

**Autism Advocates
Meeting Minutes
November 26, 2008**

Agenda

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| <ol style="list-style-type: none">1. Use of family stories2. Roles & responsibilities3. Information to exchange4. Messages to send5. Bridges we don't want to burn | <ol style="list-style-type: none">6. Preparation for key questions7. Debriefing afterwards8. Getting everyone's input9. Going forward together10. Using our best wisdom |
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Participants: Bob Hoffert, Bruce Murry, Cathy Haarstad, Donene Feist, Vicki Pederson, Sandy Smith, Holly Majors, Jocelyn Sloan, Sharon Solum, Jalene Suda, Carlotta McCleary, Janice Kern.

Key Topics/Ideas discussed

1. **Use of family stories in the meeting** – The meeting could get bogged down if we go through many stories. At the same time they are poignant, rich in context and provide valuable information. Examples we might need for the meeting would be cases of people covered by BCBS. Consensus:
 - We will use family stories to underscore our points as we go to make a factual and less emotional message that is easily dismissed.
 - FVND is willing to put together a family stories book for the legislative session (this will be helpful as part of our overall strategy for the session). Donene has forwarded a template to use in sharing your story. Please share with families and forward to fvnd@drtel.net
2. **Talking points for the meeting: Key ideas (also see attached):**
 - a) The incidence of ASD is rising. Begin by inviting BCBS to discuss some of that data with us. Be prepared to introduce it if they don't (see attached).
 - b) BCBS already covers a range of services (e.g. speech). Let's acknowledge that.
 - c) Care coordination and physician participation in planning are important.
 - d) Inviting BCBS to speak about that helps position us to present a logical argument for covering a broader range of treatment options for ASD.
 - e) Be prepared to insist on the need for medical treatments for what is a chronic, neurological, lifelong condition.
 - f) Position ourselves to talk about trends in services, concerns and challenges faced by the families.
 - ◆ The difficulty of accessing information and services in **rural** communities
 - ◆ Limited provider knowledge of the condition & treatment options
 - ◆ Coverage for evidence based medical treatments for ASD
 - ◆ Support for services which are available only at a distance
 - ◆ Differences in coverage options from BCBS in different states
 - ◆ Differences in coverage options for other chronic medical conditions

- ◆ The difficulty in finding trained service providers
- ◆ High stress levels and divorce rates among families of children with ASD

3. Doing Our Homework:

Be prepared to counter viewpoints regarding medical vs. educational treatments with factual information.

4. What We Want:

- An ongoing dialogue and commitment from BCBS to join or create a task force to look at these challenges and to move forward in obtaining treatment options for children and adults with ASD **(Keep talking)**.
- To consider coverage for evidence-based treatments on a prior approval basis by creating with families and other partners a set of criterion that are reasonable, fair and affordable **(Family Voice)**.
- To find common ground and work together to create a more thoughtful use of resources in a way that benefits all of the people and employers of ND **(Family Choice)**.

5. Our Opening Approach:

- Make Introductions – Use these to establish credibility
- Welcome/appreciations – Thank BCBS for agreeing to meeting, appreciate the opportunity to visit with them about these important issues
- Reference our conversation of last summer and what brought us to this point (Cathy H).

“Maybe it would be helpful to begin by looking at the increase in numbers of people in ND with ASD reported by BCBS.”

6. Our Middle and Closing:

- Use the talking points to get our central messages through
- Join the conversation in positive/strategic ways.
- Take notes to share afterwards.
- End on a positive notes and try to get specifics for a next meeting.
- Join the debriefing session at the Holiday Inn (see email)

7. Strategizing for the Legislative Session:

Outside of this we need to start strategizing for the legislative session.

- 1) Share family stories through FVND
- 2) Draft our own ideas for what to include in legislation related to the Autism Waiver
- 3) Meet with Senator Joan Heckaman on Dec. 2nd to view legislation.
- 4) Identify republican and democratic senators from both houses to sponsor the legislation.
- 5) Develop fact sheets and informational resources to share with the legislative branch.