

Autism Plan Advisory Committee

Purpose:

The Autism Plan Advisory Committee's purpose is to advise the state representatives on how to move forward with the priorities of the plan.

Norms:

- *We work hard to start the meeting on time, people come as soon as they can & they will inform the group at the beginning of the meeting if they need to leave early*
- *We allow people to finish speaking*
- *We are respectful of one another in discussions of children, adolescents and adults with ASD, their families, and the professionals, programs and agencies that work with them*
 - ***Discussion about confidentiality: these are open meetings; therefore, the discussion and comments are not confidential; we agree to speak positively and not negatively about specific people, programs, etc., e.g. it is OK to talk about a program as an example of challenges and gaps in the system, but not personalize***
- *We actively solicit diverse ways of looking at things*
- *We uses first person language (e.g., child with autism, versus autistic child)*
 - *Our emphasis is the "personhood" of the individual*
- *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 norm periodically and make changes as needed*

Minutes

September 21, 2009

9:30am-11:30am

Berlin DOE- Cavern Conference Room

- **Welcome and introductions:**
Karin Hayes, Gretchen Platt, Susan Ryan, Katy Chaffee, Monica Hutt, Linda Chaim, Steve Contompasis, Liz Jordan-Shook, Laurie Mumley, Clare McFadden, Claire Bruno, Mike Mulcahy, Rhoda Butler, Claudia Pringles, Carol Hassler, Amy Cohen
Roles: Facilitator – Claudia
Timekeeper/Rudderkeeper: Rhoda
Recorder: Claire
- **Review committee's purpose:** Clare explained the committee's purpose – to provide advice to Clare and Claire on how to move forward with the priorities of the plan; Clare and Claire, in turn, go back to their agencies with the recommendations and get approval to move forward; now that the committee has co-chairs, the hope is that the work progresses in a timely fashion
- **Brief history of how we got here:**

2007 legislation passed requiring the state to develop a plan and report to the legislature to address the needs of individuals with ASD from birth to death in their homes, schools and communities.

Summer 2007 through fall 2007 – six committees worked to develop recommendations for the plan

2008 report to the legislature; 57 recommendations needed to be prioritized;

Spring 2008 – steering committee developed the 7 priorities

Advisory committee was created to provide advice on how to move forward on the plan; first meeting held in March 2009

Claudia: the priorities came from the 57 recommendations from the report; Clare explained that there is a lengthier report that outlines all of the goals

- Request for leave of absence by member: An advisory committee member has requested a one year leave of absence and she has suggested a person who is willing to take her place; Clare explained that there was a procedure for applying for membership on the committee; Linda Chaim indicated that if she needed a leave of absence she would need to go back to the VCSEA to find a replacement; Clare – we have categories of applicants who were not chosen to be on the committee; **discussion:** look at the applications received as well as request an application from the person who has been suggested to replace the member; it is important to replace the member with an individual who fits the same category and geographic location; C & C will bring back several candidates to the committee for approval. Claudia suggested that openings be posted on the website for general information.
- Leave of absence: should there be a time limit for a leave of absence? a year is a long time for a leave of absence, it is not fair for the replacement to be asked to leave after the year is over; the replacement person will not need to leave at the end of the leave of absence; **Generally, a leave of absence will be granted but the person requesting the leave will need to reapply when s/he is able to return to the committee.**
- Present Update on Goals A, B, C, E, F, and G: Clare provided quick update (handout provided and is attached to these minutes)
 - Goal A: I-LEHP – early piloting of the M-CHAT at Mousetrap Pediatrics; pilot is moving along; modules are being developed for M-CHAT training; we need (Steve and Clare) to be involved with the CIS teams to be sure that they are aware of the M-CHAT being used in pediatric offices; Laurie: physicians need to be sure that the questions are clear to parents/caregivers; be sure of the interpretation of the questions
 - ADOS ADI-R: Steve and Clare will work together to figure out who will be trained next;
 - Learn the Signs Act Early campaign: parent awareness needs to continue; there may be a New England summit in the spring on Learn the Signs; CDCI is the lead on this; Clare is circulating the draft of “Best Practice Guidelines for the Diagnosis of Pervasive Developmental Disorders”.
 - Goal B: use of federal stimulus money may be used for early intervention services; waiting to hear;
 - Goal C; MOU has been written; Carol would like a copy
 - Goal D: discussion will take place later

Goal E: subcommittee of autism task force is working on competencies for case managers; that subcommittee will be meeting in October; draft of competencies should be available for review at the end of October; Steve – will the advisory committee be getting a draft? Yes, Clare and Claire will get a draft of the competencies to the committee November 5th, training on supported employment; Alan Kurtz and Janine Collins will be presenting; Clare will be sending training information out to the list-serv

Goal F: surveys will be sent out on October 17th to all special ed. directors; Claire explained the questions; Carol: should training needs/credentials for new employees be included in the survey?

Goal G: nothing new

- Provide input/comments on Best Practice Guidelines for the Diagnosis of PDD: Members should send their comments to Clare. She needs the comments within a week.

- Present information on Goal D: Clare – the committee has gathered information from various agencies pertaining to how the dissemination of information happens across the state; we have shared this information at previous meetings; now, we need to brainstorm how to make the system better; after the brainstorming we will prioritize the suggestions, Clare & Claire will go back to their departments with the recommendations to determine how we will move forward;
Review of the various agencies that provide some form of information: VT 211; Children with Special Health Needs; VT Family Network; Vermont Federation of Families for Children’s Mental Health; Autism Task Force Website; Parent Support Groups (currently 9 support groups in Vermont), also peer support groups, VT Division of Disability and Aging Services Autism listserv; DOE and DAIL autism specialists; Department of Disabilities, Aging and Independent Living website; Developmental Disability Designated Agencies; Mental Health Designated Agencies; Aging and Disability Resource Centers – Northeast Kingdom and Champlain Valley; Children’s Integrated Services Teams; Center for Disability and Community Inclusion – I-Team; Department of Health website; Autism Society of Vermont; Rutland police (and others); Stern Center for Learning and Language; Private practitioners in Chittenden county; Specialized Schools; Augmentative Learning and Movement Center; Behavior Analytic Services; Vermont Center for Independent Living; RDI Consultants; Vocational Rehabilitation; Vermont Developmental Disability Council; Disability Law Project

- Brainstorm suggestions for moving Goal D forward: how can we improve what we already have without any new dollar? Clare cautioned that there will be no financial infusion in this economic climate;
 - A cross link that is on all of the sites and locations; link to one website where all of the information is accessible to all
 - Identify a handful of agencies (possibly 5) that will the most updated information
 - Related to VT-211: should there be a 211 algorithm? Enhance the 211 system so that “autism” is searchable
 - Regular meeting (on-going meetings) with key stakeholders from the 5 information dissemination groups to gather/share information about new/updated resources

- One website within AHS/DOE that is maintained
 - Support a person (full or part time) at VFN dedicated to autism
 - A person needs to have the role of keeping everything up-to-date; information is needed on site on how to guide the person through information gathering and connection to resources
 - First steps: team make-up: physicians, referral to FITP; developmental services intake person; team members should be the providers of information; sped coordinator; parent support agency; advocate;
 - Bridge program: case management paid by Medicaid through the designated agencies; these case managers need to be trained to provide the assistance that parents need; (inconsistent trained personnel across the state); training CIS teams
 - Developmental disabilities specialist at VFN
 - Organizers for parents, such as the Joshua project – puts together a care plan for families to help organize; could a web site help families with organization of services/people, etc.
- Reach consensus on 3-4 suggestions:
 - Themes: websites/web information; VFN; process to keep people up-to-date;
 - (VFN – clearinghouse for information)
 - Committee is recommending a web page be developed (calendar will be developed; use a website already in existence; the website will be house with the person in charge of maintaining the site;
 - **Recommendations:**
 - VFN person to be “in charge” of information
 - Web site
 - Communication link in place to assist in keeping updated information
- C & C will bring recommendations to their agencies for input
- **Set agenda for next meeting:** Members agreed to have the co-chairs and state representatives develop the agenda
 - **October 19, 2009, 9:30am-11:30am**
 - **Berlin DOE Cavern Conference Room**