



# **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 are developmental disabilities?

- Learning disabilities
- Language delays
- Autism spectrum disorder
- Down syndrome
- Genetic syndromes
- Cerebral Palsy
- 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





# Vanderbilt Kennedy Center Mission

- To facilitate discoveries and best practices that make positive differences in the lives of people with developmental disabilities and their families







## 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?

- 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?

- Administratively, part of **Vanderbilt University Medical Center** with affiliated faculty and staff within **Vanderbilt University**.
- Includes the **Treatment and Research Institute for Autism Spectrum Disorder (TRIAD)** and the **Vanderbilt Consortium 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



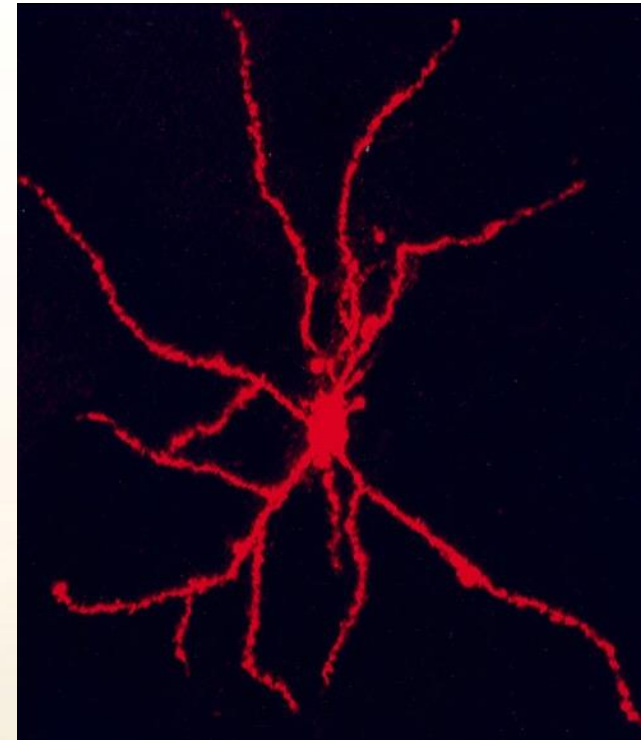
# Interdisciplinary Research, Training, and Service

- 220+ faculty in all 10 Vanderbilt schools and colleges
- 26 departments
- From Genes...
- to Brain...
- to Behavior...
- to Intervention...
- to Family Supports...
- to Communities...
- to Public Policies



# Intellectual and Developmental Disabilities Research Center (IDDRC)

- NICHD P50 Grant
- Translate basic discoveries into new interventions and treatments
- Provides Core Services
- Communicate scientific discoveries to the public
- Prepare the next generation of researchers







## **IDDRC Grant (NICHD) supports Research Core Services of VU Faculty who are VKC Members or Investigators**

### **Administrative Core**

Administration; fiscal services; Training and education; Technical Services; Communications (Jeffrey Neul, MD, PhD)

### **Clinical Translational Core**

Study Support and Consultations; Recruitment; Research Registries (Beth Malow, MD)

### **Translational Neuroscience**

Magnetic Resonance Imaging; Human and Mouse Neurophysiology Services (EEG, ERP, eye-tracking) (Laurie Cutting, PhD)



## **IDCRC Grant (NICHD) supports Research Core Services of VU Faculty who are VKC Members or Investigators**

### **Behavioral Phenotyping**

Human phenotyping; Mouse behavioral phenotyping; translational science  
(Sar Peters, PhD, Fiona Harrison, PhD)

### **Data Sciences**

Biostatistics consultation and education; access to large-scale data analysis;  
extraction of IDD-related information from unstructured text data  
(Hakmook Kang, PhD)

### **P50 Research Project**

Antipsychotic-induced Weight Gain in Autism Spectrum Disorder  
(Sharon Davis, PhD, Angie Maxwell-Horn, PhD)



# StudyFinder and Research Match

- [vkc.vumc.org/studyfinder](http://vkc.vumc.org/studyfinder)  
searchable database
- Research registry  
[www.researchmatch.org](http://www.researchmatch.org)

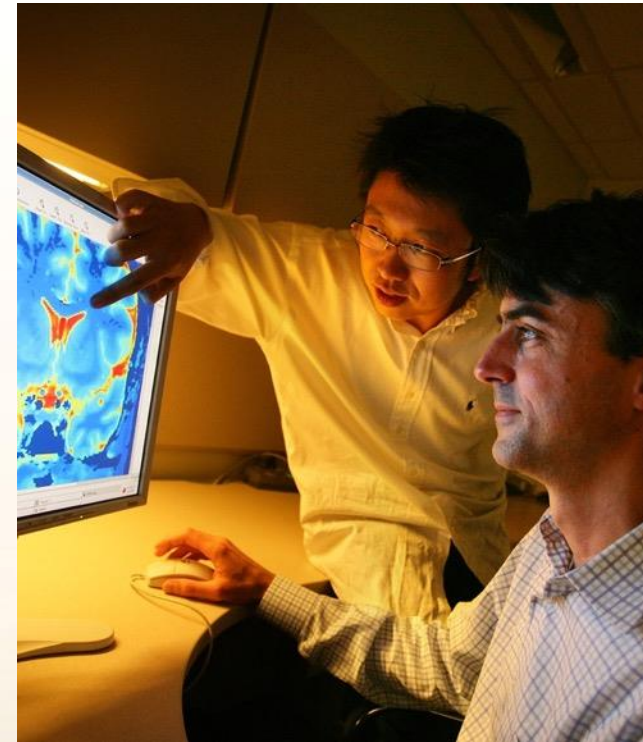






## VKC-Affiliated Research Training

- 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





## 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
  - **Julie Lounds Taylor, PhD**
  - **Pablo Juárez, M.Ed., BCBA**





## VKC UCEDD

- Focus on systems change
- One of only few centers in country to be both an IDDRC and a UCEDD and to have a LEND program
- Community Advisory Council







## 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
- UT Center on Developmental Disabilities UCEDD
- Disability Rights Tennessee
- Tennessee Council on Developmental Disabilities

Network Project Examples – Statewide Secondary  
Transition, Tennessee Inclusive Higher Education Alliance



## VKC UCEDD Preservice Training

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







# VKC UCEDD Preservice Training

Training opportunities have included

- ACM Lifting Lives Music Camp
- Disabilities, Religion and Spirituality
- Next Steps at Vanderbilt
- Next Steps at Vanderbilt Summer Institute
- Tennessee Disability Pathfinder
- TRIAD Autism Training
- Volunteer Advocacy Project



## 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



## vkclearning.org





## Examples of UCEDD Research

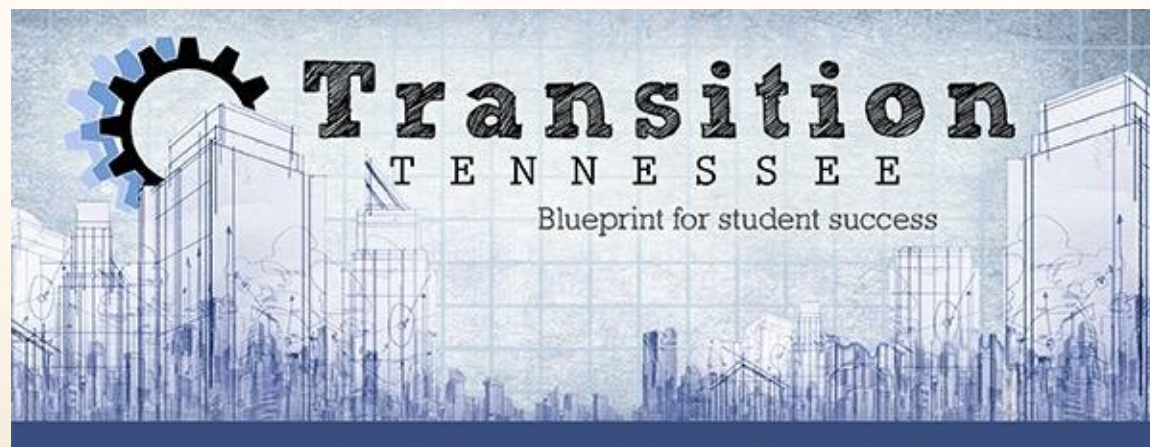
- Next Steps at Vanderbilt – longitudinal study to examine employment and other outcomes for graduates of this postsecondary education program for young adults with IDD
- Tennessee Administrative Database – using Vanderbilt’s “synthetic derivative” database system to examine the many health issues of individuals with Down syndrome
- Autism
  - 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)
- **Robert Hodapp**, PhD, Director of Research



# Transition Tennessee

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

VKC UCEDD and Tennessee Department of Education  
provide training and technical assistance on best practices  
for transition following high school





## Learning Assessment Clinic

- Academic assessments for students, ages 5-25 years, with learning challenges
- Goal is understanding learning differences in order to support effective learning
- **Rachel Hundley**, PhD,  
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
- Support in transition to employment
- Ambassadors peer supports
- **Ariana Amaya, Ph.D.**, Program Director





## VKC Affiliated with VUMC Clinics

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





# Health Care for Adults with Intellectual and Developmental Disabilities: Toolkit for Primary Care Providers

- Online resources for health care providers, patients, and families
- [www.iddtoolkit.org](http://www.iddtoolkit.org)
- General Issues
- Physical Health Issues
- Health Watch Tables
- Behavioral and Mental Health Issues
- On-line training modules for professionals and families







## 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





# Arts and Disabilities Program

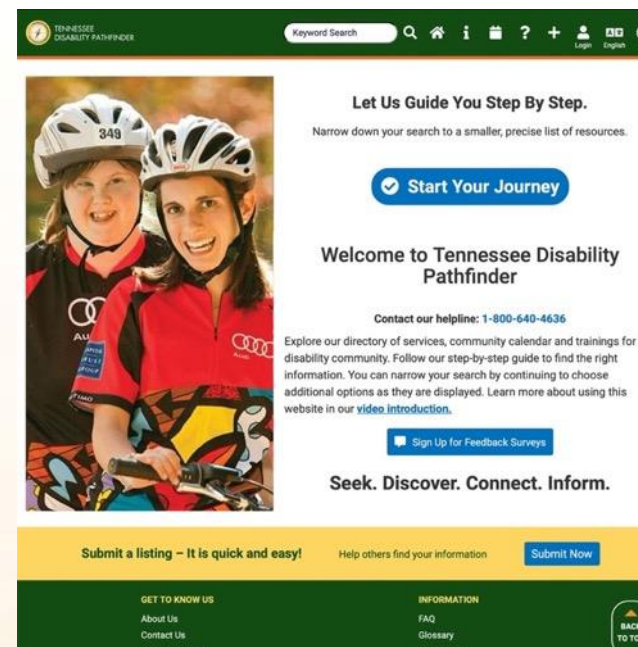
- Arts exhibits by persons with disabilities at Vanderbilt Kennedy Center and in the community
- Art workshops for persons with disabilities
- **Laurie Fleming,**  
Project Coordinator





# Tennessee Disability Pathfinder

- Statewide Information and Assistance Helpline:
  - (615) 322-8529 (local)
  - (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
- TNPathfinder.org includes database searchable by TN county and service type, plus national resources
- Regional training and technical assistance







## Communication and Dissemination

- Website – [vkc.vumc.org](http://vkc.vumc.org)
- *Notables* monthly e-news
- *Monday Morning Message* – weekly e-newsletter
- Products (e.g., Tips and Resources fact sheets, manuals) and other support for research and outreach projects
- Research seminars, conferences, workshops, and outreach events (60-70 annually)
- Social Media – FaceBook
- **Courtney Taylor**, MDiv, Director of Communication & Dissemination; **Elizabeth Turner**, Associate Director

# Website: [vkc.vumc.org](http://vkc.vumc.org)



# Discovery newsletter and Monday Morning Message

Number 40 | Summer 2013 | Vanderbilt University

**Summer Learning, Ripples Broadening Trainees Gain Experience** BY COURTNEY TAYLOR

Summer programs at the Vanderbilt Kennedy Center are in full swing. Adolescents and young adults with disabilities are acting in the theater, singing on the stage of the Grand Ole Opry, and learning what life at college is all about. The summer programs' activities and goals encourage self-esteem, self-respect, and compassion in the campers while teaching valuable life skills and providing much needed social opportunities. However, campers are not the only ones benefiting. Typically developing high school, undergraduate, and graduate-level students are serving as peer partners, counselors, and investigators and are gaining valuable professional and personal development experience working with people with disabilities.

**SENSE Theatre Camp: It Takes a—Troupe!**  
 "I've been acting for 6 years," said University School of Nashville sophomore Isaiah Ford. "I love theater, and I thought it would be a lot of fun to be a peer counselor. I didn't know much about autism, but now I feel like I have learned so much about it. Just, my peer, wasn't interested in participating at first, but I just helped him. When we did exercises, I would kind of encourage what I was doing and he really happy and then him how much fun it was. Eventually he joined in with me, and we started having fun together. That was really cool."

At SENSE Camp, peer counselors like Isaiah are actors, but they also serve as inter-venters. Their primary role is to model appropriate social and emotional behavior while playing theater games, performing, and interacting socially with the campers with autism. They are essential to the SENSE Theatre program's treatment case, and therefore need to be highly motivated and compassionate individuals.

"It takes a unique person to be a successful peer counselor in our program," said Rhye Corbett, Ph.D., assistant professor of Psychiatry and SENSE Theatre founder. "Children, by nature, are pretty self-focused. Our program requires that our peers are focused on others and are really thinking about the well-being of the camper. That's hard."

*Continued on page 3*

**New Knowledge From Summer Fun** BY COURTNEY TAYLOR

While Vanderbilt Kennedy Center (VCKC) summer programs provide meaningful growth and development opportunities for campers and valuable educational experiences for trainees, they also provide unique venues in which to investigate developmental and learning through research. In the summer programs, researchers are developing innovative treatment models and are even debunking commonly accepted characteristics of a genetic phenotype.

**The Question of Approach**  
 When ACM Lifing Live Music Camp director Maria Fisher, Ph.D., began investigating the social behaviors and characteristics of individuals with Williams syndrome, she did not expect her findings to challenge the widely accepted scientific literature. However, shifting what we think we know about people with Williams syndrome has not been an uncommon occurrence in the Music Camp research. Last year, Miriam Lense, a graduate student in Clinical Psychology, conducted a study to investigate a reported aptitude for music and uncovered musical interests, or tone-deafness, in many of the campers. This year she explored the mechanics of music by looking at emotional responses and assessing the ability to keep beats and to recognize patterns in music.

Fisher's current research also builds upon data she collected at the 2012 Camp. People with

*Continued on page 2*

Sam Link has taken part in research studies during ACM Lifing Live Music Camps.

**highlights**

- Be Who You Are—Ambassadors for Next Steps at Vanderbilt 5
- TRIAD Families First, Growing Strong 6
- Hormones and Hygiene and Disabilities! Healthy Bodies Toolkit 8
- Hope is Why We Do This—Bob Romero & ACM Lifing Lives Series 11

**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 12:00-1:00 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://lend.kc.vanderbilt.edu/moodle24/>. 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 VCK. Chris Lemons 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 Laurie Fleming.

**Kennedy Center Lecture: The Next Generation of Pediatric Brain Imaging Studies and Their Relevance for Future Clinical Practice**  
 February 27

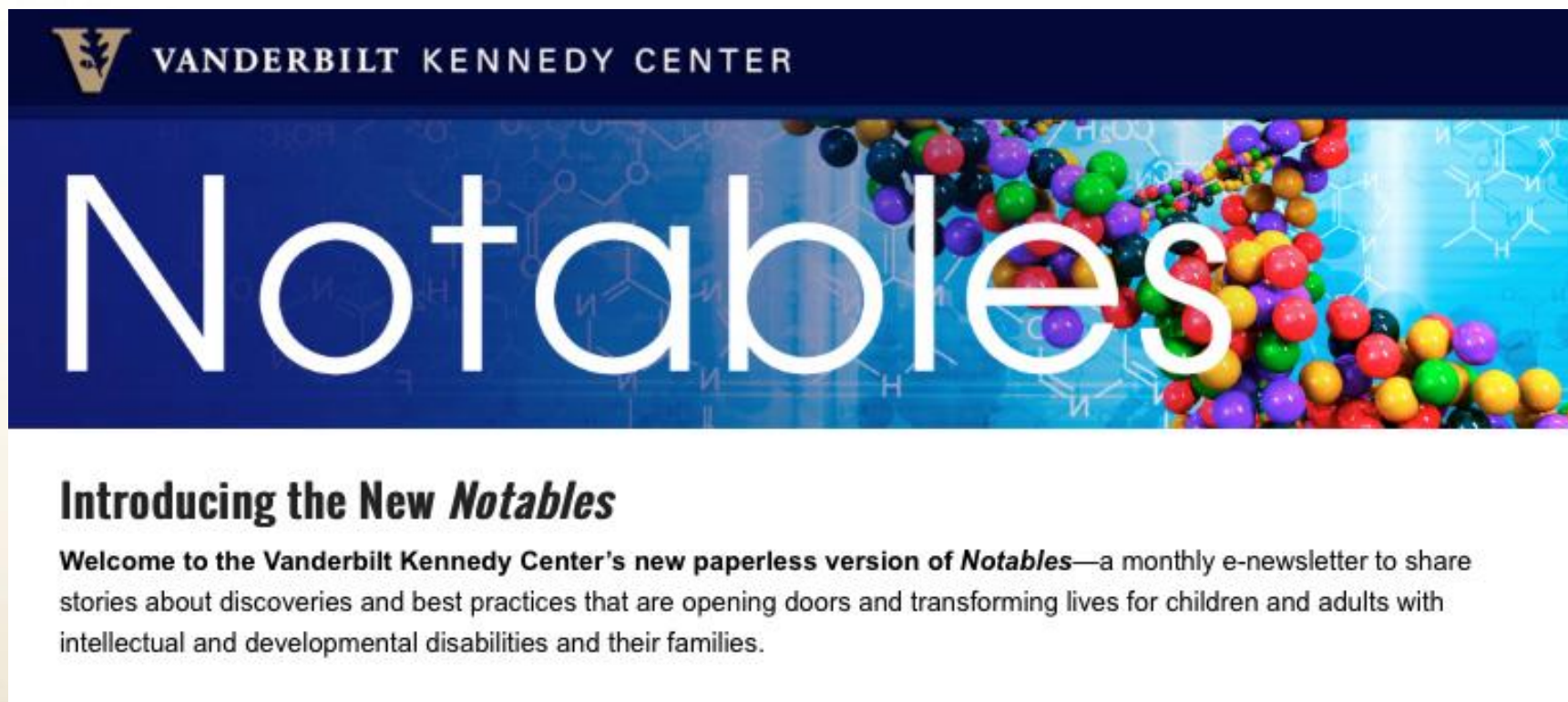
Bradley Peterson, M.D., Director, Center for Developmental Neuropsychiatry, Columbia University, will present his lecture "The Next Generation of Pediatric Brain Imaging Studies and Their Relevance for Future Clinical Practice" on Thursday, Feb. 27, at 4:00 p.m. in Room 241 of the Vanderbilt Kennedy Center. Please note that there will not be a reception. For planning purposes, please register to attend. For more information, call (615) 322-8240.

**Augmentative and Alternative Communication (AAC) Workshops**  
 February 27-28





## VKC Notables – Monthly e-newsletter



# Resources



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



# Events



Research seminars, conferences, workshops, and outreach events (60-70 academic year)





## **Treatment and Research Institute for Autism Spectrum Disorders—TRIAD**

**Zachary Warren, Ph.D., Executive Director**

**Pablo Juárez, M.Ed., BCBA, Co-Director**  
**Alacia Stainbrook, Ph.D., BCBA-D, Co-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: [autismresources@vumc.org](mailto:autismresources@vumc.org)
- Website: TRIAD.vumc.org







## TRIAD Services

- Diagnostic and Evaluation Services
  - Provided through Child Development Center, Division of Developmental Medicine, Vanderbilt Pediatrics
- Reaches across TN both with **direct contact** and **telepresence**







## 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 Early Intervention Services

- Collaboration with TEIS
- Training and consults to families of children (12-36 months)
- Home, clinic, and telemedicine-based visits
- Professional development opportunities, including webinars, topic-focused series, and coaching are also available for early intervention providers affiliated with TEIS.





## TRIAD School-Based Pre-K through 12 Services

- interactive training and consultation for administrators, teachers, paraeducators, school psychologists, and other professionals serving TN students
- partnership with the Tennessee Department of Education
- provide free online education, live workshops on focused topics, and consultation, coaching and mentorship for educators across the state.





# TRIAD Professional Training

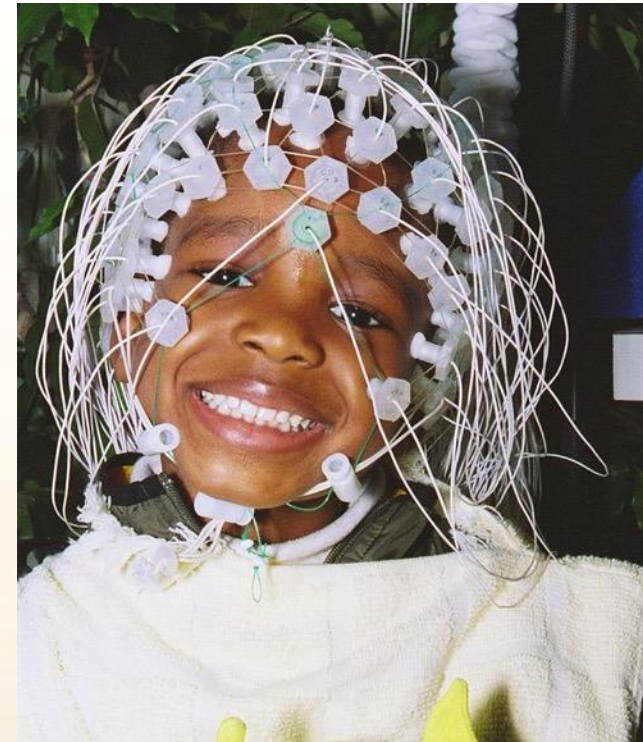
- Screening Tool for Autism in Toddlers and Young Children (STAT) Test Kit, Online Tutorial, and STAT Workshops
- STAT-MD training for community pediatricians and related health professionals - in collaboration with Tennessee Chapter of American Academy of Pediatrics and VKC LEND Training Program





## TRIAD Research Projects

- The diagnosis of autism
- Identification of genetic and core behavioral features of autism
- The nature and treatment of sleep disturbance in children with autism
- Early intervention with children at risk for autism
- Development of siblings of children with autism
- Understanding the health and well-being of parents with children with autism.
- The prevalence of autism (ADDM, CDC)







## **Leadership Education in Neurodevelopmental Disabilities— Vanderbilt Consortium LEND**

**Evon Batey Lee, PhD, Director**  
**Cynthia Chambers, PhD, Associate Director (East TN)**  
**Rachel Goode, MD, Associate Director (Middle TN)**





## Vanderbilt Consortium 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 Kennedy Center (Grantee)**
- **Six collaborating institutions**
  - Belmont University
  - East Tennessee State University
  - Meharry Medical College
  - Tennessee State University
  - Vanderbilt University
  - Vanderbilt University Medical Center
- **Tennessee Disability Coalition (Family Voices)**



# LEND Interprofessional Training

<b>Audiology</b>	<b>ETSU, Vanderbilt</b>
<b>Deaf Education</b>	<b>Vanderbilt</b>
<b>Genetic Counseling</b>	<b>Vanderbilt</b>
<b>Medicine</b>	<b>ETSU, Vanderbilt</b>
<b>Nursing</b>	<b>Vanderbilt</b>
<b>Nutrition</b>	<b>ETSU, Vanderbilt</b>
<b>Occupational Therapy</b>	<b>Belmont, Milligan</b>
<b>Parent/Family</b>	<b>Family Voices</b>
<b>Public Health</b>	<b>Meharry</b>
<b>Pediatric Dentistry</b>	<b>Meharry</b>
<b>Physical Therapy</b>	<b>Belmont, ETSU, TSU</b>
<b>Psychology</b>	<b>ETSU, Vanderbilt</b>
<b>Social Work</b>	<b>ETSU, UT-Nashville</b>
<b>Special Education</b>	<b>ETSU, Vanderbilt</b>
<b>Speech-Language Pathology</b>	<b>ETSU, Vanderbilt</b>





# 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

## 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



## Other Activities

- Individual Training Plan
- Care Navigation Practicum
- Group Project
- Advocacy and Policy Meetings
- Community Agency Visits
- Clinic Observations
- Research
- Attend Disability-Related Presentations

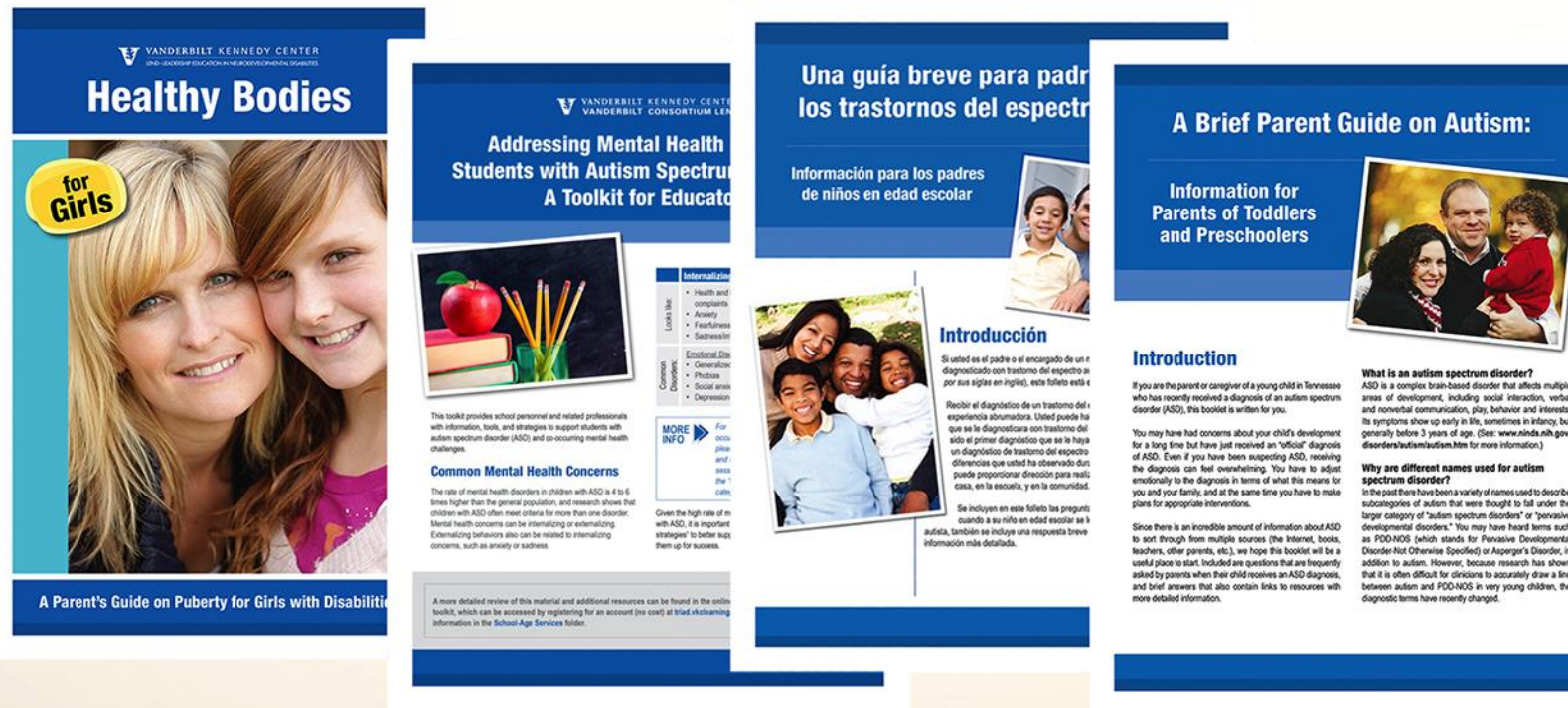


## Community-Based Training

- *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*



# Educational Materials



Developed in collaboration with  
VKC Communications, LEND, UCEDD and TRIAD



# The Vanderbilt Kennedy Center



***Working together with individuals with disabilities, families and communities for better tomorrows***