Medical Home Practice Group Notes

Revised Description
The Medical Home Practice Group promotes the implementation of the Medical Home approach in the care of children and youth with ASD and other Developmental Disabilities. The Medical Home approach to care is family-centered, culturally competent, compassionate, accessible, comprehensive, coordinated and continuous.

In the Medical Home:
- families and youth are supported as decision makers in their care;
- children with Autism Spectrum Disorders, Development Disabilities and other special needs are identified early though the use of validated screening tools;
- children and youth access timely quality diagnostic services;
- care is coordinated across the spectrum of care and
- families are linked to the services and supports they need.

2 priority areas identified during the May 20th meeting:
- Early Identification and Diagnosis
- Care Coordination

Items for Policy Practice Group Consideration: lack of consistency regarding diagnosis and waiver eligibility based on county of residence; access to diagnostic services, reimbursement for developmental screening (available to pediatricians but not family physicians)

Education and Awareness Practice Group Notes

Revised Description
This group will identify priority areas for community and public outreach and awareness to increase public awareness of ASD and other DD; help develop collaboration among stakeholders in order to foster coordinated outreach and awareness efforts; facilitate the use of culturally appropriate outreach and awareness materials and strategies so that all cultural, ethnic, linguistic, socio-economic, and underserved populations area reached; and facilitate the integration of recent research findings and evidence-based practice into outreach and awareness efforts.

Priority Issues
- Access to curriculum for public and community trainings
- Identify those who conduct trainings and the types/content of trainings available
  Future action step suggested: Contact ASW chapters, regional centers, UW-Extension, and other organizations or groups to identify these trainings
- Partner with other CoP groups, such as Professional Development and Family Supports, to identify trainings
- Providing consistent evidence-based messages, information, and educational materials about ASDs and DDs
  o “Learn the Signs. Act Early.” Campaign
Cultural Sensitivity
- Informed by research and evidence when possible
- Disseminating the information to formal and informal groups and identify avenues for connecting the groups to the information or trainings they need: (e.g., support groups, organizations, educational)
  - Future action step suggested: Identify the target individual(s) in each who need the information and can disseminate it to others
    - Partner with other CoP groups, such as Professional Development and Family Supports, to enhance this dissemination

Action Step
- Draft and distribute a survey to collect information about ways in which stakeholders (CoP-ASD/DD contact list, RCT contact lists, others?) are engaged in education and awareness activities.
  - What can they offer? (curriculum as well as trainers)
  - What do they need?
  - What requests are they getting which they cannot fulfill?
  - What do they do with requests they themselves cannot fulfill?

Other:
- Social Marketing—Is it possible to do social marketing around this issue to help with the campaign for consistent education? (e.g., TV screens at grocery stores, billboards)
- Breadth of Outreach and Awareness—Compile information on ASDs, co-occurring disorders and mental health issues, and other DDs
- Logic Models—We can create a logic model if needed to provide a graphic for understanding this process.

Youth Transition

Revised Description:
The group came up with some key elements for the definition for this Practice Group. It should include all aspects of transition including the transitions from school to work, independence, medical decision making, living arrangements, sexuality, legal, social and family supports. The words adolescent and relationships should be there since young adulthood is all about relationships.
The facilitators will draft a definition and send it out for input.

Name of Practice Group:
The group discussed the name of this Practice Group and felt that it was confusing so we chose to rename it: Youth Transition and Young Adult Issues.

Priority Issues and Action Steps:
- Equal access to best practices with standardization across the board.
  - Action Step: Invite DPI to the table
- Preparing youth to be self-advocates
  - Action Step: Share models of curriculum, checklists and other transition resources.
Other:

Role of school personnel in providing information to families: First possible intervention; need referral mechanisms; let family know where they can turn to; need collaboration to give families information. In Pewaukee, several school districts pool their resources to invite key experts into speak to parent groups on specific topics. Role of IEP team in making sure that parents get the information that they need. There are transition checklists (and Opening Doors booklets) out there but parents don’t always get them. It is a patchwork approach with pockets of best practice and lack of standardization across the state. Even though there is a transition page in the IEP, the quality of how this is used varies. Twenty percent of the school districts are audited each year and transition is an area where problems consistently arise. Need for information to be regionalized.
We need a DPI representative on this Practice Group.
Theme: How to consistently get good information to families.

Transition is bigger than work experience, but in some school districts that is the main focus of transition. There may be reasons for this, for example in Dane County, the work in high school directly correlates to the work a student obtains post-high school because of an interagency agreement. Parents are being told that their children are ready to graduate at 18 and then the student doesn’t have anywhere to go once they leave.
Group discussed transition issues around graduation. At UW Stout high school students can take classes (Al Noll has more information on this). Families should know that starting at age 14, the IEP can include social and other skill goals related to transition.
DVR doesn’t come early enough. Job placement- Schools are getting better but carefully looking at job skills as well as the skills to live life independently is critical. Mary mentioned a class in her district which addresses all of these transition skills and she will send us the information on this. It could be a model for others to replicate. We should look at how to utilize all possible school resources (e.g., school psychologists, counselors, nurses) not just special education resources. Mentorship is needed. How do we help parents see that their child can be successful not just academically but also socially. We need a list of what is supposed to happen at transition according to DPI.
Theme: The student has individual interests and others should help the student to identify these. We should give energy to helping the youth figure out what he/she wants.

Policy Practice Group Notes

Revised Description:
Add “action” to definition.
i.e.: “This group will identify priority, and take action in, areas that need attention related to policies that impact the lives of families with children with ASD /DD.”
-Tabled for further discussion.

Priority Issues:
- Introduce legislation for residential home sprinklers (Safety Issues). Had discussion about “Child Alert” program with the state.
- Discussed improving the waiver.
• Building a system of support infrastructure information assistance (funding and talking to “live bodies”).
• Greater level of coordination and consolidation of funding.
• Requirement for what a “behavior specialist” (Qualification for what that means).
• Disparity among ethnic groups and poor vs. other states. Unable to access education records. Try to get DPI to release records.
• Seclusion/Restraints in schools from DRW report. (Bill currently being drafted)
• Unknowledgeable about what is “out there”.
• Insurance parity in regards to mental health restrictions (autism is only a small piece of the pie). I.e.: what it means to the health structure.

Action Steps:
  1) Try to get DPI to release education records. (Maureen)
  2) Waiver issues (Liz)

Parent Supports

Revised Description
This group will identify and address priority areas related to promoting healthy, thriving families and supporting parents as decision makers, leaders, advocates and partners with providers.

Priority Area One:
Caregiver health and well being, including reducing parental stress.

Action Steps:
• Raise awareness of consequences of not taking care of yourself (mindful parenting)
• Further investigation of face to face parent supports
• Resources for relief from caregiving, including respite
• Resources for Mental Health including part for the caregiver family

Priority Area Two:
Information Dissemination—Where? Who? What?

Action Steps
• Learn more about resource mapping
• Identifying WHO is disseminating WHAT
• Is the information available now what families need or is something missing.
• Include in Gail survey: “What information are you disseminating? “To whom?”
Professional Development/Evidence-based Practice Group

Revised Description:
This group will identify and address priority areas that need attention relating to professional development for those who serve individuals with ASD (and other DD). These areas will include evidence-based practices as they relate to early identification, screening, referral, assessment, and diagnosis of developmental disabilities, including ASD, as well as evidence-based therapeutic approaches that address the different and changing needs of children and young adults, and their families, as they grow and develop throughout childhood to adulthood, across service systems. (The concepts were discussed, the wording not finalized)

Priority Areas:
1) early ID of children – recognizing signs, referring for assessment and diagnosis
2) training across professions, ensuring that multidisciplinary, collaborative approaches are used, and that the same information is shared for parents and educators
3) recognize and address the needs (services and supports) of people with ASD across the lifespan as people age and change

Action Steps:
What do professionals need to know between basic child development and instruction/ training on evidence-based therapies? - come up with a checklist of what (content/methods) to include in a basic training on “understanding autism”
Concepts:
- this content could be used/should be appropriate for different professional groups, administrators, families, communities
- this content needs to address the following related to ASD: etiology, brain-based theory, communication deficits, social deficits, safety issues, sensory issues, cognitive issues, cultural issues
- what skills do professionals need to have to work in this field?
- How do professionals get support from administrators to get this kind of training and get “buy-in” to developing a basic understanding of autism by all levels of professionals

Community Services

Revised Definition
This group will identify priority areas that need attention related to systems of care for birth to 21.

Priority Area:
Families need guidance to determine what questions they need to ask of medical providers, schools, service providers, recreation, social etc.
Parents need to know how to ask good questions.
1) What do parents need to ask to insure a provider isn’t just riding the autism wave?
2) What do parents further along down the line wish they would have asked?

Action Steps:
- Contact Family Voices and Parent to Parent to see if they have a list of questions parents need to know to ask. (Julia Stavran)
- Include these two questions at Regional Core Team Meetings and report back. (Tim)
- Work on a list of “systems” to be included as we look at community systems. (Through email)

Other Discussion
Funding issues
- Some providers that are funded don’t have autism specialists.
- There could be areas to collaborate with Policy Group (funding, coverage, etc.)

Coordination of Services
- **The coordination between the medical side and the educational side has room for improvement.** Services seem to be better connected when B-3 is involved especially with Service Coordination. Families don’t receive that from schools. It seems the older a child gets, the harder it is to find services.

- **Families don’t always know what they need, but know they need something.**
- Professional supports are under capacity and can’t be the whole answer.
  - Social groups for individuals with ASD
  - Person to person mentor to support and facilitate joining (very uncomfortable doing it along)
  - Northern region AUSome group for middle schoolers—parents wait for this group and then after the group there is nowhere for the kids to go.
- **A need to develop natural supports for families—families sharing with each other strategies that have worked, although each family is different.**

Can communities utilize the LaCrosse Task Force model and pull together a team to help improve the natural and professional supports in there community?

Resources
- Current guides are missing information. There needs to be an access point that has the information on all the resources maybe even a service coordination component. Sometimes need a neutral agenda free perspective. The Regional Centers for CYSHCN can help in this role, but maintaining quality information is challenging.
  - How can we build their capacity?
    - Increase awareness
    - Increase presence
    - Increase credibility
    - Build relationship with community partners to maintain a quality information flow and stay up to date.
    - Listen to families stories
Support the community resource mapping project

- Resource guides should include “what makes your organization different?” How do you work with children with autism?
- Current guides have too much information:
  - Key points for guides:
    1) What is the primary info about the organization and what makes them different.
    2) Contact information, hours, expenses, etc.

There seems to be an umbrella of resource available, but if a person starts on one road, they don’t have access to others. We need to help us all look beyond our own niches.

- **How can we help professionals access quality information about autism?**
  - No real incentive today. It seems to be a personal motivation that drives some to increase their knowledge.
  - Could use capacity building grants to work with professional and personal mentors to spread information. Use experts holding office hours and taking calls to answer questions from other professionals

WIC formula
  - WIC is instituting new formula guideline which will have an affect on CYSHCN mothers. So far we have no details, but will need to make sure the Regional Centers and others are aware and ready.