Autism Community of Practice – Parent Supports Group

July 28, 2009

Attendance
Peggy Helm-Quest
Nancy Alar
Lezli Redmond
Emily Levine
Leann Smith
Amy Leventhal
Morton Gernsbacher

Agenda
1) Minutes Review
Minutes were reviewed.

2) Consensus Statement
The consensus statement was discussed at length, including issues of stigma. Illinois began their work with inviting all stakeholders and then developing the consensus statement. The document helped establish a baseline level of agreement to work on system building and collaboration. This activity provided a platform of unity and how an understanding of Autism would be applicable to all children with disabilities. See attached Illinois Consensus statement.

Conversation moved to a discussion on Stigma as an issue which leads to social isolation.

Child and family unit can be isolated both purposefully by family, by child, or by community.

The challenging behaviors become isolative for the child and for the family.

Divisiveness within the Autism Community regarding education, treatments and therapies and causation factors, including cure/non-cure philosophies, and is Autism a culture in and of itself.

Conflicts within the whole Disability Community and where Autism “fit’s” - SED, mental health disability, cognitive disability, developmental disability, and ADHD regarding where services can be provided.

It was decided that the Consensus Statement was a policy issue and that the Parent Supports Committee would hand this task over to the policy group for review and recommendations.

Priority Area 1 – Caregiver health and well-being, including reducing parental stress including trauma and grief.
Questioned
What do health care providers currently give to parents?

Gaps
• Develop a listing that parents could be given that helps them think about interventions.
• Mentoring program, similar to Hands and Voices (children that have a hearing disability) with trained parent mentors. ASW, ASW chapters, Parent to Parent. Support across the lifespan.
• Families that have a newly diagnosed infant have different goals than those whose children have been diagnosed later at ages 2-3, 5, 7, 9 and et cetera and also those who have had a diagnosis for many years. Parent’s goals may be different leading to stress. What is in place that addresses the changing needs of families and those with Autism?

**Priority Area 2 – Information dissemination**

**Questioned**
- Family support – lack of support for families/marriages
- Questions- Where to refer families for counseling?

**Gaps**
- Strength-based family support. Mental health needs of the family. Need for family therapists who understand the issues that Autism bring to the therapy session. Lack of such therapists. Where do you refer families for counseling
- Diagnosing adults. Supports across the lifespan
- Low income and minority families accessing information and services
- Common story of families “shopping’ for physician’s and providers who embrace similar philosophies as the parents

**3) Next Steps**
Parent to Parent. Peggy will send information regarding Hands and Voices and Wisconsin Sound Beginnings to this group.

**Question**
Interviewing questions when looking for a mental health provider.
Issues regarding low-income families and accessing therapists.