A Week In the Life of
VANDERBILT KENNEDY CENTER

2010 Annual Report

Developmental Disabilities  |  Discoveries  |  Best Practices
A WEEK in the Vanderbilt Kennedy Center
Discoveries and Best Practices

Our researchers, clinicians, and educators take steps every day of every week toward making positive differences in the lives of persons with disabilities and their families. We do this in partnership with you—our community of children and adults with disabilities, families, service providers, advocates, and donors. We are motivated by the stories of families affected by disabilities. One in 5 children has a developmental disability. Roughly 20% of U.S. families have a member with a disability. When you hear the personal stories of many of our researchers and staff, you learn how their families, too, have been affected by disability. For 45 years, week by week, the Vanderbilt Kennedy Center family has focused on disability—and ability.

Researchers in basic science labs work daily striving to unravel the complex processes of typical and atypical development in genes and chromosomes, cells and mitochondria, neurons and synapses. Developmental disorders as wide ranging as autism, fragile X syndrome, depression, and schizophrenia are studied through animal models.

Brain imaging is providing insights into behavior and learning. It is helping us understand reading and math disabilities, ADHD, language development and interventions, features of autism spectrum disorders in diagnosed children and their siblings, creativity and schizophrenia, early aging in Down syndrome, and more. Brain imaging studies are leading toward ways to predict which individuals will most likely respond to a specific intervention and to measure whether that intervention is working even before it is apparent in behavior.

Translating research findings into practice is what we’re about. Today, evidence-based practices are at work in such programs as the Reading Clinic, Learning Assessment Clinic, Britt Henderson Training Series for Educators, and TRIAD’s screening, diagnostic, and outreach training for families and educators. Best practices are under development in such model programs as the Behavioral Health and Intellectual Disabilities Clinic at Vanderbilt, Next Steps at Vanderbilt postsecondary education for students with intellectual disabilities, Parent Stress Intervention Project, Vanderbilt Autism Treatment Network, and Volunteer Advocacy Project. Researchers and families take part in clinical pharmaceutical trials for such disorders as autism and fragile X.

You can tour some VKC labs but you can’t truly tour this Center because its work goes on all over the campus; in communities across the state; at Head Start programs, school systems, training sites; and in multiple sites across the country as our researchers collaborate with other major research universities and consortia on genomics and other areas.

Over 200 creative faculty in the Vanderbilt University Medical Center, Peabody College, College of Arts and Science, and Engineering, and 100 dedicated staff are a part of our Center’s family. Training next generations of disability researchers, educators, and service providers is an essential part of our mission. At annual VKC Science Days, over 100 undergraduates, graduate students, and postdoctoral fellows have presented research posters. The VKC University Center for Excellence in Developmental Disabilities (UCEDDD) was renewed for a second 5-year cycle. The UCEDD encompasses over 40 programs that, in some way, have reached individuals or families in every Tennessee county.

Our work today also is about the future—of individuals with disabilities, of young researchers who will make tomorrow’s discoveries, of clinicians who will provide evidence-based care, of educators who will include students with disabilities and promote learning for all, of service providers who will support the self-determination, inclusion, and independence of persons with disabilities and support their families. Training across disciplines of future leaders is integrated into virtually all of our Center’s research and services. In 2010, the UCEDD and the Leadership Education in Neurodevelopmental Disabilities (LEND) Training Program had 32 long-term trainees and 157 intermediate trainees. Our UCEDD and LEND community continuing education events reached about 2,000 persons in 2010.

Economically, these are challenging times. Thanks to visionary donors, we are able each year to award Discovery Grants for innovative pilot studies. This has helped our researchers successfully garner NIH and other federal and foundation funding. Today, VKC research includes 106 grants, with an annual total cost of $34.3 million. This record of success when only 22.55% of NIH grants are funded is a marker of the extraordinary quality of VKC researchers. Much of our model services and training would not be possible without support from State of Tennessee departments, the Tennessee Council on Developmental Disabilities, corporate donors, and foundations like ACM Lifting Lives and the John Merck Fund. Every gift of each individual donor is valued and used wisely.

This issue of Discovery tells our story through photos of a typical week at the Vanderbilt Kennedy Center, on campus and in the community. You’ll see discovery in process, far-ranging services, education from the university to the community and state, and the central role played by you—our families and friends, community providers and educators, disability advocates and donors. Thank you.
Elizabeth Story and Andrew Van Cleave, Next Steps at Vanderbilt students, presented a collage to artist and friend, Mary Jane Swaney. Her generous support made it possible for Next Steps at Vanderbilt students to create collages with artist-in-residence Elizabeth Garlington at Vanderbilt’s Sarratt Art Studios. The collages expressed their unique selves and aspirations and make up the exhibit Reflections in Collage/Reflections in College.

Through playground video cameras, Blythe Corbett (Psychiatry) and Tori Stromp (seated) are viewing play, or social interaction, of children with autism and trained peers. This is just one of many behavioral, biological, and neuroscience strategies Corbett is using to evaluate the socioemotional responsivity of children with autism in the SENSE lab (Social Emotional Neuroscience Endocrinology).

Lynnette Henderson (Pediatrics) works with organizers of ASK (Agencies Serving Kids) in Tullahoma who meet monthly to share information. As she does at more than 90 community events throughout the year, Henderson shared information about research projects benefitting children and StudyFinder and Research Family Partners, web-based gateways for VKC research. She also shared information on VKC services, training, and print and online resources.

Cellular images like this are central to the work of Randy Blakely (Pharmacology), who is exploring how neurotransmitters regulate chemical signaling among neurons. His lab uses techniques in molecular biology, biochemistry, imaging, genetics, and animal models to understand processes involved in such disorders as depression, ADHD, and autism.
TOP: Research on ways to improve reading and math instruction take place in classrooms of Metro Nashville and other public school systems. Lynn Fuchs, Doug Fuchs, and Donald Compton (Special Education) are conducting studies on RTI—Response to Intervention. In one large-scale study, second graders receive whole-class (Tier 1) mathematics instruction. Students with risk for poor outcomes also receive a second tier of intervention: small-group tutoring on content that is aligned with the classroom program. Individual students receive instruction at the level of intensity needed to help them learn effectively.

MIDDLE LEFT TO RIGHT: Parents of children with disabilities are practicing qigong (gentle movement, breath, and stillness) as a way of reducing stress. This Mindfulness-Based Stress Reduction and a Positive Parenting Curriculum are methods of stress reduction being compared in a study led by Elisabeth Dykens (Psychology & Human Development). Parents are leading the interventions. Pablo Juárez leads a session for educators as part of TRIAD’s Outreach Training. As more young children are diagnosed with autism, public school systems are serving more children—making training a critical need for school systems. Partnering with the Tennessee Department of Education, TRIAD Outreach Training, directed by Nicolette Brigham (Pediatrics), provides services ranging from child-specific consultations to system-wide training. In January 2011, statewide training began for early childhood educators.

Sticky mittens is one of the clever ways that Amy Needham (Psychology & Human Development) is using to study factors that contribute to infants beginning to reach independently for objects and become motivated to explore their world. One goal is to create interventions involving sensory substitution that would allow infants with visual impairments to perceive the consequences of their actions on objects through nonvisual ways.
TOP LEFT: Adam Anderson (right, with research fellow Ha-Kyu Jeong) studies brain connectivity and development using MRI at the Vanderbilt University Institute of Imaging Science.

BOTTOM LEFT: Kathleen Lane (Special Education) talks with teachers attending the Britt Henderson Training Series for Educators. Teams from area school systems travel to the VKC monthly during the academic year to attend the Britt Henderson Training Series for Educators. The teams support one another, share ideas, and problem-solve ways to implement research-based strategies in their own classrooms. These 2-hour evening workshops address both academic and behavioral concerns. The Series is free of cost to schools through an endowment from the Robert and Carol Henderson family in memory of their son Britt.

RIGHT: James Sutcliffe (Molecular Physiology & Biophysics) works on dissecting the genetics of autism using a combination of molecular and statistical genetic approaches, informed by altered physiology and neurodevelopment observed in individuals with autism. He and other VKC researchers are members of national genetics research consortia on autism.
THURSDAY a week in the life of

PHOTOS FROM PAGE 6

TOP: Tracy Pendergrass is helping a mom who called Tennessee Disability Pathfinder’s toll-free helpline to identify services for her child. Multiple statewide needs assessments in Tennessee have indicated that disability information is a critical need. That need is met by Pathfinder, a partnership of the VKC and the Tennessee Council on Developmental Disabilities. Pathfinder’s website has a database searchable by service type and county, and a 2011 services directory that can be downloaded. Multicultural outreach is a priority.

MIDDLE LEFT TO RIGHT: (1) Voting rights event honors Eunice Kennedy Shriver, champion of the value of persons with disabilities. (2) Sheryl Rimrodt (Pediatrics) and Laurie Cutting (Special Education) are viewing composite images of brain activity in research on dyslexia. (3) Research in labs of VKC investigators explores basic mechanisms of nervous system development and response to injury. BethAnn McLaughlin (Neurology) produced this image in a study she spearheaded that identified a critical new molecular trigger that allows cells to “ramp up” their defenses before a major stroke.

PHOTOS FROM PAGE 7

TOP LEFT: Next Steps at Vanderbilt students with friend and patron Linda Brooks.

BOTTOM LEFT: SibSaturdays, fun and support for siblings whose brother or sister has a disability.

LEFT TOP TO BOTTOM: (1) A technologist prepares to monitor a child’s sleep in studies of sleep disorders in children with autism led by Beth Malow (Neurology). (2) Mark Wallace (Hearing & Speech Sciences) testing a child in project with Stephen Camarata (Hearing & Speech Sciences) investigating sensory integration treatment for autism. (3) Linda Dupre (VKC Grants Development Director) consults with VKC investigator Sarika Peters (Pediatrics) (4) The Vanderbilt LEND (Leadership Education in Neurodevelopmental Disabilities) is a partnership between the VKC and Pediatrics. Here Tyler Reimschisel (Developmental Medicine) is presenting to pediatric residents so that they will be better prepared to provide interdisciplinary, family-centered, coordinated care to children with developmental disabilities and their families. (5) At Lunch & Learn for Music Community, Lorie Lytle (VKC Leadership Council), Seth Link (ACM Lifting Lives Music Camper), and Erin Spahn (ACM Lifting Lives).
TOP: This child “driving” a jeep is helping us learn about stuttering and emotion. Edward Conture (Hearing & Speech Sciences) and Tedra Walden (Psychology & Human Development) are using physiological measures of emotional arousal, observation of emotional behaviors, parent report, and speech, language, and hearing tests to study how emotions and conversational speech and language influence stuttering and other dysfluencies.

MIDDLE LEFT TO RIGHT: This Reading Clinic student is among 29 this session, including students with developmental disabilities, who are becoming readers through intensive, individualized, one-to-one tutoring using assessment and instructional methods proven by research to promote reading. Licensed, experienced teachers and supervised, advanced undergraduate and graduate students provide the tutoring—contributing to the training of future teachers.

Michele Mosely, Peer Mentor, works with Josh Murray at the Behavioral Health & Intellectual Disabilities Clinic at Vanderbilt. A VKC partnership with Psychiatry, the Clinic serves individuals with developmental disabilities, ages 17 and up, who have behavior issues or mental health disorders. Training future providers and developing best practices are among the aims of the Clinic, directed by Bruce Davis (Psychiatry).

While Eva is playing, she’s receiving a therapy to help her talk more clearly. In the Clear Talk Project, Paul Yoder (Special Education) is comparing two inventions that research suggests are especially good for children with Down syndrome. Children ages 5-12 years receive hour-long therapy sessions, twice a week, for 6 months.
TOP LEFT TO RIGHT: (1) Megan Hart (Tennessee Disability Pathfinder) presents at a LEND Core Seminar. LEND trainees in 13 disciplines from Vanderbilt and four area universities attend this Seminar, one component of year-long training to prepare them to assume leadership roles in interdisciplinary, family-centered, culturally competent, coordinated health care for children with developmental disabilities. (2) Making our universities, communities, and states more welcoming for persons with disabilities was the focus of the VKC visit by Sharon Lewis, Commissioner of the federal Administration on Developmental Disabilities. A parent of a child with a disability, Lewis describes this as “passion work.” Lewis talked with Next Steps at Vanderbilt students, LEND and UCEDD trainees and faculty, and Community Advisory Council members. (3) Ray Johnson (Anesthesiology) manages the Neurochemistry Core, a VKC research support service core shared with the Center for Molecular Neuroscience. For more than 30 years, Johnson has worked with VKC investigators to review experimental needs, to establish protocols, and to provide rapid and reliable assay results. Neurochemistry is among several Basic Neuroscience Services.

MIDDLE LEFT TO RIGHT: (1) John Shouse (Autism Society of Middle Tennessee) works with representatives of State agencies, autism family organizations, and other agencies on the Tennessee Autism Summit Team. The Team’s goal is to improve the Tennessee service system for individuals with autism and their families. The VKC has more than 20 Community Partners with whom it collaborates. (2) Portia Carnahan is hard at work here 3 mornings each week as an AmeriCorps member. For individuals with disabilities, AmeriCorps service is an effective way to gain employment experience. Unemployment and underemployment is a challenge in the disability community, which is why employment is now an area of emphasis in the VKC UCEDD. (3) Begun with a gift from Ann and Monroe Carell Jr., TRIAD Families First workshops are held on evenings or Saturdays to provide parents with ways to help their young children with autism build language and communication, play, and social skills, and manage challenging behaviors. Over 30 workshops have been held, serving over 800 parents from 3 states.
Andrea Warren and her son Taylor drove from Atlanta to take part in research to better understand behavior and development in Prader-Willi syndrome (PWS), a genetic disorder associated with severe overeating, obesity, and behavior problems, but also unusual strengths. This holistic study includes genetics, neurochemicals that regulate mood and appetite, lifespan development, and successful living (e.g., food, work, daily living, leisure). The goal is to develop behavioral and dietary interventions that lead to positive outcomes for persons with PWS and their families.

TOP TO BOTTOM:
(1) Grace Kulbaba administers a variety of tests to assess Taylor’s strengths and weaknesses and problem-solving tasks like jigsaw puzzles, an unusual strength in PWS.
(2) Elizabeth Roff, Research Coordinator, interviews Taylor’s mom to collect data on Taylor’s development and behavior and on family strengths and concerns.
(3) Taylor wears a sensor net that makes it possible to monitor brain activity while he looks at images of food and nonfood items and of faces, or hears clicks or tones. Eye tracking is done as well.
A Special Thanks to the Community

Vanderbilt Center for Discovery Donors
January 1, 2010-February 28, 2011
($1,000 and above)

Dr. & Mrs. Stephen J. Eskind*


Anonymous

Vanderbilt Kennedy Center Donors


Corporate and Foundation Donors

ACM Lifting Lives
ASCAP Foundation
Autism Speaks
Delhi Down Syndrome Association of Middle Tennessee
F2 Industries, LLC


DISCOVERY | Winter 2011 11
This issue of Discovery tells our story through photos of a typical week at the Vanderbilt Kennedy Center, on campus and in the community. You’ll see discovery in process, far-ranging services, education from the university to the community and state, and the central role played by you—our families and friends, community providers and educators, disability advocates and donors. Thank you!
March 22* 
Disabilities, Religion, and Spirituality 
Helping Individuals With Intellectual Disabilities Cope With Loss  
Panel discussion. Register at kc.vanderbilt.edu/registration  
Co-Sponsor Alive Hospice  
Tuesday 12 noon

March 23* 
Developmental Disabilities Grand Rounds  
New Approaches Toward Understanding the Genetic Architecture of Autism  
Jonathan Haines, Ph.D., T. H. Morgan Professor of Human Genetics and Molecular Physiology & Biophysics; Director, Center for Human Genetics Research, VKC Investigator  
Wednesday 8 a.m.

March 24 
Discovery Lectures/Lectures on Development and Developmental Disabilities  
How Gene Expression and Neurobiology Contribute to Rett Syndrome and Other Neurodevelopmental Disorders  
Huda Y. Zoghbi, M.D., Professor of Molecular & Human Genetics, Pediatrics, Neurology, and Neuroscience, Baylor College of Medicine; Investigator, Howard Hughes Medical Institute Co-sponsor Department of Pediatrics  
Room 208 Light Hall  
Thursday 4 p.m.

April 1-2* 
Augmentative and Alternative Communication Workshop  
• Friday  
Perspectives on AAC: A Parents’ Panel  
6-8:30 p.m. No cost.  
• Saturday  
Curriculum Adaptations for Students with Complex Communication Needs  
Pati King-DeBaun, M.S., CCC-SLP  
Register at kc.vanderbilt.edu/registration—fee listed. Co-Sponsors Vanderbilt Bill Wilkerson Center, Hearing & Speech Sciences, LEND, Special Education; Disability Law & Advocacy Center of Tennessee, Technology Access Center, Prentke Romich Company (PRC)  
Saturday 8:30 a.m.-5 p.m.

April 4* 
Lectures on Development and Developmental Disabilities  
Title TBA  
Karl Deisseroth, M.D., Ph.D., Associate Professor of Bioengineering and Psychiatry & Behavioral Sciences, Stanford University  
Monday 4:10 p.m.

April 5* 
Research Ethics Grand Rounds  
“Curing” Disabilities: Ethical Considerations  
Panel Discussion  
Tuesday noon

April 6* 
Britt Henderson Training Series for Educators Using Self-Monitoring in Academic Interventions  
For school teams, individuals, parents  
Register at kc.vanderbilt.edu/kennedy/henderson  
Information (615) 343-0706  
Wednesday 5-7 p.m.

April 8-9 
Third Annual Tennessee Adult Brothers and Sisters (TABS) Conference  
For adult siblings of individuals with disabilities. Program details on registration webpage. Holiday Inn at Vanderbilt, 2613 West End Ave., (888) 465-4329 (call for room reservations) $50/person, $25 student  
Fee covers materials, meals, and gift  
To register (required): kc.vanderbilt.edu/registration  
Contact (615) 343-0545 ashley.coulter@vanderbilt.edu  
Friday-Saturday

April 16*  
SibSaturday  
For siblings 5-7 and 8-13 years who have brother/sister with disability Games, friends, conversation  
$10/child or $20/family. Financial assistance available. Advance registration required. Register at kc.vanderbilt.edu/registration

April 18 
Capacity Building Institute, Postsecondary Education for Students with Intellectual Disabilities  
Strategies and resources for college faculty and administrators and community leaders to develop and implement inclusive postsecondary education options for students with intellectual disabilities.  
Registration (required) kc.vanderbilt.edu/registration  
Contact (866) 936-8852 laurie.fleming@vanderbilt.edu  
Monday 9 a.m.-4 p.m.
**BEHAVIORAL HEALTH AND INTELLECTUAL DISABILITIES CLINIC**
For individuals with intellectual disabilities, ages 17 and up, with behavioral and mental health challenges
Contact (615) 343-9710
behavioralhealth@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
Contact (615) 936-5118
patty.abernathy@vanderbilt.edu

**READING CLINIC**
Assessment and tutoring for students through middle school
Contact (615) 936-5118
patty.abernathy@vanderbilt.edu

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

**TENNESSEE DISABILITY PATHFINDER**
Helpline, Web-Searchable Database with Calendar and Resource Library, Print Resources
www.familypathfinder.org
English (615) 322-8529
Español (615) 479-9568

**TRIADSCHOOL-AGE SERVICES**
With the Tennessee Department of Education, TRIAD offers free autism-specific workshops for parents, school personnel, and the community in locations across the state.
Information and registration, contact Linda.Copas@tn.gov, (615) 741-7790
See also www.state.tn.us/education/speced/announcements.shtml

**ASMT EVENTS**
Autism Society of Middle Tennessee
ASMT event information
(615) 386-9002, www.dsamt.org

**COMMUNITY EVENTS**
- **MARCH 26, 2011**
  Family-to-Family Outreach Conference
  Nashville Main Library
  www.tndisability.org/familyvoices

- **APRIL 10-16, 2011**
  Week of the Young Child
  www.naeyc.org/woyc

- **JUNE 2-3**
  Tennessee Disability MegaConference
  Nashville Airport Marriott
  www.tndisabilitymegaconference.org

**DSAMT EVENTS**
Down Syndrome Association of Middle Tennessee
DSAMT event information
(615) 386-9002, www.dsamt.org

- **MAY 13-14**
  Statewide Conference:
  Fired Up! For Down Syndrome
  Brentwood United Methodist Church, 309 Franklin Rd
  Registration begins Feb. 1