

State of Vermont
Autism Task Force Meeting
MINUTES

2-8-08

Task Force Meeting 10:00 am –1:00 pm

Community National Bank’s Meeting 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: Lisa Erwin-Davidson, Jim Caffy, Susanne Engels

PRESENT: Claudia Pringles, Marie-Christine Potvin, Amy Cohen, Clare McFadden, Claire Bruno, Stan Baker, Jessica Levi, Doug Smith, Angela Timponr and Steve Contompasis, Linda Mulley

Establish Roles

Facilitator:	Stan Baker
Recorder:	Marie-Christine Potvin
Timekeeper:	Steve Contompasis
Rudder Keeper:	
Equalizer:	
Processor:	Claudia Pringles
Wellness:	Jessica Levi
Jargon buster:	Clare McFadden

Members Updates:

- Clare has some informational material (ASD 101) for parents and primary caregivers. She is test-driving the material with a first group. It will then be available for other groups to use.
 - Working with DAIL on trainings
- Government council on disability's next newsletter will be about ASD. The newsletter goes to local businesses.
- Rutland Regional Community partnership will focus over the next year on improving ASD services.
- Anne Barbanos has started a weekly radio program about ASD on Tuesday morning
- Camp Kaledioscope will occur again this summer.
- Claudia shared information about a group of parents who meet to address specific issues. She would like us to help recruit more members for this group and distribute information. Clare can share information with her list serve.
- LEND programs will be offering funding around training for diagnosis purposes through the Combating Autism Act (\$200,000-\$250,000). As some methodology for this gets brainstormed, Steve would like some input about the methodology at the next meeting
- Linda mentioned the movie "Today's Man." It describes the strengths and challenges of children with Asperger's Disorder.

Membership Update:

- Composition of ATF membership
 - 7 active parents (3 in Washington County)
 - 13 professionals
 - Representatives from Dept of Ed and AHS
 - No individual with ASD at this time

- Recruitment of Parents

Where in VT should recruitment of parents focus? Should we continue to focus on recruitment in the southern part of the state? Parents have expressed a need to better understand what ATF does – maybe info on the website about this would be helpful.

One parent had expressed interest in the past. We will ask him for more information. In addition to this, we will seek interests from others in the community. Asking for a guided letter that would include the information about the ATF norms would be of help. A resume would also be helpful if available and we can ask parents\professionals to describe their experiences around ASD.

We will continue to share with new members the ATF norms and ways the ATF makes decisions.

- Recruitment of Individual with ASD - Possibilities

- Max Barrows = Washington County
 - David Leon = Chittenden County
- Stan will give Claudia contact information about these two individuals

ATF Subcommittee Updates in Relation to Autism Report

Current ATF Subcommittees:

- Governance Subcommittee: Members: Jessica, Steve, Angela
 - Goals:
 - Define who the ATF is
 - what is our influence
 - create a survey to see if VT population knows what the ATF is
 - look at other models of ATF formal or informal.
 - Steve mentioned the 5-year goals for the committee and thinks that many of them have been addressed in the Legislative report.
- Training: Members - Clare, etc.
- Evidence-based practice - Members: Linda, Tim, etc.
- Transition: Members - Stan, etc.
- Early Intervention - Members: Claire, etc.
- Website Committee – Members
- Tool Kit Committee - Members: Amy Cohen and Marie-Christine Potvin

What are next steps for these ATF subcommittees?

Discussion about the subcommittee's roles going forward took place. Should we focus on internal ATF issues or continue to focus on the broader plan in relation to the steering committee. The Steering Committee will reconvene at a later date (March 14th) to develop an implementation plan (i.e., action plan) from the report. The ATF subcommittees may be charged with working on specific action plans.

How do we balance this with maintaining/expending the ATF website and the toolkit, continue with our role as advocate, work toward the summer institute, unify voice for professionals/parents/agencies in VT, etc?

A question is raised about the membership of the Legislative Study Steering Committee in relation to implementation of the plan since that committee was not formed for that purpose. Should the membership of the steering committee change as its purpose changes?

Process of Autism Plan: Now and Future

- **Plan was presented to senate and house in January 2008** – They requested that recommendations be prioritized and a timeline created. They also want a report on the progress made toward the recommendations by the end of the legislative session.
- **Steering committee will reconvene in February.**

- **Claire and Clare have begun to do some work on the recommendations** – for example, Claire is beginning to explore why parents choose to home school their children with ASD who are eligible for special ed.
- **There are 2 other Legislature committees that the report went to** – They have not yet requested a meeting.
- **Language for System of Care funding priorities for individual to obtain jobs was not included** – We discussed whether this might have been included in other recommendations.
- Secretary of AHS and Education did not make many changes to the ASD Report.
- **Budget** – If budget changes occur it will likely be in 2010. Is there any chance that children’s home and community-based services will be restored as a system of care funding priority?
- What can we do to help these recommendations be funded?
 - Contact local legislators: The ATF will create a **sample email** for people to share with their legislator in order to bring attention to the ASD report and to the specific priorities.
 - The ATF could write a letter to Legislature (Stan will make sure that all ideas are included from today’s discussion).
 - Letters in support of the ASD Report
 - Potentially listing ATF member’s priorities in the ASD report.
 - We need to let legislators know that new money is needed.
 - The letter should focus on long-term range priorities as opposed to addressing specifically the Bill related to Regional Centers. Letters should include the need for additional funds to support new projects. Maybe we could ask for legislation that ties into the report beyond the centers.
 - Specify that ATF is available as a resource.
 - Could include the need for home and community-based services. These needs are partly contained in the current budget around EPSDT but that will not cover the need completely.
 - Action Plan: Angela will draft the **ATF letter for the legislature**. Angela will share the letter with Chairs. Letter could be delivered by the Sergeant at Arms to the appropriate legislative committee.
- Some of the recommendations around diagnosis might be addressed through LEND funding and some of the recommendations around info are on the ATF website.
- Autism is on the radar at the legislature. Legislators are discussing the ASD report.
- Legislators want to respond to specific requests. Currently the only bill they have in front of them is the Regional Centers bill. Do we want to support that? Discussion about whether this is the best use of the money took place. Some believe that the waiver would be a better place to spend this money. Some are not sure that the Centers as described in the current bill are the best way to make an impact. \$500,000 for Centers although substantial may not be enough to meet the need and the Centers’ purposes have not been fully fleshed out.
- There should also be a need for a letter from ATF to the steering committee around the ATF priorities.

ATF Meeting Times:

The ATF is cancelling the March 14 meeting. We will next meet April 11, 2008 10am-1pm. (This is to focus on legislative action and so the Steering Committee can meet in between this meeting and our next meeting in April.)

Tool Kit and ATF Website:

- Clare is working on the grant money for the website. At this point ASVT has to respond to the request. There is no more money for changes to the website until this money has been processed. Linda will contact Lisa about this issue.
- At this point we are not in favor of revamping the website but will use the money to continue to maintain the website and focus on website content.
- We could ask for additional funding from VT DOE and AHS for expanding the website through letters to both of these agencies. Before that we would need to discuss what content needs to be added. This could be done at the next meeting.
- The health topics within the toolkit could be expanded. Steve would like to do this later this year but will need help (Stan and Amy offered to help).
- Amy will help to establish efficacy rating based on the work done by TEACCH. Clare will send the articles to AMY.
- The toolkit committee will meet about reviewing the current toolkit.
- Carryover from last minutes: Linda will work on a write up for collaboration.

HEC:

- HEC (Higher Education Collaborative) is offering a course of study around ASD.
- HEC is collaboration between UVM and Johnson state and led by Dennis Cain.
- The funding from VT DOE to HEC will stop in about 1 year.
- Linda is requesting support from us and others, especially parents, in support for funding of HEC. Letters of support should be around the helpfulness and essential nature of the HEC trainings specifically around Autism. Linda could draft a letter and send it to Claudia.
- Maybe the Combating Autism Act could be a source of funding
- Linda will send the ASD competencies that were developed through HEC.

Summer Institute:

- Stan reported on his Action Plan Responsibility. Doug and Max agree to do workshops.
- Clare reported that Lisa was concerned the afternoon free workshops are not sufficiently focused on parents' concerns. Would like one afternoon for resource-fair.
- Opinions: Make sure that topics are more varied, adult-issues have not been addressed much before which is why there was a proposal of some emphasis on this for Summer 08. Should we look at the parent's training-survey, could 2 workshops run in parallel, etc?
- Could we add something around "challenging behavior in kids who are non-verbal" Ed S. will be invited by Clare and let Amy know.
- Parent's pow-wow typically occurs on Sunday after the ASD 101. We recommend keeping it on Sunday.
- These decisions need to be done ASAP so the brochure can get out.
- Claudia will check with VPIC who did the Bullying workshop

- Should we do Circle of Friends Again?
- Claudia offered to do a workshop around legal issues now or in the future.

So keep... (If we double up on some days)

1) Resource fair – 1 afternoon alone

Double these 2 per afternoon:

- 2) Bullying (VPIC or circle of friends)
- 3) Challenging behaviors – Ed
- 4) Literacy groups in adults with ASD
- 5) Role of Self Advocacy in adults with ASD
- 6) RDI

Agenda item for next meeting:

- Discuss possibility of a Vermont day at the Autism Institute in the future.

Wellness:

- Jessica shared a personal story.

Processing:

- Productive meeting with nice discussion.

Next Meeting:

April 11, 2008 10am-1pm.

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