

Autism Disorder Council Retreat Summary

Friday, November 7, 2014

9:00 am to 1:00 pm

ATECH, Concord, NH

Facilitator: Claudia Ferber and prepared Retreat Summary

Notetaker: Jennifer Pineo

Participants: , Dr. Greg Prazar, Sarah Aiken, Elizabeth “Liz” Collins, June Adinah Rachael Alling, Thea Davis, Ellen Boudreau, Brian Huckins, Viki Gayhardt, Adrienne Evans, Teresa Bolick, Audrey Knight , Bonnie Rothermel, Pamela Di Napoli, Amy Frechette, Rae Sonnenmeier, Heather Gage

Brian introduced Claudia Ferber, facilitator for the retreat. Participants introduced themselves.

Claudia provided an overview of the retreat agenda and reviewed Group Guidelines (which everyone agreed to). She introduced the retreat’s goals:

- Celebrate Your Accomplishments!
- Get re energized to move forward the work in the upcoming year
- Learn the results of the Statewide Needs Assessment that will inform and influence the Council’s future work
- Identify goals and workgroups to move forward the “Plan”
- Assign to or identify workgroups that need to be established to be established to move forward the “Plan”
- Finalize a Council Meeting Schedule for the upcoming year

Claudia distributed and asked participants to return a Council Meeting Survey to Jenn at break.

The morning work focused on Accomplishments, Work Still Going On and No Longer Necessary to be a focus of the Council.

Accomplishments

Individuals individually answered the question “What do you feel has been accomplished?”. Responses were read aloud and followed with a discussion about what participants felt contributed to the success.

Accomplishments

NH Awarded a federal planning grant to fund the Autism State Plan <ul style="list-style-type: none">• More \$\$\$ CARA (Federal)	Publishing the <ul style="list-style-type: none">• “Red Book• The Commission Report”• Annual Reports Completed
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Autism9 1 1	<p>Creation/Development of the “Council”</p> <ul style="list-style-type: none"> • Increased Membership • Stakeholders gathered in this Council to focus on ASD and related DD.
Webinar and Training on DSM V	Increased opportunities now
<p>Training provided to providers</p> <ul style="list-style-type: none"> • M-CHAT Project for PCP’s 	Regional Collaboratives: Concord, Nashua and Manchester
Statewide Training law enforcement and first responders	Website Design
NH Autism Registry	START and crisis supports
Statewide Needs Assessment	Building on what exists w/o duplication
Passing Connor’s Law	Establishment of ASD Programs @ UNH, Rivier, Antioch
NHABA efforts to educate the state on behavior analysis & Autism	Certification Program of behavior analysis in Autism (Antioch)
Policy Relating to ASD	Workforce: doubled the number in NH of Certified Behavior Analysis
<p>LEND sponsored on going activities including:</p> <ul style="list-style-type: none"> • ADOS Training • Social Thinking Training • Pediatrician Training on Early Screening and Identification 	<p>Insurance Company</p> <ul style="list-style-type: none"> • Educating about ABA Treatment for Autism •
<p>Advocacy on ASD</p> <ul style="list-style-type: none"> • Establishing a voice with Insurance Company • Luncheon (ES, ASNH, IOD) for Legislators -preceded formation of the Commission • Energizing People Around NH 	<p>Raising Awareness of ASD issues and incidence</p> <ul style="list-style-type: none"> • Public • Legislative • Dissemination of Information to pediatricians to assist with early identification • More Information about ASD for parents, schools and community members • Focus Groups for parents and self-advocates
<p>Education</p> <ul style="list-style-type: none"> • trained 23 parents in basics of autism family support “CAPS” • on going workshops and training • The Rae & Amy & Judah Class 	<p>ACT Early Ambassadors X3</p> <ul style="list-style-type: none"> • Summit and Team
Funded Open Forums	NAWG
<p>Assessment and Treatment Planning</p> <ul style="list-style-type: none"> • Interdisciplinary Diagnostic Assessment and Treatment Planning • Focus on using validated developmental screening in medical practices 	<p>Services-Increased and Improved</p> <ul style="list-style-type: none"> • Expansion of Dr Services (Community Partners • Specialized Autism Case Management in some regions • In Schools •

<p>Fundraising</p> <ul style="list-style-type: none"> • All Abilities Festival 	<p>Identification</p> <ul style="list-style-type: none"> • Decreased age of children identified • Better identification of children, family and provider's needs
<p>Improved Public Policy</p> <ul style="list-style-type: none"> • more/better guidelines and policies developed and shared 	

Accomplishments: What Contributed to the Successes?

- Past and Present Energy and Commitment of people in the room (Council)
- Diversity Skill Set
- Personal Interest
- Leadership Training
- Elimination of silos
- Identify the need for support of families across the lifespan
- Persistent-“nosy”- in accessing information
- Federal funding, support and training
- Shared vision
- Growth of “Autism Speaks”
- Interest of families across the lifespan

Current Work that needs to be continued

Individuals were asked to identify the work that is currently going on and then what would be need to move the work forward.

<p>State Plan</p> <ul style="list-style-type: none"> • Moving State Plan from planning to implementation • Support Council and workgroups • Regional Collaboratives HUMAN SERVICE WORKGROUP • Maintain/sustain an integrated family support network • Website: updates (Virtual Resource Center) • Continue to work to support people with ADS • Collaborative work with outside groups i.e. Area Agency, DHHS, Legislature 	<p>Services</p> <ul style="list-style-type: none"> • Consistency of services available statewide (school, area agency, community) HUMAN SERVICE WORKGROUP • Expanding support/services for families e.g. help with challenging behaviors, transition planning • Develop to enhance individuals with Autism to find and hold employment • Accessibility • Specialized Case Management in all Area Agencies • Identify Resources/Services/Supports
<p>Parent Education</p> <ul style="list-style-type: none"> • NHABA • Self Advocacy 	<p>Regional Collaboratives HUMAN SERVICE WORKGROUP</p>

<p>Funding: Grants, Advocacy, Insurance Changes</p> <ul style="list-style-type: none"> • People writing grants=\$\$ • ABA Medicaid Benefit • Medicaid Funding!! INSURANCE WORKGROUP • Payment for needed care/services 	<p>Workforce/Professional Development e.g. IOD, NHABA, COUNCIL WORKGROUP</p> <ul style="list-style-type: none"> • Training on Early Development and Screening (ASQ, MCHAT) • Earlier Identification, Screening and Diagnosis • On going Awareness Training for providers • Treatment-research based to Physicians • Education about what is ASD
<p>Advocacy/Public Awareness</p> <ul style="list-style-type: none"> • Education of lawmakers • Parents Advocating for their children • Increase Public Awareness Efforts • ACT Early Regional Summit being planned ACT EARLY AMBASSADORS • Watching the upcoming Managed Care Implementation of Phase II 	<p>Data Collection</p> <ul style="list-style-type: none"> • Gathering from SIS Interviews to determine need for adults • Capturing #'s re: ALL diagnosed w/ASD DATA GROUP
<p>Needs Assessment</p> <ul style="list-style-type: none"> • Complete and distribute • Title V Federal MCH Needs Assessment (due to Feds by July 2015) 	<p>Disability Policy Changes</p>
<p>Adult Issues</p> <ul style="list-style-type: none"> • Employment, housing IOD and VOC REHAB 	<p>Workforce Expansion</p> <ul style="list-style-type: none"> • More providers for direct support to people with Autism
<p>Research</p> <ul style="list-style-type: none"> • Outcome studies for treatment effectiveness for children with Autism 	<p>Diagnostic Services</p> <ul style="list-style-type: none"> • Statewide expansion of Diagnostic Services • Consistency/availability of screening and diagnostic evaluations EARLY SCREENING WORKGROUP • Answering Needs of those with ASD
<p>Diagnosing children with ASD before age 2</p>	<p>Trainees NH LEND Program</p>
<p>Assistance finding/getting information and services</p>	<p>Registry</p>
<p>Fundraising Efforts SMALL GROUP OF COUNCIL MEMBERS, NO FORMAL GROUP</p>	

What is Needed to “MOVE FORWARD” the work?

Build and support the professional field/workforce RED BOOK	Help psychologist and others finish schooling which is expensive and the positions they secure are usually low wages; need to find ways so they can afford to work in the field Suggested 3 year commitment in statework and their education loans will be forgiven ex. tech (Brian)
Increase screening/diagnostic especially for older youth	Need more providers currently only resource Dartmouth Need standard practice of evaluation for older youth
Qualified Prescriber esp Medicaid (Brian)	Psychiatric Services needed Only 2 medications currently approved (Greg)
Insurance	Over 6 commercial insurance carriers do not cover evaluation; this gets put back on the school district becomes an Insurance Carrier vs SPED Laws **see Massachusetts
Policy Work (Sarah)	Educate policy makers (policymakers as broad) e.g. school boards and especially lawmakers who seem to have a limited knowledge
Volunteer Workforce	Need to find ways to fund positions for people/organizations that are dedicated to improving services and supports to persons with ASD Parents needed to be reimbursed for their involvement as they cannot work for free-they bring valuable knowledge and experience to the conversations.
Educate	Business community to gain understanding of the important role that family members have to improve the system and support them in their role as volunteers; some businesses do encourage their employees to perform community service.
Lack of Advocacy Body	Identify way to meet normal role of advocacy organization-lobby *MMC will support adult system of care

No Longer Necessary

Participants were asked to think about the work they have been doing on goals and within the workgroups. The work has been very successful. Participants were asked to identify any work that can be now “checked off” the TO DO list. The group identified :

- the use of certain words and language in bills/policy has been addressed that previously had negative impact/misrepresented individuals with ASD.

Statewide Needs Assessment

Rae and Jenn presented an overview of the Statewide Needs Assessment Report. Participants were provided a DRAFT copy of the Report. There was discussion and recommendations. See “Action Steps” below regarding follow up.

Moving Forward

Participants were asked to individually reflect on questions below and then in small groups identify a minimum of (3) Goals or General Focus, etc. They then reported out, had time for questions and clarification. The participants then voted on (3) Goals/General Focus they would like to see “move forward” in the upcoming year.

1. Goal or General Focus for the Council work in 2015
2. What they saw would be the intended Outcome or Product?
3. Indicate if the work should be done in a workgroup? An existing workgroup or new group?

Small Group Membership:

- Group 1 Vicki Gayhardt, Liz Collins and June Adinah
- Group 2 Bonnie Rothermel, Brian Huckins, Audrey Knight and Adrienne Evans
- Group 3 Sarah Aiken, Jenn Pineo, Teresa Bolick and Greg Prazar
- Group 4 Rae Sonnenmier, Heather Gage, Amy Frechette, Ellen Boudreau

Priorities for 2015

These were the identified priorities.

Goal/General Focus	Outcome or Product	Workgroup: Existing or New
1. 10 Votes (combined 2 goals) a. Every Person w/ASD in NH has access to Evidenced-based Assessment & Intervention (Group #3 Item II) b. Expanding access to diagnostic services across the lifespan (Group#4 -Item 5)	a. Every Community Agency & Professional Group have access to information on evidenced based practices and make a plan to use it b. Protocol that Greg mentioned & plan and/or expansion	a. Reconfigure H.S. and Education Workgroup b. Screening & Diagnostic Workgroup

<p>2. 8 Votes (combined 2 goals)</p> <p>a. Centralized point of contact and Parent to Parent Network (Group #4-Item 1)</p> <p>b. Organized Method of autism-specific parent to parent support and advocacy (Group#1-Item 1)</p>	<p>a. Paid position for Information and Referral</p> <p>b. Families know who to contact</p>	<p>a. Scening and Diagnostic Workgroup</p> <p>b. There is an existing newly created council workgroup on Parent to Parent Support</p>
Goal/General Focus	Outcome or Product	Workgroup: Existing or New
<p>3. 7 Votes (combined 2 goals)</p> <p>a. Get Needs Assessment completed and converted into an ASD State Plan by August 2015 (Group 2-Item 1)</p> <p>b. Create an ASD system of care model for NH (Group 1-Item 2)</p>	<p>a. State ASD Plan</p> <p>b. Create a road map to follow for coordinated, integrated care</p>	<p>a. Needs Assessment Workgroup with Existing State Plan Workgroup</p> <p>b. Will be the State Plan Group</p>
<p>4. 7 Votes (combined 2 goals)</p> <p>a. Medicaid State Plan needs to include services for kids with ASD (Group 2-Item 3)</p> <p>b. Expanding access to diagnostic services across the lifespan (Group 4-Item 5)</p>	<p>a. Improved paid services for kids (0-21) on top of what schools provide</p> <p>b. Protocol that Greg mentioned and plan for expansion</p>	<p>a. New but existing ABA workgroup (name needs changing,etc.)</p> <p>b. Screening and diagnostic services covered by insurance</p>

Below are the additional Goals/General Focus items, etc. that were submitted by the small groups for consideration as a Priority for the upcoming year. These will be reviewed periodically as work progresses.

Group # and Goal #	Goals/General Focus	Outcome or Product	Workgroup: Existing or New
Group #1 Item 3	Follow up survey of any high school staff that is involved in transtion to work	To develop a clear picture of when and how this currently takes place	New
Group#2 Item 2	Once State Plan completed apply for Implementation Grant	Funded Implementation Grant Application	New-grant application workgroup

Group #2 Item 4	Increased public and professional education	Better understanding by hospitals, law enforcement, first responders of needs of kids/families/adults with ASD	Revive/New Safety Committee Workgroup
Group#2 Item 5	Improve statewide availability of regional points of reference for supports	Regional (?) with expertise available statewide	Existing Human Services Workgroup
Group#3 Item 1	Input & Advocacy by Council on MMC Business and Policy	Influence contract to allow app. service prov. By app people. App. Intensity level	New subcommittee pulled into QC or Insurance Workgroup
Group# 3 Item III	Input from stakeholders (school family members) to PCP Society about how PCPs can improve how they deliver care to individuals with ASD and family	Improved communication between groups Create a brief for PCPs	Subcommittee of Public Awareness Workgroup
Group #3 Item IV	Having someone to update and maintain website for example resources and calendar	ASD Council website becomes first place people go for information	Rae and Amy
Group #4 Item 2 Note: received 3 Votes	Addressing needs of Adults	Unmet needs report and recommendations as the population increases and more help is needed	Independent Workgroup
Group#4 Item 3	Improve & Increase Professional Development for school administrators	Resource document that provides professional development opportunities with qualified professionals	Education Workgroup
Group #4 Item 4	IEP Etiquette re: Autism	IEP Teams and protocol designed for students with ASD: -longer meetings scheduled -consider student's needs to attend	Education Workgroup

Parking Lot Items

There were items that participants ask be captured for future discussion:

- Standards of Care
- Individualized Services and Supports
- Funding of service and support system

Other Business

Council Leadership Positions

Brian presented to the participants the need to fill a co chair position for the Council. Further discussion about the need to fill Treasurer and Secretary positions. Important to begin to build a strong infrastructure to sustain the Council. All were asked to consider how they could assist in filling these positions.

Website

Participants voted to hire Amy Frechette to manage input of information for the website. This is a paid position for Amy. Rae Sonnenmeier will work with Amy and all postings.

2015 Meeting Schedule

Jenn shared the results of the Council Meeting Survey. Appears there will be some changes. She will send out a confirmation of meeting day, dates and time. See Action Step below.

Action Steps

Statewide Needs Assessment Report

- Participants asked to send any content suggestions to Jenn by Friday, November 14, 2014
- Participants asked to send their credentials and titles, etc to Jenn for the Report
- Teresa Bolick will send research to Rae and Jenn
- Liz Collins will send data to Rae and Jenn

Meeting Schedule

- Jenn will be following up with folks who did not complete the Council Meeting Survey and send out a confirmation.

Council Positions

- Council Members asked to consider stepping forward to fill the positions of Co chair, Treasurer and Secretary.