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**Language Development and Intervention Studies**

**KIDTALK-TACTICS Project (KTTP)**

The aim of this intervention project is to train parents of young children ages 18 months to 5 years of age in naturalistic language teaching strategies that can be used in everyday routines and activities. Parents are provided with individualized training and a home education guide. The program is designed to improve language development and academic readiness in children with Down syndrome. **Funding:** Vanderbilt University Early Education and Development Program.

**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. **Funding:** National Institute of Child Health and Human Development, Greenfield Family VKC Discovery Grant.

**Future Directions**

VKC researchers are seeking funding to pursue other areas of Down syndrome research. For example, Tricia Thornton-Harms, 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.

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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

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 Dyken, Ph.D. (Psychology & Human Development)
Contact Rosanne Carmean (615) 875-5080
Funding: APRA 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

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)
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Issues Across the Life Span

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PI: Sasha Key, Ph.D. (Hearing & Speech Sciences); Elisabeth Dyken, Ph.D. (Psychology & Human Development)
Contact: Dottija Jones, (615) 343-1961
Funding: Beasley Family VKC Discovery Grant

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/otbnov
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

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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 Camarota, Ph.D. (Hearing & Speech Sciences), Paul Yoder, Ph.D. (Special Education)
Contact Mary Camarota, (615) 936-5130
Funding: National Institute on Deafness and Other Communication Disorders

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PI: Elisabeth Dykens, Ph.D. (Psychology & Human Development)
Contact Roxanne Carmean (615) 875-5080
Funding: APRA Challenge Grant–National Center for Complementary Alternative Medicine

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.

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 social isolation, decreased 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).

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Survey: http://tinyurl.com/ofnbov
(615) 322-8948
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**PI:** Ann Kaiser, Ph.D. (Special Education), Juliann Woods (Florida State University)

**Funding:** U.S. Office of Special Education

The Biology of Down Syndrome

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The aim of this innovative pilot project is to 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 lead 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

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

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**BioVU:** Lou Muggia, M.D., Ph.D. (Pediatrics)

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**Funding:** U.S. Office of Special Education

(615) 322-8240 | Toll-Free (866) 936-8852 | kc.vanderbilt.edu