Practice Group on Community Systems

Updates:
1) Connected Robin Mathea (Parent to Parent) with Emily Levine (ASSEW) to help build a statewide network of parents with a child with ASD willing to talk with and support parent who has a child newly diagnosed with ASD.
2) Bobby Peterson from ABC for Health will be working with the Community Systems group to filter a presentation for parents concerning the new insurance mandate. This will start in November once the guidelines are published with a possible presentation date for February.

Continued discussion on the “questions parents need to ask”:
Need to understand the background of the parents in relation to geography, resource availability, socio-economic factors, insurance, etc. We want to make sure all parents have access to information and questions they need to know about to help them access resources and make decisions. Some barriers to service include socioeconomic, language, geography, cultural. Need to meet families where they are at and help them understand “what are they getting into” in relationship to in home therapy. What do we do if we don’t have space? Can there be centered based therapy?
Can information be given out at Wal-mart—where people are?

Action step:
Research what kind of access toolkits or resource map are available. CONCISE information about service delivery; step by step what to do next. Adapt a toolkit for underserved/hard to reach populations—inner city/rural/different language/literacy challenged, etc.
Group needs to talk about and decide what are we looking for in a toolkit.

Practice Group on Policy

The group decided to take further steps on the issue of data sharing between DPI and DHS, which would require an MOU between the two State agencies. This issue is at a critical juncture at this time because Dr. Durkin will be preparing the competitive application for future funding of the ASD surveillance project in December or January, and without the MOU, funding will be denied.

At DHS, Claude Gilmore (Youth Policy Director) and Dr. Seth Foldy (DPH Division Administrator) are already aware of this issue. At DPI, there is a new Superintendent (Dr. Tony Evers). Jeff Spitzer-Resnick believes that it will be possible to get a meeting with Dr. Evers soon to discuss this issue with him.
The group decided on using several different approaches together, with the following action steps:

1. Continue with the grassroots approach of letter writing already talked about and in the white paper.

2. Jeff and Nissan will work together to schedule a meeting with Dr. Evers, the new Superintendent at DPI. Emphasize what will be lost without DPI’s support. Dr. Durkin will attend the meeting as well to answer any questions. Need to make sure that if DPI’s main objection is protecting families, then we also need to have parent/family representation of some form.

3. Nissan and Jeff will also work to keep key legislators informed through contacts they already have, and to gain their support.

4. Dr. Durkin and Dan Bier will draft a letter of support that can be signed by key stakeholders, either as individuals or as representatives of their agencies or organizations. Once ready to go, the letter will be distributed via our CoP listserv.

5. Sharon Fleischfresser and Claude Gilmore will follow up within DHS to move this forward.

6. Liz Hecht and Dawn Wians will tailor information for parents and parent groups that can be sent out through various avenues, including potentially Family Voices’ listserv.

Additional issues discussed that the group will consider for future meetings:

1. working to improve the systems around the waiver to better serve families – Liz Hecht will send out information for discussion at our next meeting

2. Seclusion and restraint issues, including draft of new legislation from Jeff Spitzer-Resnick.

**Practice Group on Professional Development**

Pilar Guzman described the radio novella project that was just launched to educate Hispanic parents about resources and supports for families of children with special needs.

Area of professional development not addressed – is community development (some education and awareness) related to professional employers and others who don’t have a basic knowledge, need training (mention of “old” JEFA program – job training program for people with disabilities, job coach system, employers had sliding pay scale for trainee
– this may be something the transition group is working on), now Laura Owen’s CEO program with national recognition, resource for transition group

Idea: Novella for employers around employing an individual with ASD

Next steps now that we have the competencies –
What universities with special ed programs and certificate programs in WI have a “minor” or specialization in serving those with ASD, are they using the competencies?

With the competencies, could also look at other programs besides special ed to see what competencies are relevant to different types of training programs?

Maybe use a portfolio system to look at what is included in an ASD specialization?

What is unique to our practice group – looking at the advanced skills needed across disciplines and agencies, how parents are included, how this works for teams

Action step – we will look at the national competencies with the framework as stated above in the unique statement

Did we finish our first goal/action plan? – we did find out what is out there, the new national competencies, other resources/material/curricula which will be available through the resource repository, this may be enough work on this first action plan.

**Practice Group on Medical Home**


Wynne shared the CYSHCN roadmap as a resource
All agreed that it would be important to have a few key basic resources to share with all families/providers

Content:
* Generic roadmap for the State (utilize existing cyshcn version as a start)
* Create insert called “Getting a Parent Started (GPS)” or the ASD/DD GPS – place for ASD specific information
* Place for child specific information to be added

Create a cover letter for providers to be signed by CYSHCN Program (Sharon); WI-AAP (Mala Mathur)
Draft product to be shared with Parent Support Group
Practice Group on Youth Transition

The group identified resource materials. Bill shared that in addition to the Ausome Social group there is now a restaurant group that includes a group of teens who go to restaurants to practice restaurant etiquette.

We discussed the need to have more of an emphasis on self determination in the transition process. Kate shared information about the Oregon Youth Transition Program [http://www.ytporegon.org/](http://www.ytporegon.org/).

We discussed the challenges to early transition including the need to start early, focus on children not just parents and make sure that individuals understand their own condition. Participants emphasized the importance of having opportunities where professionals can hear from individuals on the Spectrum. We asked if there are evidence based practices about transition through the National Professional Development Center on ASD. It was suggested that there is not yet enough research in this area.

In the Medical world there are pathways for each diagnosis. Could there be something like this for children and youth with ASD (e.g., academic essentials, after school plan, social skills, health care information, parental readiness). Could there be a cheat sheet for parents? There is a lack of consistency across the state. Could our Practice Group establish standards of best practices? How do we get the information into the hands of parents? How do we disseminate information? We want to list the venues where transition information can be disseminated including: ASW chapters, Regional Centers for CYSHCN, First Step, conferences, meetings, newsletters, websites, youth panels, statewide teacher conferences, state superintendents leadership council, principals, directors of special education and transition coordinators.

We want to make sure that we know of all of the resources available for youth in transition, so Amy will send everyone the Resource List that documents Wisconsin resources. We can update this overtime. Participants will review this and let Amy know of other items to add.

Next Meeting: Amy will send out a Doodle and subsequently set up a teleconference.

Practice Group on Parent Supports

Action Steps

- Develop questions for families to use when interviewing family counselors.
- Consider compiling guide of resources to five to families upon diagnosis – similar to Baby Steps.
Plan New Action Steps
Supporting Families
- Review brainstormed questions from the July 29 call. (all)
- Think about additional questions. Investigate existing resources for Medical Home professionals when working with families who have children with Autism. (all)
- Research the web regarding relationships – curriculum of Family therapist – investigate existing training materials for MH professional for kids on autism.
- Bring information on Colorado’s “Give Me a Break” program, especially the section on how to select respite. Begin thinking about developing booklet or notebook for the child to share information to the provider. (Deb and Emily)

How is this Practice Group Unique?
This group focus is on - Promote healthy, thriving families by reducing family stress by addressing the mental health and respite needs of families. (How will Medical Home become the conduit to make this happen?) Challenge is when pediatricians look at parenting – with an understanding that atypical parenting occurs because families are dealing with atypical children’s development.

Ways this work may overlap with other groups
- Receive reports from Regional Community of Practice Workgroups. (Regional Workgroups)
- Connect with UW - Whitewater Special Ed. program to share information with psychology department. (professional Development Workgroup)
- Mental Health wellness of families. (Medical Home)
- Sharing resources with medical practices – Family Fact Sheets/MCHAT shared with medical practices. (Medical Home)

Practice Group on Education and Awareness

Priority Issues:
The group reviewed the notes for the Education and Awareness Practice Group from the meeting on May 20, 2009. Gail Chodron provided an update on the Action Step identified at the May 20 meeting: an online survey was created and launched to collect information about the capacity to provide ASD-related education and awareness activities in Wisconsin. The survey will be used to compile information about individuals and agencies that provide education and awareness activities across the state, what topics they provide trainings on, what audiences and what parts of the state they serve. This information would assist regional centers, individuals, and groups in accommodating requests for such trainings. A flier about the survey was distributed to the CoP and broader Connections listserv via email and through a flier that was included in the folder for the CoP meeting.
The group discussed mechanisms for distributing the survey further, and how to make information gained from the survey broadly available. The use of a website was proposed. The national sharedwork.org site was discussed as a possible option, but it may not be readily enough available to all users/public. The group discussed the alternative of creating a Wiki, Google site, or another free, easily sustainable source. The group discussed how to advertise availability of such a website. Having a link to the site posted on websites of the Autism Society of Wisconsin, United Way of Wisconsin, and Regional Centers for CYSHCN, WI First Step, and other sites were suggested.

Website content was discussed. Ideally, the website will contain the name of the agency and individual trainer/consultants who provide trainings. However, the individuals who provide trainings change frequently, so it was decided that a better option would be to include links to the individuals or agencies themselves so that current information is provided. The group discussed possibility of including resource libraries of some training materials for parents and professionals. The library for parents would include a variety of evidence-based resources. The library for professionals would contain training materials and presentations. This would be of value for geographic or topical areas where trainings are not widely available, as they would allow someone to adapt materials and create trainings as needed. One challenge is monitoring the material to make sure it is evidence-based and accurate. The group discussed whether library for professionals should be open to public or only to members (discussion of ownership of training content, and problems associated with maintaining integrity of curriculum).

The use of electronic mailing lists (i.e., Listserv) and community Internet forums were discussed as ways to distribute trainings to individuals of interest and to post requests for specific trainings. ASW had a listserv of trainings but it got too big, so it may be best to see if the Listserv can be available by area (i.e., regional centers). Elizabeth Martinkus has a successful YahooGroup! that includes trainings, which may serve as a model.

Items that the group will address in the future include ensuring cultural competency of the website (i.e., trainings, training materials) and additional ways to distribute information about the website.