Supports for Family Well-Being for Children with ASD/DD

March 12, 2012
Discussion Notes

- What experiences have you had with the Family Well Being for families with children with ASD/DD? (Please include your organization as well as others you interacted with.)

What worked well?
- Letting the person tell you where they are and what they need
- Dong just follow the “101 ways” binder without reviewing and understanding
- Provide with short options (immediate)
- Take small steps
- Knowing where parent is at
- Be transparent- Be professional
- Using screening and assessment tools
- Ask parent- what do they want for “outcomes”
- Provide specific skills to help parent identify their own needs and how to cope
- Provide what they need when they need it
- Helping parents gain a more global perspective
- Limit resources to specifically what individual families need at a given time
- Connecting with other individuals who have had similar experiences to your own and can offer their advice (e.g., parents, autism society, internet resources)
- Maintaining hope and positive thinking = motivation
- Participating in/modeling stops for parents (e.g., helping them through first IEP)
- Being prepared
- Child participate
- Respite invaluable
- Parent Advocates/ Life Coaches
- Money makes it happen
- Family/Friend Support
- Employers are more educated receptive
- Whether or not to disclose Dx e.g., employment
- Parent support
- Suspend judgment
- Recognizing parenting stress/overwhelmed
- When children have friends
- Supportive spouse/partners
- Counties
  - Different level of fund resources, passion
  - Families move to get resources in state/out of states
  - Move away from support systems
- Special ED home-visit/ check-in proactively
- Roadmap for IEP- parent, child, teacher tasks
- Public health home visits- culturally sensitive
- Time
- Sibling/family respite

What didn’t work well?
- Connecting parents when you are not sure they can be a good listener.
• Giving resources and info without really asking what they need
• Overwhelming parents
• Encouraging parents to stay in denial for too long
• Offering resources when they aren’t asked for
• Flooding families with information/resources
• Failing to recognize where a family is at in regards to coming to terms with their child’s diagnosis

• Needed
  o Educate parents/how do we increase parent readiness
  o Parents need to education others
  o Need to know how
  o Respite:
    ▪ Need more
    ▪ Need qualified
    ▪ Can be expensive
    • Burden of funding?
  o More mental health providers
    ▪ Need to accept MA
  o To incorporate guardianship info into IEP
  o Employment
    ▪ Educate employers
  o Adult services

• Lack of money
  o Services
  o Supports
  o Basic needs

• Turn over of care providers
• Constantly being the educator (parents)
• Not enough home visits

What resources did you use?
• Lots in SE WI
• Navigation Guides
• ASW info
• Social Services
• Other Parents
• Life coaching
• Mind Body Spirit Retreat
• Middleton Special Ed
• Birth-3
• Waiver system?