Disabilities—Hope Through Discovery
Research, Service, Training, and Dissemination

Jeffrey Neul, MD, PhD, VKC Director
Laurie Cutting, PhD, Associate Director
1 in 5 children has a developmental disability

The Vanderbilt Kennedy Center (VKC) can help
What do the 1 in 5 have?

Troubles thinking, learning, growing, behaving, communicating, feeling, relating

– Learning disabilities
– Language delays
– Autism spectrum disorder
– Down syndrome
– Rare syndromes
– ADHD
– Cancer survivors
– Acquired disabilities
How does the VKC help?

- Research: causes, treatments
- Dissemination: information to others
- Supports: services: clinics, programs
- Training: students and professionals
- Partners: families, communities, state
- Policy: local, state, federal

*Disabilities—Hope through Discovery*
Mission

• To facilitate discoveries and best practices that make positive differences in the lives of persons with developmental disabilities and their families
What is the VKC?

- A University Center for Excellence in Developmental Disabilities, part of a national network of 67 such centers supported by the Administration on Intellectual and Developmental Disabilities, U.S. Health & Human Services.
What is the VKC?

- A national *Eunice Kennedy Shriver Intellectual and Developmental Disabilities Research Center*, one of 14 supported by the *Eunice Kennedy Shriver* National Institute of Child Health and Human Development. Founded 1965.
What is the VKC?

- Administratively, part of Vanderbilt University Medical Center with affiliated faculty in Vanderbilt University.
- Includes the Treatment and Research Institute for Autism Spectrum Disorder (TRIAD) and the Vanderbilt LEND Training Program, supported by the Bureau of Maternal & Child Health, U. S. Health and Human Services.
VKC is part of national DD Network

and among few centers to have IDDRC, UCEDD, and LEND programs
VKC UCEDD

- 2005 designation as a University Center for Excellence in Developmental Disabilities
- Four core functions of all UCEDDs
  - Training
  - Research
  - Service/Technical Assistance
  - Dissemination
- Co-Directors
  - Elisabeth Dykens, PhD
  - Elise McMillan, JD
VKC UCEDD

- Focus on systems change
- One of only few centers in country to be both a UCEDD and an IDDRC, and to have a LEND training program
- Community Advisory Council made up of individuals with disabilities and family members (over 50%) and representatives of disability organizations

Disabilities—Hope through Discovery
VKC UCEDD Areas of Emphasis

- Education and Early Intervention
- Employment
- Health and Mental Health
- Quality of Life
Tennessee Developmental Disabilities Network Partners

- Vanderbilt Kennedy Center UCEDD
- University of Tennessee Boling Center UCEDD
- Disability Rights Tennessee
- Tennessee Council on Developmental Disabilities


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VKC UCEDD Preservice Training

- Undergraduate, master’s, doctoral, postdoctoral or residency representing disciplines across Vanderbilt and VUMC
- UCEDD Trainees work with VKC-affiliated faculty member mentors
- Individualized program in disabilities
- Evon Lee, PhD
  UCEDD Director of Training
VKC UCEDD Preservice Training

Training opportunities include
• ACM Lifting Lives Music Camp
• Disabilities, Religion and Spirituality
• Next Steps at Vanderbilt
• Next Steps at Vanderbilt Summer Institute
• Reading Clinic
• Tennessee Disability Pathfinder
• TRIAD Autism Training
• Volunteer Advocacy Project
• Research projects
VKC UCEDD Community Training

- Developed collaboratively with community organizations, practicing professionals, and individuals with disabilities and their families
- Examples: Tennessee Disability Pathfinder Series, Britt Henderson Training Series for Educators, Volunteer Advocacy Project
Examples of UCEDD Research

- Next Steps at Vanderbilt – longitudinal study to examine employment and other outcomes for graduates of this postsecondary education program for young adults with IDD
- Tennessee Administrative Database – using Vanderbilt’s “synthetic derivative” database system to examine the many health issues of individuals with Down syndrome
- Autism studies – Study examining the ways in which specific characteristics of individuals with ASD relate to the services they receive – Study looking at the effects of where a family lives (rural vs. urban)
- National Core Indicators – Tennessee data
- Robert Hodapp, PhD, UCEDD Director of Research
UCEDD Services and Technical Assistance

- Cutting-edge, evidence-based services and supports to address pressing needs of persons with disabilities and families
- Focused on serving people in Tennessee and the Mid-South
- Strive to integrate service, training, research and dissemination across all UCEDD projects
TennesseeWorks

- AIDD Systems Change Project to increase access to meaningful employment for individuals with intellectual and developmental disabilities.
- Partners with state and local departments, parent support organizations, disability non-profits and employment-related agencies
  - **Erik Carter**, PhD, Faculty
  - **Elise McMillan**, JD, Faculty
Social Work Services

• Provides services to individuals with disabilities and families through:
  – Person-centered planning
  – Brief counseling
  – Referral services
  – Supporting self-advocacy activities

Carol Rabideau, LCSW

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Reading Clinic

- Provides individualized assessment and tutoring for elementary-school children, including students with intellectual or other developmental disabilities
- Tests new research approaches for best ways to teach children to read and to assess reading
- Trains future teachers and community professionals
- Laurie Cutting, PhD, Faculty Director
Learning Assessment Clinic

- Academic assessments for students, ages 5-25 years, with learning challenges
- Assessment provided by a developmental pediatrician, a reading and language specialist, and a psychologist
- Goal is understanding learning differences in order to support effective learning
- **Sheryl Rimrodt**, MD, Faculty Director
Next Steps at Vanderbilt

- Individualized 4-year certificate program of postsecondary study for persons ages 18-26 with intellectual or developmental disabilities
- VU classes and life skills training
- Internships on and off campus
- Participation in Vanderbilt Best Buddies activities
- Support in transition to employment
- Ambassadores peer supports
- Tammy Day, MEd, Program Director
- Erik Carter, PhD, Faculty Director

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VKC Affiliated with VUMC Clinics

- Center for Child Development Clinics—Developmental Medicine, Department of Pediatrics
  - Autism, Down Syndrome, Fragile X, Rett Syndrome, Neurogenetics, Spasticity
- Genetics Clinic
- Down Syndrome Adults Clinic—Internal Medicine

Disabilities—Hope through Discovery
Health Care for Adults with Intellectual and Developmental Disabilities: Toolkit for Primary Care Providers

Online resources for health care providers, patients, and families

www.idd toolkit.org

General Issues
Physical Health Issues
Health Watch Tables
Behavioral and Mental Health Issues

Online training for health care providers and family members

Disabilities—Hope through Discovery
VKC Summer Programs

• **Next Steps at Vanderbilt Summer Institute**
  Intellectual and developmental disabilities

• **SENSE Theatre**
  Autism spectrum disorder

• **Academy of County Music Lifting Lives Music Camp**
  Williams syndrome

*Disabilities—Hope through Discovery*
Britt Henderson Training Series for Educators

- Annual series of 2-hr workshops for public and private school teams
- Support and training in implementing evidence-based practices
- Led by UCEDD faculty and staff
- Elise McMillan, JD, Faculty Director
Volunteer Advocacy Project (VAP)

- Trains persons interested in becoming special education advocates to support families of children in disabilities in schools
- 40 hrs of training over 12 sessions held in Nashville and video-conferenced at other TN sites
- After completing training, each person commits to working, at no cost, with four families of children with disabilities
- **Elise McMillan**, JD, Faculty Director
Arts and Disabilities Program

- Arts exhibits by persons with disabilities at Vanderbilt Kennedy Center and in the community
- Art workshops for persons with disabilities
- Laurie Fleming, Project Coordinator
Tennessee Disability Pathfinder

- Statewide Information and Assistance Helpline:
  - (615) 322-8529 (local)
  - 1-800-640-4636 (toll-free)
- Disability information specialists serve individuals of all ages, all types of disabilities, and all nationalities
- Megan Hart, MEd, Program Director
- [www.familypathfinder.org](http://www.familypathfinder.org) includes database searchable by TN county and service type, plus national resources
- Regional training and technical assistance
Multicultural Outreach Program

- Mission: To help alleviate barriers to accessing disabilities, provide cultural awareness training, information, and assistance to families with diverse cultural backgrounds
- Multilingual (English/Spanish/Arabic) staff and interpreter services available
- Camino Seguro database available in English and Spanish
- Spanish-speaking support group for parents of children with disabilities and technical support for other groups
- 2009 AUCD Multicultural Council Award for Leadership in Diversity
- **Alexander Santana**, Project Coordinator

Disabilities—Hope through Discovery
Disabilities, Religion, and Spirituality

• Provides disability-related training to current and future religious leaders and educators (VDS Field Education site, workshops, presentations)

• Develops practical materials to equip congregations with supports they need to meaningfully include pwd and families (Visual supports, manuals)

• Conducts research (Flourishing, Disability Ministries)

• Collaborates nationally with network of UCEDDs (National Collaborative on Faith and Disability faithanddisability.org, Putting Faith to Work)

• Erik Carter, PhD, Faculty Director

Disabilities—Hope through Discovery
Communication and Dissemination

- Website – vkc.mc.vanderbilt.edu
- Products (e.g., Tips and Resources fact sheets, manuals) and other support for research and outreach projects
- Research seminars, conferences, workshops, and outreach events (30-40 annually)
- Social Media – FaceBook, Twitter
- **Jan Rosemergy**, PhD, Director of Communication & Dissemination; **Courtney Taylor**, MDiv, Associate Director; **Elizabeth Turner**, Communications Coordinator

*Disabilities—Hope through Discovery*
Website: vkc.mc.vanderbilt.edu
Discovery newsletter and Monday Morning Message

Monday Morning Message
A weekly update from the Vanderbilt Kennedy Center

This Week

LEND Core Seminar: Early Intervention Services
February 24
Melanie Schuele, Ph.D., Associate Professor, Hearing and Speech Sciences, Vanderbilt Bill Wilkerson Center, and LEND Faculty, will give a lecture titled "Early Intervention Services" on Monday, Feb. 24, 2014, from 12:00:00 p.m. in Room 241 of the Vanderbilt Kennedy Center. To maximize your learning, objectives and preparation materials for this seminar may be found at http://people.vanderbilt.edu/~obp10. From the calendar on this page, click on or hover over the Core Seminar date, then click on the title that appears in the pop-up box.

Down Syndrome Journal Club Meeting
February 26
The next meeting of the Down Syndrome Journal Club will be Wednesday, Feb. 26, at 8:30 a.m. in Room 241 of the VNC. Chris Leners will focus the discussion on ways to better study the relationship between the DS behavioral phenotype and reading interventions. CME credit will be offered. For more information, contact Laura Fleming.

Kennedy Center Lecture: The Next Generation of Pediatric Brain Imaging Studies and Their Relevance for Future Clinical Practice
February 27
Bradley Peterson, M.D., Director, Center for Developmental Neuropsychiatry, Columbia University, will present his lecture "The Next Generation of Pediatric Brain Imaging Studies and Their Relevance for Future Clinical Practice" on Thursday, Feb. 27, at 4:00 p.m. in Room 241 of the Vanderbilt Kennedy Center. Please note that there will not be a reception. For planning purposes, please register to attend. For more information, call (915) 322-9724.

Augmentative and Alternative Communication (AAC) Workshops
February 27-28
Introducing the New Notables

Welcome to the Vanderbilt Kennedy Center’s new paperless version of Notables—a monthly e-newsletter to share stories about discoveries and best practices that are opening doors and transforming lives for children and adults with intellectual and developmental disabilities and their families.
Products

(e.g., Tips fact sheets, manuals) and other support for research and outreach projects
Events

Research seminars, conferences, workshops, and outreach events (30-40 academic year)
UCEDD Public Policy Team

- Enlists VKC, VUMC, VU, community, and state resources to develop a proactive approach to educating for advocacy related to legislative and other public policy to support individuals with disabilities and their families.
- Activities include annual “Educate to Advocate” training, participation in Disability Day on the Hill with TN Legislature and AUCD Disability Policy Seminar and visits with TN U.S. Delegation in Washington, D.C.
- Produces theme-focused TN Kindred Stories of Disability in partnership with The Arc Tennessee and distributes to TN Legislature and on VKC website Resources.

Disabilities—Hope through Discovery
Treatment and Research Institute for Autism Spectrum Disorders—TRIAD

Zachary Warren, PhD, Executive Director

A. Pablo Juárez, MEd, BCBA, Director
TRIAD Mission

- **TRIAD** is dedicated to improving assessment, intervention, and educational services for children with autism spectrum disorder and their families while advancing knowledge and training.
- Email: TRIAD@vanderbilt.edu
- Website: TRIAD.vanderbilt.edu
TRIAD Services for Families

• Diagnostic and Evaluation Services
  – Provided through Child Development Center, Division of Developmental Medicine, Vanderbilt Pediatrics

• Families First
  Free workshops for parents of young children with autism.
  – Free childcare available
Vanderbilt Autism Resource Line

• Toll-free 1-877-ASD-VUMC [273-8826]
• Local 322-7565

• Offers free referral services
• Provides information about Vanderbilt behavioral and medical clinics, and current clinical research projects
• Nina Harris, Autism Family Services Coordinator
TRIAD Professional Training and Consultation

- School Consultation Services
  - Collaborative Child-Focused Consultations
  - Program Consultations
- TRIAD professional development opportunities for educators, psychologists, and other community professionals
  - Online (5-min to 1-hr)
  - Onsite, presented statewide and regionally (3-hr to 4 days)
TRIAD Professional Training

- Screening Tool for Autism in Toddlers and Young Children (STAT) Test Kit, Online Tutorial, and STAT Workshops
- STAT-MD training for community pediatricians and related health professionals - in collaboration with Tennessee Chapter of American Academy of Pediatrics and VKC LEND Training Program
TRIAD Research Projects

- Identification of early behavioral and biomedical markers
- Early social and communication development
- Sleep behavior and biology
- Early intervention for core deficits
- Sensory and perceptual processes
- Neural correlates of restricted behavior and interests
- Social skills intervention delivered via humanoid robots
- Effective professional development practices
- Behavior assessment in medical settings
TRIAD Clinical & Research Networks

- Autism Treatment Network
- Baby Siblings Research Consortium
- Toddler Treatment Network
- Simons Simplex Collection
Autism Treatment Network (ATN)
Funded by Autism Speaks

• Offers coordinated medical care between pediatricians and other medical specialists in neurology, metabolics, genetics, and gastroenterology
• Forms a repository of clinical data used to develop standards of care with 17 other universities across North America
• Beth Malow, MD (Neurology) is the Principal Investigator of the Vanderbilt ATN
• Zachary Warren, PhD (TRIAD Director) co-investigator

Disabilities—Hope through Discovery
IDDRC Objectives

- Translate basic discoveries into new interventions and treatments
- Communicate scientific discoveries to the public
- Prepare the next generation of researchers
Interdisciplinary Research, Training, and Service

- 220+ faculty
- Medicine, Peabody, Arts & Science, Nursing, Engineering, Blair [Music], Divinity, Law, Owen [Management], Graduate School
- 26 departments

- From Genes...
- to Brain...
- to Behavior...
- to Intervention...
- to Family Supports...
- to Communities...
- to Public Policies
IDDRC Grant (NICHD) supports Research Core Services of VU Faculty who are VKC Members or Investigators

- **Administrative Core**
  Administration; Fiscal Services; Training, Education & Communications; Technical Services (Jeff Neul, MD, PhD)

- **Clinical Translational Core**
  Recruitment; Registries & Epidemiological Databases Mining; Neurobehavioral Phenotyping & Outcomes; Facilitating Clinical Trials (Zachary Warren, PhD)

- **Translational Neuroimaging Core**
  MRI; Psychophysiology Measures (EEG, ERP, eye-tracking); Tool Development (Laurie Cutting, PhD)

- **Neuroscience Core**
  Mouse Behavioral Phenotyping; Neurochemistry; Molecular Neurobiology & Genomics; Scientific Instrumentation (Ron Emeson, PhD)

- **Biostatistics & Bioinformatics Core**
  Biostatistics Consultation; Platform Development & Complex Modeling; Leveraging BioVU/Synthetic Derivative (Hakmook Kang, PhD)
StudyFinder and Research Match

- vkc.mc.vanderbilt.edu/
  StudyFinder searchable database
- Research registry
  www.researchmatch.org
VKC-Affiliated Research Training

- Development of Psychopathology: From Brain and Behavioral Science to Intervention
- Graduate Neuroscience Training
- Vision Research Training
- Neurogenomics Research Training
- Training in Biomedical MRI & MRS
- Special Education Graduate Programs
Leadership Education in Neurodevelopmental Disabilities—Vanderbilt Consortium LEND

Tyler Reimschisel, MD, Director

Evon Batey Lee, PhD, Associate Director
Vanderbilt LEND

- Training Program funded by HHS Maternal & Child Health Bureau
- Prepares health professionals to meet complex needs of children with neurodevelopmental disabilities by providing family-centered, community-based, culturally competent, interprofessional services
- Prepares health professionals to assume leadership roles and to develop interprofessional team collaboration and advanced clinical and research skills
Vanderbilt Consortium LEND Partners
Vanderbilt Kennedy Center (grantee)

• Vanderbilt University
  – Vanderbilt School of Medicine, Department of Pediatrics, Division of Developmental Medicine
  – Department of Hearing and Speech Sciences
  – School of Nursing
  – Vanderbilt Hospital Nutrition Internship Program

• Belmont University
• East Tennessee State University
• Meharry Medical College
• Milligan College
• Tennessee State University
• University of Tennessee
• Tennessee Disability Coalition
  – Family Voices of Tennessee

Disabilities—Hope through Discovery
LEND Interprofessional Training

- Audiology
- Deaf Education
- Nursing
- Nutrition
- Occupational Therapy
- Parent/Family Resources
- Pediatric Dentistry
- Pediatrics

- Pharmacy
- Physical Therapy
- Psychiatry
- Psychology
- Social Work
- Special Education
- Speech/Language Pathology

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LEND Curriculum

Key Concepts:
• Interprofessional
• Family centered, community coordinated care
• Vulnerable populations
• Cultural and linguistic competency
• Research
• Advanced (clinical) practice
• Life course
• Special focus on autism and pediatric audiology

Core Seminar Series
• Weekly online learning modules include asynchronous team work
• In-person evening sessions with cases, simulations, role-playing to apply content from modules

Monthly Leadership Seminars
• Monthly evening sessions
• Small group work
• Develop leadership knowledge, skills and attitudes

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Other Activities

- Individual Training Plan
- Group Project
- Family Mentor Experience
- Advocacy and Policy Meetings
- Teaching Experience
- Independent Project
- Community Agency Visits
- Advanced Clinical or Practicum
- Clinic Observations
- Research
- Attend Disability-Related Presentations
Community-Based Training

- *Screening Tool for Autism in Two-Year-Olds (STAT)* - training for health professionals
- *Screening Tools And Referral Training Evaluation and Diagnosis (STAT-MD)* - training for community physicians and other behavioral providers
- *Coordination with Title V Agencies (Tennessee Dept. of Health)* - monthly videoconferences recorded and provided online for viewing by staff across the state
- *Community Education in collaboration with Dept. of Hearing and Speech Sciences*
- *Educate to Advocate*
Tennessee Autism Summit Team

Learn the Signs. Act Early.
Tennessee Autism Summit Team

- Initiation by AUCD, MCHB and CDC (Learn the Signs: Act Early Campaign)
- Coordination by VKC and the UT Boling Center UCEDDs and LENDs
- Goals: Public awareness, family support, training and coordinated system of care
- 2009 multi-state conference and follow-up statewide meetings with wide range of stakeholders
- Mini-grants
- State planning grant for coordination of services for children and youth with ASD and related disabilities
The Vanderbilt Kennedy Center

Working together with individuals with disabilities, families and communities for better tomorrows
Additional slides follow
Include depending on audience
A Developmental Disability is

- Significant and lifelong
- Begins before age 22
- Affects learning and thinking
- Affects skills of daily living

Persons with developmental disabilities are people first, with strengths and strengths. They have hopes and dreams, and can be self-directed and self-advocates. They are part of families and communities.
Disability Terminology Tips

- Use “people first” language (a person with a disability, not the disabled)
- Use “disability” rather than “handicap”
- Refer to a person’s disability only when relevant
- Avoid “victim” language, e.g., “suffers from...”
- Avoid “hero” language, e.g., “brave”
- Use “typical” rather than “normal”
- Consult “disability etiquette” guides
- Ask an individual whether assistance is desired
Multi-level partnerships with....

- Vanderbilt University and Vanderbilt University Medical Center departments, centers, and clinics
- VKC Leadership Council
- VKC Community Advisory Council
- VKC Community Partners
- State of Tennessee agencies
- Other universities in Tennessee and other states
- Individuals with disabilities and their families
By Comparison....

- Childhood cancer 1 in 6,500
- Juvenile diabetes 1 in 500
- H1N1 child death 236 cases
- Pediatric AIDS/HIV <100 cases
- Developmental disabilities 1 in 5

Disabilities—Hope through Discovery
VKC Services and Outreach

- Arts and Disabilities
- Disabilities, Religion, and Spirituality
- Britt Henderson Training Series for Educators
- Learning Assessment Clinic
- Next Steps at Vanderbilt (Postsecondary Education 2-Year Certificate)
- Reading Clinic
- Tennessee Adults Brothers and Sisters (TABS) Network

- Summer Programs: ACM Lifting Lives Music Camp (Williams syndrome), Next Steps Summer Institute (intellectual disabilities), SENSE Theatre (autism)
- Tennessee Disability Pathfinder and Multicultural Outreach Program (www.familypathfinder.org)
- TennesseeWorks.org
- Volunteer Advocacy Training Program
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