

Williston Session – Comments From Participants

Awareness of Focus Group

- Oral Johnson – Upper Missouri Health Unit
- Social Services sent out a flyer (4 people)
- Family-to-Family e-mail
- Parenting coalition in Williston
- Dr. Cook's office pop-up stand
- Phone call from Social Services in Crosby

Accessing information about Programs/Services

- I call Social Services and find pamphlets at clinics
- PATH office
- Special needs teachers
- Doctors, schools, other parents
- Networking with others
- Being bold and proactive in finding resources – this is frustrating – it takes time, we have no central location for information – Social Services doesn't even know about some of this stuff
- We need someone to coordinate “What should I do for my child at this stage?”
- Need someone who knows the kid (comprehensive file) to coordinate care
- Internet (obtain worldwide information, but ND wants to distinguish all in state before recommending out of state care)
- ND should put more information on the Internet
- Care is disjointed
- Frustrated with filling out same information all the time
- You hear about a program and you go through all the paperwork and then find out you don't qualify
- It is hard to find services that apply to your child

Additional comments regarding access to information

- have a case manager that takes responsibility for coordinating care
- ND should put more information on the Internet
- Can find information, but not the right kind of care here in ND
- Information is not released from one agency to another – they won't even release it to the parents, but have no problem releasing the information to the schools and other physicians
- It would be nice to have that information so there was continuity in care
- We feel as though we have to answer the same questions over and over
- ND state will not pay medical assistance to go out of state, but will not look at her child here in ND

“Medical Home” –A Central database

- Central database so physicians anywhere (country-wide) could look at the file – primary Doctor at home could follow up after seeing a specialist in another state
- Password access only
- Computer or phone access (a variety)
- We need someone to help coordinate what to do with the child and what to expect
- Someone needs to have a comprehensive file about our children
- Right now it is a very disorganized system
- Have to fight ND to go out of state for care – have to fight for medical assistance
- Unanimous support as long as it is private
- Parents should be allowed to add information to files or reports – they are the primary source of information – the parent knows the child more than the doctor
- A “comment” section so you document if treatment worked or not
- Coordinator needs to know about travel opportunities, Angel Flight, Wings of Mercy, etc., gas assistance Ronald McDonald house, hotels and airline discounts available for each family

Assuring Quality Care – How would you grade this?

- A - gone above and beyond, receive mailings from the clinic
- A – received help, but would like to know of more financial help
- A – Dr. in Minot
- C – Drs. in Billings – do not provide information
- A – very helpful, good school system
- A – medical
- C – Ward County Social Services – very lax about information
- D to a B – use to get information myself, but now receiving more
- A – medical staff
- C – programs and obtaining information
- A – medical staff
- C – coordination of information, no team approach
 - people don’t think outside the box
 - they don’t look at individual plans for their child
 - people are willing, but do not follow through
- B – care and no pediatric specialist, no knowledge beyond basic knowledge
 - we will lose our social worker after our daughter is adopted
 - we will also lose our qualification issues
 - we will have to start all over building a file when the Doctor leaves and we have to get a new Doctor – no files are transferred
 - misinformation across the board – referrals are a problem – sometimes I need them and didn’t know it

Services Which Are Lacking

- Lacking OT/PT, need home-based therapy, therapists are spread too thin – they are willing, but they don't have enough time, no pediatric psychiatrist or psychologist
- No audiologist in this area – have to travel to Minot
 - Williston Doctor will not see her daughter until after she has been to Minot
- Dr. Olson will see her after she has been to Billings
- Need a pediatric specialist
- No one can help with chemical intervention (Depression, ADHD)– have to travel to Minot
- We need more doctors here

Family Involvement

- More respite care givers – very little here
- Social Services use to have respite care, but not anymore
- Opportunity foundation in Minot – will pay for daycare – funded by the state
- One family was given the funding, but could not receive the care, not enough qualified caregivers
- Easter Seals no longer represented in Williston
- Lack of information in this area

Role of Children's Special Health Services (CSHS) Program

- 2 of 12 aware of the program
- Coordinator of care like an admissions counselor at a college helps you plan
- Someone to discuss care needs with
- More publicity
- More information
- Keeping an updated list of Doctors who provide what care services
- Advocate ND and encourage physicians to move here
- Advocate fighting for changes that take place (laws)
- Advocate fighting to keep the services we do have

Financial Matters

- Medicaid, private insurance (special programs that policy didn't cover), reimbursement for travel from county, I was denied social security
- Medicaid – primary care Doctor always has to write referral letter
- I was denied to leave the state because there was a specialist in the state
- Need pre-approval too far in advance
- By the time the paperwork goes through, the condition of the child has changed
- We have no specialist here for my child, but we are expected to get care in ND
- In California, they would pay me to stay home and take care of my child
- Insurance should be for medical care – babysitting shouldn't be added to cap for insurance
- Northwest Human Services drops the child after age 3
- After 3, they are rolled over to the next program
- One family is state and federally funded because she is a therapeutic foster parent
- She would like to have financial assistance for out-of-state conferences
- Families are exhausted by the end of the day, just from the daily care – they have no time to coordinate care
- One lady will not trust IEP people until all have same view of her children
- One parent not waiting for IEP, it takes too long to organize
- The parent is the primary care giver, but we need someone provide resources and tell us where to find help or information
- There are courses people can take to become certified caregivers under respite care
- We need more funding from North Dakota
- Various needs but they all get the same funding
- Financial assistance should be based on unique health problems

Recommendations for Improvement

- Really good information on the web – online discussion groups – Mayo clinic
- Family-to-family network – they pair you up with same medical problems but no other situation similarities (i.e. going to Minneapolis for care, etc.)
- It's hard to find time to go to support groups on-line – I can do it when it's convenient for me
- A central coordinator for each community that can connect families with each other
 - parents could talk to other parents who have already been through the situation
- A Minot hospital showed a parent what a 10 year old looks like, so she knew what to expect (clef palette)
- General community awareness of other families that have special needs children
- More awareness about special needs in the community
- More awareness equals more acceptance
- Inform the community so know what cerebral palsy is, so others know what the condition looks like
- Integrate the special needs children into the classroom more
- Educate the teachers
- Kids want to know, so the sooner they are informed about the child, the better

Additional Recommendations for Improvement

- Special needs should get extra money
- Assistance should be upon the specific need of the child
- Therapeutic foster parent is state and federally funded
- Money in investments should not be counted in for income
 - you are then disqualified for assistance when you have retirement accounts, savings, etc.
- You can never get ahead
- You cannot even save for future needs of the child (wheelchair lifts, etc.)
- Welfare system (healthy kids get the stuff, not the special needs children)
- There is that gap where you can't afford to go to work
- We need more social workers to lighten the load so they have time to check up on cases
- Parents need help getting their feet on the ground and get started with their child