

DISCOVERY



VANDERBILT KENNEDY CENTER



From tiny genes to
big public policies:
**HOW THE
VANDERBILT
KENNEDY CENTER
ENCOURAGES
PRECISION CARE**

Director's Message

For more than 50 years, the Vanderbilt Kennedy Center (VKC) has worked to improve the lives of people with developmental disabilities. We have long recognized that a multitude of methods and approaches are necessary to achieve success. Built upon the remarkable strength of educational and behavioral approaches at Peabody College, over the years the VKC has integrated into this foundation innovation in basic neurobiology. This combined approach has allowed for a deeper understanding of underlying causes, enhanced exploration into biomedical approaches to therapy, fostered community relationships, and enabled an expansion into public health and policy.

These ever-expanding approaches and methods are critical to furthering our overall mission. However, we recognize there are challenges. Developmental disabilities are highly variable, even within a single "disability." For example, there is a high degree of variability amongst people with autism with regard to the underlying cause, specific characteristics, other medical coexisting conditions, skills, and response to standard therapies. Similarly, although all people with reading difficulties share challenges with extracting information

from written text, not all respond the same way to particular learning methods. The overall variation in causes, features, and response to intervention make the development of a "one-size-fits-all" approach to developmental disabilities suboptimal.

We need a tailored approach. This is not a foreign idea in the world of disabilities. In the educational world, VKC members have been conducting research into developing educational and behavioral interventions that address individual differences for well over 50 years. In the medical world, great advances are being made in "personalized" or "precision" medicine, which is usually defined as finding the right medicine for the right person at the right time. We recognize that successful approaches to improving lives will need to consider the full range of approaches utilized in the VKC, so rather than "precision medicine," we think of

"precision care" for developmental disabilities. This still rests on the fundamental idea of identifying the right approach to improving the life of a person with a developmental disability and providing it at the right time. This approach or "care" might be a specific

educational intervention, a targeted behavioral therapy, or specific medications. Furthermore, the idea encompasses empowering remote communities to be capable to provide such care, and to shape larger policy around these issues.

Moving forward, the VKC will continue to encourage efforts to foster the idea of precision care at a biomedical, behavioral, and educational level and to bring these same concepts to the community

and policy levels. I hope you enjoy this issue of *Discovery* featuring some of the ways we have been applying this concept in our activities, and will join us in future efforts of improving the lives of people with developmental disabilities.



Jeffrey L. Neul, M.D., Ph.D.

Message from Vanderbilt University Medical Center



Jeffrey R. Balsar, M.D., Ph.D.

Vanderbilt University Medical Center (VUMC) is recognized as a national leader in precision care. We think of care holistically—health, certainly, but also social, behavioral, educational, and

environmental factors that define individual well-being. We are extraordinarily proud of the distinguished history of the Vanderbilt Kennedy Center (VKC) in discovery in the field of intellectual and developmental disabilities.

Through decades of investment, VUMC has led the nation's efforts in DNA biobanking

and biomedical informatics. BioVU, our DNA resource that embeds de-identified medical records, is among the world's largest and is leading to discoveries that support precision care across a wide range of conditions.

The VKC is leading our understanding of precision care within the context of developmental disabilities. For example, a grant received recently from the National Institute of Child Health and Human Development will leverage BioVU to identify better predictors of health challenges in people with Down syndrome, while paving the way for targeted therapies. VKC-affiliated researchers are focused on drug discovery related to Rett syndrome, with an eye towards identifying treatments that can be targeted towards people with the specific genetic mutations that cause this condition. This approach provides a clear path towards

precision care for a specific neurodevelopmental disorder, while providing a blueprint for how to approach precision care in other genetic disorders as well.

From basic science discoveries to clinical trials of new drug therapies to behavioral and educational treatments and support, the VKC is focused on precision interventions that will enhance **individual** quality of life of children and adults with disabilities. The VKC has always reflected Vanderbilt's culture and compassionate focus on the holistic needs of the individual. The future is exceptionally promising as the Center leverages the institution's cutting-edge capabilities and leadership in precision medicine to fundamentally improve the care and lives of people with developmental disabilities.

Precision and Individual Differences in Research

Understanding sensory differences

- Mark Wallace, Ph.D., Louise B. McGavock Endowed Chair; Professor of Hearing & Speech Sciences, Psychiatry & Behavioral Sciences, and Psychology
- Tiffany Woynaroski, Ph.D., CCC-SLP, Assistant Professor of Hearing & Speech Sciences
- Carissa Cascio, Ph.D., Associate Professor of Psychiatry & Behavioral Sciences

We rely on information from our senses to understand the world around us. Many children with autism spectrum disorder (ASD) show differences in how they process sensory information that may affect their ability to engage with and learn from their world. Individuals with ASD may also have difficulty integrating information from multiple sensory

modalities, such as the sound of persons talking and the sight of their moving face and mouth.

Working through the Vanderbilt Kennedy Center, we are providing the most comprehensive characterization of sensory function in children with autism to date. We are examining how sensory features relate to the social difficulties and other “core” symptoms that define autism. We are using state-of-the-art brain imaging technologies to elucidate differences in brain structure and function that may underlie differences in sensory function and broader autism symptoms, providing a compelling view into the sensory brain in individuals with autism.

Ultimately, we hope to leverage this increased understanding of sensory function to carry out

a clinical trial that tests the effect of a novel intervention that targets sensory differences in children with autism. The proposed study will incorporate research design elements and advanced analytic approaches to identify the children with ASD who are most likely to benefit from sensory-based treatment and to identify behavioral and neural mechanisms by which such a treatment may work.

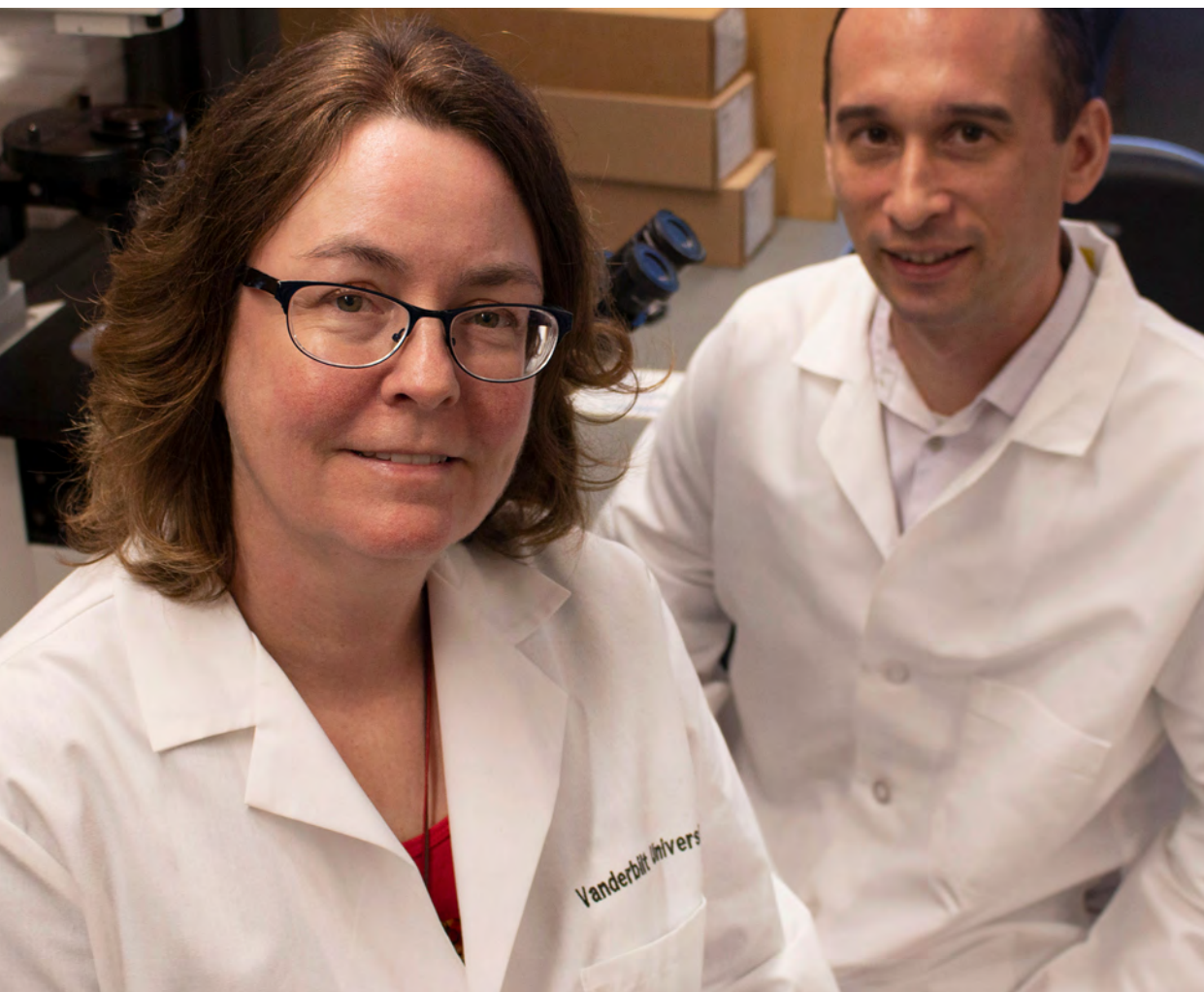
Tailoring treatment methods

- Paul Yoder, Ph.D., Professor of Special Education

Almost all of the treatment studies I’ve conducted over 31 years examine whether individual differences prior to treatment affect the extent to which treatment works. Taking a “personalized” approach allows us to identify

Pictured: Tiffany Woynaroski, Ph.D., walks a research participant through the McGurk task, which measures the extent to which one is integrating auditory and visual speech information.





The mission of the Vanderbilt Kennedy Center is to facilitate discoveries and best practices to improve the lives of persons with developmental disabilities and their families.

particular treatment methods that are best suited to individual needs and characteristics of the children we serve.

For example, in one of our studies, we confirmed a prediction that children with Down syndrome who had initially good verbal imitation skills would learn to speak more clearly when taught with a particular method. The method involved having the therapist repeat the child's poorly formed utterance prior to using adult pronunciation (i.e., speech recasts) rather than being asked to immediately imitate the adult models. The children with initially poor verbal imitation abilities benefited (or failed to benefit) about equally from either treatment method.

Currently, we are testing whether an early intervention method called ImPACT facilitates communication better for infants who are greatest risk for autism and other communication disorders than infants who are at moderate risk.

Uncovering individual differences and responses

- Colleen Niswender, Ph.D., Research Associate Professor of Pharmacology; Director of Molecular Pharmacology, Vanderbilt Center for Neuroscience Drug Discovery
- Rocco Gogliotti, Ph.D., Research Instructor in Pharmacology

Rett syndrome (RTT) is caused by mutations in a gene called methyl CpG binding protein 2 (MECP2), which "reads" signatures embedded in each person's DNA. In our work in RTT, we have found dramatically reduced expression of a protein called metabotropic glutamate receptor 7 (mGlu7), and have evaluated the effects of a test compound. The compound potentiates mGlu7 activity and corrects numerous deficits in cognitive, social memory, and breathing tests in animal models.

We are now optimizing drug leads for mGlu7, which we hope can be progressed into eventual clinical trials. Importantly, we also recently found that mGlu7 levels are not decreased in all individuals with RTT, but that reductions appear to be dependent upon each person's specific MECP2 mutation. This information is critical in helping determine which patients might respond best to an enhancement of mGlu7 activity and potentially identify individuals who may be at an increased risk of side effects with mGlu7-targeted drugs.

This personalized medicine approach will allow us to optimize our drug development process, and we anticipate that this will provide an increased likelihood for success in RTT clinical trials.

Moving beyond one-size-fits-all interventions

- Julie Lounds Taylor, Ph.D., Associate Professor of Pediatrics and Special Education

I think a lot about the heterogeneity of autism spectrum disorder. Trying to understand the

specific needs of subgroups of individuals uses a precision care perspective. As I do intervention research, I focus on who seems to benefit most from the intervention and why. The intervention might need to be altered or individualized to meet the needs of different groups of people. We cannot make blanket statements, and one-size-fits-all interventions are unlikely to reflect the diversity of needs.

New funding allows for exploration of nuances of Down syndrome

The Vanderbilt Kennedy Center received a 1-year grant from the National Institute of Child Health and Human Development to access Vanderbilt University Medical Center (VUMC) electronic medical record information and biological samples to develop a deeper understanding of critical issues in Down syndrome and to provide an infrastructure for future analyses.

The grant allows researchers to add targeted research questions related to Down syndrome across the VKC Intellectual and Developmental Disabilities Research Center (IDDRC). The Synthetic Derivative, which includes more than 20 years of VUMC's de-identified electronic medical record data and BioVu, VUMC's database of de-identified DNA samples that can be linked to data in the Synthetic Derivative, are key components as researchers begin this new path of discovery.

Sharing knowledge about Rett syndrome

Families, caregivers, educators, clinicians, therapists, and researchers came together in October for the inaugural Rett Syndrome Education Day. The event was a rich and informative day of topics and discussion that covered research updates, medical and therapeutic intervention strategies, and Tennessee-specific programs and services.

THE VKC HAS

200+

faculty from all 10 VU schools and 34 departments

• • • • •

80

research studies funded by NIH and other agencies in the VKC IDDRC

• • • • •

234

research publications in 2017-18

Pictured page 4: (1) Jeff Neul, M.D., Ph.D., with families attending Rett Syndrome Awareness Day. (2) Julie Lounds Taylor, Ph.D., with a research participant. (3) Colleen Niswender, Ph.D., and Rocco Gogliotti, Ph.D. (4) New NIH funding will increase our ability to understand, predict and develop precision care for individuals with Down syndrome. (5) Graduate student, Jacob Feldman prepares a participant for an EEG. (6) Paul Yoder, Ph.D., conducts a language intervention study.

Vanderbilt Consortium LEND 2019 Nashville Trainees





Training that incorporates individualization

Precise instruction

Neena Saha, Special Education Graduate Student, Vanderbilt University



The various projects I've been involved with as a UCEDD trainee, including supervising in the Reading Clinic, have allowed me to see the importance of precise,

individualized instruction. For the field of early reading, precision is critically important for reading development. Research shows that precise leveling of texts is important for young readers so they don't get frustrated. This is especially important for struggling readers. Under the direction of Dr. Laurie Cutting, we are in the early stages of developing technology that precisely matches struggling readers with appropriate text.

A focus on the individual

Kim Woodward, Research Nurse Specialist III, Vanderbilt University Medical Center



Individualized care means I tailor my care, from medical decisions to psychosocial interventions, to the individual patient and his or her family. In my training with the Vanderbilt

Consortium LEND, I was struck by the program's continual focus on the individual as unique. This mindset encourages me to approach my patients with precision care as a model. There is always the delicate balance of providing excellent, individualized health care while maintaining efficiency. I've come to learn approaching with an individualized mindset, strong clinic staff support, and logistical support help to maintain that balance.

Teaching to the person

Jacqueline Day, Special Education Graduate Student, Vanderbilt University



I am a teacher and individualized care is the most important thing we can do. No two students are the same and individualizing their plans is the best way to make sure they are

getting the supports they need.

Working together to provide individualized care

Christopher Moore Daniell, graduate student, Psychological Sciences, Vanderbilt University

Personalized care means finding the treatment or therapeutic approach that meets the needs of the individual person. My time as a trainee with the UCEDD has made me consider all of the different fields and people that comprise a care-team for any one individual, and how working together can ultimately design what works best for that person.



Pictured page 6: (1) Vanderbilt Consortium LEND trainees will assume leadership roles to serve children and young adults with neurodevelopmental and related disabilities. (2) Erik Carter, Ph.D., leads a discussion at a Tennessee-Works Partnership meeting. (3) Megan Hart, director of Tennessee Disability Pathfinder. (4) Participants at a TRIAD Train the Trainer workshop. (5) Laurie Cutting, Ph.D., in her lab with graduate student Neena Saha.

IN 2017-18

60

community trainings were attended by

2,200

participants

.....

This included training by the TRIAD Families First project, webinar series on classroom management and early childhood communications, and the Tennessee Disability Pathfinder community education series

63

UCEDD and LEND long-term trainees each devoted 300 or more hours

- UCEDD trainees included graduate students from Special Education, Social Work, and Psychology
- LEND trainees included participants from Audiology, Deaf Education, Medicine, Nutrition, Occupational Therapy, Physical Therapy, Psychology, Public Health, Social Work, Special Education, Speech Language Pathology. The cohort also included family members as full participants.





Individualized approaches to service and supports

Family needs come first

Whitney Loring, Psy.D., Assistant Professor of Pediatrics and Psychiatry & Behavioral Sciences; Coordinator, TRIAD Families First

A precision approach applies to a group-based model of care like TRIAD Families First in two primary ways. The first is how we individualize content given the unique differences of each family. Throughout our workshops, we focus on the components that make a strategy successful and then highlight multiple video, photo, and case examples of how this can be implemented across various age and skill levels. We then embed small group activities where caregivers work together to practice strategies before applying it to their own situation. With consultant assistance, they then complete an action plan that focuses on how they plan to implement the strategies within the context of their own family's unique situation.

The second way we use a precision approach is in how we individualize the modality to reach families where they are. In addition

to our base model of a live workshop, the program is also livestreamed to nine locations to allow families to attend who may be unable to travel to Nashville. For those unable to or uncomfortable with attending the group trainings, a series of basic online training modules and written materials are available in both English and Spanish.

Volunteer advocates meet individual needs

Ellen Casale, Coordinator, Volunteer Advocacy Project; Special Education Graduate Student

The Volunteer Advocacy Project (VAP) trains individuals to become special education advocates. It is designed to help each advocate individually access content and support to have their personal advocacy needs answered. Though we present standard content, participants are encouraged to ask questions and follow-up with presenters to meet their individualized needs. We also understand that providing effective support to families of children with disabilities means being aware of how individual needs factor into the larger picture. The VAP embraces a one-size-does-not-fit-all approach to advocacy.

Providing one-on-one support

Megan Hart, director, Tennessee Disability Pathfinder

Through our helpline, Pathfinder staff provide one-on-one support to connect individuals with disabilities, their families, and others

to appropriate community resources. We have a culturally diverse staff that includes professionals, family members, and/or individuals with disabilities who have many years of experience working in the disability field. Because of this, we know that each situation is unique and that needs must be considered through an individualized lens.

Assessments ensure unique camp experience

Each year, campers with Williams syndrome taking part in the ACM Lifting Lives Music Camp undergo an array of assessments of functional abilities before and during the week of camp. The assessments assist camp staff in tailoring counselor's skills to the campers' unique abilities and allow maximum independence and interaction with other campers and musicians. In addition, many campers use their personal feedback report, which gives an excellent snapshot of their unique strengths and weaknesses, to help them at home with educational accommodations, vocational placements and supports to access additional services they require in their home community.

Pictured page 8: (1) Participants at TRIAD Families First workshop. (2) Staff of Tennessee Disability Pathfinder. (3), (4) Families from the 10-Year Anniversary Celebration of TRIAD Families First. (5) 2018 Volunteer Advocacy Project graduates.

Pictured page 9: (1) ACM Lifting Lives Music Campers. Photo by Getty Images/Terry Wyatt, Courtesy of ACM Lifting Lives

IN 2017-18

67

family and community members served by VAP

.....

15,352

visits to the Pathfinder website and 1,923 helpline calls & emails

.....

775

participants in 12 languages served by the Multicultural Outreach Program



Considerations from Families Living in Rural Counties



Impacting public policies that affect the lives of Tennesseans with disabilities

Making Choices: Supported Decision Making

In April 2018, Tennessee enacted legislation that helps adults with disabilities to retain the right to make choices about their own lives. Education about Supported Decision Making (SDM) was a high priority for the VKC in 2017-18.

Public policy advocate Jonathan Martinis delivered the Martin Luther King, Jr., Commemorative Kennedy Center Lecture “Supported Decision-Making: Protecting Rights, Ensuring Choices” in January.

The VKC participates in the **Supported Decision Making Workgroup**, which includes eight disability organizations in Tennessee. Trainees in the Vanderbilt Consortium LEND program and UCEDD aided the workgroup this year by reviewing SDM materials and resources, interviewing individuals and family members, developing training materials, and assisting in the area of policy development.

Educating Policymakers: VKC on the Hill

Janet Shouse, coordinator of the IDD Health Care Toolkit, took part in a panel discussion at **Tennessee Disability Day on the Hill** highlighting state services for people with disabilities and the importance of individual advocacy.

VKC UCEDD faculty and staff participated in the **Federal Disability Policy Seminar**. The Tennessee team made Hill visits to discuss Medicaid, Social Security, SNAP, and Inclusive Higher Education.

Christina West, Assistant Vice Chancellor for Federal Relations in Vanderbilt University’s Office of Federal Relations, Elise McMillan, J.D., co-director of the UCEDD, Senior Associate, VUMC Department of Psychiatry,

joined Courtney Taylor, VKC Associate Director of Communication, and Will McMillan, a Next Steps at Vanderbilt graduate, in meeting with Sen. Lamar Alexander’s staff to discuss reauthorization of the Higher Education Act.

The **Tennessee Kindred Stories of Disability** project brings individual stories and experiences to Tennessee and national policymakers. In 2018, stories from individuals with disabilities and families living in rural counties highlighted the barriers that families face when attempting to access services and supports such as health care and education.

Encouraging Employment: Partnering with State Agencies

The VKC takes part in the **Employment First Task Force**, established by Gov. Bill Haslam in 2013. The Task Force supports the commitment of State agencies to increase integrated, competitive employment for people with disabilities. This year marks the fifth report of the Task Force. It highlights the path to employment for Tennesseans with disabilities and the importance of collaboration between state agencies, communities, and employers in providing more opportunities.

The VKC has a seat at the **Employment Roundtable**, hosted by the Tennessee Council on Developmental Disabilities. The group is comprised of representatives from 10 State of Tennessee departments and Tennessee Developmental Disabilities Network partner Disability Rights TN.

Pictured on page 10: (1) Christina West, Courtney Taylor, and Will McMillan on Capitol Hill. (2) Kindred Stories of Disabilities highlights unique needs of Tennessee’s rural residents. (3) Jeff Neul, M.D., Ph.D., Jonathan Martinis, J.D., and Elise McMillan, J.D. (4) Janet Shouse at Disability Day on the Hill. (5) Rochelle Frazier-Beard, legislative staff for Rep. Bob Ramsey, at Educate to Advocate. (6) Participants at Educate to Advocate.



Bryshawyn Jemison (VKC CAC member) with Andy Imparato (executive director, Association of University Centers on Disabilities)



Tennessee Developmental Disabilities Network Directors Elise McMillan, J.D., Bruce Kiesling, Ph.D., Wanda Willis, and Lisa Primm at the Annual Meeting of the Association of University Centers on Disabilities



Vanderbilt Kennedy Center Leadership Council

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

Mrs. Honey Alexander
Mrs. Melinda Balser
Mrs. Jean Ann Banker
Mrs. Melissa Beasley
Mrs. Ann Bernard
Mrs. Barbara T. Bovender
Mrs. Linda Brooks

Ms. Mary L. Carlson
Mrs. Ann Eaden
Mr. Glenn Funk
Mrs. Bernice Gordon
Mrs. Carol Henderson
Mr. Robert W. Henderson, Jr.
Mrs. Gail Gordon Jacobs
Mr. Robert E. Landreth
Mr. and Mrs. Chris and Becky Link

Mrs. Lorie Hoppers Lytle
Mrs. Thomas E. Nesbitt, Jr.
Mrs. Shirley F. Speyer
Mrs. Sue Spickard
Mrs. Mary Layne Van Cleave
Mrs. Patricia W. Wallace

Ex-Officio Members

Dr. Laurie Cutting
Mrs. Elise McMillan
Dr. Jeffrey Neul
Dr. Jan Rosemergy
Mr. Tim Stafford

Vanderbilt Kennedy Center Community Advisory Council

Tina Prochaska, Chair
Robyn Lampley, Vice Chair

James Boehm
Brandon Brown
Mary Ellen Chase
Alicia Cone, Ph.D.
Joanie Crowley
Zach DeBerry
Colleen Dudley
Traci Foyster
Carrie Hobbs Guiden
Kathy Irvin

Bryshawn Jemison
Alison Kirk
Kelsey Loschke
Gina Lynette
Carolyn Meyer
Niya Moon
Doria Panvini
Jaimie Patrick
Marnique Riley Strickland
Angela Webster

Sign Up for VKC Notables

In this monthly e-newsletter read about discoveries and best practices that are opening doors for children and adults with intellectual and developmental disabilities and their families. Send your email address to kc@vumc.org to subscribe.

Contact Us

Email

kc@vumc.org

General Info

(615) 322-8240 [local]
(866) 936-8852 [toll-free]

Giving

vkc.mc.vanderbilt.edu/vkc/giving/

Website

vkc.vumc.org

Stay Connected

Find Us...



Vanderbilt Kennedy Center

Discovery is a publication of the Vanderbilt Kennedy Center designed to educate our friends and the community, from Nashville to the nation. The Center is a *Eunice Kennedy Shriver* Intellectual and Developmental Disabilities Research Center funded by the *Eunice Kennedy Shriver* National Institute of Child Health and Human Development, and a University Center for Excellence in Developmental Disabilities (UCEDD) funded by the Administration on Intellectual and Developmental Disabilities (AIDD). *Discovery* is supported in part by Grant No. U54HD083211 from *EKS* NICHD, AIDD Grant No. 90DD0825-01-00, and LEND Training Grant No. T73MC30767 MCHB/HRSA. Vanderbilt University is committed to principles of Equal Opportunity and Affirmative Action. ©2018 Vanderbilt Kennedy Center, Vanderbilt University Medical Center.

Jeffrey Neul, M.D., Ph.D., Center Director
Laurie Cutting, Ph.D., Associate Director
Tim Stafford, M.M.H.C., Director of Operations
Jan Rosemergy, Ph.D., Deputy Director, Director of Communications

UCEDD: Elisabeth Dykens, Ph.D., Co-Director
Elise McMillan, J.D., Co-Director and Community Service and Technical Assistance
Evon Lee, Ph.D., Training
Robert Hodapp, Ph.D., Research
Jan Rosemergy, Ph.D., Dissemination

LEND: Tyler Reimschisel, M.D., Director
Evon Lee, Ph.D., Associate Director

TRIAD: Zachary Warren, Ph.D., Executive Director
Pablo Juárez, Director

Discovery: Editor: Courtney Taylor
Graphic Designer: Kylie Muccilli
Staff photography: Pam Grau; Nicholas Holt; Kyle Jonas; Tony Maupin; Sarah Mustian; Kylie Muccilli; Vanderbilt Photography

