

State of Vermont
Autism Task Force Meeting
MINUTES
5-11-07

Subcommittees Meet 9:30-10:30 am

Task Force Meeting 10:30 am –12:40 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: Patty Prelock, Claudia Pringles, Pascal Cravedi Cheng, Lisa Erwin Davidson, Erin Russell, Cindy Marshall, Steve Contompasis, Clare McFadden, Nora Sabo, Angela Timpone, Jessica Levi, Kate Rogers, Doug Smith, Laura Weaver Grady, Hilary Melton

GUEST: Carol Hassler

MEMBERS SENDING THEIR REGRETS: Linda Mulley, Lisa Lawlor, Claire Bruno, Tim Fox,

Establish Roles

Facilitators: Patty Prelock
Recorder: Patty Prelock
Time Keeper: Pascal
Rudder Keeper: Jessica
Equalizer: Nora
Processor: Steve
Wellness: Laura

Introductions

Congratulations to Claudia Pringles for passing the bar exam

Announcements

[The Vermont Autism Advocacy Line is LIVE!](#)

The Vermont Autism Advocacy Line is available for families to call in and check on the status of legislative bills and other advocacy related issues pertaining to Autism. The line is sponsored by ARCH of the Upper Valley and AAWARE and staffed by parent volunteers.

[Call 1-888-649-2720](#)

NAME CHANGE for Howard Community Services—it is now **HowardCenter**

Updates from Clare McFadden, AHS Consultant

- Claire reported that AHS has given \$7000 to Parent to Parent of Vermont to support families to attend conferences
- Local cable TV show for 30 minutes in the Northwest part of the state with a young man with autism and his mom
- Claire will be attending a conference in Philadelphia with 20-25 different states & each will be sharing how they are addressing the population needs for autism and brainstorming creative solutions

Legislative Update on Senate Bill 121 (Cindy Marshall, Jessica Levy & other members of the Legislative Committee of the ATF)

- S121 is out and on its way to the Governor's desk
- The final bill did have a balance of input from the previous 2 bills
- Several members on the Task Force testified in support of the bill and what needs to be emphasized
- A group of parents met with the legislators to thank them for their support & there is a desire to have a public signing

- The Governance Subcommittee of the ATF would like to have a liaison committee from the Task Force to work with the group who is developing the plan required by S121; they would like it to include a parent, a professional & the chair of the governance committee of the ATF (see attached minutes from the ATF Governance Subcommittee)
 - Clare's and Cindy's impression is that a plan will be developed at DAIL & then this will be brought to several entities for input, but it is not really clear how this will work
 - Claudia, in her review of the bill, suggests that the plan 'will be developed in collaboration with...' and it seems that development of the plan should involve collaborators at the beginning of the process
 - There is a need to have a planning committee from all those collaborators mentioned in the bill
 - ♣ **ACTIONS:**
 - Clare will share the feedback from the ATF with Teresa Wood
 - The ATF Governance Subcommittee will draft a letter & send to Patty to review and send onto Teresa Wood requesting our involvement in the development of the plan as dictated by S121

Summer Autism Institute June 25-29

It was agreed we should still do an Autism 101 training for families with newly diagnosed children

ACTIONS:

- Lisa Lawlor will request a room for Sunday, June 24 from 2-5 pm
- Patty, Cindy and Steve will schedule a conference call to review the content for this 101 training
- Need to advertise this 101 training through—P2P, Autism Support Daily, AAWARE, peer navigators—Cindy Marshall; CMSI; Clare will advertise in local papers

Parent Summit is being planned

- Claudia and Jessica get back to Patty & Lisa Lawlor about the needs for the submit & if they want it for Sunday or Thursday

Do we want to have a resource table?

- If you can send your flyers (250) to Lisa Lawlor at least one week prior to 250, then materials can be available for the resource fair on Thursday of the Institute
- Clare will prepare a flyer about the ATF website and what we can provide as an information resource for families and professionals

Do we want to be listed in the resource directory?

- Just put in our website and indicate there is up to date information on the website

Review of Best Practice –General Guidelines (Tim Fox & Linda Mulley)

- Move to next meeting as Linda and Tim were unable to be at today's meeting

Finalize membership policy (Cindy Marshall)

- Erin Russell reported that she and Cath Burns need to increase direct service role and must go on the inactive membership list
- Now have 2 direct service professional openings
- Bessie Weiss would like to be an inactive member & would like to attend a meeting when appropriate
- Have an application for a parent interested in the ATF who is also an attorney from Washington County

QUESTION: Should we pursue representation from the southern part of the state before we put it out to parent from Washington County since we have several parents on the ATF from Washington County?

ACTIONS:

- Claudia Pringles will put out a recruitment effort for the Southern part of the state
- Cindy will go ahead and send the resume from the parent interested in participation for review by the Task Force
- Claudia will join Cindy as Co-Chair of the Membership Committee to replace Erin
 - Thank you Erin for all your work and contribution to the Task Force
- Membership Policy Amendments
 - **ACTION:** Cindy will send to Patty Prelock the membership changes for a vote via e-mail
- We still need an individual with ASD on the Task Force
 - **ACTION:** Patty has made contact with a UVM college student who has AS and may be interested

Update from Governance (Steve)

See attached minutes from the Governance Subcommittee

See attached survey results completed regarding overall awareness of the ATF
Clare McFadden will be meeting with Senator Sanders & the Subcommittee suggests Angela Timpone work with Clare McFadden as she begins her discussions with Senator Sanders

Act 264 Advisory Board members (11:40-12:40)

Jo-Anne Unruh, private practice & Education Specialist on the Interagency Team & Julie Welkowitz, psychologist, faculty member in graduate program in community mental health in NH joined the Task Force to review recommendations for ASD & determine possible collaborations (*see handouts*)

- Shared information about what has been happening on the ACT 264 board
 - Grew out of ACT 264 bill—to create coordinated services for children and adolescents with emotional –behavioral disabilities
 - Comprised of 3 parents of children with MH, 3 providers, 3 advocates

- Recent change in focus to include a wider range of disabilities
- Required to come up with recommendations for the 2007 Interagency System of Care (see handout)
 - ♣ **Trauma**—coordinator has been hired through AHS; recommendations were to continue to fund this position & expand representation to education; child & family agencies would develop training needs around this area
 - ♣ **Interagency agreement**—continued staff support from Division of Mental Health, ongoing qualitative and quantitative data examining how the agencies are working to address system of care needs; recommit to annual reporting
 - ♣ **Transition age youth**—task force on Transition would expand beyond foster care system but would consider youth from a variety of need areas across disabilities and other challenge areas; funding the JOBS program, creating funds for housing & Medicaid eligibility for youth
 - ♣ **ASD**-creation of an implementation group to plan for regional capacity across the state of VT—to include reps from DOE, DOH, DDAS, VR, DCF, Higher Ed, ATF, VCHIP, DMH, consumers, families, new agency team, autism & family advocacy organizations

NOTE: Act 264 Board will meet with each of the commissioners to send their recommendations forward & then recommendations are sent to the field; they also meet with Senate & House representatives

QUESTIONS POSED BY JO-ANNE & JULIE FOR THE ATF TO CONSIDER

- *How is the interagency agreement working?*
 - How does the community find out who is the local interagency team—this information is not getting out to people?
 - Happy to see #9 included as this clarification is needed—sometimes it would make more sense to have developmental services be the lead agency—also extends to issues of defining who is the ‘case manager’
 - There is no expert case manager from beginning to end—no consistency
 - Collaboration has been none existence for older youth looking for jobs, etc.
 - Gaps in education across the state
 - Also confusion on issues of MH and ASD—no real service coordination across the lifespan; really need more consistent representation
 - Problems for teenagers and adults—for example of lack of effective job coaching and loss of job for young man with autism who has excellent skills—what does that mean for children and young adults with less skills; is there a possibility for a trade or technical school program?
 - Transition is not really at 21—it is artificial—each child needs a life plan
 - DD is at the table but they can’t do anything with no money

- Cindy is seeing a change in stigma from DD to MH—works for some; the entitlement is coordination—if you don't have any services, then there is nothing to coordinate
- It is not MH or DS—it is Autism—we need to be in line—it is not one or the other; at the Local Interagency Team meetings—it's like we are always re-inventing the wheel; there's no continuum—we are dreaming up what is needed especially with the increase in intensive needs for some children with ASD
- *What are we recommending regarding the current legislation?*
 - How do the recommendations for S121 + ACT 264 board work together?
 - Who should be added into the representation?
 - ♣ Representation from VT Chapter of the AAP; Kim Aakre
 - ♣ Someone from the business world
 - ♣ ACCESS office at UVM
 - ♣ Child Development Division –includes the Family Infant Toddler Program
 - ♣ Health Care Funding—Medicaid representative as a partner as well as some
 - ♣ Law Enforcement
 - ♣ VT Association for Business, Industry and Rehabilitation
 - ♣ Where does housing—living arrangements—Office of Economic Opportunity; Supportive Housing @ DAIL
 - ♣ There is a Division of Autism in MA—look at their structure
- *What issues should the board to keep in mind in their future planning?*
 - Would like to see a graph of individuals with ASD over time included
 - Would like to see #10 added which would focus on maintenance of skills throughout the lifespan
 - More language about prevention—recognition of increased rate of MH conditions for individuals with ASD when it is not dealt with earlier on
 - Add screening and identification
 - General Awareness—Chamber of Commerce
 - Medical Home is missing –what is missing is home health services including related services (e.g., OT, PT, SLP)
 - Claudia had developed a list last summer that identified what key stakeholders were looking for and will share that with Jo-Anne and Julie

ACTIONS:

- Julie and Jo-Anne will report back to their group and offer some ways of how they might work together with the ATF
- Patty will continue to include the ACT 264 board in our discussions about implementation of s121
- Jo-Anne will be the contact with us and ACT 264

Scheduling for next year's meetings

- Patty will send out a proposed schedule for August through May
- Patty will work with Clare to find a potential location to a retreat day in August
- We may need to schedule a meeting in June or July to initiate planning regarding S121

Agenda Setting for Next Meeting(s)

- E-mail list and information sharing/responding
- Best Practice Guidelines
- Update from website committee
- Update from training subcommittee
- Adverse affect
- Case Management recommendations
- Circle for Friends – brainstorm how we can advocate for these programs occurring in schools
- Identification of children in Vermont—who should be responsible for this?

Processing

We had a tremendous number of ideas to share and action plans are being met

We renegotiated time

Got through the priority items

Wellness

Laura shared a story of her son who was shopping to prepare a meal for the family—looking at labels to determine if ice cream can be used because grandmother has Celiac's disease! Never underestimate the intellect of individuals with ASD.