

Information and Resource Handout
for
AUCD's Family Support Special Interest Group (FS SIG)

LEND Family Discipline Network



What Is the Lend Family Discipline Network?

The Network consists of family members who have served as LEND faculty members for as long as 25 years as well as family trainees and other interested LEND administrators/faculty. Since 2004, Family Discipline Faculty have worked together to address issues unique to family inclusion in LENDs and beyond. Members represent LEND programs across the country and bring their experience in academic and advisory capacities in numerous areas. They have also provided technical assistance through their AUCD 2007 publications: *“Promising Practices in Family Mentorship”*, *“LEND Family Discipline Competencies”*, and *“Partnering with Professionals: Family-Centered Care from the Family Perspective”*, Journal of Family Social Work (2010) as well as numerous presentations at the annual AUCD and AMCHP Conferences. Since 2013 they developed The LEND Family Involvement Assessment; a national survey identifying graduating LEND trainees’ perception of the impact and importance of family involvement (of any kind) in their LEND experience. This survey identified eight types of family involvement including: 1) family members serving in the professional role of LEND or university faculty and staff, 2) family members serving as interdisciplinary team members in clinical settings (e.g., family support coordinators), 3) families from the community serving as mentors to host LEND trainees for home or community visits, 4) families sharing their personal stories as guest presenters or panelists during LEND, 5) family members from the community serving as LEND program advisors, as advisory board members, research participants, or consultants for clinical issues or thesis preparation, 6) training curricula that incorporate topics specifically focused on family and disabilities, 7) family members participating as LEND trainees from the family discipline and 8) family members participating in program planning, implementation, and evaluation. The LEND Family Involvement Assessment has consistently endorsed the value trainees place on family involvement and how much that involvement has contributed to the impact of their LEND experience.

11/2015- 12/2016 Activities

- Presentation at AUCD of the findings of the Development of the Family Recruitment Survey (summer 2015)
- Presentation at the Patient-Centered Primary Care Collaborative (PCPCC) on Family Involvement in Training
- Family Involvement Survey – 26 LENDs participated
- White Paper based on findings of the LEND Family Involvement Survey and Implications for other MCHB and related training programs – *in progress*
- Collaboration with the FS SIG to identify family support curricula – *in progress*
- Creation of the LEND Family Discipline Trainee Facebook page
- Presentation at AUCD 2016 - *Fabric Not Fringe: Weaving Family Involvement Strategies into LENDs and Other Professional Disability Related Training Programs*

The National Community of Practice for Supporting Families of Individuals of I/DD

The National Community of Practice for Supporting Families of Individuals of I/DD originally began in 2012 as a project funded by the Administration for Intellectual and Developmental Disabilities - Connecticut, District of Columbia (DC), Oklahoma, Tennessee, Washington and Missouri (as the mentor state)- to build capacity through a community of practice across and within these states to create policies, practices and systems to better assist and support families that include a member with I/DD across the lifespan.

Participating states have changed the front door to the system, improved cultural considerations in supporting families, guided and influenced policymakers and helped shape waivers and other Medicaid authorities to focus on supporting families and individuals throughout the lifespan. The National Association of State Directors of Developmental Disabilities Services (NASDDDS), along with the University of Missouri Kansas City Institute for Human Development (UMKC IHD), partner to support states, work to impact national policies, develop products and tools, and provide technical assistance.

In July 2016, eleven (11) new states joined the CoP in addition to the original states. While each state approach varies, all participate with the mutual commitment to support the goals identified in the 2011 Wingspread Family Support Summit which is as follows, "Overall Goal of Providing Support: 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 more information, visit <http://supportstofamilies.org/>

The Family Support Research and Training Center (FSRTC)

The Family Support Research and Training Center (FSRTC) is a collaboration of researchers and organizations who are focused on synthesizing and generating knowledge about the needs and experiences of families who provide support to children and adults with disabilities across the life course. Because family support is similar across different types of disability and across different age groups, we aim to bridge different resources and information across these groups to inform more cohesive policies and practices related to family support.

The FSRTC aims to engage families and stakeholders in investigating the needs of families who support their family members with disabilities, and in exploring the kinds of supports and promising practices that are needed for families to fulfill this important societal role. The FSRTC has three main objectives: (1) Define the state of science in family support; (2) Generate new knowledge in the critical policy areas of self-direction and managed care and in culturally competent peer-to-peer family interventions; and (3) Generate and implement a vision for policy and practice in family support through a national resource center.

The FSRTC is housed at the University of Illinois at Chicago's Institute on Disability and Human Development. **For more information, visit: <http://fsrtc.ahslabs.uic.edu/>**

The Council on Community Advocacy (COCA)

The Council on Community Advocacy (COCA) assists AUCD Central Office and network programs in advancing policy and practice for and with people with disabilities, their families and communities. The Council supports the association by:

- Building effective partnerships with other AUCD Councils and Committees, federal agencies, and other national disability groups.
- Building the capacity of local University Center Consumer Advisory Committees (CACs), including identifying needs for assistance, providing technical assistance, and disseminating information about exemplary and innovative practices.
- Envision, actively advocate for, and disseminate information about the next generation of policy, legislation, and practice that will help make the promise of full participation a reality.
- Developing leaders and mentors from the community of individuals with disabilities and family members in addition to our professional partners that build the capacity of the network to affect change at the local, state, and national levels.
- Assisting in the development of standards for participation of people with disabilities and family members in UCEDD education, research, and service programs and in AUCD functions.
- Serving as a model and resource for others working to infuse the participation of people with disabilities and family members into disability and community program planning, research, and evaluation.

The Council leadership structure includes several internal committees and two co-chairs. Council By-Laws stipulate that one co-chair must be an individual with a disability, and the other be the family member of an individual with a disability. The three-year, staggered co-chair positions carry with them a seat on AUCD's Board of Directors.

Full Council membership consists of one representative of each UCEDD, designated by that UCEDD's director. The Council continues to strive to meet its long-term goal of full membership. The COCA has engaged in strategic planning and activities as part of its mission. Most recently, in this vein the Council completed a survey, report, and recommendations on AUCD network supports to advocates, particularly those with disabilities. It has also engaged in collaboration with other AUCD Councils, most recently the Council on Research and Evaluation in developing a webinar on advocacy and research.

FEDERAL LEGISLATION IN SUPPORT OF FAMILIES WITH A FAMILY MEMBER WITH IDD

LEGISLATION PASSED INTO LAW

Older Americans Act of 2006

The Older Americans Act of 1965 was the first federal level initiative aimed at providing comprehensive services for older adults. It created the National Aging Network comprised of the Administration on Aging on the federal level, State Units on Aging, and Area Agencies on Aging at the local level. The network provides funding for nutrition and supportive home and community-based services, disease prevention/health promotion services, elder rights programs, the National Family Caregiver Support Program, and the Native American Caregiver Support Program. In 2016, the reauthorization of the Older Americans Act expanded access to the NFCSP, making its services available to older parents of adult children with a disability.

Lifespan Respite Care Act of 2006

The Lifespan Respite Care Program was authorized by Congress in 2006 under Title XXIX of the Public Health Service Act (42 U.S.C 201). Lifespan Respite Care programs are coordinated systems of accessible, community-based respite care services for family caregivers of children and adults of all ages with special needs. Such programs reduce duplication of effort and assist in the development of respite care infrastructures at the state and local levels. Once implemented, Lifespan Respite Care programs work to improve the delivery and quality of respite services available to families across the age and disability spectrum.

Since 2009, Congress has appropriated approximately \$2.5 million per year to implement Lifespan Respite Programs. As of 2016, competitive grants of up to \$200,000 each were awarded to eligible agencies in thirty-five states and the District of Columbia.

Family Opportunity Act of 2005

The Family Opportunity Act (FOA) is federal legislation passed as part of the Deficit Reduction Act of 2005. It offers states the opportunity to:

- Apply for one of up to ten Home and Community Based Services (HCBS) demonstration waivers for children with severe emotional disturbances;
- Apply for grants to fund Family-to-Family Health Information Centers;
- Restore Supplemental Security Income (SSI) benefits to certain previously eligible families of children and youth with special health care needs (CYSHCN); and,
- Create a buy-in program to expand Medicaid coverage to children who meet SSI disability criteria and whose family incomes are too high to be eligible under current regulations but fall below 300% of the Federal Poverty Level (FPL).

Families of Children with Disabilities Support Act of 2000

Title II of the Developmental Disabilities Act, titled Families of Children with Disabilities Support Act of 2000, addresses issues of family support. The purpose of this title is to assure that individuals with developmental disabilities and their families participate in the design of and have access to needed community services, individualized supports, and other forms of assistance that promote self-determination, independence, productivity, and integration and inclusion in all facets of community life, through culturally competent programs authorized under this title. PNS provides the only source of funding for the Title II Family Support. Cuts in 2011 eliminated funding to state projects under this Title.

Medicaid Home and Community-Based Waivers

Medicaid HCBS provide services to the eligible individual, but that can also benefit the family. These include, for example home modifications, respite, personal or attendant care and family and consumer education. Medicaid managed long-term supports and services are also starting to recognize the important role of families and offer supports such as caregiver assessment, and in some instances supports and services.

Individuals with Disabilities Education Act (IDEA) Parent Training and Information Centers

Parent Training and Information Centers (PTIs) and Community Parent Resource Centers are authorized in Part D of the Individuals with Disabilities Education Act (IDEA) and are funded by the U. S. Department of Education, Office of Special Education Programs. Parent centers serve families of children and young adults from birth to age 22 with all disabilities: physical, cognitive, emotional, and learning. They help families obtain appropriate education and services for their children with disabilities; work to improve education results for all children; train and inform parents and professionals on a variety of topics; resolve problems between families and schools or other agencies; and connect children with disabilities to community resources that address their needs.

PENDING LEGISLATION

RAISE Recognize Assist, Include, Support and Engage Family Caregivers Act

U.S. Senator Tammy Baldwin, a member of the Health, Education, Labor and Pensions (HELP) Committee, today applauded the passage of her bipartisan *Recognize, Assist, Include, Support, and Engage, or [RAISE Family Caregivers Act](#)*, by the United States Senate. Introduced with U.S. Senator Susan Collins (R-ME), the legislation would direct the Secretary of Health and Human Services to establish and sustain a National Family Caregiving Strategy to support family caregivers. The Strategy shall identify specific actions that Federal, State, and local governments, communities, health care, long-term services and supports and other providers, employers, and others can take to recognize and support family caregivers in a culturally competent manner, including with respect to the following: Promoting greater adoption of person- and family-centered care in all health and long-term services and supports settings, with the person receiving services and support and the family caregiver (as appropriate) at the center of care teams. The legislation will now move to consideration by the House of Representatives.

ABLE Act of 2014- Proposed Amendments to the Act, June 2016

On March 17, a bi-partisan group of Members of Congress introduced a package of bills aimed at enhancing the benefits provided through the [Achieving a Better Life Experience \(ABLE\) Act](#). This package of bills consists of the following three pieces of proposed legislation: the [ABLE Age Adjustment Act \(S. 2704/HR 4813\)](#) would raise the age limit for ABLE accounts to age 46. Currently, individuals with a severe disability that occurred prior to the age of 26 are eligible to open an ABLE account. The [ABLE Financial Planning Act \(S. 2703/HR 4794\)](#) would allow families to rollover savings in a 529 college savings plan into an ABLE account. The [ABLE to Work Act \(S. 2702/HR 4795\)](#) would allow individuals and their families to save more money in an ABLE account if the beneficiary works and earns income.