

Minot Session – Comments From Participants

Awareness of Focus Group

- Pathfinders Conference
- Pathfinders
- Family to Family network
- Daycare provider
- CRC
- Special Services (Minot public schools)
- NOMI
- ND Paths e-mail
- Friend
- Direct mail

Accessing information about Programs/Services

- Newspaper
- Clinics should put information in their lobbies about services offered by Children's Special Health Services
- Need a central coordinating center
- Letter from supervisor
- Case managers, Pathfinders
- Even with Pathfinders, we have to pay co-pay, etc.
- Information isn't available (on the base either)
- County case workers aren't being provided knowledge
- Dr. at Trinity has been good source of information
- Psychiatrist in Minot is good
- Souris Valley won't follow Dr Recommendations
 - they don't want to travel to rural school districts where we are (Kenmare)
- Limited staff in rural schools – lacking services
- Should not be right when schools will not follow Dr Orders
- One lady contacted Byron Dorgan to get information and was treated and acted upon quickly
- Military helped pay for evaluation of a child – school system did not
- Air Force Base has been after the school to get them to comply
- Doctors need to be willing to give out information
- Orthodontist needs to provide information and not base decisions of giving information on compensation
- When paid for by me and my insurance the Doctor recommended different treatment – services sometimes based on money rather than the best treatment
- Doctor dropped us when we didn't want our daughter in treatment with drug addicts
 - we filed a complaint with the Medical Board
- CAPH (Child Adolescent Partial Hospitalization) program is geared towards teens and young adults not towards kids with mental disabilities
 - took her daughter out of the program, then lost Medicaid

Working with Health Care Professionals

- Don't use our children as guinea pigs – Doctors sometimes do not know what is wrong, so they try and use meds to solve the problem
- Need to educate the Doctors of all conditions
 - go to conferences
 - get brochures, etc.
 - trial and error is all they know what to do
 - side effects can be permanently damaging
- Referral process is frustrating– Minot wanted to send daughter to MSP instead of Fargo or Bismarck
 - Minot sends kids to Minneapolis when the same specialties are offered in North Dakota
- We have to take our own initiative
- Everyone thinks Minneapolis is the best place to go, but we had better care in Fargo
- People skip Doctors in ND because of the mentality of Doctors not knowing anything here
- Minot doesn't have the services available, very comprehensive in Grand Forks
- Services aren't provided in rural schools
- One mother wanted a full-time sign language teacher, but Glenburn would not pay for it
- One family thought the small school system would be good – but they were wrong, now they want to move out of the school district because of lack of care they have received

Lacking Services

- Training for parents with special needs
- Brothers and sisters need someone to talk with
- SIB Shop
- Schools and teachers need to know what to do in the special cases
- Teachers are scared to stand up for the battle to get staff for special needs kids

- Need reimbursement for travel
 - gas
 - meals
 - hotel rooms
 - we have no family here to help
 - others with extended family use them to death
 - taking off time from work
 - daycare for other children

- check into gambling organizations for money with NDAD
- NDAD don't know who to refer you to
- NDAD and Animal places
 - bad at returning calls and do not know who to refer you to
- Visible disability is what they base Medicaid on
 - this is wrong because many children are mentally disabled
- Friends and neighbors look at you as trying to get money for the government
- They think if you're dressed nice, you don't need help financially
- Medicaid form – you no longer have to provide assets and income
- Denied right away – then tried back and got help

- SSI personnel treats people differently
 - all need to be trained the same
 - they treated many families terribly
 - they point fingers all the time and do not take responsibility

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

- Only 2 of the 9 knew about CSHS
- Helping families, coordination of care, know who the families need to contact for more information, advertise what services they offer
- They are limited to certain health conditions – they do not cover mental disorders
- Why don't they pay parents to help kids if there is no one to help in the schools?
- Parents are unprepared to deal with kids: they are not doctors and teachers, etc.
- One mother found out info. and had to educate the school and Doctor, but then they view us parents as nothing like we don't know anything
- One mother was turned in for educational neglect when we didn't send her to school when she has having thoughts that were inappropriate
- Need to meet families with kids who have the same problems so we can talk and e-mail
 - family picnic – to get people together
 - forums where daycare would be provided
- Provide training for day care providers to help children with special needs
 - the providers now do not feel equipped
- Ward County takes money away if a meeting (such as this focus group) is considered work and it is not "earned"
- You can never get ahead – you earn money and they take it away
- Elks have been good to work with

Financial Matters

- SSI – I don't even try anymore – I end up paying back because I make \$1 over the limit
 - it's based on what the whole family makes
 - you can't save any money
 - you feel terrible – they know everything you have in your accounts, etc.
 - it should be based on child not family income or you'll never get ahead
 - we have to prove our needs all the time
 - it is better to be single and poor
 - the entire family suffers for one child's condition
 - Family subsidy keeps getting cut – you're lucky if you get half of what you ask for
 - it's never enough
 - too much paperwork – it is hard to be a good parent and work at the same time
 - we should not have to prove we get Medicaid every day of our lives
 - we don't need someone second-guessing us

Financial Matters continued...

- Elks works well helping families
- People don't realize the cost of having a child with special needs
- You don't have a life – you can't go out and do anything fun because of the restrictions of the child
- No one should be put in the situation of an uncomfortable life
- I've had to quit my job – I needed to be close to home
- One mother was told they were above the threshold – didn't qualify for Medicare and couldn't find respite care
- Mostly all of the coordination and care falls on the mom of the child
- You get to the point of where you think "Why do I have insurance?"
- I was trying to make ends meet and I was told to drop insurance and not go back to work
- Inclusion – shouldn't have to send our children to institutions
- Can't trust just any babysitter
- I need someone trained who I can trust to leave my child with
- It would be nice to know where to get money from
- These special needs programs continue to get cut
- No one will fight for us
- This country has forgotten about their families

Programs

- SIB SHOP
- ND Infant Development
- Job Service – Brenda Helgremson
- Northwest Ventures
- ND Interagency Coordinating Council