### Physician Education and Medical Home Groups

**Present:** Wynne Cook, Sharon Fleischfresser, Layla Hamizadeh, Maren Miller, John Dunn, Meg Steimle, Bonnie Klein-Tasman, Emily Levine, Kara Van Vooren, Lezli Redmond, Richard Barthel

**Medical Home Practice Group Update**
- Medical Home Implementation
  - Promote early identification
  - Train on use of ASQ and MCHAT
  - Post-Screen next steps while waiting for diagnosis and/or services
- One-Page summary of resources for families is available on Connections Website
- Review G.P.S.—Getting Parent Started
  - Tool to help parents take the next step
  - Brief individualized plan after screening/evaluation
  - Wynne Cook has piloted the tool with ASD/DD/Chronic Illness both before and after initial evaluation at Western Regional Ctr for CYSHCN
  - Feedback has been positive
  - Questions:
    - “Goal” versus other identifying word?
    - Insurance coverage is usually top questions—how address?
    - Automatically put regional center number first?
  - John Dunn has also piloted the tool

**Urban Autism Summit Physician Education Update (Emily Levine)**
- Sharing work with Parent, Awareness and Education Action Groups
- Three year grant to educate families in child development
  - Partnering with Allen Wells at UWM, Next Door Foundation and
Focus groups to discuss child development and who to people see if they have questions or problems

- ASSEW continues to fund some Grand Rounds at CHW (Dunn/Crisco in Feb 2010)
- Looking at what zip codes are high poverty rates
  - Who are the practitioners serving those areas?
  - Who are the physician who need education to screen, refer and direct to resources
  - Follow Dunn/Crisco collaboration model?

16th Street Clinic
- Holds monthly clinics for ASQ and MCHAT with 2 evals/month
- Has improved time to diagnosis
- Now booked through April
- Still have access problem
- Mostly Hispanic population—maybe work with Community Health Center and MLK to serve more African-Americans?

Discussion
- Not just “all about the waiver”
- 2 pieces of waiting—before diagnosis and after diagnosis
  - Need to shorten the time to diagnosis
    - Build capacity—need more trained diagnosticians in Wisconsin
    - Work with school systems to improved education diagnosis
    - Utilize Regional Center to promote education and awareness at the same time as screening training
  - Need to connect better with Birth to Three
    - Medical Home Webcast Series will include one on Birth to Three
  - New Initiative
    - Starting January 2010—Recruit 30 Primary Care Practices
      - Get ASQ and AAP toolkit and Newborn Hearing Screeing
      - Goal is to improve early identification
      - Stipend of $500 for practice and stipend for Birth to Three involvement
  - Other ways to reach Primary Care Providers
    - Train in residency programs
    - Continuity Clinic
    - Grand Rounds

Issue raised
- Richard Barthell (MCW) stated he does 3-4 evaluation per week and that Primary Care Providers and not willing to be a medical home.
- Emily stated that sometimes the primary care provider doesn’t feel competent, feels challenged, not able to provide services, doesn’t have the time

Solutions offered
- Coach the doctors to respectfully say “I don’t know, but I will find out or refer you to someone who can help.”
  - This approach is not covered much in residency training
Might be possible to add
- Very important as the negative could leave parents frustrated and lead to “physician bashing” and mistrust.

Issue raised
- Difficult to refer to CHW for diagnosis because they don’t have a single portal.
- Need other options instead of relying on the single physician in her/his office

Other
- Use network of families to determine if Learn the Signs, Act Early is visible
- Areas of overlap between Medical Home and Physician Education could include making sure outreach and awareness training includes referring to Birth to Three and possible use of the roadmap and GPS.

Awareness, Community Systems, Education and Awareness Group

Present: Karen Cohen, Amy Masek, Tim Markle, Kirsten Cooper, Carrie Arneson, Linda Tuchman, Julila Stavran, Bob Johnston, Jennifer Freitag, Diane Bazylewicz

Urban Autism Summit Awareness Action Group Update
- Received a grant from the Greater Milwaukee Foundation that starts in January
  - PI doctor from Medical College
  - Next Door Neighborhood House
  - Focus Groups with ASSEW to identify barriers to service and access
    - i.e. caregivers of children without autism to see what people know about autism
- Meets monthly at MCFI

Community Systems Practice Group Update
- Has identified many systems of high priority

Education and Awareness Practice Group Update
- Developed survey to find out providers and will make a list of providers.

Discussion
Identify how to make people of all cultures aware of autism—autism affects all groups
Large resource guides too overwhelming and maybe not culturally appropriate
IDEA—DVD to reach populations who won’t read literature or have access to the Net
  - Show typical development and show red flags
  - How make multicultural when autism is already a large spectrum?
  - One format—different versions?
  - Is Debra Feign(sp) working on that globally?
  - Is CDC already producing that?
  - For the Hmong—what about a story blanket?

IDEA—Develop a decision tree of how information can be disseminated to different cultures.
IDEA—Utilize CDC media spot and customize for area and cultures.
IDEA—How utilize Metlife as they provide specialists to go in and talk with families about the complexities of financial planning for CYSHCN.
IDEA—Milwaukee MADA channel 14/96? Community television station could help disseminate information as well as other community television stations around the state. Usually looking for programs.

**ACTION STEPS**
- All members—Disseminate Education and Awareness Survey
- Carrie—Contact CDC to determine customization of media spots
- WEAP (Dr. Sallows)—contact Debra Feign(sp?) to determine status of DVD
- Amy M and Karen C—serve as liaisons between practice group and action group
- Tim—send out Doodle for Tele-meeting in January to report on updates and plan for next CoP meeting Feb. 10, 2010 at the Sheraton, Madison.

**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.

NPDCA 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.

Educator Support/Professional Development Group

Present: Glenis Benson, Dan Bier, Mary Cimbalnik, Susan Donohoe, Ellen Franzone, Bill Helm, Nate Helm-Quest, Brian Johnson, Dennis Joyce, Barbara Kilp, Erin Miller, Elizabeth Ofstedahl, Jeff Spitzer-Resnick, Lynn Stansberry-Brusnahan, Mary Stone, Mary Kate Sullivan, Jennifer Townsend, Linda Tuchman, Annette Valeo, Kelly Wegner, Gerogia Yanicke

After comparing work-to-date from the Urban Autism Summit Action Group and CoP on ASD and other Developmental Disabilities, the discussion quickly focused on the need for better prepared special education teachers and coaches.

There was a consensus that all Wisconsin teacher training institutions should be at the table with DPI to discuss what is really needed in the area of autism and what DPI could require as part of certification. Currently, everyone is working in isolation and any “Autism 101” development may be duplicative.

The combined group decided to focus on:

- Opportunities for more advanced training statewide
- Pilots / Models for coaches (both external and peer)
  - What are we learning?
  - How is it working?
  - How to embed research.
- DPI / Institutions of Higher Education (IHE) partnerships to promote support for:
  - IHE (with CEC standards for autism and other developmental disorders)
  - CESA and other autism consultants
- Listserv to access for problem-solving, sharing
  - Exchange of results and supports across programs
  - Focus on Positive Behavior Intervention Supports (PBIS) as means to (+) support for all children including those with ASD