

Minot Session – Written Feedback

1. In what ways do you find information about programs and services available to you and your child?

- ND Pathfinders and ND Pass, NCHSC
- Other parents
- County Social Services
- Diabetes Association
- Case Manager at North Central Human Services Center in Minot
- Networking – friends, co-workers, etc. – teachers have been helpful
- Pediatrician has been helpful
- DD Case Manager (2)
- School (2)
- Family physician (3)
- Call agencies we've worked with for assistance (example: referrals)
- Internet (2)
- PATH
- Partnerships
- Pathfinders
- It helps us provide better special care for her cerebral palsy needs when it is in a brochure or in the Sunday's tribune as an insert
- Newspaper
- Social workers

2. Who is the service provider who primarily coordinates care for your child? (by title or profession)

- Case Manager with partnership
- Johnson Clinic providers – Dr. Schovebery, Dr. Selland, Dr. Nieme – Dentist
- Self...some help from DD Case Manager
- Beth Feist – Development Disabilities Case Manager (2)
- Mom
- Psychologist
- Psychiatrist
- LSW
- Dr. Laura Schield – Pediatric Psychiatrist
- Dr. Kristen Sobus and Dr. Jeff Haasbeek

3. What other health care professionals or service providers assist in organizing or coordinating care for your child?

- Pathfinders, ND Pass, Peace Garden Special Services
- Dr. Gentile
- Dr. Melissa Moilan
- ND School for the Deaf
- Partnerships
- PATH
- Pediatrician
- Garrison Family Clinic/Garrison Hospital – Denise Gradin
- Great Plains Rehab – Bismarck – Peter Davidson – PT
- Key Care Medical – Minot
- Dr. Gomez, who is the child psychiatrist at Trinity Riverside. He will be taking Gene's case when we get back from Minnesota

4. What do you like about the way your child's care is coordinated?

- Group approach
- Good communication with school and doctors, poor follow through from SVSS fro recommended services based on evaluations by independent providers
- Convenience – we can stay in the state, we actually have a great school system and programs in the hospital
- Beth and others try their best but sometimes being over worked and expected to do more with less does tend to stretch people's patience with the system

5. On a scale of one to five, with one being poor and five being excellent, how well do you feel your child's health care needs are being met overall?

5 (2)

2 – Orthodontist was poor in quality as well as the overall attitude and availability of appointments

1 ½

4 (3)

3

Since Gene was recently in residential care – and we have seen the difference in health care systems, we do tend to be very concerned about North Dakota's health care system. We realize that Minnesota has more revenue to work with but it does tend to make a parent very concerned

6. What methods are currently in place to help assure quality care for your child?

- IEP at school (2)
- None
- Treatment Plans
- School IEP
- Military exceptional family members program
- Periodically visits to specialty doctors
- Physical Therapist 1/week for 1 hour
- Respite care, psychiatrist, school is still an issue

7. Have you gone out of state to obtain specialized services for your child? If so, where did you go and for what reasons?

- No (5)
- No – nothing has been recommended and we don't know
- Yes –St. Paul for heart surgery
 - Minneapolis for immune system problems
- Yes – Santa Monica, California for an eye specialist
 - Staten Island, New York for the research center
 - Iowa City, Iowa for a neurologist (synesthesia)
 - Fit Simmons in Denver, Colorado for diagnose
- Grand Forks – multidisciplinary evaluation
- Yes – he is currently in residential care because North Dakota did not have room for him

8. In what ways have you or your child received support or services from the Department of Human Services, Children's Special Health Services unit?

- Currently have partnership services
- Infant Development
- Insulin diabetes supplies not covered by all health insurance
- Orthodontist care (2 years of braces)
- DD Case Manager – has found some services
- Medicaid (2)
- Family subsidy
- Respite care
- DD
- Infant Development
- First District Health Unit – Health tracking (braces)
- Partnerships
- None – Souris Valley Special Services provides OT through school environment
- We receive medical benefits to help pay for what our BCBS policy does not pay for
- Setting up with various programs for Gene

9. What types of financial assistance are you aware of that are available to support the special health care needs of your child?

-Family subsidy (4)

-Medicaid (3)

-SSI (2)

-Children's Special Health Services

-Elks have helped us with travel and lodging

-NDAD has helped with software programs

-None (2)

-I am unaware of any except for medical benefits to help pay for what BCBS does not cover

-Since Gene is adopted we received a subsidy of him being on Medicaid

10. Have you ever been denied health care services because of financial barriers?

-I actually just cancelled appointments or asked for different types of prescriptions, etc.

-Haven't qualified for some services because of our "high income"

-No – PATH is hard because we have to pay our BSND copay and coinsurance

-Yes

-No (2)

-We have been denied Medicaid because of financial reasons

11. What one recommendation do you have for improving the care provided for your child and family?

- Centralized information center which could direct you to the appropriate facilities and care centers for the type of problem the family is meeting – then coordinating the care**
- I feel sometimes I don't even know what's available or what is reasonable to ask about. We all need a central person to advocate for us and our individual needs...someone with time and money resources to look out for information on what's out there. Coordination!!**
- More financial assistance**
- More local resources**
- Coordination of services – more dialogue between professionals**
- Individualize!**
- Centralized resource center**
- Wrap around services to include support for siblings and parents. Everything is geared around the affected child! But we haven't found anything to teach and support siblings and parents.**
- Availability of a multidisciplinary evaluation team in Minot for psychology, OT, PT, education and speech**
- Travel reimbursement for those of us that do not have care in our community – not all communities can provide special care and needs for all special needs. If it is far enough away hotel and meals also would be helpful.**
- Understanding that everyone has individual needs and it is very hard to send a child away who has been abandoned earlier in his life but we had to think of what would be best for him. It did not turn out to be quite the blessing but we would not recommend it for any family to have to struggle through.**