



WAISMAN CENTER

UNIVERSITY OF WISCONSIN-MADISON
University Center for Excellence in Developmental Disabilities

ISSUE BRIEF 2024

Leveraging Model Direct Services to Meet the UCEDD Mission

The Waisman Center UCEDD

The Waisman Center is designated by the Administration on Disabilities, within the U.S. Department of Health and Human Services, as the University Center for Excellence in Developmental Disabilities Education, Research, and Service (UCEDD) for the state of Wisconsin. It is one of 67 UCEDDs nationally. The UCEDDs are legislatively authorized through the Developmental Disabilities Assistance and Bill of Rights Act of 2000 (DD Act) to provide core functions and to maintain an infrastructure for leveraging additional public and private funds that support individual programs and projects. For example, in fiscal year 2023 the UCEDD received over \$8 million to manage 30 different projects.

At the Waisman Center, the Intellectual and Developmental Disabilities Research Center (IDDRC), the Leadership Education in Neurodevelopmental and Related Disabilities (LEND), and the UCEDD are co-located in contiguous space within one building. This proximity offers a unique opportunity for core function layering, cross-program integration, and collaboration.

This brief offers a historic and current overview of how model direct services support the full inclusion and self-determination of people with developmental disabilities and their families in alignment with the DD Act and UCEDD mission. A selection of key terms used in the brief is provided on the last page.



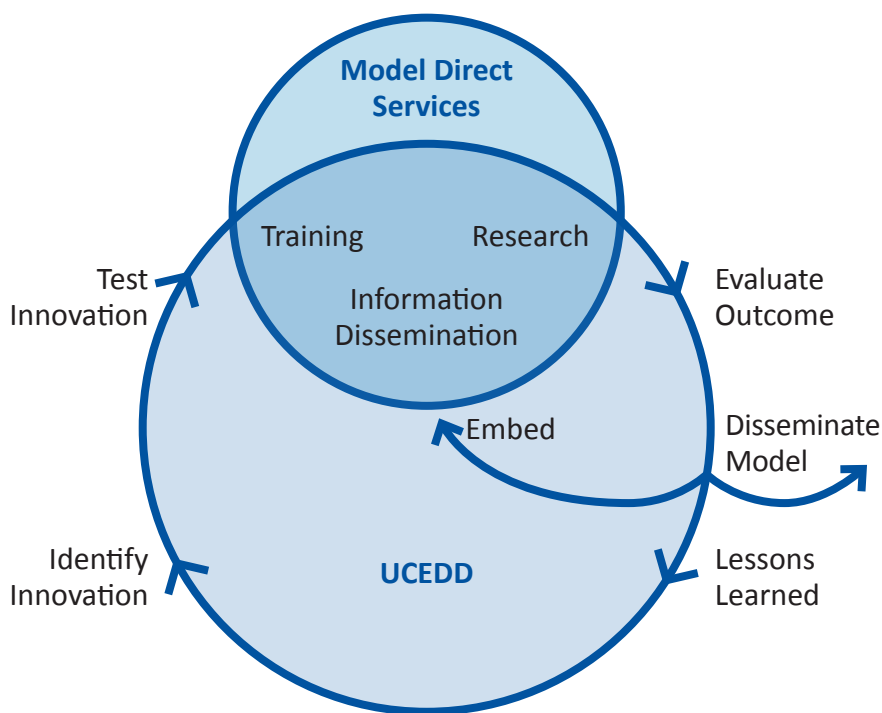
Background

President Kennedy signed Public Law (PL) 88-164 on October 31, 1963. This landmark legislation authorized assistance with the construction of research centers and University Affiliated Facilities to improve the lives of individuals with developmental disabilities through research, training, and clinical services. The University of Wisconsin-Madison was among the first group of universities to receive construction funding for a research center in 1965 and for a University Affiliated Facility in 1968. In the 60 years since its inception, this legislation has been reshaped each time it was reauthorized into what we now know as the DD Act. The combined research center (now the IDDRC) and University Affiliated Facility (now the UCEDD), laid the foundation for what would become the Waisman Center in 1973.

"Congress finds that disability is a natural part of the human experience that does not diminish the right of individuals with developmental disabilities to live independently, to exert control and choice over their own lives, and to fully participate in and contribute to their communities through full integration and inclusion in the economic, political, social, cultural, and educational mainstream of United States society."

DD Act of 2000

UCEDD Model Direct Services: Continuous Improvement in Systems of Care



UCEDD **model direct services** (e.g., clinical care) are different from other community-based services. They are “model” in that they adhere to the UCEDD mission and guiding principles, especially its commitment to excellence. They are affiliated with the university and are intentionally designed to **test** innovative, evidence-based service-delivery models for individuals with developmental disabilities and their families. They are expected to integrate training, research, and information dissemination into the model. They are “direct services” because they provide a specific needed service. The UCEDD has several longstanding “anchor” programs which ensure that there is a stable infrastructure (e.g., staffing, funding stream) to support ongoing service and innovation. Continuous improvements to systems of care occur as **lessons learned** drive new approaches. Effective models are sustained through collaborations/grants/contracts or are **disseminated** to partners.

Model Direct Services are Leveraged to Meet the UCEDD Mission

The table below illustrates how model direct services provide a setting for service, training, research, and information dissemination.

WHO benefits from the model direct service	WHAT does the model direct service offer to each collaborator	HOW does the model direct service meet the UCEDD mission
Individuals with DD and their families	Receive direct services -assessment, care, support, education, navigation, coordination, intervention, treatment	↑ Access to specialized services for individuals with DD ↑ Individuals with lived experience educate professionals about their experiences, including gaps in services ↑ Partnership with training and research ↑ Timely, accurate, and useful information is shared
Community-based professionals	Receive training and technical assistance from model services staff	↑ Capacity of local providers to provide care ↑ Community providers skills, knowledge, and self-efficacy ↑ Establish innovative model/approach in local setting
University faculty and staff	Access to clients, patients, students for research and QI	↑ Discovery builds evidence-base for best practices ↑ Research is translated into practice and/or policy ↑ Continuous improvement in service
Future professionals	Receive interdisciplinary training within a direct service setting while in a university degree program	↑ Best practice skills/knowledge while learning in a context that demonstrates the perspectives and roles of other disciplines who work with individuals with DD
UCEDD faculty, staff, and program leadership	Disseminate information about the needs/gaps for individuals with DD, their families, providers, and systems of care	↑ Individualized information is disseminated to recipients of service ↑ DD Network partners, AUCD Network, and state agency collaborators align to identify and address statewide and national needs/gaps ↑ Decision makers turn to the UCEDD for expertise

All Waisman Center UCEDD Model Direct Services work to maximize core function integration.

Historic Example

In the 1960s, Harry Waisman MD, PhD, was one of the first physician-researchers to operate an outpatient clinic for children with developmental disabilities and genetic conditions in Wisconsin. Dr. Waisman's work in the identification and treatment of phenylketonuria (PKU) included an emphasis on early identification, treatment, support for the family, and ongoing follow-along care concurrent with **training and research**. Dr. Waisman's high standard for clinical care ensured an exemplar **model direct service** that positioned the clinic to receive funds from the Maternal Child Health (MCH) Bureau in 1968 to form a Diagnostic Treatment Unit. The early MCH funds required that **interdisciplinary service delivery** was integrated with **training future professionals** and with **research**. The MCH funds also directed grantees to work with their state agencies to advance improvements in care for individuals with developmental disabilities and their families. Dr. Waisman worked with the state Department of Health Services to advance policy to protect individuals at-risk for and/or with developmental disabilities. Dr. Waisman was instrumental in advancing mandatory screening for PKU, allowing for early detection, treatment and prevention of intellectual and developmental disabilities for infants with PKU. In 1965, Wisconsin implemented blood screening for newborns. In the last 50 years, the **model service, training and research** in the clinics has proven effective and the direct service component of the Waisman Center Clinics is sustained by a partnership with a large regional health care system called UW Health. Despite the growth and changes in health care delivery over the decades, the model that was established in the 1960s for university programs and shaped in Wisconsin by Dr. Waisman's pioneering clinical and research work continues at the center named in memory of Dr. Waisman.



Current Example

One of the most enduring model direct services at the Waisman Center UCEDD is housed within the **Augmentative and Alternative Communication (AAC) Program**. The AAC Program impacts individuals across the lifespan who are experiencing significant communication difficulties. This anchor program provides the infrastructure needed to test new approaches to practice. It includes all four UCEDD core functions (service, training, research, and information dissemination) in its program design.

The AAC Program's primary model direct service is the Communication Aids & Systems Clinic (CASC) with clinical space on the first floor of the Waisman Center. CASC offers clinical services in partnership with UW Health, a regional health care system. Speech-language pathologists and an occupational therapist provide individual assessments of communication needs and feature matching for appropriate tools and strategies (including speech-generating devices). Currently, CASC is the only service of its type in Wisconsin.

In an effort to strengthen the statewide AAC capacity, multiple approaches are utilized. Locally, AAC staff travel to community-settings to offer **training and technical assistance** to individual AAC users and their teams through a contract with the Dane County Department of Human Services. Statewide, funds from the Department of Public Instruction facilitate work with students who need AAC and their school teams to strengthen the school team capacity. Broadly, AAC Program staff offer local community providers in Wisconsin and nationally, education and case consultation using videoconferencing technology through Project ECHO® (Extension for Community Healthcare Outcomes).

The AAC Program also builds statewide capacity through **training future professionals**. Speech-language pathology graduate students and one clinical fellow complete the LEND training program each year. Collaborations with the UW-Madison Department of Communication Sciences and Disorders lead to clinical placements and opportunities for AAC staff to guest lecture and teach courses.



On the upper floors of the Waisman Center, IDDRC investigators learn more about communication in individuals with developmental disabilities through **research**. Collaboration with researchers in the building and nationally strengthen the transfer of research-based approaches to clinical practice.

A few miles away at the State Capitol and state agency departments, policy and decision makers turn to the AAC Program for **information** on the evidence-base for AAC and the barriers to access. Collaborations with agency partner groups contribute to statewide improvements in the systems of care for AAC users. In all of these ways, the AAC model service is leveraged to meet the mission of the UCEDD.

Waisman Center UCEDD Model Direct Service Programs

Augmentative and Alternative Communication (AAC) Program provides individuals who are experiencing communication challenges, and the providers who work with them, tools, and strategies.

Children's Resource Center-South provides families with children and youth with special health care needs with information, referral, and follow-up services.

Community Training, Intervention, and Evaluation Services (TIES) provides behavioral and psychiatric support to children, adolescents, and adults with developmental disabilities and challenging behaviors.

Waisman Center Clinics provide evaluation, diagnosis, clinical care, and/or treatment for children and/or adults with or at-risk for a developmental disability or genetic condition.

Waisman Early Childhood Program offers a center-based inclusive early childhood program for a developmentally diverse group of children ages 1 through 6.

Wellness Inclusion Nursing provides assessment, consultation, and training to community agencies and individuals with developmental disabilities.

Key Terms Used in this Brief

AUCD: The Association of University Centers on Disabilities

DD: Developmental Disabilities

DD Act: Developmental Disabilities Assistance and Bill of Rights Act of 2000

IDDRC: Intellectual and Developmental Disabilities Research Center

LEND: Leadership Education in Neurodevelopmental and Related Disabilities

UCEDD: University Centers for Excellence in Developmental Disabilities Education, Research, and Service

UCEDD Core Functions:

1. **Pre-service Training** is when students from different university departments learn together, with individuals with lived experience, about ways to help people with developmental disabilities.
2. **Community Services** help people with developmental disabilities to live in their communities through:
 - Community Training** and coaching that builds the capacity of community members and policy-makers to support individuals with developmental disabilities.
 - Model Services** that provide services and supports while finding new ways to help individuals with developmental disabilities through demonstration and model activities.
3. **Research and Evaluation** lead to understanding the causes, impacts and interventions for individuals with developmental disabilities and their families.
4. **Dissemination of Information** is a way to help many people learn about developmental disabilities.

Resources

- AUCD Model Services Tip Sheet https://www.aucd.org/docs/urc/TipSheets/tipsheets_2020_0508_model_services.pdf
- Fifield, B., & Fifield, M. G. (2020). The Origins of University Centers on Developmental Disabilities: Early Expectations and Legislation. *The Developmental Disabilities Network Journal*, (1), 15-33. <https://doi.org/10.26077/Y5EM-E046>
- Public Law 106-402, 106th Congress, October 30, 2000: Developmental Disabilities Assistance and Bill of Rights Act of 2000 <https://www.congress.gov/106/plaws/publ402/PLAW-106publ402.pdf>
- Waisman Center 50th Anniversary Timeline <https://www.waisman.wisc.edu/50th-timeline/>