

**Family Support Special Interest Group (FS SIG)
of the Association of Centers on Disability (AUCD)**

BACKGROUND

University Centers for Excellence in Developmental Disabilities (UCEDD) have played key roles in family support for a decade or more. Some UCEDDs have contributed to research in the area of family support.

SIGs are open to anyone in the network, serve as a mechanism for sharing information, engaging in dialogue, and generating new ideas. SIGs are led by one or more individuals from the network (with AUCD staff support if needed); they typically meet in person at the AUCD Annual Meeting and may share information via email, conference call, or webinars throughout the year. Because SIGs are driven by the interests of the AUCD membership, new SIGs may emerge while ones that have run their course may disband.

Others have established and maintained active family support councils to address systems change locally, statewide and nationally. UCEDDs have employed family members as faculty and staff in their programs and many recognized leaders in family support are associated with UCEDD and/or LEND programs.

From 1999 - 2011, at least 16 UCEDD programs managed family support initiatives funded by the US Administration on Developmental Disabilities (ADD) discretionary grants for *Projects of National Significance (PNS)*. Some of these initiatives were Family Support Systems Change grants and others were *Family Support 360^o* grants.

In 2008, AUCD agreed to establish a Family Support Special Interest Group. AUCD Special Interest Groups (SIGs) are made up of individuals in the AUCD network who have a common topical interest.

In 2009, UCEDDs were excluded as eligible applicants in PNS funding for Family Support PNS grants. Family Support continued to be a focus within many UCEDDs and the importance of forming a cohesive network to promote discussions, shared learning and to raise the importance of Family Support within the AUCD network became more apparent.

CHRONOLOGY OF KEY ACTIVITIES

November 2008: The initial FS SIG Meeting was held at the AUCD Conference and Annual Meeting, Washington, DC. The Family Support SIG was started for the purpose of bringing UCEDD members together to share information and identify ways to promote forward movement in all areas of family support. Twenty-two people representing UCEDD and LEND programs attended the meeting. The focus of the meeting was on identifying what the UCEDD and LEND programs are currently doing in the area of family support and leadership and to identify ways to raise awareness of family support and leadership within the UCEDDs and AUCD.

August 2009: FS SIG Conference Call – Twelve people participated in the conference call. The focus of the meeting was on developing strategies for elevating family support and leadership within the individual UCEDDs and the network as well as forming a network to address family support nationally.

October 2009: FS SIG Conference Call -Seventeen people participated. The focus of the call was on further actions to ensure that family support and leadership are recognized as a body of practice and components of the UCEDD core functions.

November 2009:

The 2nd FS SIG Meeting was held at the AUCD Conference and Annual Meeting, Washington, DC. Members of the FS Sig participated in groups to address two questions: 1) How do we make Family Support and Leadership part of our core work and values within the UCEDD and LEND?; 2) How do we play a key role in moving family support and leadership forward at the national level? The groups identified the need to raise national awareness of family support and leadership as well as the need to identify logical roles for the UCEDDS in moving the family support agenda including research, literature support and infusing family support into all aspects of the UCEDD core functions. The group also identified a need to meet with the new Commission of ADD to share information about the UCEDD work in family support and leadership and to determine the Commissioner's interests in this area.

A subgroup of FS SIG met with Sue Swenson, former ADD Commissioner, and Kim Musheno, AUCD Director of Legislative Affairs to discuss ideas and issues related to planning a national agenda for family support.

March 2010: An informal **email survey** was sent to FS SIG members to solicit points to consider in preparing family support briefing materials for newly appointed ADD Commissioner, Sharon Lewis.

April 2010: A small **workgroup** of FS SIG members met in Washington DC to develop strategies and talking points for meeting with Commissioner Lewis and to discuss strategies to advance a national agenda on family support. The group also reviewed and made recommendations for the Family Support section of the DD Act. Based on the meeting in April, a representative group was designated to meet with the commissioner.

May 2010: A **conference call** was hosted with the small workgroup to continue activities and assignments from the April meeting in Washington DC.

June 2010: FS SIG members participated in a **meeting with ADD Commissioner Sharon Lewis** to discuss the Commissioner's vision and plan for family support. Based on this meeting, Commissioner Lewis agreed to support a national conference to address planning a national agenda for family support. Commissioner Lewis requested that a diverse group of leaders be represented in the planning of the conference and in the conference participants.

July 2010: A **proposal** was submitted to secure funding for the national conference and upon confirmation of the funding; a coordinator was hired to manage the planning efforts for the conference. A planning committee was established and a proposal was submitted to the Johnson Foundation to request that they host the conference at Wingspread.

November 2010: The 3rd FS SIG Meeting was held at AUCD Annual Meeting and Conference. Members were updated on activities during the past year, which included a meeting with the ADD Commissioner. Attendees discussed how their UCEDD was elevating family support and leadership and what their UCEDD calls family support activities/programs. Members discussed having an FS SIG repository for family support information, a list serve and a research sub-committee.

December 2010: Twenty-seven FS SIG members completed a **survey** to provide feedback to the Family Support Summit planning committee that has been put together on behalf of the Administration on Developmental Disabilities (ADD).

March 2011: FS SIG members attend the **Wingspread Conference** (Family Support Summit) in Wisconsin. The Wingspread Planning Committee appointed staff from two UCEDDs, who are SIG members, to develop the Wingspread Final Report.

Spring 2011: FS SIG members attended the ***Envisioning the Future*** regional summits/listening sessions sponsored by the Administration on Developmental Disabilities.

September 2011: AUCD signed onto a Lifespan Respite Coalition letter to federal appropriators urging full funding for the Lifespan Respite Care Act, Title II Family Support program, and the National Family Caregivers Support program.

October 2011:

The Family Support SIG email list was opened up to the full membership in the form of a list-serve hosted by AUCD and a Family Support website was established on the AUCD site.

AUCD signed onto a coalition letter to the Joint Committee on Deficit Reduction (Super Committee) urging support for all programs that support family caregivers, including the Family Support programs funding through the Projects of National Significance.