

**Family Support Special Interest Group (SIG) Meeting  
AUCD Annual Meeting and Conference  
Washington, DC  
November 18, 2013  
Meeting Notes**

**Attendees:** Wanda Felty, Rachel Patterson, Susan Yuan, Barbara Levitz, Ann Palmer, Emily Holmes, Sheryl Feuer, Karen Irick, Cindy Fisher, Susan Bryant, Richard Glaesser, Heather Williamson, Jennifer Marshall, Catherine Mikitka, Melissa Mullineaux, Katie Arnold, Matt Bogenschutz, Tera Yoder, Bahjo Mahamud, Heba Atyah, Maureen DeLongis, Michon Swemon, Janet Seide, Elizabeth Adeler, Fran Goldfarb, Jeannie Dwyer, Carol Reitz, Sally Harlow, Alexandra Ellison, Paula Burckhard, Jenness Roth, Mark Smith, Susan Palmer, Renee Alvarez, Tia Nelis, Lynda Honberg, Barbara LeRoy, Glenn Fujiura, Tamar Heller, Angela Martin, Sheli Reynolds, Liz Hecht, Kim Musheno

### **Welcome and Overview**

- **Introduce Steering Committee:** Members introduced themselves and invited participants to join the steering committee and provided a brief description of the steering committee activities including coordinate training opportunities on FS, facilitate the listserv, highlight national policy proposals impacting families, and to facilitate discussions regarding promising practices in FS
- **Review Revised FS SIG Purpose Statement:** Participants were asked to review the updated statement and invited to offer feedback or comments via the FS SIG listserv.

Handout: Family Support Special Interest Group of AUCD Purpose Statement

- **Introductions:** Participants were asked to indicate which UCEDD or LEND they represent, their perspective (individual with a disability, family members, UCEDD/LEND staff, etc.), and their participation in the FS SIG (first-time participant, previous participant). It should be noted that the majority of first-time participants greatly outnumbered previous participants.

Handout: Family Support Special Interest Group of AUCD Chronology

### **FS SIG Website and Partnerships**

- **Introduce New SIG Website:** Rachel Patterson created an updated version of the FS SIG website. This page can be accessed at the AUCD website: <http://www.aucd.org/template/page.cfm?id=864>. The website is listed on the "Issues" tab at the AUCD website under "SIG" (Special Interest Groups).
- **Update on Sibling Leadership Network (SLN):** Katie Arnold provide an update on recent activities/status of the SLN. The SLN has grown to 13 state chapters with 17 additional

state chapters in development. In June, the SLN hosted a national conference in Pittsburgh with more than 80 participants. Yesterday, the SLN collaborated with the FS Community of Practice project, Self-Advocates Becoming Empowered (SABE), and National Youth Leadership Network (NYLN) to facilitate a AUCD Conference Pre-Conference Session on advancing the movement of Self-Determination together which was well attended.

## **Federal Policy Updates**

- Kim Musheno, AUCD Director of Legislative Affairs, and Rachel Patterson, AUCD Policy Analyst, provided updates on the following legislation:
  - Family Medical Leave Act
  - Lifespan Respite Act
  - National Family Caregiver Support Program
  - Older Americans Act
  - UN Convention on the Rights of Persons with Disabilities
  
- The following pieces of legislation were also highlighted as potential support and advocacy opportunities:
  - Funding for Family to Family Health Information Exchange Projects
  - Newly proposed legislation regarding estate plans and self-management of plans by individuals with disabilities

## **National Initiatives Updates and Discussion**

Sheli Reynolds provided an overview of the evolution of the movement to support families and the federal grant initiatives (past and current) aimed at supporting families. Over the last several decades there has been an evolution of supports that began with family advocating on behalf of individuals with disabilities (primarily parent advocacy) which gave rise to the self-advocacy movement with individuals advocating on their own behalf, and now an expansion to include a sibling movement. However, this transition has also resulted in a diverse set of policies and practices of programs that is identified as “family support”. As a result, the Administration on Intellectual and Developmental Disabilities (AIDD) sought to comprehensively describe these services and support, building a National Agenda of Family Support. In 2012, the “Wingspread Report: building a National Agenda of Family Support” was published (website:

<http://www.familysupportagenda.org/FSNA/nationalagenda/partners.aspx>). From this report several recommendations including a more comprehensive definition of FS, recommendations for ongoing data collection regarding FS, and recommendations related to funding of FS services and supports. Following this report, AIDD has utilized its grant resources to fund several initiatives focused on data collection. The currently funded projects are the National Community of Practice on Supporting Families of Individuals with Intellectual and Developmental Disabilities across the Lifespan, Family Information System Project, and the

Residential Information Systems Project. This FS SIG is a “vehicle” to make sure FS is infused in all AUCD activities (UCEDDs, LENDs).

### **Specific Action Items and Moving Forward with the Family Support SIG**

- 1. Update FS SIG Listserv with participants who attended the meeting:** Angela has sign-in sheet and will create a database of names, contact information so participants can be added to the listserv.
- 2. Invitation to FS Community of Practice Webinars will be sent to the FS SIG Listserv:** Sheli will send this information to the FS SIG Listserv after it is updated.
- 3. CRPD Action Alerts to FS SIG Listserv:** Rachel will send CRPD Action Alerts to the FS SIG Listserv.
- 4. Family to Family Health Information Exchange (F2FHIC):** Family Voices Executive Director, Lynda Honberg, attended the FS SIG and will email an action alert to FS SIG Listserv. There is a proposed action to extended/continue funding of the F2FHIC projects.