

Autism Advocacy Meeting
July 18, 2008
Anne Carlson Center for Children

Participants: Donene Feist, Janice Kern, Vicki Peterson, Bruce Murry, Carlotta McCleary, Jalene Suda, Sandy Smith, Marcia Gums, Jennifer Hefter, Cathy Haarstad, Kris Wallman, Rhonda Eppelsheimer, Mark Sloan, Ruth Lewis, Senator Joan Heckaman, Gina Horgan, Bob Hoffert, Dan Howell

Welcome!

Introductions:

Donene set the stage for why we gathered today:

1. NDDHS is considering development of an Autism Waiver for ND during the legislative session.
2. They requested input from advocate groups and families on what service areas should be included.
3. Other states are also initiating insurance mandates for coverage of ABA for Autism.

We are considering what we want to do in the next legislative session hopefully together.

Review of survey results: Donene Feist submitted a copy of the survey results (see attached).

1. The comments on needs around assessment make sense given the status of evaluation and the inconsistencies across ND.
2. Family training was one of the highest areas of interest
3. The survey was conducted to include the school age population even though the department might be focusing on early intervention and transition age students.

Consideration of Legislative Options

Carve out Waivers:

Bruce gave out a definition of Medicaid and carve-out waivers. Within Medicaid some programs are mandatory and some are optional through a waiver – sometimes called a carve-out waiver. This allows a

state to waive or bypass certain rules such as waiving asset and income requirements in order to pull in more federal dollars.

We discussed this in context with state government definitions and eligibility criteria for Medicaid as this will impact what we decide to do. We also noticed pending court cases that may impact decisions.

ND currently has several waivers already. If ND develops a carve-out waiver for Autism we have an opportunity to increase services.

Concerns

1. Limiting eligibility so that some diagnoses on the spectrum are eliminated.
2. Limiting services to some populations (e.g. focusing mostly on early intervention and youth/adult and not on school age population)
3. Defining early intervention as birth to three when many children still get a much later diagnosis

Encouraging signs:

1. The Department is taking the initiative on this issue
2. The Department is sharing some information and appreciative of our work as advocates

The DHHS may submit an OAR – Optional Adjustment Request to the Governor’s budget. A request to submit six OAR has proceeded from Deb Balsdon to Carol Olson. The Autism Waiver is designed to cover 30 children at a rate of \$20-25,000 per child. The remaining OARS are for: Transition age youth (16-23 years old); Medically fragile; Medical home; Brain Injury. The total amount for the OARS is about 4.5 million dollars (Thanks to Dan Howell for obtaining this information).

We are now awaiting Carol’s response to that. Cabinet level budget meetings will take place near September. Certainly budget decisions are being made now.

Review of Background Information:

We reviewed different reports and information sources and what they mean.

We discussed definitions of eligibility and research on different populations of children with autism and how definitions will support or hurt our efforts.

- 1) We will need to have very clear research information to inform our work.
- 2) Other pieces of legislation passed may impact our population
- 3) We can use functional definitions to avoid leaving out populations
- 4) The Medicaid requirement for eligibility in an Autism carve-out waiver may be different than the typical ND definition of developmental disabilities.
- 5) We need all parties at the table with solutions for families.

Discussion: "Who's first?" – meaning who should pay first - was a pivotal question that guided us in thinking about where to begin. Insurance, NDDHS, families, schools? We also discussed who can pay for what and who can't.

We discussed the power of parent voice and what does and doesn't work to influence legislators. There are several legislators who may be supportive on both sides of the table. Approach is everything.

What is the need and how we document that will impact what we can do.

- 1) Do we have the data we need to present any particular approach
- 2) How do we handle the data we have
- 3) What is available to meet the need
- 4) What is the best option and why
- 5) What do you think and what do you think would work

Possible Recommendations/Decisions

- 1) See if the OAR for the Autism waiver is picked up
- 2) Participants are invited to send a letter to:
 - a) Medicaid office
 - b) NDDHS senior staff
 - c) Governor's office

to try to influence that process that the OAR is picked up. (Letters could be from both individuals and groups). We should make sure they are signed and out by August 1.

- 3) Since we don't know what is in the OAR, we will work later to get specific pieces into it as soon as it becomes public information. We will get the content of the OAR out to people ASAP.
- 4) Cathy Haarstad will work with partners to prepare information on the incidence of Autism in ND and document the need describe who pays for services now and if not why not.
- 5) Letter content – thank the Department of Human Services for their initiative, reiterate the need, ask to be at the table etc.
- 6) Bruce & Donene & Carlotta will draft initial content for a letter and send the draft out to all participants next week for comment.

Consensus:

- 1) Individuals and groups will send the letters described above
- 7) We will use the word *neurological* in reference to ASD to distinguish it from an emotional or behavioral condition that may be discounted as a need that can be met primarily through education and not through health care. Using the term neurological will keep our options open.
- 8) We will work on developing more informational resources
- 9) Cathy Haarstad will share print information on what a carve-out waiver may be with the group.
- 10) Donene will create space on the Family Voices Website and bulletin board to post resources, information, updates, and discussion trends specific to our work together.

Other Issues: Other Legislative initiatives that will/may be introduced:

Newborn hearing screening
Traumatic Brain Injury
Medical Home
Medically Fragile

ACCC is investing 1.2 million dollars in 3 communities GF, JS, BM, in-home support for children over the next year. Their goal is to eventually serve more children in communities than at the center.

ACCC plans to make their lobbyist available to the Autism Advocacy Group.