



VANDERBILT KENNEDY CENTER
FOR RESEARCH ON HUMAN DEVELOPMENT

Down Syndrome Research

There are few research centers across the country with such a wide range of researchers concerned about Down syndrome as are here at the Vanderbilt Kennedy Center (VKC) and Vanderbilt University. This breadth and depth of research across disciplines help us to meet the goals of the National Institutes of Health Down Syndrome Research Plan, announced January 2008—and most important, allow us to contribute to improved quality of life for children and adults with Down syndrome and for their families.

In some instances, VKC researchers focus exclusively on Down syndrome. In other instances, they focus on developmental disabilities generally, and individuals with Down syndrome are included. Here we summarize current studies on Down syndrome, including the Principal investigator (PI), funding source, and contact information for studies still seeking participants.

Language Development and Intervention Studies

❑ **KIDTALK-TACTICS Project (KTPP)**

This is a community-based, early communication intervention model for young children ages birth through 5 with significant language delays and their families. About 40% of the children enrolled have Down syndrome. Parents are provided individualized training to use KIDTALK-TACTICS naturalistic language teaching strategies in everyday routines and activities. KIDTALK strategies also are taught to teachers. The naturalistic language interventions in this research are well-tested in a variety of children and have consistently led to positive, measurable outcomes.
PIs: [Ann Kaiser, Ph.D. \(Special Education, Vanderbilt University\)](#), [Juliann Woods \(Florida State University\)](#)
Funding: [U.S. Office of Special Education](#)





©IMAGES BY BARBARA LISTOCK/PHOTO.COM

❑ **Social Communicative Effects of Language Intervention**

VKC researchers have done a series of studies on the effects of naturalistic early language intervention strategies implemented by parents and therapists, including Enhanced Milieu Teaching (EMT). Children with significant intellectual disabilities, including children with Down syndrome, show better long-term outcomes when their parents are trained to use EMT. The current study compares short- and long-term outcomes for (a) children whose parents were trained in EMT and who received training from a skilled therapist; and (b) those who only received training from a skilled therapist. All children were seen at home and in the clinic. The study included multiple measures of generalization across settings. About one third of the children in the study had Down syndrome. This study is complete and data are currently being analyzed. Results will be published in a peer reviewed journal.

PI: Ann Kaiser, Ph.D. (Special Education)

Funding: National Institute of Child Health and Human Development

❑ **Articulation Intervention**

This program uses intervention techniques that have proven successful with children who have difficulty speaking words clearly and provides these same techniques to children with Down syndrome, 5 to 12 years old. Children receive free evaluations and treatment sessions or language monitoring, and services are provided at child's school (with permission). The goal is to optimize language development for children with Down syndrome.

PI: Stephen Camarata, Ph.D. (Hearing & Speech Sciences), Paul Yoder, Ph.D. (Special Education)

Contact Mary Camarata, (615) 936-5130

Funding: National Institute on Deafness and Other Communication Disorders

❑ **Effects of Intensity of Early Communication Intervention**

The goal of this study is to determine whether an intervention, Prelinguistic and Linguistic Milieu Intervention, will result in more positive outcomes when it is provided at high intensity (5 hours/week for 9 months) compared to low intensity (1 hour/week for 9 months). All children will be followed for another 6 months. Participants are young children with general communication delays, including children with Down syndrome.

PI: Steven Warren, Ph.D. (University of Kansas),

Vanderbilt PI: Paul Yoder, Ph.D. (Special Education)

Funding: National Institute on Deafness and Other Communication Disorders

Family Life

❑ **Parent Stress Intervention Project**

Parents of children with disabilities, including those with Down syndrome, often experience high levels of stress—but research has yet to be done to identify effective stress-reducing interventions. This project compares two methods of stress reduction in these parents: a Positive Parenting curriculum and Mindfulness-Based Stress Reduction. Parents of children with disabilities are leading the interventions, and two of the parent mentors have children with Down syndrome. Data on parental health, positive and negative psychological states, and biomarker indices of stress are being collected and will help evaluate the first-ever randomized trial of stress reduction in parents of children with Down syndrome and other disabilities.

PI: Elisabeth Dykens, Ph.D. (Psychology & Human Development)

Contact Roxanne Carreon (615) 875-5080

Funding: ARRA Challenge Grant—National Center for Complementary Alternative Medicine

❑ **Does Your Child Do That?**

Problem behaviors—for example, damaging things or hurting others or one's self—often occur in individuals with developmental disabilities, including in children with Down syndrome. In this study, parents of children with developmental disabilities who have problem behaviors are asked to complete a survey that explores when these behaviors start, what they look like, and how parents respond. Findings will inform recommendations for treating problem behaviors.

PI: Joseph Wehby, Ph.D. (Special Education)

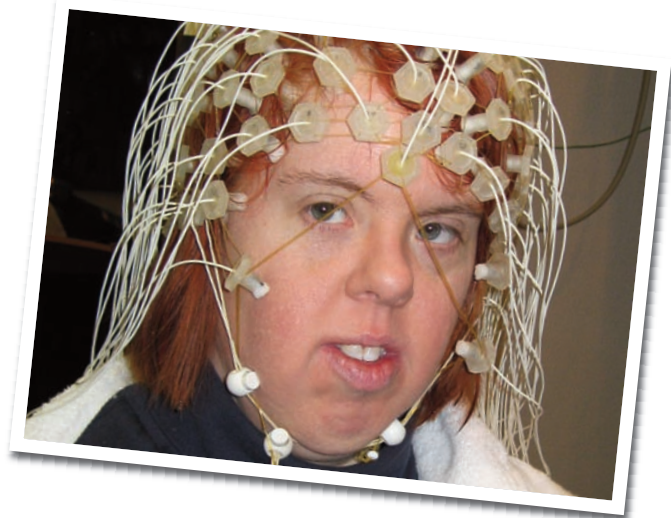
Contact: Rachel Robertson, (615) 322-6063

Funding: Institute of Education Sciences, U.S. Department of Education

❑ **Siblings—A National Perspective**

In collaboration with The Arc of the U.S., VKC researchers conducted a national, web-based survey of adult siblings of persons with disabilities. Of the 1,200 responses received, 280 were from siblings of a brother/sister with Down syndrome. Compared to siblings of persons with other conditions, siblings of brothers or sisters with Down syndrome reported closer, more affectionate, and more positive relationships; however, such relationships were not as close when the sibling with Down syndrome was 45 years or older. Graduate students and faculty continue to “mine” this rich dataset, and findings already have led to recommendations to The Arc for ways that siblings can be supported.

PI: Robert Hodapp, Ph.D., and Ann Kaiser, Ph.D. (Special Education); Richard Urbano, Ph.D. (Pediatrics)
Funding: The Arc of the U.S.



provide new clues about aging and interventions in Down syndrome.

PI: Sasha Key, Ph.D. (Hearing & Speech Sciences); Elisabeth Dykens, Ph.D. (Psychology & Human Development)

Contact: Dorita Jones, (615) 343-1961

Funding: Beasley Family VKC Discovery Grant

Issues Across the Life Span

❑ **Safety Training in the Community**

Parents of young adults with intellectual disabilities often have concerns about their son or daughter's safety in community settings. These concerns are especially salient when the young adult also shows increased sociability, trust of strangers, or poor social judgment. This project, led by a graduate student in special education, offers individualized training for young adults, 18 to 25 years, to learn to respond appropriately to lures from strangers. Participants include young adults with Down syndrome. Findings to date indicate that young adults with intellectual disabilities can learn safety skills in a short, 2-week training period.

PI: Robert Hodapp, Ph.D. (Special Education)

Contact: Marisa Fisher, (615) 202-0773, marisa.fisher@vanderbilt.edu

Funding: Dissertation Enhancement Award, Special Education Endowment Funds; also funded in part by Grant No. T73MC00050 from the Maternal and Child Health Bureau, Health Resources and Services Administration (HRSA), Department of Health and Human Services (HHS).

❑ **Understanding Aging in Down Syndrome**

Since adults with Down syndrome are prone to premature aging, this project aims to understand early signs of aging in individuals with Down syndrome. The study includes adolescents ages 16-20 years, and adults, ages 35-40 years. Parents or caregivers answer questions about their family member's daily functioning, learning, and memory. Participants with Down syndrome take part in a range of engaging activities while their brain waves or brain activities are being recorded. This noninvasive approach has yet to be widely used in Down syndrome research and will

Understanding the “Big Picture”

❑ **Survey of Statewide Needs for Services**

It is essential to understand the needs of individuals with developmental disabilities and their families if service systems are to be truly responsive. In collaboration with the Tennessee Developmental Disabilities Network, VKC researchers are assessing disability service needs in Tennessee. A survey, disseminated across the state to individuals with disabilities, their families, and professionals, gathered data on services in education, home and community-based programs, transition services, employment, funding, and health care. Data collected will inform our work within the network for the next 5 years.

PI: Robert Hodapp, Ph.D. (Special Education)

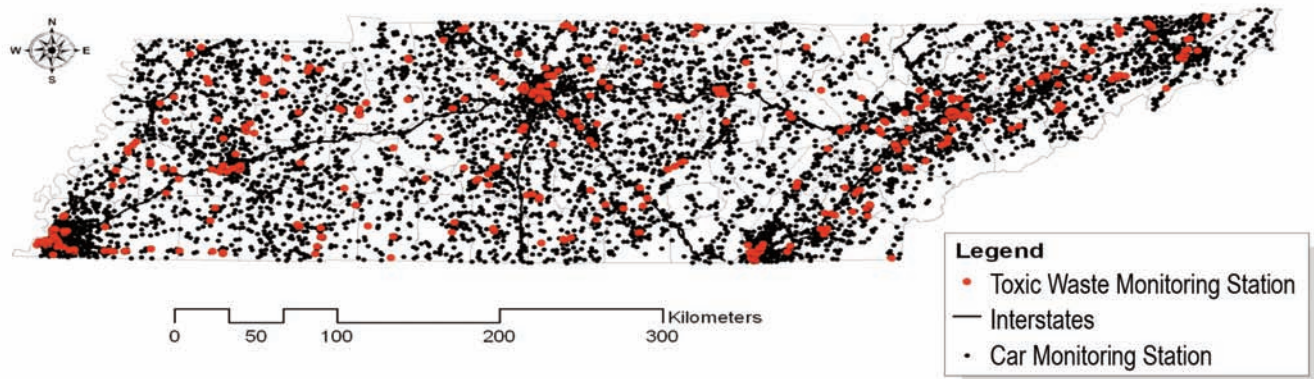
Survey: <http://tinyurl.com/ofnbov>
(615) 322-8946

Funding: Administration on Developmental Disabilities

❑ **Population-Based Studies**

VKC researchers are analyzing Tennessee State records of births, deaths, marriages, divorces, and hospital discharges over periods beginning as early as 1990 to understand basic demographic, health, family, and other characteristics associated with Down syndrome. Plans are underway to also link these records to those for newborn hearing screenings and cancer. Current studies fall into two broad areas—families and health—and often compare

Air Pollution Stations Across Tennessee



data on Down syndrome to data on families of children with other disabilities or the general population. Family studies include: the amount, timing, and correlates of marriage and divorce among parents of children with Down syndrome; demographics of mothers of children with Down syndrome, which has implications for service and support systems; and the births of one or more siblings following the birth of a child with Down syndrome. Health studies have focused on infant mortality, prematurity, low birth weight, and hospitalizations early in life. A new area of work involves linking health records to pollution in Tennessee in order to examine whether respiratory problems may be affected by pollution in the air or industrial sites. Other new comparative studies focus on the health of mothers of children with Down syndrome.

PI: Robert Hodapp, Ph.D. (Special Education),
Richard Urbano, Ph.D. (Pediatrics)
Funding: National Institute of Child Health and Human Development, Greenfield Family VKC Discovery Grant

The Biology of Down Syndrome

□ Generating Stem Cells

The aim of this innovative pilot project is make a human stem cell model of Down syndrome. The researchers will make induced pluripotent stem cells from skin samples of individuals with Down syndrome, which will led to direct experimental studies of Down syndrome patient-specific neurons. This will enable, for the first time, studies assessing differences at the cellular level among individuals who vary in their cognitive, behavioral, or medical profiles. This would make it possible to compare individuals with high function in one aspect of the Down syndrome phenotype with those having severe disability in that same area—offering the hope of linking cellular events to the spectrum of higher-order cognitive and neural features that perplex researchers and caregivers.

PI: Aaron Bowman, Ph.D., and Kevin Ess, Ph.D., M.D.
(Neurology)
Funding: VKC Hobbs Discovery Grant

□ Congenital Heart Disease

The Medical Director of the Vanderbilt Down Syndrome Clinic is beginning a collaboration with VKC colleagues to investigate the impact of heart disease in children and adults with Down syndrome.

PI: Tracy McGregor, M.D. (Pediatrics)

Research Infrastructure

□ Down Syndrome Clinic Registry and BioVU

The Medical Director of the Vanderbilt Down Syndrome Clinic is collaborating with VKC colleagues to develop a research infrastructure within the Down Syndrome Clinic. These efforts include a research registry of Down syndrome patients, so that families can be contacted for future research, as well as a repository of medical, behavioral, and other data. This information can be linked to DNA samples in Vanderbilt's BioVU program, which can be used for future studies.

PI: Tracy McGregor, M.D. (Pediatrics)

BioVu: Lou Muglia, M.D., Ph.D. (Pediatrics)

Future Directions

VKC researchers are seeking funding to pursue other areas of Down syndrome research. For example, [Tricia Thornton-Wells, Ph.D.](#) (Molecular Physiology & Biophysics) is applying for funds to support genetic and imaging studies in Alzheimer's disease, which would include Down syndrome. [Elisabeth Dykens, Ph.D.](#) (Psychology & Human Development) plans to apply for funds to study well-being, health, and mental health in young adults with Down syndrome.