

State of Vermont
Autism Task Force Meeting
MEETING MINUTES
11-14-08

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: Marie-Christine Potvin, Kate Rogers, Lisa Erwin-Davidson, Holly Betit, Clare McFadden, Steve Contompasis, Hilary Melton

PRESENT: Stan Baker, Amy Cohen, Terry Holden, Rob Marcellus, Jim Caffry, Angela Timpone, Pascal Cravedi-Cheng, Claudia Pringles, Joy Wilcox, Patty Prelock, Tim Fox

Establish Roles

Facilitator: Stan Baker
Recorder: Patty Prelock

Time Keeper: Amy Cohen
Rudder Keeper: Ron Marcellus
Equalizer: Jim Caffry
Processor: Claudia Pringles
Wellness: Joy Wilcox

Introductions

Welcome to another new family member: Ron Marcellus

Updates from members

RBI—Claudia has been traveling across the state talking about restricted behavioral intervention (RBI); she will be attending the Vermont Council of Special Education Administrators meeting to share this information.

Higher Education Collaborative (HEC) started a series of workshops over VIT on ASD; the first one was held on Nov. 11 in which Patty Prelock talked about the “5 things every child with ASD should have in their program;” nearly 100 people attended around the state; the next one is scheduled for Dec. 14, entitled “How to teach this kid?”

I-TEAM just completed statewide trainings with about 275 attending.

Camp Kaleidoscope=>working to address the waiting list for families participating in this summer weekend event for families of children with ASD; last year all 22 slots were filled but there were 25 families on the waiting list; they have opened early registration and 14 families who previously attended have registered; there are now 8 new family slots available which will be assigned by lottery; the deadline for registering is Feb. 15; check out their website: www.cgcvf.org; the camp is open to families in the Northeast; on this round there will be a priority for teens and for girls.

Clare McFadden put Jim Caffry in touch with the state auditors office who asked about autism insurance as this was requested by Legislators Morrisey and Pugh—the state auditor is looking at information that Jim shared with them.

The Baird Program serving children with ASD got a grant from the state to provide services for 5 children under 3 years of age through the Family Infant & Toddler Program—all 5 children have been offered services within 5 days of getting a diagnosis.

Lamoille County has limited services and the school has been unwilling or unable to initiate a Circle of Friends group so Terry Holden is developing a circle of friends in her home; the interest for participation has been high with 19 children calling and indicating an interest in participating in the Circle of Friends for her 7 year old son with autism; Terry reported that the children are intuitive and doing

well in figuring out how to engage with her son who continues to prefer engaging with the parents of the children; Terry is staying positive about the possibilities!

The SUCCEED Program through the Howard Center is underway—it is a collaborative program with 7 students (6 with ASD) living off campus with a RA where other students going to UVM live; they all have UVM student benefits; the SUCCEED program provides classes on study skills, relationship skills & job skills along with one or more courses that the students can take from UVM; the students will graduate with a certificate after 2 years and they will be allowed to graduate with UVM students. Currently the program is looking for another house, and hoping to move the numbers to 18 students. They are likely to have a waiting list because of the interest shown and success of the program so far.

In Bennington County, a group has been formed that is working on community outreach; Ron Marcellus' family was chosen for the C-3 Program (PCA hours & funding move to more flexible funding opportunities)—so families could buy whatever programming needed; 100 families were selected from a lottery to participate in the C-3 Program. Ron also reported that his family is participating in a research project in Boston as Mass General in which they are looking at families of children with ASD and creating a DNA data bank; they put families up for 3 days & the families participate in the testing; the project would like additional families to participate.

Brainstorm Ideas for Speakers for the Summer Autism Institute: June 22-26, 2009

- The Task Force members identified several possible speakers for the ASVT and UVM to consider in planning the Summer Autism Institute including:
 - Lynn & Bob Koegel=>Pivotal Response Training
 - Sally Rogers=>MIND Institute, UC-Davis
 - Paul Yoder &/ or Wendy Stone=>both at Vanderbilt; doing research in Prelinguistic Milieu Teaching, More Than Words & early identification
 - Michael White=>in New Jersey; blending behavioral & other approaches; he is part of a school with lots of teens
 - David Wacker=>teaching parents to address problem or challenging behaviors
 - Peter Mundy; Neurological basis of joint attention; University of Miami
 - Kathleen McLaughlin=>Sexuality in developmental disabilities—could she do something for ASD
 - Amy will send Patty contact information
 - Dennis Reed=> has a program in North Carolina for older adolescents & adults; focuses on how to prepare independence & job skills
- **Free workshops & Other activities**
 - Sunday—Autism 101; 2-5:00;
 - Parent Only Support Meeting on Hot Issues 5:30-7:30
 - One evening VABA—Monday evening or whatever evening there is a speaker on behavioral issues

- 3:30-5:00 evenings planned by the ATF
 - Disclosure—how & when do you explain to your community about your loved one with ASD; how do you make it understandable—to community, peers, & child themselves
 - SPEAKER: Amy Cohen (confirmed)
 - SUCCEED Program—what have we learned & where do we go with this; include students
 - SPEAKERS: Students & Staff from HowardCenter Developmental Services (confirmed—Stan will lead)
 - Understanding the legal framework to advocate for your child & adult needs:
 - SPEAKERS: Jim Caffry & Claudia Pringles (confirmed)

ACTION: Speakers for free workshops will let Patty know if there is a day they can't do it, so we can plan the week

Autism Plan Steering Committee Update

Claire Bruno reported that in September, the recommendations for priorities were sent to legislators in the Senate & house Committees. The following 7 priorities were included:

- **GOAL A: Children in Vermont are screened & diagnosed for developmental disabilities, including ASD as early as possible**
 - PROGRESS: Committee of VT clinicians will be meeting about establishing guidelines for diagnosis on Dec. 5; the attempt is to enhance consistency of DX and appropriateness of services ASAP even for those considered at risk; Kate Rogers & Helen Keith have been working on evaluation guidelines for FIT & schools
- **GOAL B: All children 0-5 in VT receive receive effective, individualized early intervention services consistent with the NRC recommendations from 2001 as soon as the diagnosis is seriously suspected (screened positive by professionals as per AAP guidelines)**
 - PROGRESS: Not yet started
- **GOAL C: Responsibilities within AHS, including all departments, & DOE are clearly defined**
 - PROGRESS: A draft is in the process of being written
- **GOAL D: Coordinated Autism resource dissemination should be created to act as an information clearinghouse & promote collaboration among school staff, families, state agencies & community providers & build capacity in all areas of Vermont to address the needs of individuals with ASD & their families**
 - PROGRESS: A list of all the currently existing information dissemination resources has been generated; this will be the first task for the advisory committee to advise on
- **GOAL E: Professionals who provide services to individuals with ASD will demonstrate competencies that reflect the experience needed when working with individuals on the spectrum. Training will be available to all**

professionals for building capacity to meet the needs of individuals with ASD & their families

- PROGRESS:
 - The ATF has been asked to make initial recommendations for competencies & experience needed of case managers in education & human services
 - In the last 12 months, the following trainings have been provided by AHS or DOE; Fall 2007, Positive Behavior Support (3 days); Spring 2008, Structured Teaching/TEACCH trainings (3 trainings in 3 locations); July, 2008—TEACCH in Newport, VT (5 day intensive); October, 2008—Developing Employment Opportunities for people with ASD for Voc Rehab & Supported Employment staff (2 day training in Burlington); other miscellaneous trainings across the state;
 - **ADD:** HEC is running coursework each semester to prepare ASD case managers
- **GOAL F: Educational services that provide the full range of continuum of supports and services will be available to students with ASD throughout Vermont**
 - PROGRESS: Surveys are being developed to determine what services are being provided
- **GOAL G: Adults with ASD receive needed support to live in the community across all settings and to realize their hopes and desired goals. Adults with ASD are competitively employed**
 - PROGRESS: Additional training for employment staff is planned for this upcoming year; Howard Center has developed the SUCCEED program—an innovative post-secondary program that supports students in building skills for independence; UVM received a grant to improve accessibility of teaching for student with disabilities, i.e., Universal Design; DAIL will be looking for opportunities to collaborate with UVM in terms of increased accessibility and supports for students with ASD

Part of priorities will be the creation of an *Advisory Council* to oversee what is going on. Currently, Claire and Clare are working to develop the committee following the state process & going back to Act 35 to have a structure in which to develop this committee. There will be applications to fill the slots for this Advisory Committee.

Clare & Claire will continue to move forward with the Autism State Plan with the assumption that these priorities will remain in the forefront; most of those who signed off on the plan, however, are no longer at the table; Sue Schmidt has been working with Claire & Clare but she was appointed by Cindy LaWare so it is unclear what her status will be. There is a financial crisis and it is likely there will be cuts in both DOE and AHS. Some of the legislators who were the most vocal for ASD, were not re-elected (.g., Chair of Senate Education Committee); not sure where others stand; 2 people on House Education Committee were also not re-elected.

Claire & Clare will continue to push the Autism agenda forward. They are being asked to work with funding currently available and make adjustments in how the available dollars are used to address the priority goals. Timelines for goal completion range from 12-24 months.

Claire also noted that she found the 2008 State Profiles on the ASA website. As she is perusing the document, she is finding some valuable information from which we might be able to draw ideas or input for the implementation of our own plan.

ACTIONS:

- ATF would consider writing a letter of support for the forward movement of the Autism Plan once we know who the new Commissioner will be
- It was recommended that Claire & Clare consider the possibility that parents be a part of the process that makes a decision about who are the parents are that sit on the Advisory Council.

Membership Committee Update

Claudia noted that we have one opening for a professional slot on the ATF with the resignation of Doug Smith. Currently, we have 10 parents, 12 professionals & have designated 2 slots for individuals with ASD.

Stan & Angela have communicated with Max & David (the 2 individuals with ASD being considered for the open slots). Both gentlemen are being extremely cautious about moving forward; Max is worried that he has too much going on right now; David has reservations about getting to and from the meetings. Another possible consumer was recommended—her name is Nicole; Claudia also knows a young man in Montpelier who is nonverbal.

Some ideas were discussed to facilitate the ease with which our consumer members could participate. For example, would we consider a rotation system or would that be too disruptive. Are there other ways we can get consumer input via e-mails, feedback on discussion items, etc. Certainly, support personnel for the individuals are welcome and encouraged. Maybe we ask Max & David to come to one meeting and see how it goes and then determine next steps. It was also raised that it is important to consider those who have different skills than consumers with Asperger disorder.

ACTIONS:

- Stan will continue the discussions with Max & David & get a final sense of the possibility; he will ask them to just try to come to one meeting & remind them of the availability of bringing a support person.
- If either Max or David are unable to participate, Stan will contact Nicole
- Claudia will wait to connect with her possible consumer contact until Stan follows-up with his

Claudia is working on possible professional and family candidates for the ATF. There are 2 excellent possibilities for the professional position but she has not yet received their information. She also has information from an excellent parent & we have 2 other parents who had previously expressed their interest. Claudia would also like to get updated information on all current members.

ACTIONS:

- Claudia will circulate the updated member form to all members at a future meeting
- Claudia will bring forward the possible candidates for the ATF professional slot once she receives all the background information to share with the group

TOOLKIT Update

Review of updates for the medical pieces on the website

- This work has yet to be done
- Stan, Steve, Marie-Christine & Amy will revisit the medical pieces
- We will need to review what toolkit items are more specific to VT & determine what links we want to make to other resources nationally
- Autism Speaks has a 200+ page toolkit that we may wish to look at

ACTIONS:

- Bring medical issues one pagers for ATF to review, make recommendations & give to Toolkit committee to take back for revision & update by January
- Amy will send out an e-mail to Toolkit committee about their task
- ATF toolkit is not listed with Autism Speaks, so Amy will check it out and get VT on the toolkit list

Website updates

Hilary sent an update as she was unable to attend today. She met with our webmaster, Chris yesterday went over again the to-do list from the last meeting. He still has some things to do-- and said he would work on it tonight and tomorrow. She will check on his progress again early next week. If there are any other changes-- people can email Chris directly-- but also please cc Hilary so she can check up on progress.

Here's a link for the recent statistics for usage of the website.

<http://www.autismtaskforce.com/webstats/>

Other Committee Updates

- **Insurance**=>The committee asked the questions, how do we make a presentation & who makes that presentation in this next legislative session? About 20 states have enacted autism specific legislation. Jim & Ron wanted guidance one how we bring this message forward—does it come from a parent group; if we go in with a

legislative proposal, who would do it and on whose behalf would we speak?
Would we work with Autism Speaks as they have a process to do this?

The Insurance committee can go forward on behalf of the ATF and vet it through the 9 parent groups across the state and then take it forward; need to hit Legislators in January, so this needs to be ready to get feedback next month; We can include what we have learned from other states.

ACTIONS:

- Jim will prepare a blurb about what would be the benefit of private insurance to families—what is it and what is it not—including gaps in services
 - Insurance committee can present the information at the ATF meeting at the December meeting & get feedback
 - Insurance committee can send the information out to all the other parent groups in the state to get their input.
 - Insurance Committee will then work with targeted legislators to bring this to the January legislative agenda
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- **Competencies**=>will report next time
 - **Workload**=>will report next time

**Agenda Setting for Next Meeting =>Dec. 12
Meeting at Community National Bank in Barre**

- Committee reports
 - Insurance Committee—review document
 - Competencies Committee
 - Workload Committee
- Letter to the secretaries to support the forward movement of the Autism State Plan
- Rescission-strategy=>talk about advocacy, funding, work that we can do to support the needs & maintaining a base of support for ASD in these current financial times
- RBI (Claudia)
- Electronic meeting

NOTE: Toolkit will be revisited at January meeting

Processing

Good productive meeting—excellent discussions

Wellness

3rd grade student gave his teacher a hug; she was wearing a locket & he asked what is in there; it is where you can put your hopes and dreams; the child opened it & said into the locket, "I want to go to Sea World" and slammed it shut.