

Overview of UCEDD Activities: Supporting Families Agenda

University of Wisconsin – Waisman Center, UCEDD



About the Wisconsin UCEDD

<http://www.waisman.wisc.edu/cedd/>

The mission of the University of Wisconsin Waisman Center, University Center for Excellence in Developmental Disabilities (UCEDD) is to support the full inclusion and self-determination of people with developmental disabilities and their families through:

- Development of personnel qualified to provide services in the health, education and social service systems.
- Provision of services, technical assistance and the dissemination of information.
- Improvement of assessment, service and support approaches.
- Contribution to the advancement of new knowledge about the causes and prevention of developmental disabilities, the impact of disabilities on individuals and families, and the efficacy of different assessment, intervention and support methods.

The following principles reflect the core values and approaches that are common to activities of the UCEDD.

- Person and family-directed care and support, including culturally competent services.
- Inclusion of all people with developmental disabilities in the community.
- Interdisciplinary approach to service and training, including interagency partnerships.
- Best practices and evidence-based approaches to service and training.

Highlights of UCEDD Financial and Infrastructure Commitments

Wisconsin core funds are used to support:

- Family Support and Leadership is one of seven Areas of Emphasis for the UCEDD
<http://www.waisman.wisc.edu/cedd/AoEabout.php>
- A UCEDD policy specialist assists all UCEDD projects to disseminate research and information to educate policy-makers.
- A UCEDD research director focuses on evaluation and dissemination of UCEDD work including policy briefs.
- Family navigators are located in specialty clinics to assist families with information and assistance on a broad range of topics.
- UCEDD staff includes family members and self-advocates who contribute to a wide range of project activities.
- UCEDD staff provides support for family and self-advocate participation in policy education.

Who Does This Work Reach in Wisconsin?

85,895 Individuals with I/DD Live in Wisconsin



National Agenda for Supporting Families

The overall goal of supporting families, with all of their complexity and diversity, is to maximize their capacity, strengths and unique abilities so they can best support, nurture, love and facilitate opportunities for the achievement of self-determination, interdependence, productivity, integration, and inclusion in all facets of community life for their family members.

Supporting the family is defined as a set of strategies targeting the family unit but that ultimately benefits the individual with I/DD. Supporting the family strategies are intended to assist the family members who have key roles in the provision of support and guidance of their family member with I/DD to address emotional, physical and material well-being of the entire family.

Policy, Systems and Societal Change

Strategies must be designed, implemented and funded in a manner directed by the family unit. They should be flexible, comprehensive, and coordinated.

Survival Coalition of Wisconsin Disability Organizations is a cross-disability coalition of more than 40 state and local organizations and groups. For more than 20 years, Survival has been focused on changing and improving policies and practices that support people with disabilities of all ages to be full participants in community life. <http://www.survivalcoalitionwi.org/>

Health Disparities and Individuals with Developmental Disabilities Initiative is a collaborative advocacy effort to bring attention to the need to acknowledge and address health disparities among individuals with developmental and other disabilities. A blueprint to address health disparities and a data report are several products of the initiative. <http://www.waisman.wisc.edu/healthdisparities/>

Think College is implementing a statewide plan to promote postsecondary opportunities for adult learners with intellectual disabilities. School districts around the state are developing transition-based programs in partnership with their local technical college or university to provide access to the college experience including college courses, job opportunities and activities available on campus.

Family Support systems change initiatives have been supported with UCEDD funding using previous PNS grants and current UCEDD staff chair the WI-DHS Children's Long-Term Supports Council. The UCEDD supports a Family Action Network listserv and family leadership education.

Monitoring System Issues for Children/Youth with Special Needs documents needs that individuals with disabilities and families experience in their attempts to navigate services and supports, their ability to access those services, and problems they may have in receiving quality service. Periodic reports are then submitted to Family Voices of WI and are pooled with other information to assist them in their ongoing advocacy/systems change efforts with their partner agencies, one of which is the Waisman Center UCEDD.

Promise Grant Wisconsin refers to Promoting Readiness of Minors in Supplemental Security and is a five year multi agency effort to increase the education, career and income outcomes of children/youth with special health care needs receiving SSI. UCEDD staff coordinates the leadership team for the grant, family listening sessions and training activities.

NIRS DATA

DISCOVERY & NAVIGATION

- Information, education, and training on best practices within and outside of disability services
- Planning, accessing and coordinating community supports
- Advocacy and leadership skills

CONNECTIONS & NETWORKS

- Connecting and networking family members with other family members, including parents with disabilities, self-advocates, siblings, grandparents, and others.
- Formal and informal structures for peer support

DAY-TO-DAY NEEDS

- Services and goods that are specific to the daily support and/or caregiving role the person with I/DD. Such as, respite, crisis prevention, systems navigation, home modifications and health/wellness management of caregiver

Waisman Resource Center provides information and assistance to about 100 families and providers per month on a wide range of disability related issues.

Threshold Wisconsin is a contract to provide local administration of certain steps in the eligibility determination process for the Wisconsin Medicaid Katie Beckett Program (KBP), Family Support and Children's waivers in the counties of south central Wisconsin.

Day with the Experts presents community educational events focused on Autism, Down syndrome, cochlear implants, Cerebral Palsy, and the Grandparents' Network. The events feature presentations by researchers and clinicians, as well as a panel discussion with individuals and family members.

MCH LEND provides advanced training to graduate students, family members, self-advocates, and community professionals to improve systems of care that promote the prevention of disabilities and assure access to family-centered, community-based services and supports for children with neurodevelopmental disabilities

Transitioning Together is a research project that provides training and support in a group setting to adolescents with ASD and their families, to assist them to successfully transition into adulthood.

Families As Leaders (FALS) offers a multi-session intensive leadership learning opportunity for families who have a family member with I/DD and special health care needs.

CYSHCN Collaborators Network works together with national, state and community-based partners to link children to appropriate services, close service gaps, reduce duplication and develop policies to better serve families.

Peer Support and Peer Network is a school-based research project to investigate methods to utilize peer support and networks to enhance academic performance of individuals with I/DD.

LOV-Dane, using principles of community organizing, developed and supports a county-wide family network, as well as a network of community partners, to work on common priorities to reach goals of

Safe at Home/Sound Response is an alternative approach to ongoing overnight staffing for people with I/DD. Sound Response offers a combination of off-site monitoring with quick response by familiar professional staff, as an effective service model for assuring safety and promoting independence. Sound Response strives to supplement direct staff support through the creative use of technical/mechanical supports.

Wellness Inclusion Nursing is a community based nursing program that is designed to provide assessment, consultation and training to caregivers, agencies and staff providing care to individuals with I/DD.

Community TIES Program offers support to children, adolescents and adults with developmental disabilities who reside in Dane County and present challenging behaviors. TIES seeks to enable individuals to remain in their natural environment utilizing and teaching non-punitive ways to redirect or modify specific behaviors. Support and consultation occurs in the community based environment where a person's challenging behavior occurs.

<p>and their families.</p>	<p>community living and participation.</p> <hr/> <p>COW Community Outreach Wisconsin provides community training and consultation programs that provide training to direct support workers, families and individuals with I/DD and many others working to serve and support those with disabilities.</p> <hr/> <p>Let's Get to Work Project is a collaboration with the Wisconsin Board for People with Developmental Disabilities and offers training to families and youth participants and will develop and implement policies and practices that elevate community expectations and overall employment outcomes for youth with I/DD.</p>	<p>Low incidence diagnostic clinics provide clinical care through specialty clinics that are operated in collaboration with UW Hospital and Clinics and several UW academic Departments.</p> <hr/> <p>Waisman Early Childhood Program is a center based early childhood program that is meeting the needs of a developmentally diverse group of children ages 1 through six years. Approximately two-thirds are developing typically and one third may have a special education need.</p> <hr/> <p>Dane County Self-Directed Services Initiative provides useful information pertaining to Dane County's Self-Directed Services (SDS) program to consumers, guardians, family and friends.</p>
----------------------------	------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------	---------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------