

UCEDD Tip Sheets



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ASSOCIATION OF UNIVERSITY CENTERS ON DISABILITIES
THE LEADERSHIP, EDUCATION, ADVOCACY & RESEARCH NETWORK



Research

What is Addressed in this Tip Sheet?

This tip sheet will provide guidance on the planning and implementation of the research core function. According to the [UCEDD logic model](#), the definition of research is as follows: "Implementation of basic and applied research, program evaluation, and analysis of public policy on issues impacting individuals with developmental disabilities."

Why is this Important?

Research is a UCEDD core function, according to the DD Act Section 153(a)(2)(C):

Section 153 (C) (C) Conduct of research, which may include basic or applied research, evaluation, and the analysis of public policy in areas that affect or could affect, either positively or negatively, individuals with developmental disabilities and their families.

Further, the Office of Intellectual and Developmental Disabilities (OIDD) issued a final rule in 2015 providing guidance on implementing the DD Act (45 C.F.R § 1328.6 2015). In this guidance, OIDD specifically mentions the need for each UCEDD to have a written plan for how their program will implement the core functions as outlined in the DD Act. This is echoed in the UCEDD

funding opportunity, in which each applicant must provide a five-year plan for carrying out the core functions within the context of their settings (HHS-2018-ACL-AOD-DDUC-0251, p. 14, in the section Content and Form of Application Submission).

How have other UCEDDs structured their demonstration services?



Vanderbilt Kennedy University Center for Excellence in Developmental Disabilities

As one of the few institutes of higher education that houses a UCEDD, a LEND and an IDDRRC, Vanderbilt provides a supportive, interconnected framework for their research. Vanderbilt has four areas of emphasis:

- Education and early intervention
- Employment
- Health and Mental Health
- Quality of Life

These guiding principles are embedded into all of Vanderbilt's 40+ service and outreach programs.

Volunteer Advocacy Project

The Volunteer Advocacy Project (VAP) was started in 2008 by a long-term UCEDD trainee and doctoral student named Meghan Burke. Burke saw a need for an advocacy project at Vanderbilt and spearheaded it herself. VAP is a 12-week program with a 3 hour a week time commitment designed to help advocates learn about special education law, advocacy, and procedures. Since its inception, it has expanded to 6 to 9 sites across the state of Tennessee, with 60-80 attendees per workshop. The topics in each workshop run the gamut of special education issues- from IDEA, to eligibility and evaluations, functional behavior assessments and person-centered planning. Presenters include Vanderbilt professors, state agency officials, and lawyers.

Each applicant takes a pre-test and a post-test to gauge their level of knowledge before taking the workshop and after. The after-test contains the same questions and is related to knowledge of special education rights. The second part of the assessment addresses their level of comfort in advocacy, how comfortable they feel in exercising their rights and advocating before officials, etc. 70% of program participants are parents or family members of people with disabilities, and there is a wide range of professions represented.

Several research products/studies have resulted from this project:

1. Program Effects
 - a. Knowledge and comfort-skill in advocating
 - i. Attendees at VAP showed more knowledge and authority in advocacy
 - b. What changes during training?
 - i. Empowerment and a general sense of having more control, as a result of the advocacy training process
2. Advocates
 - a. Predictors of future advocacy
 - i. Self-image as a predictor of long-term advocacy
 - ii. Identity in the disability community
 - b. Advocate experience

- i. What are the formative steps?
- ii. What are the backgrounds of those who are frequent advocates?
- iii. What does the advocacy experience look like for people of color?
- iv. Studies showed that parents of children on the autism spectrum were more likely to advocate in the long term, so the content for VAP has been adapted to include more content that is suited to these families.

Guiding Principles for prioritizing research at UCEDDs

- Embed research into all service and outreach. Utilize existing infrastructure and capabilities- staff knowledge, distance capabilities, partnerships- to inform your research
- Intentionally involve trainees in multiple roles
- Include a range of stakeholders, including faculty, trainees, students, persons with disabilities and their families
- Collaborate with community agencies, state and local experts, and a CAC

Embed research into all service and outreach.

Kansas University Center on Disability Studies (KUCDD)



The University of Kansas is a research institution, whose focus is on enhancing existing knowledge about self-determination in order to support health and participation for people with intellectual disabilities, whose engagement is often affected by outside forces. Existing factors like federal and state policies, caregiver training, and existing supports can help determine their level of participation and ability to live independently, in a community. Fortunately, skills like decision-making, goal-setting, and problem-solving can be learned, enabling people with intellectual disabilities to live a self-determined life. KUMC also houses a UCEDD, a LEND and an IDDRC.

One example of the way in which KUCDD utilizes its body of research for practical purposes can be found in the Intervention Research on Self-Determination. This longitudinal research project takes place in multiple high schools across Maryland and Delaware. It includes a cohort model, following ninth grade students over three years. The goal is to look at the effects of interventions promoting self-determination, and to allow time for those developmental constructs to build in inclusive general education settings. The research informs evidence-based practices to promote student self-determination by supporting students through a self-regulated problem-solving process in which they set a goal. They then create an action plan to achieve that goal and then reflect on their achievements, adjusting their action plan as needed. The project also tracks the types of supports needed by teachers, asking questions like: how do their views of self-determination change over time? How does this affect instruction? The research informs the design of interventions that increase positive post-school outcomes, including post-secondary education enrollment, competitive and integrated employment, and community access and participation.

To facilitate the sharing of research, KUCDD develops automated programs and creates codebooks that are aligned with up-to-date data.

Another project, conducted in partnership with the Kansas IDDRC, uses a data-driven approach to understand the relationships between health, community participation and self-determination. It takes a large data approach to understanding the relationships between health participation and self-determination by linking data from a national registry for people with Down syndrome (DS-Connect) and the inventory developed at KUCDD.

Working across ongoing projects enables KUCDD staff to explore innovative methods to researching developmental disabilities. To facilitate the sharing of research, KUCDD develops automated programs and creates codebooks that are aligned with up-to-date data. If the data is shared, others can more readily understand the contents of the data, how it's coded, and what it means. Was it a randomized control trial or an observational study? These and other granular details are immediately knowable, while others are available upon request.

Lessons Learned

- Strong partnerships are key for developing consistent opportunities for communication, collaboration and innovation
- A diversity of perspectives is necessary for robust research



Waisman Center, University of Wisconsin-Madison

The Waisman Center's mission is to advance knowledge about human development, developmental disabilities and neurodegenerative diseases across four core functions: research, service, training, and outreach. Their focus is on applied, community-based research. The UCEDD's guiding principles are:

- Family and person-centered care
- Community inclusion
- Interdisciplinary approach
- Evidence-based practice

These four principles are foundational to all programs, and individuals with intellectual and developmental disabilities should be an active part of research at all levels. Waisman's work grows out of collaborative relationships with families, agencies and the other programs and is strengthened by a robust background in both quantitative and qualitative research methodologies. Other key collaborators include the Department of Health Services, Waisman Center clinics, public schools, and the Centers for Disease Control and Prevention. LEND faculty in particular are very active in producing research projects, which speaks to Waisman's interdisciplinary approach. LEND trainees can learn essential research skills, while enhancing the experience and expertise applied to each project. Although Waisman's research projects have been disseminated via peer-reviewed articles and presentations, it recently committed to an increased emphasis on sharing research results with a much wider audience. LEND trainees have been active in developing issues briefs, many of which discuss useful research takeaways in easily accessible language.

LEND trainees can learn essential research skills, while enhancing the experience and expertise applied to each project.

Major Research Projects

- Longitudinal Study of Adult Long-Term Care
 - Multi-year survey of adults with intellectual and developmental disabilities accessing long-term care services
- Assessment of Early Intervention Outcomes (AEIOU) for children who are deaf/hard of hearing
 - Multi-phase study which involves data collection from children diagnosed with hearing loss and enrolled in early intervention
- Transitioning Together
 - Psychoeducational intervention for individuals with ASD and their families, successfully adapted to multiple settings and for Spanish speaking families
- Evaluation of Developmental Monitoring using LTSAE in Child Care and Early Head Start Settings
- Wisconsin Surveillance of Autism and Other Developmental Disabilities (ADDMM)
 - Ongoing epidemiological data collection on the prevalence of ASD and CP in Southeast region of Wisconsin.

What are the Relevant resources?

- [Webinar: Research by UCEDDs](#)
- [UCEDD Logic Model](#)
- [Vanderbilt Kennedy Center](#)
 - [Volunteer Advocacy Project](#)
- [Kansas University Center on Disability Studies](#)
 - [Self Determination Research](#)
- [Waisman Center, University of Wisconsin-Madison](#)
 - [Longitudinal Study of Adult Long-Term Care](#)
 - [Assessment of Early Intervention Outcomes](#)
 - [Transitioning Together](#)
 - [Wisconsin Surveillance of Autism](#)

For More Information

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