

Overview of Illinois UCEDD/LEND Activities: Supporting Families Agenda
University of Illinois at Chicago, Institute on Disability and Human Development



July 1, 2013-June 30, 2014

About Illinois UCEDD

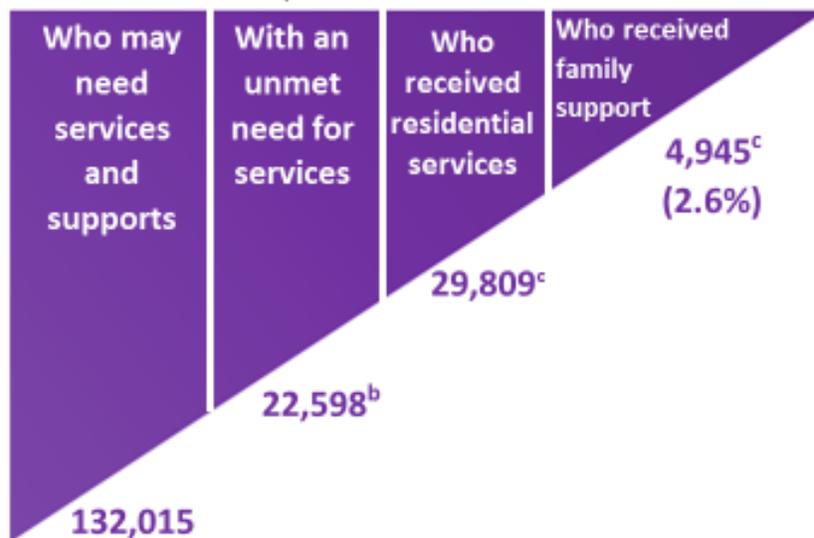
The Institute on Disability and Human Development (IDHD) is dedicated to promoting the independence, productivity and inclusion of people with disabilities into all aspects of society. IDHD realizes its mission through its academic department, clinical services, research centers and community programs. The mission is addressed by **conducting research** and **disseminating information** about disability to educators, policymakers, businesses, government agencies, service providers and the general public. IDHD also provides **clinical and community service activities**, and through the Department of Disability and Human Development and other academic departments, offers **interdisciplinary pre-service training**. The values of cultural diversity, consumer choice and self-determination are emphasized across the life span in all training, public service, and research activities of the IDHD. For more info visit: www.ahs.uic.edu/dhd/

Highlights of IL UCEDD Financial and Infrastructure Commitments

- Host the Sibling Leadership Network national offices and the Executive Director position
- Staff salaried positions for Self-Advocacy Specialist as well as bilingual Latino family support staff
- Support for Grupo SALTO, a support group for Latino families of people with autism
- Serve primarily underserved minority families through the Developmental Disabilities Family Clinics

Who does this work reach in IL?

Est. total of 189,367^a Individuals with IDD in IL



^a U.S. Census (2013). IL census data by the 1.47% prevalence rate of DD

^b Illinois PUNS data retrieved on Sept. 8, 2014: <http://www.dhs.state.il.us/page.aspx?item=56036>.

^c Braddock et al., The State of the States in DD 2014 (preliminary edition). Boulder: Department of Psychiatry and Coleman Institute, University of Colorado and Department of Disability and Human Development, University of Illinois at Chicago.

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 IDD. 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 IDD to address emotional, physical and material well-being of the entire family.

Policy, Systems and Societal Change

Strategies designed, implemented and funded in a manner directed by the family unit and are flexible, comprehensive, and coordinated.

- **Latino Family Support Research Projects:** This includes an NIH study examining the cultural equivalence of the autism assessment for children with Spanish speaking families; a project to empower Latino families who have a child with an autism spectrum disorder (ASD) which is aimed at reducing service disparities for Latino parent and children; and a project that helps Latino parents promote participation among children with ASD.
- **Sibling Leadership Network (SLN):** The SLN is a national nonprofit with state chapters dedicated to providing information and support to siblings of people with any type of disability across the lifespan. The SLN was a promotional partner of the Disability Policy Seminar.
- **Sibling Policy Forums:** This project engaged people with disabilities and their siblings in a policy discourse about long term services and supports through Sibling Policy Forums held in Illinois. An Advocacy Toolkit was created to give sibling the tools to get more involved in policy and advocacy efforts. Siblings shared their stories and two videos were created on sibling perspectives related to Employment First as well as Future Planning provisions in the Older Americans Act.
- **The State of the States in Developmental Disabilities** does research on how much money states report going to support families in the family home, aging caregiver data which estimates the number of individuals living with families and the number of aging caregivers. The State of the States also wrote a research and policy brief on siblings of individuals with IDD.
- **Special Education Advocacy training for families** provided education to parents of students with disabilities to learn their rights under Individuals with Disabilities Education Act (IDEA). Trainings were provided in English and Spanish so parents could learn to advocate regarding special education services in urban, suburban, and rural sites in Illinois.
- **Evaluations of State Operated Developmental Center closures** (Howe, Jacksonville, and Murray), as well as the **Ligas Consent Decree**, look at people transitioning from state institutions. The evaluations address family support and assess family appraisal and well-being by conducting interviews with stakeholders to better understand their experiences with rebalancing, in addition to impacting home based services and influencing policy regarding waiting lists.
- **Rehabilitation Research and Training Center on Developmental Disabilities and Health (RRTCDD):** The RRTCDD has the following goals for people with IDD: increase understanding of health status, health access, and health behaviors; improve health and function through health promotion interventions; and, improve health care access through integrated care practices. Examples include: Demographic research on the political arithmetic of disability and the American family; Leading the National Task Group on Intellectual Disabilities and Dementia Practices; and research on the impact of Integrated Care on policies and practices for people with disabilities and families.

| <p>DISCOVERY & NAVIGATION</p> <ul style="list-style-type: none"> • <i>Information, education, and training on best practices within and outside of disability services</i> • <i>Planning, accessing and coordinating community supports</i> • <i>Advocacy and leadership skills</i> | <p>CONNECTIONS & NETWORKS</p> <ul style="list-style-type: none"> • <i>Connecting and networking family members with other family members, including parents with disabilities, self-advocates, siblings, grandparents, and others.</i> • <i>Formal and informal structures for peer support</i> | <p>DAY-TO-DAY NEEDS</p> <ul style="list-style-type: none"> • <i>Services and goods that are specific to the daily support and/or caregiving role the person with I/DD</i> • <i>Such as, respite, crisis prevention, systems navigation, home modifications and health/wellness management of caregiver</i> |
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| <p>The Leadership Education in Neurodevelopmental and Related Disabilities (LEND) Program: This one year interdisciplinary training program incorporates both didactic and hands-on learning in clinical and community-based settings. The LEND aims to prepare future leaders who will serve children with neuro-developmental disabilities (including related disabilities and autism) and their families through coordinated, culturally competent, and family-centered care, as well as public health services and policy systems change. The IL LEND includes family members and self-advocates as both faculty and trainees. The IL LEND has a family discipline and a self-advocate discipline.</p> <hr/> <p>The Future is Now is a curriculum for adults with disabilities and their families to jointly plan for the future. Participants prepare a letter of intent that lays out their dreams for the future and identifies the steps required to transform this dream into a reality. A peer support model is used where family members and self-advocates are co-trainers and breakout sessions with peers are incorporated in the training. This state-of-the-art approach to future planning was developed, implemented and evaluated by IDHD’s RRTCADD.</p> | <p>Grupo SALTO, a monthly support group of over 435 Spanish-speaking Latino families of children with an autism spectrum disorder (ASD) facilitated by the Developmental Disability Family Clinics Hispanic Team, offers educational sessions for parents, including a support group specifically for fathers. Also, they provide a sibling support group, as well as an arts, dance, and music program for children with ASD.</p> <hr/> <p>Autism Spectrum People in Education, or ASPE, is part of The Autism Clinic and TAP Training Center. This peer support group for college students on the autism spectrum from all over the Chicago-land area meets on a biweekly basis during the academic year. The group focuses on peer interactions, support and relationship building in a fun environment.</p> <hr/> <p>IDHD hosts the Sibling Leadership Network (SLN), which is a national nonprofit with state chapters dedicated to providing siblings the information, support, and tools to advocate with their brothers and sisters and to promote the issues important to them and their entire families. In 2013, the National SLN Conference brought together siblings from 22 states as well as Canada and Japan. The SLN’s website provides information and resources for siblings and their</p> | <p>IDHD’s interdisciplinary Assistive Technology Unit (ATU) has been providing services to underserved individuals with developmental disabilities in northern Illinois for the past 20 years. Assistive Technology (AT) evaluations are provided to approximately 200 individuals of all ages with a range of disabilities each year. Evaluations predominantly take place at the work site, or the family home.</p> <hr/> <p>Developmental Disabilities Family Clinics provide quality clinical and family support services with a life course approach, as well as community education and training. Their services include comprehensive interdisciplinary diagnostic assessments, specialized individual and group therapies, and family support in Spanish and English with a strong commitment to minority populations.</p> <hr/> <p>Intervention study for Latino mothers of children with disabilities: A culturally-based health education intervention was developed for Latina mothers who care for children and adults with IDD. The aim of the intervention is to improve</p> |

Research Brief on Family Support in Managed Long-Term Services and Supports. A research brief was developed for First in Families of NC on the impact of managed care on family support and sets they could take in the state.

The National Gateway to Self-Determination has a clearinghouse for resources, training, and information on promoting self-determination for people with IDD, including best practices and evidence-based activities. IDHD is one of 5 UCEDD partners with NGSD to do research, provide recommendations, and disseminate NGSD materials.

Pre-service training for students on family support: Academic courses on family support are taught for undergraduates, masters, and doctoral students such as Family Perspectives on Disability. Also, internships are provided to train students in leadership skills and ways to effectively work with families of people with disabilities.

families. The SLN provides peer support through chapter events as well as extensive TA by phone and email to siblings and their families as well as professionals.

Dating Skills Groups and Parent Education About Sexuality: The Family Clinics have been running dating skills groups for young adults and adults with IDD as well as running groups designed to support parents in educating young adults and teens with IDD about sexuality.

Taking Charge: Directing Your Supports is an intervention for people with IDD and their families who utilize home based support services. This curriculum empowers individuals with IDD and their families in directing their own supports.

Self-Advocacy Specialist, Tia Nelis, works on a variety of projects that impact family support. She is an active member of Self Advocates Becoming Empowered (SABE) and Project Vote. As an internationally recognized leader in the self-advocacy movement, Tia also provides TA to self-advocacy organizations across the country.

The Peer to Peer HealthMessages™ Program is an evidence-based program that trains people with intellectual disabilities to be Healthy Lifestyle Coaches and mentor their peers.

confidence in engaging in positive health activities, to increase positive health behaviors, and to reduce stress. In partnership with El Valor, a community based organization, 100 Spanish speaking mothers of children and adults with IDD enrolled in the study. The intervention was delivered by promotoras de salud or community health workers who were themselves mothers of children with IDD. The promotoras conducted 8 home visits to participants to deliver the health oriented content.