A Webinar from AUCD’s Special Interest Group on Family Support

The Roles of UCEDDs/LENDs in Advancing Thinking, Practice and Policies that Support Families

September 10, 2014, 3:00 PM – 4:30 PM ET
Webinar Overview

• Introductions
• Presentation
• Q & A
  • You can ask a question by pressing the * then # key to request the floor. Questions will be answered in the order they are received.
  • You can also submit any questions throughout the webinar via the ‘Chat’ box below the slides.
  • The moderator will read the questions after the presentations.
• Survey
  • Please complete our short survey to give us feedback for the next webinar!
UCEDDs Represented Today

• Institute on Disability and Human Development, University of Illinois at Chicago (UCEDD/LEND)

• Developmental Disabilities Institute, Wayne State University (UCEDD)

• Center for Interdisciplinary Learning and Leadership, University of Oklahoma Health Sciences Center (UCEDD/LEND)

• Waisman Center, University of Wisconsin - Madison (UCEDD/LEND)
Speakers

Katie Arnold (kkeiling@uic.edu) is Director of Community Education at the Institute on Disability and Human Development (IDHD) at the University of Illinois at Chicago.

Wanda Felty (wanda-felty@ouhsc.edu) is the Leadership and Advocacy Coordinator for the Center for Learning and Leadership (Oklahoma's UCEDD) at the University of Oklahoma Health Sciences Center, College of Medicine and Family Faculty for the Oklahoma LEND Program.

Elizabeth Hecht (hecht@waisman.wisc.edu) is the UCEDD Specialist for Public Policy and Systems Change at the University of Wisconsin, Waisman Center.

Angela Martin (angela.martin@wayne.edu) is a Community Support Specialist with the Developmental Disabilities Institute (DDI) at Wayne State University in Detroit, Michigan.

Vyonda Martin (vyonda-martin@ouhsc.edu) is Associate Director and Community Services Director for the Center for Learning and Leadership, Oklahoma's University Center for Excellence in Developmental Disabilities at the University of Oklahoma Health Sciences Center.
Purpose of webinar

• Understand the role of UCEDD's and LEND's in the self-advocacy, family and sibling movements.

• Share examples of specific UCEDD and LEND infrastructure and activities that address support to families.

• Think about what UCEDD’s and LENDs can do to advance thinking, practice and policy to support families.
Background

DD Act: Title II-Family Support added to DD Act 1999 although with no funding appropriation

1. promote and strengthen the implementation of comprehensive State systems of family support services
2. promote leadership by families in planning, policy development, implementation, and evaluation of family support services....;
3. promote and develop interagency coordination and collaboration between agencies; and
4. increase the availability of, funding for, access to, and provision of family support.
Background

With Project of National Significance funding ADD launched family support initiatives with many UCEDDs participating:

- Demonstration grants to states (2000-2005)
- Family Support 360 Programs (2003-2009)
- National Clearinghouse and Technical Assistance Center on Family Support (2009)
- A 60% cut to PNS has significantly impacted state systems change activities 2012
- Special projects (2012- present)
  - FISP
  - COP
  - NIDDRR-RRTC on Family Support
AUCD Family Support SIG 2008

• Learn and network
• Advance thinking, practice and policies that support families
• Elevate attention to supporting families within our UCEDDs
• Meet in person annually at AUCD with periodic conference calls
• Convene a national meeting-Wingspread 2011
AUCD Family Support-SIG

• AUCD website
  http://www.aucd.org/template/page.cfm?id=864

• List serv
  http://www.aucd.org/template/page.cfm?id=766

• Webinar Update on Federal Family Support Policy

• Join us at the AUCD Annual meeting
  Monday November 10, 2014, 12:45-2:00
  !ALL WELCOME!
Family Support is a set of strategies targeting the family unit but that ultimately benefit the individual with I/DD. Strategies must be designed, implemented and funded in a manner directed by the family unit. They should be flexible, comprehensive, and coordinated.”
# Strategies for Supporting Families

<table>
<thead>
<tr>
<th>Information and Navigation</th>
<th>Networking and Community Connections</th>
<th>Services and Goods Directed to Family Unit</th>
</tr>
</thead>
<tbody>
<tr>
<td>• Best practices and values within and outside of disability services</td>
<td>• Family-to-Family Support</td>
<td>• Planning for current and future needs</td>
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<tr>
<td>• Accessing and coordinating community supports</td>
<td>• Self-advocacy organizations</td>
<td>• Respite/Childcare</td>
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<td>• Advocacy and Leadership skills</td>
<td>• Sib-shops</td>
<td>• Adaptive equipment</td>
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<td>• Useful information</td>
<td>• Support Groups</td>
<td>• Crisis prevention and intervention</td>
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<td></td>
<td>• Professional Counseling</td>
<td>• Systems navigation</td>
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<td></td>
<td>• Non-disability community support</td>
<td>• Home modifications</td>
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<td>• Health and wellness management</td>
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It is Time to Reframe Our Thinking from Building Systems That Deliver Services to Systems That Support Families and Individuals

• The Community of Practice for Supporting Families of Individuals with I/DD involves working with six states to develop systems of support for families throughout the lifespan of their family member with intellectual and developmental disabilities (I/DD).
What brings us here today?

The UCEDDs and LENDs continue to play an essential role in advancing thinking, practice and policy to support families

• Explore NIRS and develop a template to describe work we do that supports families
  – Key words

• We want to represent and share our work
# Supporting Families - Template

## Overview of UCEDD Activities: Supporting Families Agenda

<table>
<thead>
<tr>
<th>Overview of UCEDD Activities: Supporting Families Agenda</th>
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</thead>
<tbody>
<tr>
<td><strong>About the UCEDD</strong></td>
</tr>
<tr>
<td><strong>Highlights of UCEDD Financial and Infrastructure Commitments</strong></td>
</tr>
<tr>
<td><strong>Focus of the UCEDD Impact</strong></td>
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## 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.

## NIRs DATA

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<th>DISCOVERY &amp; NAVIGATION</th>
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<td>Information, education, and training on best practices within and outside of disability services</td>
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<td>Formal and informal structures for peer support</td>
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The Quest for Data

Who does this work reach in Michigan?

<table>
<thead>
<tr>
<th>Number of people w/IDD who may need services and supports</th>
<th>Unserved</th>
<th>Number of people with IDD who received services and supports</th>
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</thead>
<tbody>
<tr>
<td>145,466^a</td>
<td>101,566</td>
<td>43,900^b</td>
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Who does this work reach in IL?

<table>
<thead>
<tr>
<th>Who may need services and supports</th>
<th>With unmet need for services</th>
<th>Who received residential services</th>
<th>Who received family support</th>
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<td>132,015</td>
<td>22,598^b</td>
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Est. total of 189,367^a Individuals with IDD in IL
Institute on Disability and Human Development – Illinois’ UCEDD

- IDHD is dedicated to promoting the independence, productivity and inclusion of people with disabilities into all aspects of society.

- Through research, dissemination, clinical services and pre-service training, we emphasize 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.
Highlights of IL UCEDD Financial and Infrastructure Commitments

• Host the Sibling Leadership Network national office and the Executive Director position

• Staff salaried positions for Self-Advocacy Specialist as well as bilingual family support for Latino families

• Support for Grupo Salto, a support group for Latino families of people with intellectual and developmental disabilities (IDD)

• 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

- Who may need services and supports: 132,015
- With an unmet need for services: 22,598$^b$
- Who received residential services: 29,809$^c$
- Who received family support: 4,945$^c$ (2.6%)

$^a$ U.S. Census (2013). IL census data by the 1.47% prevalence rate of DD
$^c$ 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.
Policy, Systems and Societal Change

• Latino Family Support Research Projects
• Sibling Leadership Network
• Sibling Policy Forums
• The State of the States in Developmental Disabilities
• Special Education Advocacy training for families
• Evaluations of institutional closures
• Rehabilitation Research and Training Center on DD and Health
## Strategies for Supporting Families

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Illinois UCEDD Activities

*Discovery and Navigation*

- LEND
- The Future is Now
- Research Brief on Family Support in Managed Care
- The National Gateway to Self-Determination
- Pre-service training for students on family support
Illinois UCEDD Activities
Connections and Networks
• Support group for Latino families
• ASPiE
• Sibling Leadership Network
• Dating Skills Groups and Parent Education About Sexuality
• Taking Charge: Directing Your Supports
• Self-Advocacy Specialist
• Peer to Peer HealthMessages™ Program
Illinois UCEDD Activities

Day to Day Needs

• Assistive Technology Unit
• DD Family Clinics
• Intervention study for Latino mothers of children with disabilities
Michigan’s Center for Excellence in Developmental Disabilities
Policy, Systems, and Societal Change

- Possibilities Video Series
- Michigan Developmental Disabilities Practice Improvement Team
- Michigan Fetal Alcohol Spectrum Disorders Task Force
- Detroit Wayne Mental Health Authority Quality Care Task Force
Michigan Supporting Families (2013)

Number of people w/IDD who may need services and supports: 145,466\(^a\)

Unserved: 101,566

Number of people with I/DD who received services and supports: 43,900\(^b\)


Core Grant Supporting Families

• Research and Evaluation: Family Quality of Life Studies

• Community Services
  – Training
    • Empowerment Education for DSPs: Individuals with disabilities and Family Members are project trainers
    • Sponsor of Culture of Gentleness Conference 2014
    • Michigan Supporting and Including Brothers and Sisters 2014 Conference Sponsor
  – Technical Assistance: Information and Referral Services
Core Grant Supporting Families

• Interdisciplinary and Pre-Service Preparation
  – Individuals with disabilities and Family Members as trainers in courses
  – DDI Webinar Series for continuing education

• Information Dissemination: Webinars, DVDs, Social Media
Discovery and Navigation

- DDI Monitoring Project
- National Core Indicators
- The Arc Michigan Consumer Satisfaction Survey
- Partners Against Violence and Injustice in Michigan
Discovery and Navigation

- DDI Graduate Certificate Program in Disabilities
- Empowerment Education, Consumer-Driven Training for Michigan Direct Support Professionals
- DDI Webinar Series
Connections & Networks

- Michigan Partners for Freedom
- Michigan Alliance for Families
- Michigan Supporting and Including Brothers and Sisters
- Michigan Self-Determination Peers
Day to Day Needs

- Supporting the Educational Achievement of Minority Families
- Project TEAM: Teens Making Environment and Activity Modifications
- Students Sharing Success Learning Community
- Prescription Drug Research for Individuals with a Medical Diagnosis and I/DD
- Emergency Preparedness
Michigan: Lessons Learned

- “Family” in the NIRS Title or Activity
- Regular monitoring of NIRS entries
- Consciously thinking about how an activity supports individual, family
Oklahoma UCEDD

• We work in partnership with people with disabilities, their family members, students and professionals.

• Our partnerships enable us to identify issues, ideas, and perspectives that are the basis for planning to promote systems change, advocacy and capacity building.
Highlights of UCEDD Financial and Infrastructure Commitments

• Provide a salaried position for a family member and a self advocate who are staff at the UCEDD serving in leadership and advocacy roles at the state and national level. One is the LEND family faculty.

• Provide financial support to individual family and self advocate leaders and to Oklahoma’s Family to Family organization.

• Provide training and technical assistance
  – Direct services to support families
  – Preservice education in which families are trainers and mentors for students
How We Address Policy, Systems and Societal Change

Family and Self-Advocate Leadership: The Oklahoma UCEDD and Oklahoma LEND support both family and self-advocate leaders through mentoring, stipends and technical assistance to the Family Leadership Council (FLC) of Oklahoma and the Oklahoma Self-Advocacy Network (OKSAN).

Oklahoma Blue Ribbon Panel: The Oklahoma UCEDD and the Oklahoma Developmental Disabilities Council are key participants in the Governor’s Blue Ribbon Panel to improve services and address Oklahoma’s waiting list for people with intellectual and developmental disabilities. The Wingspread Report on Supporting Families is the standard for recommendations from the panel.

Closure of State Institutions: Oklahoma is closing state-run facilities by 2015. The Oklahoma UCEDD, in partnership with the Oklahoma Developmental Disabilities Council, has provided leadership in Person Centered Plan Facilitation for residents moving out of one the state facilities.
How We Address Policy, Systems and Societal Change

• Community of Practice in Supporting Families Across the Lifespan:
  – The Oklahoma UCEDD and the Oklahoma Developmental Disabilities Council are participating with Oklahoma Developmental Disabilities Services in a federal initiative funded by the U.S. Administration on Community Living, Administration on Intellectual and Developmental Disabilities.
  – Five states were selected to identify and implement policies and practices that will serve as a national framework for states to use to support families with members with I/DD across the lifespan
Who does this work reach?

60,837 estimated Oklahomans with Developmental Disabilities

- 74% (46,451)
- 15% (9,030)
- 11% (5,356)

Unknown: No services from DDS and not on the waiting list

Waiting List: No services from DDS

Receiving services from DDS: Waiver or State Funded

60,837 estimated Oklahomans with Developmental Disabilities
**Strategies for Supporting Families**

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Oklahoma UCEDD Activities
Discovery and Navigation

• Person Centered Thinking Training
• Self Advocate Leadership Training
• Joining Forces Conference and Rural Institutes
• Preservice Training and Mentoring of Students
• Family Leadership in Child Welfare
• Family focused training topics, ie. *Telling Your Story*
• *Guide to Services in Oklahoma* - product and training for families and professionals.
Oklahoma UCEDD Activities
Connections and Networks

• **Oklahoma Family Network** is the Family to Family Health Resources in Oklahoma and is located within the UCEDD.

• **Oklahoma Self Advocacy Network** is a partnership with self-advocates the Oklahoma UCEDD, the DD Council, Oklahoma People First, the Oklahoma Disability Law Center, and Oklahoma Developmental Disabilities Services.

• **Waiting List Meetings** - The Oklahoma UCEDD has a leadership role in planning and facilitating the Oklahoma DD Services Waiting List Meetings.

• **Family Leadership Council of Oklahoma** is a partnership of the Oklahoma UCEDD and Oklahoma LEND. The Council brings together family leaders to address ways to enhance statewide leadership and advocacy.
Oklahoma UCEDD Activities
Day to Day Needs

- **Oklahoma Family Support 360° Center**: Funded primarily by the Oklahoma Department of Human Services, provides direct support for families of children with intellectual and developmental disabilities who are Medicaid eligible.

- **Person Centered Thinking Plan Facilitation**: In partnership with the DD Council and Bios, Inc., provide individual person centered plan facilitation for people with I/DD and their families.

- **Oklahoma Respite Resource Network**: Involved in re-establishing or reorganizing the respite network.
Highlights of UCEDD Financial and Infrastructure Commitments-Wisconsin

- Family Support and Leadership is one of seven Areas of Emphasis for the UCEDD [http://www.waisman.wisc.edu/cedd/AoEabout.php](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.
Family Support & Leadership Area of Emphasis

Within the Family Support and Leadership Area of Emphasis, the Waisman Center UCEDD works to promote and strengthen the participation of families that include a person with disabilities in partnerships with professionals and providers, community members, and elected officials. With their participation in family support and leadership-building activities, families are able to assume a role in the improvement of systems of supports and service for people with disabilities and are an invaluable asset to providers and policy makers. Best practice recognizes that family members and individuals with disabilities provide a perspective critical to the successful development of effective policies and practices. Family involvement will increase the likelihood that systems of support and services are helpful, effective, and efficient and provide the greatest possible flexibility regarding the nature and use of services and support and maximize community inclusion and natural supports.

Family Support is a philosophy, a way of delivering services, and a way of organizing systems to support families in ways that maximizes their capacity, strengths, and unique abilities so they can support, nurture, love and launch individuals with disabilities within their family. Resources are allocated in ways that maximize the flexibility and responsiveness to unique and individual needs of families to accomplish this.
What can UCEDD’s do to advance thinking, practice and policies that support families?

**GOAL:** The 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. (Wingspread 2012)

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<tr>
<th>UCEDD AREAS OF EMPHASIS</th>
<th>SUPPORTING FAMILIES STRATEGIES</th>
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<tbody>
<tr>
<td>Quality Assurance</td>
<td>Discovery &amp; Navigation</td>
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<tr>
<td>Education &amp; Early Intervention</td>
<td>Connections &amp; Networks</td>
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<tr>
<td>Child Care-Related Activities</td>
<td>Services And Supports</td>
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<td>Health-Related Activities</td>
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<td>Employment-Related Activities</td>
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<td>Transportation-Related Activities</td>
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<td>Recreation-Related Activities</td>
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**UCEDD CORE FUNCTION**

**RESEARCH**
- Basic and applied research
- Policy analysis
- Research to practice
- Evaluation and impact

**EDUCATION**
- University students
- Practicing professionals
- Policy makers
- Direct care providers
- Individuals and families

**SERVICE**
- Conducting evaluations
- Clinical and other intervention services
- Connecting with emerging technology
- Providing direct health care services
- Evidence-based practices

**DISSEMINATION**
- Articles in academic journals
- Reports and newsletters
- Conferences and meetings
- Internet and social media
Policy, Systems and Societal Change

- Family Support systems change initiatives
- Monitoring System Issues for Children/Youth with Special Needs
- Survival Coalition of Wisconsin Disability Organizations
- Health Disparities and Individuals with Developmental Disabilities Initiative
- Think College-Wisconsin
- Promise Grant-Wisconsin
Waisman Center-UCEDD

Direct Services to Individuals and Families
- Waisman Resource Center provides information and assistance to callers and visitors
- Early Childhood Program model inclusive childcare
- Specialty clinics
- AIDD Family Support and Family Support 360 grants
- Self-Directed Services Initiative
- Sound Response

Community Training and Technical Assistance
- Families As Leaders
- LOV-Dane community organizing initiative
- Coalition and Advisory Group UCEDDD participation
- CYSHCN Collaborators Network
Pre-Service Training

- MCH LEND (Leadership Education in Neurodevelopmental and Related Disabilities) Family Support and Self-Advocate discipline
- Peer Support and Peer Network
- Transitioning Together

Research and Evaluation

- Leanne Smith on understanding the impact of having a child with I/DD on the family
- Marsha Mailick Seltzer life course impacts of disability on the family
- Day with the Experts

Family Support and Leadership-Related Waisman Center Products

Public Policy Specialist

Areas of Emphasis
Questions & Discussion

• How to Ask a Question
  • You can ask a question by pressing the ＊ then # key to request the floor. Questions will be answered in the order they are received.
  • Type your questions into the ‘Chat’ box below the slides and the moderator will read the questions.
What is your organization doing around Family Support?

• Information and Training
• Emotional Support
• Family Support “Services”
• Research
Thank you for your participation in this webinar.

Visit the Websites
- AUCD Website: http://www.aucd.org
- Family Support SIG Website: http://www.aucd.org/template/page.cfm?id=864

Questions about the Family Support SIG?
- Steering Committee Members:
  - Katie Arnold - kkeiling@uic.edu
  - Wanda Felty - wanda-felty@ouhsc.edu
  - Liz Hecht - hecht@waisman.wisc.edu
  - Angela Martin - angela.m.martin@wayne.edu
  - Vyonda Martin - vyonda-martin@ouhsc.edu
  - Sheli Reynolds - reynoldsmc@umkc.edu
  - Rachel Patterson - rpatterson@aucd.org (AUCD Staff Contact)

Please take a few minutes to complete our survey!