Family Supports and Parent Supports Groups

Present: Peggy Helm-Quest, Nancy Dumas-Milwaukee Cty, Jenny Stoufel-OT Prof UWM, Amy Leventhal, Jenny Stonemeier, Veronica Nolden, Joan Keuhl, Deb Berrang-RDI Consultant, Kate Szidon-National PD Center on Autism, Katie Hamm-SW student at UW-Madison, Leann Smith, Lisa Rupe-TALK about curing Autism, Communications Director for Autism, Stephaine Hess-parent, Sandy Magana, Joanne—Waisman Center, Steve Cash—parent, Vicki Moerchen-PT Professor at UWM, Pilar Guzman-Parent, Joan Ketterman-Sheboygan County

Are there areas of overlap where our two groups can improve areas of supports for families? Urban Autism Summit and Community of Practice

1. One area of commonality is Research and Research Support. Vicki Moerchen from UWM is conducting research with SEDA right now.

2. Interest in looking at the Waiver and how it’s being implemented. Concerns about the qualifications of the line therapists and the cultural competence of those therapists. SEDA has families while multiple children on the spectrum within one household. Some of the restrictions placed on families by being a part of the waiver don’t allow families to live a “normal” life.

3. Commonalities and addressing barriers.

4. Lack of acceptance of families with a child with ASD.

5. Helping families deal with the stigma of having a diagnosis. (dealing with denial and grief)

Parent Support Mission
Identify and promoting healthy and thriving families and supporting families in their various roles.

Urban Autism is very focused on the barriers of the needs of those families.

Mapping resources and helping families get connected to the resources in the community.

The intent of the Summit was to bring the right people to the table and identify the issues and take action.

Veronica’s update on the UAS Parent/Family Group.
1. Discussed doing outreach with information about resources. Flyers would explain the early signs of Autism, including developmental differences (behavior, etc.).
2. Talked about doing a Survey (not clear about the purpose of that).

Families struggle with accessing the resources, but also need support in addressing the lack of understanding about incidence and getting through the stereotype of what Autism looks like.

PSA about “What Autism looks like.”

Commonalities:
   Visibility

Can we think about what different needs are for families who are receiving waiver services. A child living in an isolated community may have very different needs than a middle class family who has access to more resources (family wide resources, not just money).

Families are forced to make a choice between getting voucher services or send their child to school. Those have very different focuses.

How do we solve the waiver?
   Flexibility, allow families the option to receive the services outside the home.
Give parents the opportunity to take a break. There is enough research that demonstrates that children need to receive services in an inclusive and collaborative.

How do we make sure that children and families of color are represented in the Evidence Based practice groups.

Evidence Based group will be bringing their findings to the state sometime in the next year.

Who really accesses the services that are available (who can access them, who wants to access them).

??Is this a conversation that needs to be included with the waiver providers??
OR is there an alternative for Parent Consultation model as being an effective intervention to be implemented in their own home.

NPDCVA has evidenced based information on Parent Model.

Take this issue to the Policy practice group.
   Look at other models that could be made available for parents who are receiving waiver dollars to make the use of those funds more flexible.
Wisconsin Autism Council will have list of meetings. You’ll get three minute public input time.

How do we do outreach to underserved groups all over the state? Start at schools with PTO groups, go and talk to parents. Collaborate with the schools

Wisconsin needs to be made aware of the Military Model. Lisa Rupe will bring information back to the group.