Community of Practice on Autism Spectrum Disorders and other Developmental Disabilities Practice Groups
Combined Notes from the March 5, 2009

Professional Development Practice Group

What would it take in Wisconsin, in the area of Professional Development to develop the infrastructure needed to support children with ASD and their families?

Core values/guiding principles

Need for linking systems

Continuing education should be available/accessible over the course of a career

Medical Home Practice Group

What would it take in Wisconsin, in the area of Medical Home to develop the infrastructure needed to support children with ASD and their families?

Areas of focus were consistent with those identified in the document Medical Home Services for Autism Spectrum Disorder and serves as a guiding document to the Practice Group.

Early Identification:
Training and Technical Assistance

- Training for primary care providers to implement general developmental screening and surveillance within their practice;
- Training for primary care providers on screening for ASD
- Ongoing technical assistance available to providers to support screening implementation in the practice setting

Policy Development

- Reimbursement for screening codes by public and private insurers
- 96110 is not reimbursed by DHS for family physicians but pediatricians

Diagnostic Services:

- Knowledge of who are providers in the community with diagnostic expertise
- Make available timely diagnostic services and supports
- Easy access to expert advise
- Diagnosis as it relates to Waiver eligibility (examples of families after being referred to one agency/facility needing to be re-evaluated leading to time delays, expense, and potential duplication of scarce resources)

Coordination of Care

Link to Community Resources and Services

Training and Technical Assistance to promote:

- Referral to Early Intervention/Early Childhood Services
- Knowledge of Waiver including eligibility criteria
What services/supports available for child and family

Parent Supports Practice Group

What would it take in Wisconsin, in the area of Parent Supports to develop the infrastructure needed to support children with ASD and their families?

Support Groups, finding them, Resource booklet, Templated Resources
National ASA has resources mapping,
Parents connecting : county workers, schools, B-3, medical community.
Bringing the silos together:

How do we bridge the medical model with the educational model. Bridging the people together who are working within each of those models. How do we bring the hom/school/community together.

Where is the front door of what all the resources all?

Transition issues, what is there to support families as they move through the service structure system?
How do we support families who are NOT living in the resource rich communities?

Spouses and family members of adults with ASD. What are the resources for adults,
Increased understanding of ADA and how it applies to adults on the spectrum.

The adult services are inadequate for adults who are not in the lower IQ range who is not eligible for disability supports (SSI).

What are the supports that are available for children who do not fit easily into another box.

How can we create community Task Forces that are broad spectrum; policy, education, medical, line-therapists, related service providers.

How do we keep those people together for the LONG TERM?
How do we build in accountability for the work of the task force?
How do we keep people invested?

How do we increase parent involvement?

Scheduling challenges.
Title I funds might be available from the schools to support families to attend, supplement childcare services.

Increasing cultural-diversity within the CoP.
Increasing attendance of adults with ASD.
How do we define “parent”? Do we mean

We need ONE point of contact to find resources once a parent gets a diagnosis (regional contacts).

- Online resource list
- Provider resources
- Co-morbid diagnosis

How do we remove the silos? What infrastructure could get rid of the silos.

We need to include parents from the beginning of the process and not as an afterthought.

Reach out to child care programs, better training/support, better systems to support children in child care settings.

- We need to support childcare facilities
- Access to high quality childcare of children with all disabilities

Summer programs for children (especially teens)

Families having access to inclusive opportunities.

- How do we remove the tendency to self-isolate from community programs that are broadly available throughout the community.

RESPITE & FAMILY ADVOCACY

Representation from the Regional Groups

**Community Systems Practice Group**

*What would it take in Wisconsin, in the area of Community Systems to develop the infrastructure needed to support children with ASD and their families?*

Obstacles
1. Funding
   - Insurance, Medicaid, Private Pay
   - Parent consultative models are not available – those that are RDI, social communication, or relationship based for example

2. Treatment Models
   - Available models. Not a one-size-fits-all treatment models.

3. Community Systems of Care
   - Infrastructure systems of Care. System of individual advocacy.
   - Senior Benefits Specialist model with back-up attorneys does not exist for children
4. Disability Divisiveness
Create a system or network which all disability groups can rally around similar issues. Divisiveness within the disability community and divisiveness among autism community on issues. Focus on the powerful commonalities that exist in the autism community

5. Communities and natural supports. How do communities build this as a structure? Develop a life course perspective of systems of care for those with Autism. Wraparound program.
Early Intervention and Preschool
Public Education
Family services and support
Residential services and supports
Vocational services and supports

Assure systems are inclusive, accessible, coordinated, integrated, flexible

6. Access to care. Systems that meet the needs of those with Autism – are not available throughout the state. What are the service gaps?

School-age Issues and Youth Transition Practice Group

What would it take in Wisconsin, in the area of School-age Issues and Youth Transition to develop the infrastructure needed to support children with ASD and their families?

School Personnel
DPI needs to be involved in this work
There need to be supports for teachers.
School personnel need to increase their understanding of children with ASD
There is a need to train school personnel

General School Issues
Length of time in school: Many students are being dropped early from school (let go at 18 instead of 21)
Placements are often inappropriate
For students who need job experience, there is no clearing house, no fluidity for parents. Parents don’t want pre-determined jobs, they want the schools to individualize the work experience based on the student’s interests and skills.

Education and Awareness Practice Group

What would it take in Wisconsin, in the area of Education and Awareness to develop the infrastructure needed to support children with ASD and their families?
One of the main topics raised was the need for a **Practice Group on Education and Awareness**

- Education and Awareness
  - Awareness and outreach
    - Need for continued outreach—What is autism? What do we know about causes? What should people do?
  - Education and training
    - Need for educational efforts related to what to do; what’s available; how to…
- Research
  - Need to know about most recent research
  - Need to plug most recent research into awareness and education efforts
- Reaching all community audiences
  - businesses
  - first responders
  - others we might not think of

Another key topic was **existing resources**

- Families need a good roadmap to navigate the system
- Families need help accessing existing resources such as:
  - Supports for parents to advocate for needs of own child
  - parent to parent
  - family support groups
- We need to better plug existing resources into one another
  - We need to know what other groups / resources can, do, and plan to offer
  - We need to have pathways of communication between groups / resources so that we all know about capacities and scope of others
  - For example, CESAs can address particular training or other needs—someone from CESA asks, What can CESAs do? What is needed from CESAs? How can he stay informed about those needs?

Two themes the group heard running through these topics of discussions were:

- Connections
  - Connecting existing resources
  - Connecting all families to ASW, local chapters of ASW, other parents support groups, no matter how / where they enter ‘system’
  - Connecting with broader CYSHCN / DD community/families
- Communication
  - We need better mechanisms and avenues for communication system-wide