

State of Vermont
Autism Task Force Meeting
MINUTES
2-9-07

Subcommittees Meet 9:30-10:30 am

Task Force Meeting 10:30 am –12:30 pm

National Bank's Community Room
308 N. Main Street
Barre, VT

Mission

The mission of the Vermont Autism Task Force is to coordinate the efforts of interested parties who serve individuals with autism spectrum disorders and their families, and to promote the implementation of best practices throughout the state of Vermont.

Norms:

- We work hard to start the meeting on time, people come as soon as they can & they will inform the group if they need to leave early at the beginning of the meeting
- We allow people to finish speaking
- We are respectful of one another in discussions of children, adolescents & adults with ASD, their families, & the professionals, programs & agencies that work with them
- We actively solicit diverse ways of looking at things
- We use person first language (e.g., child with autism versus, autistic child)
- We recognize when more information is needed before a discussion can proceed
- We clarify actions that need to be taken, by whom and when
- We collaboratively determine agenda items for a meeting and important topics that should be discussed as a group
- We revisit our norms periodically and make changes as needed

PRESENT: Doug Smith, Lisa Erwin-Davidson, Clare McFadden, Steve Contompasis, Erin Russell, Suzanne Engles, Hilary Melton, Lynn George, Patty Prelock, Cindy Marshall, Linda Mulley, Jessica Levi, Tim Fox, Nora Sabo

MEMBERS SENDING THEIR REGRETS: Claire Bruno, Amy Ducker Cohen, Claudia Pringles, Pascal Cravedi-Cheng, Angela Timpone

Establish Roles

Facilitators:	Patty
Recorder:	Linda
Time Keeper:	Doug
Rudder Keeper:	Lynn
Equalizer:	Cindy
Processor:	Steve
Wellness:	Erin & Lynn

Introductions

Updates from State Autism Consultants (Clare McFadden)

- Meeting with commissioners did happen and discussion occurred about financial resources currently available in the state by linking to other agencies, exploring what organizations are already in place that may act as resources, etc.
 - **ACTION:** Clare will send out the proposal for regional centers to all autism members as a refresher.
- Attended ABA Conference in Boston, focusing specifically on autism. 1600 people attended the conference with some useful sessions.
- Summer Autism Institute
 - Sunday – Patty, Steve, Cindy – Introductory Presentation on Autism
 - Schedule for 3:30-5 timeframe (post-conference sessions):
 - ♣ Monday: Licia Gates – Circle of Friends
 - ♣ Tuesday: Cath Burns - Toilet Training
 - ♣ Wednesday: Heidi Weiner, Kirsten Murphy – Preparing for emergency situations.
 - ♣ Thursday: Clare and Claire – Overview of available resources in Vermont: reviewing programs that are available in the state with resource fair with posters.

Updates from Other Members

- Cindy is planning a children's mental health day for 5/8/07 at Capitol Plaza. Lunch and many activities will happen. Peer navigators are now happening regionally, and many are dealing with families with autism.
- Jessica Levi – latest results of autism occurrence: 1:150

Discussion of TEACCH Program & Relationship to Regional Autism Centers

- A bill has been presented to the legislature recommending regional autism centers based on TEACCH.
- Several important considerations were discussed including the need to do something with more immediacy, to capitalize on the opportunities of increased interest in autism, to address the need for lifespan planning & adult services, to work with lobbyists in a proactive way, to unite parents to voice their concerns and need for services that recognize their desire for individualized supports for their children, adolescents and adults, to clarify confusions & dispel rumors.

Action Plans:

1. We need to prepare a briefing sheet explaining the need for services, defining our support for the regional autism centers and identifying the evidence-based and promising practices we support. We can hand this to the legislators with our names as the Autism Task Force on back of sheet.

ACTIONS: The governance & systems of care subcommittee of the Task Force will prepare this briefing sheet.

Steve will share today's discussion with Angela & ask her to take a leadership role in this effort as she already has several connections to legislators.

2. Patty will be speaking with Gary Mesibov on Tuesday, Feb. 13 and will get some clarification on his understanding of the needs in Vermont, the efforts to bring TEACCH principles to VT and the state's current efforts in training and working with his colleague, Joyce Lum. Other questions she will pose include:
 - What percentage of children and adults are supported by the TEACCH model in his state?
 - How many TEACCH sites are there across the state and how are they funded?
 - For those not served in the model, what others models of service delivery are used?
 - Is there a way to look at the framework of the adult centers to create a system that uses those without "becoming" a TEACCH center?
 - How long did it take to get to create the original center and satellites?
 - How much money was needed?
 - How many living and learning centers exist the state?
 - What is the association with the university?
3. We need to act in a timely way – people are tired of how slow the process works and commissioners need to begin to see this as a priority.

Committee Reports

1. Governance/Systems of Care
 - a. Update from Angela: Discussed legislative happenings and bill that is being proposed around autism centers. Women's caucus is showing an interest in autism & will be showing "Living the Autism Maze" on at noon at the State House on Feb. 21st. Angela feels she needs to lobby on a weekly basis until we get a comprehensive bill passed to support autism. She plans to contact Bernie Sanders office to push some follow-up on the promises he made regarding supporting autism. Angela mentioned when she talked with individuals at the State House they were essentially

unaware of the Task Force until she explained to them who we are and what we are trying to do.

- b. The Task Force Survey is ready and has been piloted with a few members with a few changes made & positive feedback regarding the ease of completing the survey. At the end of the survey, there is an autism link to the task force website.

ACTION: Jessica will send it to all task force members as a pilot and then will send it off to the larger desired audience.

2. Best Practice Guidelines: A draft is ready and will go out to members of for feedback.

ACTION: Tim & Linda will send out what they have so far before the next meeting so members can review and be prepared for the discussion

3. Early Intervention: Working on ways to increase surveillance at the primary care level for earlier identification. Letter is being drafted to Wendy Davis and Don Schwartz to put this on the pediatric training agenda. Broadly addressing developmental disabilities as well as kids on the spectrum.

ACTIONS: Committee will draft a letter about this and send out to task force members to look at.

Members should send comments to Lisa Erwin-Davidson & Clare McFadden

Clare will send to Patty to sign and send out.

Membership (Cindy Marshall & Erin Russell)

- Tried to strategize active/inactive list
- We have 24 active members now
- Erin & Cindy will look at what skills & demographics we need on the task force, and then seek members to fill out membership
- Erin created many graphs to depict demographics, participation, attendees, thus far etc.
- Proposal for membership will be addressed at the 3/9/07 meeting.

Website Committee (Hilary Melton & Lynn George)

- Kudos to the Website committee – it looks great!
- New web address: www.AutismTaskForce.com (will automatically link to this site from old one)
- Will give full proposal next month
- There is an internal system for gathering statistics with hits on our website (Hilary passed around the stats thus far)
- Bulletin board will soon be put on website
- Working on better organization of the toolkit one pagers by category and links by category
- Training and conference section will also be put up soon
- Changes can be made intermittently through the year and reported to task force for discussion when consistent suggestions are being made from those visiting the website

- Lisa Lawlor should send a request to Theresa Wood for the money never received for the website.
 - **ACTION:** Hilary will contact Lisa about this and copy to Patty
- Our goal is to keep this website dynamic and active into the future via support from the DOE and AHS.
- Efficacy ratings need to be added on.
 - **ACTION:** Clare and Linda are doing the TEACCH efficacy rating. As new research comes in, these ratings may change. Patty will keep her eye on the ratings overall and let the committee know if some need to be revisited.
- We need a very brief explanation about efficacy to place on each intervention page so people understand what the focus is in the box that indicates efficacy rating.
 - **ACTION:** Linda M. will prepare this explanation after receiving a reminder & specific instruction about what is needed from Hilary.

Agenda Setting for March 9, 2007

Measuring adverse effect in autism
 Legislative update on TEACCH process & Regional Autism Centers
 Membership Proposal
 Website Committee update
 Review of Best Practices general guidelines
 Brainstorm items for 4/13
 Decide roles for next meeting
Roles for March 9 meeting as Patty will not be at the meeting
 Facilitator: Clare MacFadden
 Recorder: Linda Mulley

Agenda Setting for April 13, 2007

Case Management Recommendations
 Circle for Friends – brainstorm how we can advocate for these programs occurring in schools
 What information can & should be disseminated to the Task Force from members?
 Identification of children in Vermont—who should be responsible for this?

Processing

Steve noted that we got through a difficult, long agenda with a good process. There is a pretty tight feel to what we need to be doing and some tough discussion occurred but it will enable us to move forward. Nora thanked the group for coming up with an action plan around a difficult topic. Patty wants the best things to happen for children and adults and understands some of the pain that families are feeling, especially

those with older kids. All of us are frustrated with the slow movement & lack of commitment at the legislative and commissioners' level.

Wellness

Lynn offered that her son is able to swallow vitamins now! Everyone has to try to respect and listen to every parent's belief and be open to all interventions no matter what they are. Erin contributed a follow-up story around a two year old she's worked with – his progress and the fact that he's now adopted into a good home.