Meeting Highlights

Purpose of the Southern Regional Team (SRT) on ASD/DD
1. Use facilitated resource mapping strategy to identify resources to support children and youth with autism spectrum disorders and their families in the southern region of WI
2. Build connections and strengthen collaborative opportunities among partners on the SRT on ASD/DD
3. Improve families’, SRT partners’, and others’ access to information about these resources in the southern region of WI

June 4th Meeting Objective
Begin to identify existing resources to support children and youth with autism spectrum disorders and their families in the southern region of WI (service area of the Southern Regional Center for Children and Youth with Special Health Care Needs)

We’re Making Connections!
- Lisa Hoeme (Imagine a Child’s Capacity) and Amy Whitehead (Connections Project) talked about partnering to provide training to underserved families in Dane County. Gail will follow-up to see if we can all coordinate to make this happen in Fall 2009
- Pilar Guzman (Birth to Three), Sandy Magana (Waisman Center), and Amy Whitehead talked about working together to provide an ASD Basics training for non-English speaking families in Dane County. As a follow-up to this, Liz Hecht (Family Voices, Waisman Center) offered to partner on this through the Wisconsin Family Support 360 grant. Gail will follow-up to see if we can all coordinate to make this happen in Fall 2009.
- Nancy Alar (ASW) spoke with Gail Chodron (Connections Project, Southern Regional Center CYSHCN) about setting up a community conversation with the AUSOME social group to learn from youth and young adults with ASD. Gail will follow up with Nancy and the AUSOME social group to schedule a community conversation in 2010 (when the group next has an opening in its schedule).

NEXT STEPS:
When you make a new connection or start a collaborative effort because of your involvement in the SRT on ASD/DD, make note of it! We’ll share these at each meeting.

Before the next meeting, review the resource guides in your binder. Think about the following questions:

- From your perspective, what are the key resources (or strengths) in the southern region?
- What resources do you know about in the southern region that are missing from the resource guides?
- In your experience, where do parents actually turn to learn about what resources exist in the southern region?
- Where do you turn to when you are looking for information about existing resources in our region?

These will form the basis of our first conversation at the next meeting. If you are able to put your answers together before the meeting, you can enter them at https://websurvey.wisc.edu/survey/TakeSurvey.asp?AI=1&SurveyID=32145L16n32H85. We will compile whatever responses we get beforehand and share them as a handout with everyone at our September meeting. You can also just bring your answers to the meeting.
Meeting Minutes

In attendance:
- Gail Chodron, Connections Project, Waisman Center (co-facilitator)
- Tim Markle, Connections Project, Department of Health Service (co-facilitator)
- Nancy Alar, Autism Society of Wisconsin
- Krysia Braun, Autism Society of Greater Madison
- Susan Donahoe, CESA #2
- Deb Dreyfus, Primary Care Physician
- Kristin Gowan, Waisman Resource Center
- Pilar Guzman, Birth to Three (Madison)
- Liz Hecht, Waisman Center and Family Voices
- Peggy Helm-Quest, Department of Health Services
- Lisa Hoeme, Imagine a Child’s Capacity
- Nell Justiliano, Wisconsin Early Autism Project
- Sandy Magana, UW-Madison School of Social Work, and Waisman Center
- Heidi Martell, Verona Area High School
- Rachel McGlynn, Richland County Health and Human Services
- Colleen Mortell, Madison Psychology Associates
- Mary Packee, Dodge County Health and Human Services
- Karl Pierick, Imagine a Child’s Capacity
- Michelle Sherman, Wisconsin Early Autism Project
- Pam Stoika, Integrated Development Services
- Amy Whitehead, DHS Children and Youth with Special Health Care Needs Program
- Dawn Wians, WI FACETS
- Donna Winnick, Dane County Human Services

Not in attendance:
- Josh Lapin, Community Ties
- Glenis Benson, Educational Psychologist

Welcome and Introductions
- The Regional Team on ASD and other DD is a partnership between the Southern Regional Center for Children and Youth with Special Health Care Needs CYSHCN, the Wisconsin DHS CYSHCN program, and community partners and family members.
- Amy Whitehead, Connections Project Coordinator, gave an overview of the Connections Initiative and explained how this three year grant comes out of the Combating Autism Act of 2006, with funding from the federal Maternal Child Health Program, to the State of Wisconsin, Department of Health Services, Children and Youth with Special Health Care Needs (CYSHCN) Program. The CYSHCN Program’s mission to promote health, family-centered services and six national performance measures and in this capacity it aims to bring key stakeholders from across the state to partner and identify resources and improve the referral process.
- Liz Hecht, Project Coordinator for the Southern Regional Center for Children and Youth with Special Health Care Needs, explained the role of the Regional Center.
- Each person had an opportunity to introduce themselves; state their personal and/or professional role and how they are able to contribute to the lives of children and youth with ASD/DD and their families. Out of the 22 people present 12 identified themselves as a parent of a child with an autism spectrum disorder or other developmental disability.
- Everyone filled out a contact sheet and collaboration scale.
Resource Mapping—Visioning

**Vision Statement:** The Southern Regional Team on ASD/DD, including self-advocates and parents, will work together to identify resources that are available to parents, self-advocates, educators, health care providers, service providers and community members. We will try to make those resources accessible and easy to use by all members of our society. We will collaborate among ourselves to improve our region.

**Visioning Exercise:** SRT members answered the question: “If we had an ideal resource and referral systems for children and youth with ASD and other developmental disabilities within our region, what do you expect the outcomes to be?” The following responses were gathered:

1. **Children and youth with ASD or other developmental disability and their families will experience:**
   - Families will know what is available
   - Access will be early, best-fitting, easy to use, timely, simple, seamless coordinated
   - Children will respond to interventions and if they don’t then innovative practices will be tried with a data-based decision making toll in place to gauge effectiveness.
   - Parents know how to make their ideas known because they have access to information and the same training/knowledge professionals get.
   - Families with lower income will have access to the same resources to improve early identification and treatment.
   - Resource will be listed alphabetically with contact name and phone number.
   - Parents would be empowered and informed to take matters into their hands; i.e. self-directed supports and will be supported.
   - Peer friendships
   - Support throughout the process that makes the families feel respect for their knowledge, day to day struggles and commitment to their child. Parents will find understanding, comfort, stress relief. Have someone to talk to. Reassured and supported when diagnosed.
   - Families will have an easy to navigate one-step system.
   - Professionals will know where to refer parents.
   - Emotional & physical comfort in school environments so that they can learn.
   - Kids will get services based on their unique challenges (EBP and RBP)
   - Early screening of all children
   - Able to reach full success/reach potential
   - Caregivers are supported
   - Access to respite and emergency care when caregiver is ill
   - Assistance with service planning and coordination
   - Intervention will be early with a minimal wait for services.
   - Ability to access natural supports and communities that get the concept of natural supports.
   - Improve self-esteem; peer supports; activities. Move toward competency goals for adulthood.
   - On line map linked to resources; peer education; dev. Steps; how to access resources and adult with ASD would get information they need.

2. **Community service providers will:**
   - Have a better communication system to collaborate and expand for trainings, events, social groups, skills groups, etc., keep it updated
   - Know area resources, able to refer others appropriately, have access to resources (i.e. job developers—do what do best)
   - Access training, coaching, consultation, natural supports
   - Better payment and access to funding
   - View parents as partners and listen to them
   - Involved Univ. students, work to reduce line therapist turn over
   - Be culturally competent
• Funding, reporting, Q & A will be organized to maximize county resources, reduce bureaucracy and maximize flexibility.

3. **Educators will:**
   • Have one place to go to for answers when they have questions
   • Trained in evidence based interventions/best practices/basic knowledge/early signs/certified in ASD
   • Partner with the family and student
   • System will be flexible
   • Set up meaningful social connections

4. **Primary and Health Care Providers will:**
   • Know and easily access resources to support parents
   • Be adequately reimbursed by insurers
   • Partner with parents/communicate/listen
   • Screen early at appropriate times
   • Access to experts
   • Be a family-centered medical home

5. **Wisconsin will have:**
   • Culturally competent and appropriate materials
   • A place to post questions, concerns, events, connect with others, be interactive, easy to use, learn of diagnosticians and providers, kept up to date, access by rural and underserved populations
   • School system that provides supports up through age 21
   • Funding flexibility
   • “Nothing about us, without us”
   • Universal service access

6. **Communities will have:**
   • Accepting/supportive peers
   • Better quality of life
   • Benefit from everyone’s contributions
   • Reduced maltreatment
   • Parents will be more productive
   • Authentic cross cultural/cross ability relationships

7. **Key themes brought out:**

   **Community, family, and individual wellbeing**
   • Inclusive communities
   • Natural supports
   • Utilize natural supports
   • Lifespan perspective
   • Mentoring/life coaching
   • Promote friendship and inclusion
   • Universal design
   • Family well-being
   • Caregiver/family emotional/mental health knowledge/support
   • Culturally competent
   • Supportive

   **Partnership and collaboration**
   • Partner with people with ASD/DD

   **Collaboration**

   **Coordination of care and systems**
   • Medical Home
   • Systems Coordination
   • Simple-straightforward
   • Less duplication of efforts
   • Flexibility of options/interventions/ supports
   • Reduce surprises in system
   • Enough capacity
   • Look to what’s already out there—across systems
   • Efficient use of money and resources

   **Identification and intervention**
   • Know how to ID red flags
• Earlier Intervention
• Evidence Based Practices
• Know how to talk to parents

Access to knowledge and resources
• Access to resources and services would be immediate and over the lifespan
• Knowledge
• FAQ website
• Innovative use of technology
• Sustainable source of resource info
• Easy navigation
• Listserv to share info.
• Compensation/Reimbursement/Funding

Working Lunch
Over lunch we discussed the following questions:

1. Who is missing from the SRCT (Southern Regional Core Team)?
   • People with an ASD/DD
   • Law enforcement/Emergency Responders
   • Mental Health Professionals
   • MMSD
   • WI Family Ties
   • Disability Rights
   • DVR
   • WECA
   • African American
   • Hmong
   • DPI

2. What are other important issues and ideas that we should consider?
   • Holding Community Conversations outside of Madison
   • Surveying people on their resource needs/usage/access
   • Ensure that training is available at the paraprofessional level
   • Are there replicable models we need to know about
   • How are parents working in partnership with schools
   • Who is providing social support in schools (all children)
   • Autism Intervention Modules are available online
   • Legal Issues—Estate Planning
   • MAGIC parent group in Middleton—another source for issues and ideas
   • Stay connected through a moderated listserv/blogging/etc. as a way to exchange dates of trainings and events.
   • Keep webcasts of trainings for parents to access when needed
   • Utilize technology like Relate Now
   • Check out First Step from end user point of view
   • Can we learn from Discharge Planners (e.g., Dave Skripka)?
   • Can we learn/partner with ADRC and IRIS?
   • What resources are available for parents with Transitions-aged youth?

The meeting adjourned at 1:00. Gail will be contacting members and setting up the next meeting date. Gail will be sending out an updated roster of participants.