

Association of University Centers on Disability Annual Meeting
Family Support Special Interest Group
December 3, 2012

MEETING MINUTES

OVERVIEW OF WINGSPREAD REPORT AND FAMILY SUPPORT COMMUNITY OF PRACTICE

Nationally we see an evolving, changing focus on the role of families. Not sure the extent to which UCEDDs is involved. Some funding opportunities do not include UCEDDs as eligible applicants.

Sheli Reynolds - Wingspread builds on previous work. The report is a basis for thinking about what to do next. The report intentionally changed language from family support to supporting. Main take away is the definition and strategies. Consider using in state level discussions and strategies to support families. Message-support families are directly connected to supported individual. Strategies for supporting families: discovery and navigation; families connecting with families; and services and supports. Family defined broadly by the person, not the system. Recommendations-some already happening. Federal grants from ACL/AIDD are helping states look at service system structures: NASDDDs Community of Practice grant, National data collection initiative; some federal policies imbed supporting families such as Lifespan Respite.

Nancy Thaler - Community of Practice (COP) on Supporting Families. Five year initiative to describe what state DD directors will do differently to actualize Wingspread recommendations. Modeled after a statewide employment network. Our systems are family systems not group home systems. In the 70s people with disabilities started living in communities just as their parents were aging into long-term care. State agencies on disability saw people needing support and responded with group homes. Focus now is on educating members with data and trends, well over 50% of people with disabilities are living with families. Changing state systems to support families will be a big learning curve for states. We don't know what a good system looks like, but will model after the successes with supported employment. What are the right policies for supporting families? State DD systems are generally a response to crisis system.

NASDDDS is currently meeting with organizations to get ideas for state level partners who will be part of the COP. Partners will be asked to complete a state self-assessment. Five states will be selected from applications submitted by state DD councils and/or state DD agencies. In addition to the five states participating in the COP, other activities will be open to all.

OVERVIEW OF SIBLING LEADERSHIP NETWORK

Kate Arnold - Sibling Leadership Network is particularly interested in promoting an understanding of the role of siblings as an extension of the family. In particular, siblings advocate with their brothers and sisters; maintain life long relationship; they often interact with classmates and neighbors. A current focus for the network is to insure that any definition of

families includes siblings; that policies need to include siblings; partners such as DD councils and LENDs incorporate siblings into their work. The SLN can be a resource to our network, for example to help start a state chapter.

UPDATE ON DATA PROJECTS

- National Residential Information Systems Project
- Family Information Systems Project

Chas Mosley - Family information systems project. FISP. 2005 NASDDDS talked about need for data about the family home. Saw a significant shift from group homes to people living with their families. Wanted to know more about who is getting services; what services are being provided. AIDD provided a grant to explore this further. HSRI, University of MN and NASDDDS awarded the grant. Pilot to look at what states can tell us. Approach uses a family advisory group and a technical user group. Starting slowly with pilot states. Looking at how many adults and children are served in the family home.

Also looking at expansion of National Core Indicators program as a data source (36 states currently participating).

POLICY DISCUSSION

Survey of UCEDDs. Policy change development. Systems change evidence base and research to practice, development of capacity.

- Want UCEDDs and LENDs to be better about implementing best practice about family support. Need to build current information into current curricula.
- National training directors council also looking at curricula.
- NIRS needs to collect data on FS.
- How do we impact reform initiatives to recognize the importance of supporting families? Employment, closing institutions priority. DOJ.
- How do we make supporting families matter? Need research to explain why to reach out to families not asking for help. What changes the trajectory of choices families make?
- Can we use a preventative public health model?
- Part C is model for family involvement.
- Survey for families with dd council follow up to wingspread.