

State of Vermont
Autism Task Force Meeting
MEETING MINUTES

1-9-09

Committee Meetings 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

MEMBERS SENDING THEIR REGRETS: Patty Prelock, Claudia Pringles, (several others missing – my apologies = Stan)

PRESENT: Stan Baker, Rob Marcellus, Jim Caffry, Angela Timpone, Pascal Cravedi-Cheng, Amy Cohen, Joy Wilcox, Jessica Levi, Holly Betit, Clare McFadden, Claire Bruno

Establish Roles

Facilitator: Stan Baker
Recorder: Claire Bruno
Time Keeper: Pascal Cravedi-Cheng
Rudder Keeper: Ron Marcellus
Equalizer: Clare McFadden
Processor: Jim Caffry
Wellness: Holly Betit

Introductions: Introductions were made;
Holly working on a task force in the Bennington area;

Updates from members:

Holly's son is thriving in the high school; numbers of the students with ASD was discussed; Claire will provide the numbers to Holly; autism task force to help build a community of support in Bennington; 2 active support groups

Ron Marcellus spoke of the pilot program of Personal Care hours into a flexible funding budget; this has been a positive process for his family; their case manager has put together a good program for his son; parent training; supplemented some OT and PT services; have targeted the funding for professional services; major concern is with the check processing company; Jim's family will be moving to the flexible funding budget; his family has not had a negative reaction to the check processing company; 150 kids are in the pilot program that will run for 18 months, at which time the program will be evaluated; the budget impact will be looked into; if it is budget neutral, then it might be opened to everyone

Clare McFadden has a PDD diagnosis committee that is working on developing guidelines for diagnosing individuals with ASD; 16 professionals on the committee; looking to get consistency across the state; and more equity across the state; DAIL will take some of the recommendations and include them in the DAIL regulations; Clare is hoping the document will be available in April

Patty and Steve have a grant through ILEHP that they are working on around training; one will focus on assessment and another will focus on parent training

Kids on the Block are applying for a grant to develop a program about students on the spectrum in schools

VR received a grant from the DD council to hire a youth employment specialist to work in the Burlington area to focus on serving individuals who need additional support to become employed, this is a pilot program; VR is writing a social curriculum to pilot in the work area

Stan Baker was ordained as a deacon in the Episcopal Church

Autism Plan Steering Committee Update:

The priorities and updates related to the priorities were sent out this week along with the application for membership of the advisory committee; the secretary of AHS and the interim commissioner of DOE signed off on the priorities; Ron Hoffman is AHS Secretary; Armando Vileseca is DOE Commissioner who begins January 20, 2009.

The advisory committee will be created as an on-going committee that will advise the work of the plan; please forward to others who may be interested in serving on the committee; especially to individuals who are on the spectrum; there is a “no funding” requirement for additional money in the list of priorities

Angela questioned the removal of the home and community based waiver on the list of priorities; this was removed due to the funding issue related to the waiver; some waivers have been cut at this time due to budgetary constraints; phone calls are being made to announce the cuts to families; the entire plan is a multi-year plan and movement will be made on other recommendations listed

Committee Updates:

Private Insurance:

Ron passed out 2 hand-outs; one is the summary of the subcommittee work; (see attachment); looking for guidance from the task force around the Mission Statement: “Given the beliefs set forth above, the first purpose of the insurance sub-committee of the VATF, is to gather information relevant and pertinent to its active and inactive members, regarding comprehensive private insurance coverage for both the habilitation and rehabilitation of Autism Spectrum Disorder. The committee members will research information from other states, and outline tasks necessary to produce a list of recommendations for its own members, and the identified legislative committee(s) and or/administration, to make the necessary improvements in coverage at a state level (BISHCA - Dept of Banking, Insurance, Securities & Health Care Administration – Health Care Administration Division).”

Mental Health parity law: legislation passed; mandate the states that any insurance company that covers medical illness must provide mental health coverage with parity. Ron and the other committee members are looking for clarification of the role of the committee; VATF is not a 501 c 3 non-profit; however, we can write letters to legislators; the insurance committee can recommend the stand that the task force wants to take; what is the role of the ATF? Can take a general global position about the increase in numbers, gaps, other states are passing laws related to private insurance that is captured in the belief statement of the insurance committee; Autism Speaks is a good resource for insurance legislation; the committee can gather all of the information and provide the information; suggestions about presenting the information to legislators were given.

Angela spoke about the need to form relationships with a few legislators; Pascal wonders if it is important to know how many families are trying to access private insurance? This should be thought about as a 2-year initiative; we should gather research and begin forming relationships now

Kirsten Murphy is another resource to the committee; it would be helpful to vote on the mission statement? Vermont approves more Katie Beckett waivers than other states; more kids have Katie Beckett waivers; one question would be if parents would access private insurance if services for ASD were paid for?; **no quorum at the meeting but we will vote on approving the “concept” of the statement; everyone at the meeting vote to accept the concept of the mission statement;**

- ❖ **Competencies Committee:** list of competencies from other areas have been accumulated from other areas; these include:
 - HEC Case Management Competencies
 - VT Childhood & Family Mental Health Case Management Competencies
 - National ASD TEACH standards
 - Council on Exceptional Children Standards
 - Professional Regulatory Body for Teachers in Scotland: Competencies for teachers of children and young people with ASD
 - Skill Competencies for professionals and paraprofessionals in VA Supporting Individuals with ASD across the lifespan
 - SF State University – Program Competencies for candidates in the AS Program (includes all ages)

From these the committee will identify autism-specific skills

- ❖ **Workload** – not much to report; plenty that has been done but not reportable at this time

Rescission discussion:

- ❖ Advocacy that happened this fall made a great difference to the process of cuts that have already taken place
- ❖ Angela has received e-mails from families indicating that the family-based waivers have been cut
- ❖ Holly helps families locate other places to look for money that they can access in other areas; help families locate other resources
- ❖ The priorities of the plan are seen by some as “fluff”; there is a lot of hostility on message board
- ❖ The waiver has created a lot of tension in the “autism world”; trying to pull together two factions
 - Individuals losing part of the waiver looking for advocacy for the funding
- ❖ Medicaid and education is governor Douglas’s focus for the next 2 years
- ❖ More major cuts will be coming in July 2009
 - next cuts will most probably be in staff time
 - we need to prepare for these cuts; families and people with disabilities is what has helped in the past
- ❖ line item “goods” under the waiver will be cut across the board
- ❖ advocacy by county may need to be looked at

- ❖ every designated agency must have a standing committee of consumers and family members, and these committees are meeting every month to discuss budget information and this is an important committee to ask about being on
- ❖ advocacy should be to protect developmental services at this time
 - advocating to keep the cuts as small as possible
 - this is a horrible climate at this time
 - what has hurt advocacy in the past is when groups fight among themselves
 - Legislators run from in-fighting among the groups
 - Is there a way to convene a discussion around the possible cuts?
 - Could the VFN call people together?
 - Maybe the VFN pull together the Vermont Disabilities Council?
 - Could VFN facilitate parents to come together?
 - There needs to be a “summit” to come together to discuss cuts and be a “unified” voice
- ❖ Joint fiscal office website has a list of all of the cuts that are being made or considered

Membership:

Dean Mooney is interested in professional membership. He understands autism. Professional note: he has done a lot of volunteering for VFN by providing lectures, socials for students; also has done consulting across the state; runs a summer program;

Nicole LeBlanc is interested in membership as a member with ASD. She has been a very effective voice in advocacy. She wants to be a member of the task force. Since we do not have a quorum we voted on the “concept” of approving these two individuals.

Those present approved both Dean and Nicole. We need other members to respond by email to Stan voicing approval or lack of approval for these candidates.

How can we encourage others to become members? How do we represent the full spectrum? Should we invite non-verbal individuals to a meeting? How would we support those individuals to be part of the meeting? How would we change dictate the pace of the meeting? At our next meeting Pascal can talk about the accommodations needed at meetings? Clare’s agency has guidelines about involving consumers at meetings.

Agenda Setting for Next Meeting - February Meeting at Community National Bank in Barre

- Pascal and Clare will talk about accommodations needed to involve stakeholders at our meetings.
- Megan Roy to present rubric she is creating
- Committee reports
- Update on unified advocacy
- RBI

- Summer Institute, week of June 22, 2009
- Electronic meeting
 - -telephone conferencing

Processing:

A lot of activity in Bennington; moving in a positive direction; C3 program is getting rave reviews; additional reviews to follow; some progress on private insurance; ATF will do research' advocacy discussion about parent advocacy and speaking in a unified voice; speaking on developmental disabilities

Wellness:

DD coordinator called Holly to tell her that there is 3.75 hours of case management available per month if no other case management, outside of school, is available.