

State of Vermont
Autism Task Force Meeting
MINUTES
1-19-07

Subcommittees Met @ 9:30-10:30 am

Task Force Meeting 10:30 am –12:30 pm
HAPPY NEW YEAR!

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: Claire Bruno, Patty Prelock, Linda Mulley, Linda Chaim, Clare McFadden, Tim Fox, Pascal Cravedi Cheng, Lynn George, Hilary Melton, Nora Sabo, Steve Contompasis, Jessica Levi, Doug Smith

VISITORS PRESENT: Heide Wener (parent & advocate with First Responders), Colleen Bancroft (SPED of Calendonina North SU), Officer Tim Tuddle (Police-First Responders), Mark Goodrow (police-First Responders)

MEMBERS SENDING THEIR REGRETS: Cindy Marshall, Erin Russell, Lisa Erwin Davidson, Angela Timpone (able to attend subcommittee meeting but needed to leave)

Facilitator: Patty
Recorder: Linda Mulley
TimeKeeper: Clare McFadden
Rudder: Steve Contompasis
Equalizer: Nora Sabo
Processor: Doug Smith
Wellness: Jessica Levi

First Responder Presentation:

- Heidi described to us an upsetting incident during which she believed her son was lost. This incident sparked thoughts of what could have happened. She attended a conference on First Responders shortly after and brought information to her local police department. Her goal speaking with us today is to make this system more available and responsive to individuals with autism and their families.
- Police response was to create a database, which is an outreach letter to families and caregivers, and an invitation to fill out information on their individual with autism. This information is entered into a confidential database so that officers will have information specific to the needs of the individual when found.
- Officer Tuddle described how the database serves his entire Rutland community. He noted that training is occurring now around mental health and developmental issues, something that didn't happen when he started out as a young officer. The information gathered provides suggestions about how not only to identify the individual but also how to approach and communicate with the individual. He's entered 15 people in the state (includes name, address, phone #, picture, personal info, emergency contact #'s), and notifies communities surrounding Rutland that this database exists for their use. They're promoting kids carrying child-ID information to notify people of needs if found.

Questions:

- *What about accessibility?* Those who are on the computer aided dispatch system (85-90% of all police departments are plus state police) have access to the system. A few have refused to participate in the system (e.g., Burlington – this needs advocacy and action from those of us who live in the Burlington area).
- The system is available only for those people with autism but notes other related problems (mental health issues, physical disabilities, etc.) There is another separate system available for Alzheimer's Disease.
- *In case of accident, will people know an individual's needs?* Child-ID's provide back up for this and officers will know to check base.

- *What about training for Search and Rescue?* – Training is in place: house and ground is searched first, then outward from there. Each city and community has a different plan.
- *What is available for parents?* Information for parents on what to do isn't available now – nothing in writing. Heidi discussed the possibility of training parents on what to do when something like this occurs.
- Steve Contompasis mentioned Project Lifesaver (www.projectlifesaver.com) that he learned about from our state police Search and Rescue Department. This operates out of Morrisville and they have information about radio tracking, to do ideas, and strategies for teaching children to be safe.
- Lynn George mentioned a well-known trainer and expert, who has been in touch with Heidi and given advice. Heidi is seeking future training from this expert. Kirsten Murphy of ARCH (Upper Valley) has also produced material on this.
- Hilary Melton suggested that the schools include a curriculum along with training that would teach kids the skills to deal with those situations and have practice opportunities available. For example, Hilary described some practice she's done with her son – e.g., what happens when car breaks down, when you are pulled over, etc. – using role play and scripts; should there be a role play and script for when a child is lost?
- Lynn George questioned how Burlington is not using same system others use (i.e. ,Vibres), and why they have developed their own system. This is of concern to us all. People could still access the database, however, through the state police system.
- Every officer with a computer can access CAD, and can email a picture to the cruiser and send information back into the system from the police cars. Burlington doesn't have this capacity as far as Officer Tuddle knows.

ACTIONS re: First Responder Information

- Pascal will check with his agency about safety & first responder information & the systems that might be used in Burlington to gather information on how to approach the Burlington Police Department
- Lynn George and Hilary Melton will work with Pascal to approach the law enforcement agency and inquire about the systems, computer, capacity, etc.
- Clare McFadden will consider the possible of a 3:30-5:00 training at the Summer Autism Institute on this topic
- Heidi Wener will write up a 1-2 pager for our website & toolkit information. Patty Prelock will send the toolkit format for Heidi's reference.
- There is also a video about First Responding produced by Lisa Lawlor and Jessica Chen – about 20 minutes. Patty or Steve will get a copy to Heidi.
- ATF Training Committee will discuss safety curriculum for schools. This could also be grant and research project (e.g. using priming strategies, etc.)
- Jessica Levi will send information on how to reach Kirsten Murphy to Heidi.
- Heidi Wener will send information to Patty about what people should do should a child be lost.

Updates from State Autism Consultants:

Claire Bruno – DOE:

- Head Starts have been requesting training on a more frequent basis. She and Clare along with Kate Rogers provided training in St. Johnsbury to about 60 Head Start employees. They will do this same training with Lamoille and Burlington Head Start Programs.
- TEACCH trainings will happen in April (5th and 12th) with Chris Knippenberg and Linda Mulley.
- I-Team will continue trainings in 4 separate locations starting in September, 2007.
- Conversations with the state legislature are ongoing. This will be a hot topic this year. Many have requested copies of White Paper. Parents have been advocating effectively to raise interest and awareness.

Clare McFadden – AHS

- The Commissions are meeting at end of this month (1/29/07) to discuss the autism regional center proposal.
- Development of training of personal care workers is underway with Lynn George (through Autism Support Daily) and Clare.
- Discussion is happening in to change the personal care monies to be more flexible, allowing families to pay higher rates or use their dollars differently than is now allowed by current rules. Survey will come in the mail about how to create this flexible system.
- Clare did a training for an agency working mainly with adults with autism – Champlain Vocational Services.
- Next Steps has been updated and posted on the Dail website (www.dail.state.vt.us), look for autism services. Create a link if you wish to access this on your own websites.
- CHAT (Chittenden Autism Team) was recently created by the schools and Baird whose purpose is to create better services via collaboration in this area.

Questions:

- *Coverage for Health Care Insurance?* Not being discussed at this time. Clare suggested people place all suggestions/data on survey.
- *Is there any discussion about increasing amounts available?* Not at this time. There is much pressure on Medicaid dollars & there will be no increases unless you can show there is an initiative that might cost less money in long run.

Updates from Other Members:

- Nora Sabo reported on Next Steps guide. She wondered if information on First Responder presented today can be added to the packet & Heidi agreed that this would be fine.

- Linda Mulley reported that a website is being established for discussing and updating individuals about the trainings and plans for incorporating TEACCH principles into what we are providing for our students with ASD. As soon as the website is available, Linda will share that with the group.

Suggested Changes to Membership Procedure from the Membership Committee
 COMMITTEE CHANGES PROPOSED & TASK FORCE SUGGESTIONS

- COMMITTEE PROPOSAL: **Terms will be for 3 years, with option to renew for additional 3 years. Maximum time will be a total of 6 years, although can be IN ACTIVE member and vote via email after 6 years of ACTIVE tenure.**
 - TASK FORCE CONCERN: There could be a loss of institutional memory if we institute term limits.
 - TASK FORCE SUGGESTION: Members will be asked at the end of 3 years if they wish to continue to actively participate on the task force. As members rotate off and on the task force consideration will be given to maintaining a minimum number of individuals who have a history of the work of the task force.
 - TASK FORCE SUGGESTION: Individuals interested in joining the task force when there are no seats available could be offered to the opportunity to sit on one of the committees.
- OTHER COMMITTEE SUGGESTIONS: **Each member will fill out a membership form which will be kept in a membership data base**
- **Data base will be maintained by the chair or co-chairs of the membership committee**
- **A waiting list will be maintained for persons interested in ACTIVE membership. The website will be used for recruiting potential participants based on the Committee's identified needs (e.g., considering demographics, specific skills, etc.)**
- **Persons interested on participating in ACTIVE membership, are asked to complete a membership form, along with submitting a letter of interest and a resume. Upon receipt, the applicant will be voted on at the next monthly meeting.**
 - TASK FORCE AGREED TO THESE SUGGESTIONS
- **ACTIVE membership will be average attendance of 9 out of 12 or more months a year, attendance 6 mos. or less out of 12 will be considered NON ACTIVE membership**
 - TASK FORCE SUGGESTION: Need to rethink this or discuss at next meeting as we rarely have 12 meetings a year and those who contact the chair and send regrets because of a prior commitment, sickness, time away should be given consideration and not be seen as inactive if they continue to respond and participate in committee work. Maybe ACTIVE is attending at least 5 out of 10 meetings with active contact with Task Force Chair when meeting is going to be missed. There might be some level in between what is active vs.

inactive—those who periodically come to meetings and stay connected via e-mail and/or committee work. INACTIVE members might be those unable to attend meetings but communicate via e-mail.

- **A grandmother clause will be given to the founding membership. Founding members may participate as INACTIVE or ACTIVE members.**
- **TASK FORCE will actively recruit individuals with ASD for membership. The membership committee will offer any accommodations or support needed to help an individual with ASD actively participate in our meetings. Trainings will be offered to supporting staff or coaches/mentors if needed.**
- **MEMBERSHIP will not include in its ACTIVE 25: 1 past chairperson, 2 consultants DOE and AHS, and 1 ASVT representative.**
 - TASK FORCE AGREED TO THESE SUGGESTIONS

OTHER UPDATES FROM MEMBERSHIP:

- Cindy will contact all inactive members to see if they want to remain on our email list.
- Once all membership forms are in, Cindy will look at the demographics and see what our need is.
- Bessie Weiss is unable to commit to the task force at this time.
- Currently, we have 22 active members and the committee will be seeking an individual with ASD (not including the 2 autism consultants & a rep from ASVT)

ACTION:

- Patty will contact the membership committee and share these suggestions.
- A revision of the membership procedures will be sent via e-mail to the group prior to the next meeting for review.

Website Committee:

- Lynn George has joined the website committee. The committee met with Lisa Lawlor and the webmaster a few weeks ago. All website changes & information should go through Hilary and Lynn using our website (www.vtautismtf.org).
 - **ACTION:** Hilary Melton & Lynn George will publish a blurb about the website/toolkit for distribution to others & will add a “counter” to website to measure number of hits.
- Committee wants to change the website name to make it simpler; members agreed.
 - **ACTION:** Committee will change our website name
- White Paper will either be linked or placed as a document to download (less space if linked)
- Committee may change the name of Toolkit.
 - **ACTION:** Clare McFadden will e-mail the committee with suggestions of categories for organizing the TOOLKIT information to Lynn George

- Steve Contompasis noted that the Toolkit is being used more now; he would like to advertise the website more.
 - **ACTION:** Efforts are being made to do this.
- Bulletin board for committee notes=>Committee needs a membership list –to determine who gets access to the bulletin board. Lynn noted some people have remained on the email list who requested not being on task force – so there is confusion. We need a clean membership list.
 - **ACTION:** Patty will work with Cindy Marshall to clean up the e-mail list and determine who would be appropriate to remain on the list.
- Subcommittee work is currently not planned for bulletin board.
 - **ACTION:** Task Force decided it would like to have the subcommittee reports on the bulletin board, via password process so all can read, so Website committee will add subcommittee information & reports on one part of the bulletin board.

Surveys Discussion (Governance and Training):

- Task Force survey – general questions about what people know about the Task Force. This survey will be distributed to everybody, various list serves – school personnel, legislators, physicians, families/parents, etc. Any surveys that address parents should be combined with training survey to avoid duplication. Intent: Do families and key leaders know we exist to help answer question of whether we need to be more formalized or not? Committee is seeking ideas about where to send this.
- Training committee survey – ready but not distributed yet. This will survey parents on what they feel would be important training for families with a recent diagnosis of autism

Ideas for listserves: Vermont principals’ association. Developmental disability websites, CDCI.

ACTIONS:

- Governance Committee to investigate Survey Monkey (**www.surveymonkey.com**) to assist the survey process
- Governance & Training Committee will work to achieve multiple outreach to get surveys out (mailings, website, etc.)
- Patty will ask Claudia Pringles to email the completed training survey to Jessica Levi who will coordinate getting the surveys out to parents and the governance survey to others on distribution list.
- Committee will document has been contacted and how many people/what kinds of people are receiving the survey – CDCI, parent to parent, etc. so that we can clearly represent who we have reached in terms of the range of families, agencies, etc.

Summer Autism Institute:

MONDAY

Helen Tager-Flusberg, Ph.D.
Boston University School of Medicine
Department of Anatomy & Neurobiology
TOPIC: Language and Communication in Children with ASD

TUESDAY

Pat Mirenda, Ph.D., Professor
The University of British Columbia
Department of Educational & Counseling Psychology & Special Education
TOPIC: Promising Approaches in Augmentative and Alternative Communication for Individuals with ASD”

WEDNESDAY

Stephen Shore, M.A., ABD
Adult with autism
Brookline, MA
TOPIC: Life on and Slightly to the Right of the Autism Spectrum: Observations on Promoting Success for People with Autism

THURSDAY

Serena Wieder, Ph.D
Associate Chair, Interdisciplinary Council on Developmental & Learning Disorders.
Bethesda, MD
TENTATIVE TOPIC: Implementing DIR Model & Floor Time in Children with ASD

FRIDAY

Howard Goldstein, Ph.D., Donald M. Baer Professor & Chair
Florida State University
Department of Communication Disorders
TOPIC: Evidence Based Practices to Promote Social-Communication in Children with Autism

Other 3:30-5:00 pm Programs during the Institute: Clare

- Cath Burns and Amy Cohen have been asked to do a session on toileting issues
- Lesha Gates has been contacted to do Circle of Friends
- Vermont ABA would like to hold a session
- Possibly consider a first responder session—targeting what families need & what is happening in their communities
- Possibly a statewide resource fair

Introduction to Autism will happen on 6/24/07 for any families or providers=>Steve Contompasis, Patty Prelock & Cindy Marshall will provide this training again this year the day before the institute

SUGGESTIONS:

Think about doing a Circle of Friends for administrator, guidance counselors, social workers and family support services.

NOTE: Lynn mentioned that there is info about this intervention on their website: www.autismsupportdaily.com (Power Point presentation on website can be accessed by anyone).

Processing (Doug): Chair did a great job with keeping the agenda moving and getting it completed. Level of participation was very high. Clare did a nice job with keeping time but also being flexible about it.

Wellness (Jessica): Described a trip with her son to NYC to see a Broadway Show (Hairspray). He loves elevators and rode to the 35th floor to get tickets, then focused on the elevators but he did great at the show – loved it, was fully engaged & a wonderful show companion. Talked with everyone during intermission, wanted to meet lead character – so he got signatures from cast members and met Tracy. Sharing with everyone that he met Tracy!

Agenda Items for Next Meeting on Feb. 9, 2007:

- 1) Circle for Friends – brainstorm how we can advocate for these programs occurring in schools
- 2) Measuring adverse effect in autism
- 3) Case Management recommendations
- 4) Membership Committee follow-up
- 5) Check in with committees and progress
- 6) Website committee
- 7) Roles for next meetings and agenda for meetings when Patty will be out of town in March & April