#stratpaper](http://www.dotcr.ost.dot.gov/asp/emergencyprep.asp#stratpaper)



# Treatment and Research Institute for Autism Spectrum Disorders

## National Early Intervention Clinical Trial

By Jan Rosemergy

**E**arly intervention for a young child on the autism spectrum is that child's best hope for the future.

A good-quality autism early intervention program has at least four benefits. First, it provides a child with instruction that builds on individual strengths to teach new skills, to improve behavior, and to remediate areas of weakness. Second, it provides information to families to understand their child's behavior and needs. Third, it offers resources, support, and training that enable parents or other caregivers to work and play with a child effectively. Finally, it improves the developmental outcomes for a child. No single treatment is suitable for all children with autism, but most respond best to highly structured educational programs.

Autism researchers work to develop, demonstrate, and evaluate early intervention treatments in order to determine which strategies provide the best outcomes for which children.

### Aim and Sites

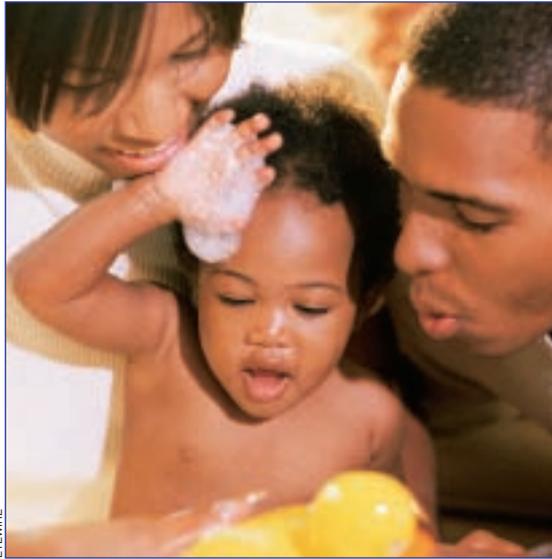
With funding from Autism Speaks, an interdisciplinary team of experienced autism researchers is comparing the provision of the Hanen More Than Words® program to community-based treatment in three national sites that offer different and variable community treatment to children at risk for autism spectrum disorders (ASD). The sites are Nashville, Boston, and Miami.

Investigators are Wendy Stone, Ph.D., professor of pediatrics and TRIAD director, and Paul Yoder, Ph.D., professor of special education, Vanderbilt University; Alice S. Carter, Ph.D., professor of psychology, University of Massachusetts-Boston; Helen Tager-Flusberg, Ph.D., professor of anatomy, neurobiology, and psychology, and director of STAART Network Center, Boston University; Dennis Russo, Ph.D., chief clinical officer, May Institute, Boston; Daniel Messinger, Ph.D., associate professor of psychology, and Peter Mundy, Ph.D., professor of psychology and director of the Center for Autism and Related Disorders, University of Miami.

### Hanen More Than Words® Program

More Than Words® is a program for parents of children on the autism spectrum developed by the Hanen Centre, which was founded in 1977 in an effort to develop effective family-centered approaches to helping young children who have language delays (see [www.hanen.org](http://www.hanen.org)).

"We had three criteria in selecting an autism early intervention treatment for this clinical trial," Stone explained. "First, it had to be based on a broad



developmental approach that is both appropriate for toddlers and specialized to children with clinical signs and symptoms of ASD. Second, it had to involve parents and focus on activities that can be implemented during the family's everyday activities. Third, it had to address the area of social-communication development, since this is a core deficit for children with ASD. The Hanen More Than Words® program met all these criteria."

The Hanen program teaches parents to (a) "read" their children's nonverbal communication, (b) follow their children's attentional lead and respond in ways that promote social interaction, (c) create and take advantage of everyday opportunities to prompt and support children's communication, (d) use language in ways that improve children's ability to understand adult language, (e) play with children in ways that enhance children's communication and language use, and (f) expand children's object play skills. Finally, the Hanen program has been shown to affect child language, parental stress, and parental interaction skills favorably.

### Study Plan

Participants will be 15- to 24-month-old children who screen positive on the STAT (Screening Tool for Autism in Two-Year-Olds) and meet a clinical impression of ASD, and their parents.

The study's investigators and their research teams in Boston, Miami, and Nashville will work with pediatricians, "child find" agencies, early intervention programs, and autism organizations in their locales to invite families to take part in this clinical trial. Following informed consent, families will be assigned randomly to either the Hanen program or to a control condition in which they receive

community-based treatment. A detailed intervention questionnaire will be used to monitor treatment utilization in both groups.

Children and parents in both groups will complete three assessments: at study entry, after 3 months of intervention, and 6 months later. Assessments include measures of children's early learning, social and emotional development, social communication, and language.

### Significance

Although increasing numbers of young children with ASD are being identified and referred for early intervention, there is relatively little research to indicate which types of treatments are effective, which children benefit most, and how much intervention is needed. Early intervention can play a critical role in children's development due to the increased plasticity of the young brain. This multisite study will examine the Hanen intervention on important outcomes for the child as well as his or her parents.

To inquire about taking part in the Vanderbilt TRIAD site of this early intervention trial or in other autism studies, contact the TRIAD Research Office, (615) 936-0265.

### Components of an Effective Treatment Program\*

- Starts intervention at a young age.
- Uses assessment information to develop individualized intervention goals.
- Involves families in assessment and intervention.
- Implements teaching goals and activities that address social interaction, language and communication, imitation, and play.
- Provides at least 25 hours per week of intervention in which the child is engaged in productive activities with people or objects.
- Uses a comprehensive curriculum that integrates a variety of intervention strategies.
- Employs a systematic approach to teaching.
- Monitors the child's progress and reassesses goals at regular intervals.
- Provides a structured and supportive teaching environment.
- Incorporates activities to promote generalization of skills to other settings.
- Employs a functional, proactive, and positive approach to managing and preventing problematic behaviors.

\*Source: Stone, W. L., & DiGeronimo, T. F. (2006). *Does my child have autism? A parent's guide to early detection and intervention in autism spectrum disorders*. San Francisco: Jossey-Bass. ●

# Leading the Vanguard of Discovery



DAN LOFTIN

## CRAIG KENNEDY, PH.D.

Professor and Chair of Special Education  
Associate Professor of Pediatrics  
Director of Vanderbilt Kennedy Behavior  
Analysis Clinic  
Vanderbilt Kennedy Center Investigator  
Joined Vanderbilt Kennedy Center 1997

## Research Interests

I am interested in aggression. My particular focus is on why people with autism and other developmental disabilities become aggressive and what causes them to remain aggressive throughout their lives. In pursuing this interest, I have developed laboratory models of aggression as well as interventions to help individuals reduce their aggressive behaviors. Our long-term goal is to develop a robust understanding of aggression that interrelates a person's genes, brain, behavior, and environment.

## Principal Investigator

- Project LINK: Integrating behavioral and health issues, U.S. Department of Education
- Leadership training in severe disabilities/autism, U.S. Department of Education

## Clinical Interests

My clinical interests in aggression focus on helping reduce aggression and teaching people more appropriate ways to interact with others. This work is conducted through the Vanderbilt Kennedy Behavior Analysis Clinic, which I direct. We serve children and adolescents with autism and other developmental disabilities in Middle Tennessee.

## National Service and Awards

- Alice H. Hayden Award, The Association for Persons with Severe Handicaps, 1991

- B. F. Skinner New Researcher Award, American Psychological Association, Division 25, 1993
- Associate Editor, *Journal of Behavioral Education*, 1994-1998
- Associate Editor, *Journal of The Association for Persons with Severe Handicaps*, 1998-2001
- Associate Editor, *Journal of Applied Behavior Analysis*, 1999-2001
- Board of Directors, Society for the Experimental Analysis of Behavior, 2004-2011

## Selected Publications

- Kennedy, C. H. (2005). *Single-case designs for educational research*. Boston: Allyn and Bacon.
- Roberts, C., Yoder, P. J., & Kennedy, C. H. (2005). Descriptive analysis of epileptic events and the occurrence of self-injury and aggression. *American Journal on Mental Retardation*, 110, 405-412.
- Harvey, M. T., Smith, R. L., May, M. E., Caruso, M., Roberts, C., Patterson, T. G., Valdovinos, M. G., & Kennedy, C. H. (2004). Possible role for the 5-HT1A receptor in the effects of REM sleep deprivation on avoidance responding in rats. *Psychopharmacology (Berl)*, 176, 123-128.

## Education

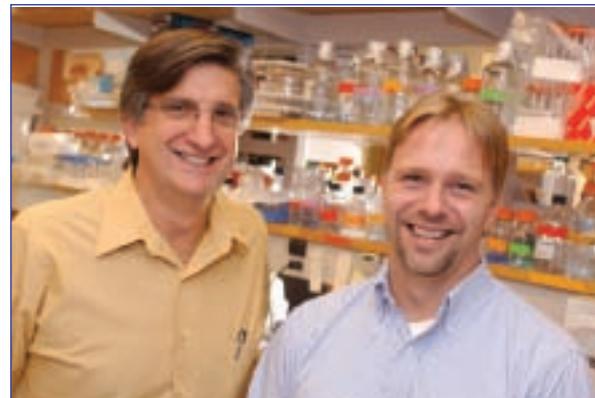
B.A., 1987, Experimental Psychology, University of California-Santa Barbara  
M.S., 1988, Special Education, University of Oregon-Eugene  
Ph.D., 1992, Special Education, University of California-Santa Barbara

## Attraction to Developmental Disabilities Research

As a college freshman, I encountered the work of B. F. Skinner simultaneously in a philosophy and psychology course, which seemed very intriguing. In the psychology course, his work was shown within the context of teaching children with autism. I began working in a program to educate children with autism and have been fascinated by this area ever since. My work has spanned basic neurobiology, experimental analyses of behavior, the development of novel educational interventions, and disability advocacy. Working with people with autism has been my focus for almost 25 years.

## Reasons for Kennedy Center Membership

The Kennedy Center has a national reputation that is second to none in developmental disabilities research. As a student I was told that the best developmental disabilities researchers in the country were at the Kennedy Center and Peabody College. Today that is still the case, with individuals from an amazing array of disciplines working together to better understand developmental disabilities. I count myself as very fortunate to be among such a talented group of scientists. ●



Pat Levitt and Daniel Campbell

## Honored for PNAS Article

By Craig Boerner

Vanderbilt Kennedy Center investigators who recently published groundbreaking research on genetics and autism in the *Proceedings of the National Academy of Sciences (PNAS)* are receiving the Cozzarelli Prize, an annual award that recognizes PNAS papers of outstanding scientific excellence and originality.

PNAS established the award in 2005 to honor late Editor-in-Chief Nick Cozzarelli, whose lab motto was "Blast ahead." Cozzarelli was known for encouraging researchers to push the envelope of discovery.

The article, "A genetic variant that disrupts MET transcription is associated with autism," is "an excellent example of these same qualities," according to PNAS Editor-in-Chief Randy Schekman.

An international team of scientists led by VKC director Pat Levitt, Ph.D., and research fellow Daniel Campbell, Ph.D., reported that a genetic variant associated with the MET gene is common in children with autism and appears more frequently in families that have more than one affected child. Although both environmental and genetic factors are likely involved in autism, mounting evidence suggests that genes play an important role in an individual's susceptibility to the disorder.

Co-authors included James S. Sutcliffe, Phillip J. Ebert, Roberto Militerni, Carmela Bravaccio, Simona Trillo, Maurizio Elia, Cindy Schneider, Raun Melmed, Roberto Sacco, and Antonio M. Persico.

Papers receiving the Cozzarelli Prize were chosen from the 3,300 research articles published in PNAS in 2006 and represent the six broadly defined classes under which the National Academy of Sciences is organized. The VKC article was recognized in Class IV Biomedical Sciences.

"It is a great honor for us to receive the Cozzarelli Prize for outstanding paper in Biomedical Sciences in 2006," Levitt said. "Dr. Cozzarelli was a great research pioneer. Having our studies placed by the *Proceedings of the National Academy of Sciences* editorial board in this context is humbling."

The award will be presented during the PNAS Editorial Board Meeting on April 29, 2007, in Washington, D.C.

To view a report of the findings in Vanderbilt's on-line *Exploration Science Journal*, see [www.vanderbilt.edu/exploration/stories/autismgene](http://www.vanderbilt.edu/exploration/stories/autismgene). ●

# Accolades

**Judy Aschner**, M.D., professor of pediatrics and director of the Division of Neonatology, has been elected to the **American Pediatric Society**, one of the oldest and most prestigious academic societies. She will be inducted at the Pediatric Academic Societies meeting in Toronto in May.



Judy Aschner, M.D.

**Camilla Benbow**, Ed.D., the Patricia and Rodes Hart Dean of Education and Human Development, has been appointed by the **National Forum on Information Literacy** to a council that will determine national standards for information and communication technology literacy.

**Vivien Casagrande**, Ph.D., professor of cell and developmental biology, has been elected a fellow of the **American Association for the Advancement of Science (AAAS)**, an honor bestowed upon AAAS members by their peers. Casagrande was recognized for her “distinguished contributions to our understanding of the cellular patterns and connections of the mammalian visual system.”



Vivien Casagrande, Ph.D.

**Ellen Wright Clayton**, M.D., Ed.D., professor of pediatrics, law, and Rosalind E. Franklin Professor of Genetics and Health Policy, has been elected to the **Institute of Medicine (IOM)**. The IOM is recognized as a national resource for independent, scientifically informed analysis and recommendations on issues related to human health.



Ellen Wright Clayton, Ph.D.

**Anne Corn**, Ed.D., professor of special education, has been named to the **Enrichment Committee 2006-07** for the **National Center for Leadership in Visual Impairment, Pennsylvania College of Optometry**.

**Steven Graham**, Ed.D., Currey Ingram Professor of Special Education and Literacy, was honored by **Valdosta State University** as its **2006 Distinguished Alumnus** for his contributions to the field of education.

**Frank Harrell Jr.**, Ph.D., professor and chair of biostatistics, has been appointed to the **National Institutes of Health Biostatistical Methods and Research Design Study Section**. Study Section members review proposals for primary research in biostatistics, clinical trial design and analysis, survey design, and measurement of health status.



Frank Harrell Jr., Ph.D.

**H. Carl Haywood**, Ph.D., professor of psychology, emeritus, received the **Achievement Award** of the **National Alumni Association of the University of West Georgia**. He was honored for his “professional achievements in improving the human condition for individuals with developmental disabilities.” Haywood also has co-authored *Dynamic assessment in practice: Clinical and educational applications* with Carol Lidz. [Cambridge University Press, 2007]

**Nea Houchins-Juarez**, M.A., B.C.B.A., behavior analyst, Vanderbilt Kennedy Behavior Analysis Clinic, presented “Assessment and intervention of noncompliance in an outpatient behavioral clinic” at the **Tennessee Association for Behavior Analysis Conference**.

**Craig Kennedy**, Ph.D., professor of special education, associate professor of pediatrics, and director of the Vanderbilt Kennedy Behavior Analysis Clinic, has been named **chair of the Department of Special Education** at Peabody College. He succeeds Dan Reschly in the position.

**Peter Martin**, M.D., professor of psychiatry and pharmacology and director of the Division of Addiction Psychiatry, has authored *Healing addiction: An integrated pharmacopsychosocial approach to treatment* (2006, Wiley). His co-authors are Bennett Alan Weinberg and Bonnie K. Bealer.

**Ralph Ohde**, Ph.D., professor of hearing and speech sciences, was named a **Fellow** of the **American Speech-Language-Hearing Association (ASHA)**. The status of Fellow is one of the highest honors ASHA can bestow.



Ralph Ohde, Ph.D.

**Wendy Stone**, Ph.D., professor of pediatrics and director of the **Treatment and Research Institute for Autism Spectrum Disorders (TRIAD)**, accepted, on behalf of TRIAD, the **2006 Agency Award of the Mayor’s Advisory Committee for People With Disabilities** at its 25th Annual Awards and Reception for Artists with Disabilities.

**Arnold W. Strauss**, M.D., James C. Overall Professor of Pediatrics and chair of the Department, and professor of molecular physiology and biophysics, has been awarded the **2006 American Heart Association Basic Research Prize** for finding genetic defects that can cause heart failure and sudden death in infants and children.

**Jon Tapp**, Vanderbilt Kennedy director of computer services, was featured on **Indiana University’s podcast, “Teach with tech.”** Tapp discussed *ProCoder DV*, the software system he developed to facilitate data collection from digital media used in research projects. Also at Indiana University, Tapp delivered a lecture, “New advancements in behavior observations.”

**Richard Urbano**, Ph.D., research assistant professor of pediatrics, and **Robert Hodapp**, Ph.D., professor of special education, are editors of a new volume *Developmental epidemiology of mental retardation and developmental disabilities*, published by the International Review of Research In Mental Retardation (vol. 33, 2007, Elsevier Academic Press).

**Terri (Mary Theresa) Urbano**, Ph.D., M.P.H., R.N., professor of clinical pediatrics, is the author of *The complete bioterrorism survival guide: Everything you need to know before, during, and after an attack* (2006, Sentient Publications). Urbano is director of training and of health for the Vanderbilt Kennedy Center for Excellence in Developmental Disabilities.

**Caresa Young**, Vanderbilt Kennedy Reading Clinic coordinator, was the **keynote presenter** at the **Fall 2006 International Dyslexia Association Conference** held at Louisiana Tech University. Her keynote address was entitled, “Response to intervention.”

The article, “Trajectories of symptoms and impairment for pediatric patients with functional abdominal pain: A five-year longitudinal study,” was selected by the **Massachusetts Medical Society’s Journal Watch** as one of their **top 10 recommended pediatric articles for 2006**. The authors were **Shelagh Mulvaney**, Ph.D., assistant professor of pediatrics, **Warren Lambert**, Ph.D., VKC assistant director of Statistics and Methodology Core, **Judy Garber**, Ph.D., professor of psychology and psychiatry, and **Lynn Walker**, Ph.D., professor of pediatrics and psychology. ●



# Susan Gray School *Where Knowledge Meets Nurture*

Peabody College of Vanderbilt • Vanderbilt Kennedy Center

## Where Are They Now?

By Courtney Evans

Often, parents of children with developmental disabilities have questions about the positive promises of early intervention, and about the quality of life that their children might expect to have as they grow and age. It is one thing to say “early intervention works,” and it is quite another to illustrate the point by visiting two Susan Gray School graduates living full and meaningful lives.



COURTESY OF BASSETT FAMILY

Rebecca Bassett—1974

### Rebecca

“I remember watching Rebecca’s teachers trying unsuccessfully to get her to make a sentence,” Janey Bassett said. “They were working on ‘I want toast,’ and it just wasn’t working. I was baffled, because she talked a lot at home. In fact, they often wrote ‘mother says’ on the paperwork as if it really didn’t happen. One day it dawned on me—Rebecca didn’t even like toast! They changed it to cookie and immediately she made a sentence.”

Rebecca Bassett was enrolled in the Experimental School (it would not become Susan Gray School until 1986) in 1974. She moved quickly through the classes with a continual and intense focus on further developing her physical and mental skills. Rebecca’s mother remembers that the teachers were always positive and always eager to advance Rebecca. Her schedule was busy, and she often missed nap time because she would move from a morning class on one level to an afternoon class on another.

“She developed the habit of sleeping in the car,” said Bassett. “She still does that to this day.”

Bassett often would visit the classroom to observe her daughter. Doing so also enabled her to form supportive relationships with other parents. In fact, it was out of these relation-

ships that the group Downs Parents of Nashville (a predecessor of the Down Syndrome Association of Middle Tennessee) was formed. It was an opportunity for parents to connect with one another and to become informed.

“We wanted to learn more about Down syndrome,” Bassett said. “The School was totally supportive, and the administration felt it was very important for the group

to be governed by parents. We wanted to be able to reach out to new parents and try to spare them some of the grief that we had all experienced.”

When Rebecca turned 4, she was enrolled in St. Bernard’s School for Exceptional Children and later started first grade at DuPont Elementary. Bassett recalls the first time she heard Rebecca reading a book aloud.

“I was watching her through a two-way mirror and she was reading, ‘The fat cat sat on the mat,’” said Bassett. “I still thrill at the thought.”

Today, 32-years-old, Rebecca lives in Cookeville, Tennessee. She lives in an apartment with her friends Renee and Jane and adores living independently. The night before she moved out of her parents’ home, she was asked to say the prayer at dinner and she prayed, “Dear God. Thank you for getting me out of here at last.”

Living independently means keeping herself busy with two jobs. She cleans government offices and works with a group from Pacesetters, Inc. at a factory near Sparta. She also volunteers at a local elementary school where she shelves library books and reads stories to the kindergarten classes.

“I love being around people,” Rebecca said. “I also love writing letters to celebrities. I met Peggy Fleming, Dorothy Hamill, and Dolly Parton. I invited Joan Rivers to my birthday party, but she couldn’t come.”

Rebecca is well-known throughout the community and is an expert on where to find the best places to eat in town. She loves to swim and write poetry and has saved enough money to take a cruise to Nassau and visit Disney World this summer.



COURTESY OF RESHA FAMILY

Bernadette Resha—1978



Bernadette Resha—2006

Last year, the Vanderbilt Kennedy Center was honored to show a beautiful mask she created for the exhibit “Why Possom’s Tail is Bare.”

### Bernadette

Bernadette Reesha is an artist. She paints on canvases as well as on purses, trivets, aprons, greeting cards, and mugs. She earns her living (a very good living) as a full-time artist. She has appeared in a major motion picture, she plays the violin, and she even dabbles in modeling. Bernadette has Down syndrome and is a SGS graduate.

“We started Bernadette there [Experimental School] when she was 2-weeks-old. This was in 1978,” said Bernadette’s mother, Gwenn Reesha. “Our time there was so very valuable. The program gave me a kick to get Bernadette started for a successful life. I remember they had me do these exercises with her, where I had to encourage Bernadette to follow an object with her eyes. I worked with her 24-7, physically and mentally exercising her. I learned techniques that helped her to focus on concentration, and, partly because of that, she developed a very strong enthusiasm about learning.”

Bernadette’s enthusiasm manifested in an ability to begin walking at 8 months and to begin reading by age 3. Reesha claims that it was because Bernadette was continually stimulated, and because she received so much individual attention that she was so advanced at so early an age.

“Typically developing kids don’t usually get that much attention,” said Reesha. “Can you imagine the possibilities if they did?”

It was not long after Reesha enrolled Bernadette in the School that she began to recognize the negative portraits being painted of people with Down syndrome in the larger community. To educate her peers, she invited Emily *Continued on page 10*

# “Artism” Exhibit, & “Autism and the Arts” Workshop

By Traci Fleischman and Jan Rosemergy



Self-Portrait (Live in the Now) by Louis DeMarco

“**A**rtism” is the term George Zuniga coined to describe the work of an artist who has autism. Zuniga is one of six artists of Project Onward whose compelling work is on display at the Vanderbilt Kennedy Center through May 30. In conjunction with the exhibit, the Autism Society of Middle Tennessee (ASMT) will hold an “Autism and the Arts Workshop” on May 24.

## Project Onward

The “Artism” exhibit showcases visual artists with autism associated with Project Onward, “an open studio for artists with special needs” that is a program of the Chicago Department of Cultural Affairs.

Project Onward’s mission is “to support the creative development of visual artists with developmental, cognitive, and mental disabilities.” Workspace, art supplies, and professional guidance are provided in a communal workshop environment in a studio at the historic Chicago Cultural Center.

“We believe that artists with special needs deserve a voice in the world of arts and ideas, and that their extraordinary work has a universal audience,” said Rob Lentz, a Nashville native who directs Project Onward. “Project Onward exhibits, promotes, and sells the artists’ works as a means to provide earned income and a sense of personal achievement, as well as to integrate the artists into the wider arts community.”

Works in the Vanderbilt Kennedy Center exhibit are available for purchase.

With Project Onward’s support, artists develop

a professional body of work that reflects a devotion to their personal vision and a desire for artistic growth. For information about the Project and artists, see [www.projectonward.org](http://www.projectonward.org).

Art is an outlet for creativity and self-expression, which is often easier to portray through drawings, paintings, and photographs than through words for many individuals with autism.

“The Vanderbilt Kennedy Center is a great venue for artists with disabilities,” said Gretchen Herbert, coordinator of recreation and arts for the Center. “By showing works here, and for some exhibits also in the community, our intent is to broaden the audience for work by exceptional artists—exceptional in every sense. The quality of work merits the exhibit being a ‘destination’ visit. Project Onward is a wonderful model of how to support the development of

artists with developmental disabilities. We dream of doing something similar here in the future.”

The “Artism” exhibit is on display in the 2nd floor lobby of the Vanderbilt Kennedy Center, with additional pieces exhibited at the Tennessee Disability Pathfinder/Recreation and Arts Office, 1114 17th Avenue S., Suite 105, during weekday work hours. It also can be viewed on the VKC website at [kc.vanderbilt.edu/kennedy/community/art.html](http://kc.vanderbilt.edu/kennedy/community/art.html).

## ASMT Workshop

The Autism Society of Middle Tennessee has long-standing interest in supporting art created by children and adults on the autism spectrum, and they have partnered with the Vanderbilt Kennedy Center in organizing previous exhibits.

“The ‘Artism’ exhibit provided a wonderful opportunity to partner again,” Herbert said, “with a reception and ‘Autism and the Arts’ Workshop.”

A reception will be held May 24, 5-6 p.m. in Room 241 Kennedy Center/MRL Building. It will be followed by the ASMT Workshop, which will celebrate music, dance, and arts therapies.

Leisa Hammett, a parent of a 12-year-old

artist with autism, will moderate the workshop. Other panelists will include Rob Lentz, director of Project Onward, and three therapists representing the fields of art, dance and movement, and music. Each panel member will describe their work and therapeutic benefits.

The workshop is one among ASMT’s monthly Education Series. The 2-hour presentations cover a wide range of topics, including communica-

tion, behavior, intervention, advocacy, and adolescent and adult behaviors. ASMT has offered these workshops for nearly a decade.

“The purpose of the arts workshop is to provide an overview of how the arts can be included in intervention and recreational programs for individuals with autism spectrum disorders,” explained Karen Coston, ASMT Education Committee chair and autism



**VANDERBILT KENNEDY CENTER**  
FOR EXCELLENCE IN DEVELOPMENTAL DISABILITIES



Butterfly Garden by Blake Lenoir

specialist. “The best aspect for parents, educators, and therapists who attend is the opportunity to hear about a variety of therapies and to ask questions.”

## Recreation and Arts

Recreation and Arts is an area of emphasis of the Vanderbilt Kennedy Center for Excellence in Developmental Disabilities. Since 1994, the Vanderbilt Kennedy Center has sponsored exhibits of art by and about people with disabilities in order to demonstrate the diverse talents of individuals with disabilities. Each year the Center hosts four exhibits, often with related community forums or arts workshops.

For information contact (615) 322-8529 ext. 14 or [kc@vanderbilt.edu](mailto:kc@vanderbilt.edu).

## Spotlight

## Continuous Support

BERNICE GORDON

By Traci Fleischman

**B**ernice Gordon's connection with the Vanderbilt Kennedy Center began when the Center was founded in 1965.

"I have had an interest in the Kennedy Center since its inception back in the mid-1960s," Gordon said. "I was a Peabody College student and became interested in the Center after taking several courses under Drs. Gray and Hobbs," explained Gordon.

Psychologists Nicholas Hobbs and Susan Gray were co-founders of the Kennedy Center. Hobbs's writings on issues in the classification of children and troubled and troubling children, as well his Project Re-ED, were influential nationally in the

treatment of children with emotional or behavioral disorders. Gray's Early Training Project inspired the national Head Start program.

"Their teachings have been a major force in my life," Gordon continued. "They were definitely pioneers in their day."

Gordon dedicates much of her time to the Vanderbilt community. In addition to Gordon's activities as a member of the Vanderbilt Kennedy



COURTESY OF BERNICE GORDON

Bernice Gordon

Center Leadership Council, she and her family are active supporters of Peabody College, the School of Nursing, and the Owen Graduate School of Management. She and her husband, Joel, have been season ticket holders supporting Vanderbilt's various sports teams for 50 years. She is a dedicated board member of the prestigious Canby Robinson Society, which honors and encourages those who give financial support to the education, research, and patient care programs of

Vanderbilt Medical Center. Gordon has four children and eleven grandchildren.

"As the previous national president of the Peabody Alumni Association, I was acutely aware

of what was going on at the Kennedy Center. I looked forward to our Alumni Association meetings where Center investigators would come in and highlight the research they were working on," stated Gordon. This ongoing tie has helped maintain a lasting bond between Gordon and the Center.

As a proud, lifelong Nashville resident, Gordon joined the Vanderbilt Kennedy Center Leadership Council with hope and determination to help get things accomplished for the Center and the community.

"I feel my role as a Leadership Council member is to be an advocate for the Kennedy Center and for the community at large. Groundbreaking work is being done at the Center. The reality is that the Kennedy Center is changing lives," Gordon said.

Gordon truly believes that small miracles happen every day at the Vanderbilt Kennedy Center.

"Working with the Kennedy Center has been very rewarding. The research is revolutionary, especially in the area of brain science, as well as in autism. The Kennedy Center is the best hope in addressing autism. Pat Levitt is one name that rises above the rest. He truly understands what the Kennedy Center represents." ●

## Where Are They Now?

from page 8

Kingsley, a *Sesame Street* writer—who also had a child with Down syndrome who appeared on the program regularly—to speak at the Kennedy Center and Vanderbilt Medical School. Reesha financed the visit personally, and arranged for Kingsley to make appearances at a variety of functions, including spending time at the Department of Health and doing interviews on local television and radio.

When Bernadette was 6-years-old, she transitioned into public school. She attended Percy Priest, then McMurray, and eventually graduated from Hillsboro High School. Reesha remembers that Bernadette's transition went smoothly.

Today, Bernadette speaks at events across the country about living with Down syndrome and about her career as an artist. Her art has been included in Vanderbilt Kennedy Center exhibits.

"I have always enjoyed drawing, but now many people are enjoying my paintings and accessories and this makes me happy," Bernadette said. "I have had fun exhibiting my art in art shows, conventions, and festivals. I have gone to many states with my art. Go to my website [www.bernadetteresha.com](http://www.bernadetteresha.com) and look around."

Bernadette is a board member of the Vanderbilt Best Buddies Chapter. She attends parties and goes dancing with her sister. Reesha remarks that Bernadette's high self-esteem is inspirational.

"She knows she is wonderful and beautiful," said Reesha. "I am blessed to have such an amazing daughter." ●

## Kennedy Center Donors

## Nicholas Hobbs Society Members

New since January 1, 2007 (\$1,000 and above)

A complete list is found at [kc.vanderbilt.edu/kennedy/giving/give2hobbs.html](http://kc.vanderbilt.edu/kennedy/giving/give2hobbs.html)

Mr. and Mrs. David B. Ingram  
Mr. and Mrs. Tandy Rice, Jr.

## Honor and Memorial Gifts

## In Memory of Dr. Becky Cox

Drs. Robert Hodapp and Elisabeth Dykens

## In Memory of Brenda Crabtree

Mr. and Mrs. Tom McMillan

## In Memory of Mollie B. Gavigan

Drs. Dan and Jan Rosemergy  
Mr. and Mrs. Timothy L. Stafford

## In Memory of Gilda Kulczycke

Dr. and Mrs. Pat Levitt

## In Memory of Teddy Roy

Dr. and Mrs. Pat Levitt

## In Honor of Dr. Keith Scott

Drs. Richard and Mary Theresa Urbano

## In Honor of Dr. Marcia S. Scott

Drs. Richard and Mary Theresa Urbano

The Nicholas Hobbs Society is made up of donors who give \$1,000 or more annually to the Center or one of its programs. Through their gifts, Hobbs Society members advance groundbreaking research in human development.

For information about joining the Nicholas Hobbs Society or making Honor or Memorial gifts, contact (615) 343-5322.

Every effort has been made to ensure the accuracy of this report, which reflects Honor and Memorial gifts **January 1-February 28, 2007**. If an error has been made, we offer our sincerest apology and ask that you bring it to our attention by contacting (615) 343-5322.

# Listening to Community Voices

By Traci Fleischman



Chris and Doria Panvini

“Nothing about us without us” is a civil rights slogan that is well-understood by individuals with disabilities and family members. The federal Developmental Disabilities Act, which authorizes the University Centers for Excellence in Developmental Disabilities Education, Research and Service (UCEDDs), wisely recognized that these centers needed to listen to and involve individuals with disabilities and family members. In addition to striving to employ faculty and staff with disabilities or family members, every UCEDD works with a “Consumer Advisory Committee.”

## Community Advisory Committee

“Our Vanderbilt Kennedy Community Advisory Committee (CAC) first met in June 2005, before we knew whether we would be designated as a UCEDD” said Elise McMillan, J.D., UCEDD associate director and parent of a son with Down syndrome. “We viewed this kind of counsel as essential for our mission. We were fortunate that Doria Panvini accepted our invitation to help us organize the CAC and then to chair it. She and the other CAC members have been our partners every step of the way, from celebrating the thrill of becoming a UCEDD to guiding us in the hard work of training, research, service, and dissemination as we work toward the full integration and inclusion of persons with disabilities.”

## Doria Panvini, CAC Chair

Doria Panvini first became aware of the Vanderbilt Kennedy Center in 1972 after moving to Nashville from New York. She was looking for a preschool program for Chris, her then 5-year-old son. Chris has an intellectual disability, as well as a hearing loss. At the time, the public school system did not enroll students with disabilities until they were at least 8-years-old.

During his teen years, Chris came to the Kennedy Center to attend a social program with

other teens with disabilities. The program was organized by Kennedy Center students and was a great success. It allowed Chris and other teens to be a part of social activities with other students.

Panvini’s strong bond with her son has motivated her to be a disability advocate. Throughout the years, she has served on committees within the Division of Mental Retardation Services (DMRS), volunteered at The Arc of Davidson County and The Arc of Tennessee, and helped found Mid TN

Supported Living.

Chairing the CAC is Panvini’s most recent challenge. The CAC advises the UCEDD leadership about community concerns and goals, and it is a full partner in planning, implementing,



Roxanne and Ian Carreon

and evaluating activities.

Panvini is a member of the VKC UCEDD leadership team and works closely with its faculty and staff, particularly with McMillan and Roxanne Carreon, Vanderbilt Kennedy Family Outreach Center coordinator. Panvini, McMillan, Carreon, and UCEDD director Elisabeth Dykens, Ph.D., identify issues and opportunities for the CAC members to learn about and to provide input to UCEDD programs and activities.

Quarterly CAC meetings allow members an opportunity to communicate with one another about important issues and concerns based on their own experiences within the disability community. The meetings also allow for a time to discuss and review programs and to bring a grass-roots, community perspective to the Center.

“Being a part of the Community Advisory Council and meeting with everyone involved with the UCEDD is a very positive experience for all of us,” Panvini said. “Our members bring a broad range of experiences and interests in disability issues throughout the lifespan. They know community needs and see how Kennedy Center programs can be helpful.”

Panvini represented the CAC at the November annual meeting in Washington, D.C., of the

Association of University Centers on Disabilities, which brings together representatives of the nationwide UCEDD network.

“In addition to getting great ideas from the work of other UCEDDs, I had a chance to meet members of other CACs and to learn from their experiences. We aim to become a model here of how a CAC and UCEDD can most productively work together.”

## Roxanne Carreon, Coordinator

Roxanne Carreon, Family Outreach Center coordinator, is equally integral to the CAC. She is the first person whom families meet when they walk into the Outreach Center. She provides staff support for the CAC and is the “go to” person for questions, contacts, and concerns. As the parent of a child with Down syndrome and a longtime disability advocate in California and now Tennessee, she, too, brings a family and community perspective.

“I am privileged to work with such an experienced and dedicated group of individuals. While I have

only been working with them for just over 2 months, I learned very quickly that this select group of Committee members is serious about their commitment to improving the lives of individuals with disabilities,” stated Carreon.

Panvini claims that the best aspect of the CAC is the interest and involvement of the members and the leadership of the UCEDD staff. “CAC members have had the opportunity to learn about the activities and research of the Kennedy Center and to be a part of the discussion of what is important to the community and how that connects with the Center’s outreach and research activities.”

For more information about the CAC, visit [kc.vanderbilt.edu/kennedy/ucedd/CAC.html](http://kc.vanderbilt.edu/kennedy/ucedd/CAC.html) or contact Roxanne Carreon, (615) 936-5118, [vkcac@vanderbilt.edu](mailto:vkcac@vanderbilt.edu).



**VANDERBILT KENNEDY CENTER**  
FOR EXCELLENCE IN DEVELOPMENTAL DISABILITIES

## Leadership Council of Vanderbilt Kennedy Center

Mrs. Cathy S. Brown, *Chair*  
Mrs. Annette S. Eskind, *Past Chair*  
Mrs. Barbara Gregg Phillips, *Past Chair*

Mrs. Honey Alexander	Mrs. Hilrie Brown
Ms. Sissy Allen	Dr. Elisabeth Dykens
Mrs. John S. Atkins	Dr. BethAnn McLaughlin
Mrs. Jean Ann Banker	Mrs. Elise McMillan
Mrs. Madge Bass	Mr. Tim Stafford
Mrs. Ann Bernard	
Mrs. Barbara T. Bovender	
Mrs. Linda Brooks	
Ms. Mary L. Carlson	
Mrs. Juanita Cate	
Mrs. Beth Dreifuss	
Mrs. Ann Eaden	
Mrs. Donna G. Eskind	
Mr. Glenn Funk	
Mrs. Charlotte Gavigan	
Mrs. Bernice Gordon	
Mrs. Carol Henderson	
Mr. Robert W. Henderson II	
Ms. Lucile Houseworth	
Ms. Bethany Jackson	
Mrs. Ruth Johnson	
Mrs. Harla Levitt	
Mr. Chris and Mrs. Rebecca Link	
Mrs. Michael F. Lovett	
Mrs. Lorie Hoppers Lytle	
Mrs. Jack C. Massey	
Ms. Andrea Blake McDermott	
Ms. Pat McNellis	
Mrs. Anne Nesbitt	
The Honorable Andrew Shookhoff	
Ms. Laurie Lee Sisk	
Mrs. Shirley F. Speyer	
Mrs. Sue Spickard	
Dr. Karen L. Summar	

*Ex-Officio Members*  
Dr. Pat Levitt

## Hold the Date

**Friday, May 18**

8 a.m. Shotgun Start

### Waddell & Reed Financial Services Charity Golf Tournament

Vanderbilt Legends Club's Roper's Knob Course

Benefiting the Vanderbilt Kennedy Center

A great morning of golf, door prizes,  
cold beverages, and lunch

Entry fee \$125/player

Contact (615) 343-5322



Discovery is a quarterly publication of the Vanderbilt Kennedy Center designed to educate our friends and the community, from Nashville to the nation. The Center is committed to improving the quality of life of persons with disabilities of thinking, learning, perception, communication, mood and emotion caused by disruption of typical development. The Center is a university-wide research, training, diagnosis, and treatment institute. It is a national Developmental Disabilities Research Center funded by the National Institute of Child Health and Human Development, and a University Center for Excellence in Developmental Disabilities (UCEDD) funded by the Administration on Developmental Disabilities.

[kc.vanderbilt.edu](http://kc.vanderbilt.edu) (615) 322-8240 (1-866) 936-VUKC [8852]

Pat Levitt, Ph.D., Vanderbilt Kennedy Center Director  
Elisabeth Dykens, Ph.D., Associate Director  
BethAnn McLaughlin, Ph.D., Faculty Director of Community & Special Projects

Tim Stafford, Director of Operations  
Jan Rosemergy, Ph.D., Director of Communications

Research Program Directors  
Kendal Broadie, Ph.D., Developmental Neurobiology & Plasticity  
Stephen Camarata, Ph.D., Communication & Learning  
Elisabeth Dykens, Ph.D., Mood & Emotion  
Ann Kaiser, Ph.D., & Robert Hodapp, Ph.D., Families  
Wendy Stone, Ph.D., Autism Spectrum Disorders (TRIAD)

#### UCEDD

Elisabeth Dykens, Ph.D., Director  
Elise McMillan, J.D., Associate Director; Services  
Terri Urbano, Ph.D., Training  
Robert Hodapp, Ph.D., Research  
Jan Rosemergy, Ph.D., Dissemination

#### Discovery

Editor/Writer: Jan Rosemergy, Ph.D.  
Assistant Editors/Writers: Courtney Evans, Traci Fleischman  
Art Director: Melanie Bridges, B.F.A.

Discovery is supported in part by Grant No. HD 15052 from  
NICHD and Administration on Developmental Disabilities  
Grant #90DD0595

Vanderbilt University is committed to principles of Equal  
Opportunity and Affirmative Action  
© 2007 Vanderbilt Kennedy Center, Vanderbilt University

NON-PROFIT ORG.  
U.S. POSTAGE  
PAID  
NASHVILLE, TN  
PERMIT NO. 85

VANDERBILT UNIVERSITY 

Vanderbilt University  
Vanderbilt Kennedy Center  
Reabody Box 40  
230 Appleton Place  
Nashville, TN 37203  
Return Service Requested



## Calendar of Events

Unless otherwise noted, events are free and open to the public. Events are subject to change.

Please check the calendar on our website [kc.vanderbilt.edu](http://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 Pathfinder Disability Calendar [www.disabilitytrainingtn.org](http://www.disabilitytrainingtn.org).

### April

**APRIL 16**

#### **Kennedy Center Lecture in Development and Developmental Disabilities**

#### **Triple Vulnerability in the Development of Anxiety and its Disorders**

David Barlow, Ph.D., Professor of Psychology and Psychiatry; Director, Center for Anxiety and Related Disorders, Boston University  
Monday 4:10 p.m. Room 241  
Vanderbilt Kennedy Center/MRL Building

**APRIL 18**

#### **Neuroscience Graduate Seminar Series Immature Brain Is Not a Miniature Adult Brain: Energy and Ions During Development**

Maria Erecinska, Ph.D., Professor of Anatomy, University of Bristol  
Co-Sponsor Vanderbilt Brain Institute  
Wednesday 4:10 p.m.  
Room 1220 MRB III Lecture Hall

**APRIL 20**

#### **Vanderbilt Kennedy Center Special Lecture Mechanisms and Consequences of Embryonic Exposure to MDMA**

Jack Lipton, Ph.D., Associate Professor of Neurological Sciences and Pharmacology University of Cincinnati  
Friday 12 p.m. Room 241  
Vanderbilt Kennedy Center/MRL Building

**APRIL 22-28**

#### **Nashville Week of the Young Child**

Vanderbilt and community sponsors  
Events to be announced.  
See [kc.vanderbilt.edu/kennedy/woyc](http://kc.vanderbilt.edu/kennedy/woyc)  
Contact NAAEYC (615) 383-6292

**APRIL 24**

#### **Action to Show We Care Forum on Quality Infant-Toddler Child Care**

Nashville Week of the Young Child Event  
Tuesday 5:30-6 p.m. Reception — 6-7:30 p.m.  
Panel Discussion  
Room 241 Vanderbilt Kennedy Center/MRL Building  
Free. Register [kc.vanderbilt.edu/pre-register](http://kc.vanderbilt.edu/pre-register) or (615) 322-8240



COURTESY OF LINDA DUPRE

### May

**MAY 7**

#### **Vanderbilt Kennedy Center Special Lecture Neuropathology of Autism**

Margaret Bauman, Ph.D., Associate Professor of Neurology, Harvard University  
Monday 4:10 p.m. Room 241  
Vanderbilt Kennedy Center/MRL Building

**MAY 18**

#### **Waddell & Reed Financial Services Charity Golf Tournament Benefiting Vanderbilt Kennedy Center**

Great golf, door prizes, cold beverages, lunch provided! Entry fee \$125 per player.  
Variety of company sponsorship opportunities at different levels available.  
To register contact Jenny Alford, (615) 343-5322  
[jenny.alford@vanderbilt.edu](mailto:jenny.alford@vanderbilt.edu)  
Friday 8 a.m. Shotgun start  
Vanderbilt Legends Club Roper's Knob Course

### June

**JUNE 8**

#### **Vanderbilt Kennedy Center Community Advisory Council Meeting**

Friday 9 a.m.-1:15 p.m.  
Peabody Library Reading Room  
Open to the public; to attend call (615) 936-5118  
To send comments, email [vkcac@vanderbilt.edu](mailto:vkcac@vanderbilt.edu)

### Arts & Disabilities

#### **Vanderbilt Kennedy Center Exhibits**

Monday-Friday 7:30 a.m.-5:30 p.m., Lobby  
Vanderbilt Kennedy Center/MRL Building

**FEBRUARY 12-MAY 30**

#### **Artism: Project Onward**

An exhibition of work by visual artists with autism from the studio of Project Onward, a program of the Chicago Department of Cultural Affairs

**MAY 24**

Reception for Artists 5 p.m.  
Autism and the Arts Workshop 6 p.m.  
**Autism Society of Middle Tennessee**  
Thursday Room 241  
Vanderbilt Kennedy Center/MRL Building

### Camps

The Vanderbilt Kennedy Center for Excellence in Developmental Disabilities, with national and community organizations, sponsor summer camps held at University School of Nashville. Costs vary; scholarships available. Unless otherwise noted, contact (615) 322-8147  
[gretchen.herbert@vanderbilt.edu](mailto:gretchen.herbert@vanderbilt.edu)

**JUNE 4-15**

#### **Transitions Camp**

For students, 16-23 years, with intellectual disabilities

**JUNE 11-29**

#### **TRIAD Social Skills Camp**

For children and adolescents, 6-18 years, with autism spectrum disorders

**JUNE 18-JULY 13**

#### **Explorers Unlimited Academic Camp**

For students, 10-16 years, with Down syndrome

**JUNE 24-30**

#### **Music Camp**

Young adults, ages 16 up, with Williams syndrome  
Contact (615) 322-1596  
[jill.bergesen@vanderbilt.edu](mailto:jill.bergesen@vanderbilt.edu)



## SibSaturdays

A Vanderbilt Kennedy Center for Excellence in Developmental Disabilities program for siblings of children with special needs, ages 5-7 and 8-13 years

Games, friends, conversation

\$10/child or \$20/family

Financial assistance available

Advance registration required

Contact (615) 936-5118

roxanne.carreon@vanderbilt.edu,

Saturdays, April 21, June 16, August 18,

October 20, December 15

Room 241

Vanderbilt Kennedy Center/MRL Building



Music Camp

MELANIE MAY

## Community Events

**MAY 31-JUNE 2**

### Fifth Annual Tennessee Disability MegaConference

Highlights include world-class speakers, informative workshops, agency fair, fun evening events, awards banquet.

Sponsored by coalition of more than 50 Tennessee disability-related organizations, including the Vanderbilt Kennedy Center.

Nashville Airport Marriott: \$79/night plus tax; reserve by May 9 to receive this rate; use keyword: TN Disability Mega Conference; contact (615) 889-9300 or toll-free (1-800) 228-9290 For information, see [tndisabilitymegaconference.org](http://tndisabilitymegaconference.org)

## Angelman Syndrome

### Angelman Syndrome Foundation

[www.angelman.org](http://www.angelman.org)

**MAY 19**

### 2007 ASF National Walk-A-Thon

Saturday 9 a.m. Registration 10 a.m. Start Nashville—Parthenon Centennial Park Information contact Jacquie Watlington [watlington@harpethhall.org](mailto:watlington@harpethhall.org)

## ASMT Events

### Autism Society of Middle Tennessee

[www.autismmidtenn.org](http://www.autismmidtenn.org)

ASMT event information (615) 385-2077

**MAY 17, JULY 19**

### Autism Orientation

Registration required. Child care available upon request.

Thursday 6:30-8:30 p.m.

Room 241

Vanderbilt Kennedy Center/MRL Building

**MAY 24**

### Autism and the Arts Workshop

See "Arts & Disabilities" section

## DSAMT Events

### Down Syndrome Association of Middle Tennessee

[www.dsamt.org](http://www.dsamt.org)

DSAMT event information (615) 386-9002

**MAY 4 & 5**

### Third Statewide Conference

### Fired Up! for Down Syndrome

Keynote speakers: William Mobely, M.D., Down Syndrome Research Center, Stanford University; Brian Skoto, M.D., M.P.P., author of *Common Threads: Celebrating Life with Down Syndrome*. Vanderbilt Kennedy Center presenters or moderators include Linda Ashford, Stephen Camarata, Robert Hodapp, Elise McMillan, Karen Summar, Caresa Young. For health care professionals, educators, advocates, self-advocates, and family members. Teen and adult tracks on Saturday. Friday-Saturday Clearview Baptist Church, Franklin TN

## Take Part in Research

### StudyFinder

Children and adults, with and without disabilities, are invited to take part in research.

See [kc.vanderbilt.edu/studyfinder](http://kc.vanderbilt.edu/studyfinder)

Contact Lynnette Henderson (615) 936-0448; toll-free (1-866) 936-VUKC [8852]

## Disability Pathfinder

### Phone, web, print resources

[www.familypathfinder.org](http://www.familypathfinder.org)

English (615) 322-8529

Español (615) 322-8529 ext. 11

Toll-free (1-800) 640-INFO [4636]

[tnpathfinder@vanderbilt.edu](mailto:tnpathfinder@vanderbilt.edu)

### Disability Calendar

Internet calendar of training and other disability-related events

[kc.vanderbilt.edu/tnpathfinder/calendar.html](http://kc.vanderbilt.edu/tnpathfinder/calendar.html)

### Statewide Directory

*2007-2008 Disability Services and Supports*

To be published in 2007 in 3 volumes:

West, Middle, and East Tennessee

\$25 per directory

To order, contact

(615) 322-8529 ext. 15

[ashley.coulter@vanderbilt.edu](mailto:ashley.coulter@vanderbilt.edu)

### Access Nashville

A volunteer organization identifying "accessibility-friendly" locations in Nashville in collaboration with volunteers in the disability and business communities. Accessibility surveys of restaurants, entertainment attractions, and hotels available on Nashville Convention and Visitors Bureau website. Volunteers receive free training. Consultation and information provided for organizations interested in replicating this project in other towns and cities. Contact (615) 322-8529 ext. 12

Projects of Vanderbilt Kennedy Center for Excellence in Developmental Disabilities and Tennessee Council on Developmental Disabilities