

**AHS Integration Efforts
Autism Planning for the Future
Meeting Minutes**

Date: Thursday, October 26, 2023
11:00-12:30

Facilitator: Molly Bumpas

Notetaker: Cheryle Wilcox

Overall Goal of our work group: How do we use our collective resources to move autism services forward for children and their families in Vermont?

Strategic Plan Goals:

- A. To challenge and advise the current system to identify creative, collaborative, and flexible strategies to deliver family-centered care throughout a child’s journey from early identification and diagnosis through adult services.
- B. Increase access to assessments, supports and services up and through transition to adulthood.
- C. Educate community about inclusion and neurodiversity.

Present: Molly Bumpas, Cheryle Wilcox, Cammie Naylor, Emily Dischino, Sarah Cavarnos, Philip Eller, Danielle Cohen, Leslie Davis, Amy Murphy, Jen Taylor, Alyssa Heilbrunn, Valerie Wood, Janelle Germaine, Kara Hurwitch, Danielle Dukette, Cassie Santo, Cortney Keene, Meagan Rohde

Agenda Item	Discussion Notes
Group Member Updates	<ul style="list-style-type: none"> • NCSS intensive ABA program is closing which is a loss of services for the community. Will be forwarding some services into other programs. This is due to financial reasons and cost reimbursement. Question was asked about what about the children and families who were receiving services through their program. NCSS is helping to transition kids to other services. <ul style="list-style-type: none"> ○ Danielle Cohen asked for the contact at NCSS to offer supports. ○ Also, contact Katie McCarthy so contact could be made with LEAs. ○ Cheryle will make these connections following the meeting today. • Katie Beckett: <ul style="list-style-type: none"> ○ Valerie Wood shared her experience: <ul style="list-style-type: none"> ▪ She received inaccurate information from DVHA about having additional time to complete the renewal paperwork, which led to the termination of her son's Katie Beckett Medicaid. ▪ She received additional information from ESD and tried to call to get through to talk to someone about the situation. When she got through their automated system (which is quite difficult to navigate), she was told there were 79 callers ahead of her.

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	<p>She stayed on the phone for two hours and 19 minutes. At that point there were still 31 callers ahead of her. Even if she had stayed on the phone all day, it was unlikely her call would have been taken.</p> <ul style="list-style-type: none"> ▪ Through her participation in closed Facebook group for parents of children with special health needs sponsored by Vermont Family Network, she has heard many other parents share similar experiences regarding the Medicaid unwind process and how this experience adds an additional, unnecessary level of stress to their lives. ▪ Cheryle has raised this to the DVHA Deputy Commissioner, and she is very interested in hearing more. <ul style="list-style-type: none"> ○ Cammie shared from a legal perspective she is also seeing Katie Beckett end for families. It is important for families to fill out the paperwork to be very overdetailed and explicit. Vermont Legal Aid offers assistance to families who are appealing. It is hard to meet criteria for Katie Beckett. Cammie shared this information: https://www.ssa.gov/disability/professionals/bluebook/112.00-MentalDisorders-Childhood.htm The Katie Beckett application goes to DVHA and then the determination for criteria is done by Disability Determination. ○ Another parent shared that Katie Beckett is not made for the layperson to fill out. Feel like it is set up to fail. Had to advocate very strongly to have it approved. ○ Vermont Family Network has great resources for families ○ Please see resource attached: Children with Special Health Needs Disabled Children’s Home (DCHC)– Katie Beckett Completing the Application Fact Sheet and information on Katie Beckett INSituational Level of Care: https://humanservices.vermont.gov/sites/ahsnew/files/documents/23-032-F-GCR-DCHC-ILOC-Eligibility-Final.pdf <ul style="list-style-type: none"> • Amy Murphy, AOE: <ul style="list-style-type: none"> ○ Wanted to share, after last meeting I contacted a previous employer in South Carolina, at the School of Social Work, to let them know about the work that was occurring here in Vermont with exploring accessibility with medical for individuals who are neurodiverse (have been diagnosed with Autism). They have a group working under Dr. Robert Hock, who are putting lots of programs into place to support individuals and families and was very interested about our discussion. If anyone wants to be put in contact with that team down there, let me know. Amy.murphy@vermont.gov

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	<ul style="list-style-type: none"> • Molly Bumpas: <ul style="list-style-type: none"> ○ CHAMP update for pediatricians to get training on autism screening: 16 pediatricians were interested in the training and went through the CARS2 tool for training. They are also getting every other week professional development and the medical homes are getting ready to assist with diagnosis. • Cortney Keene: <ul style="list-style-type: none"> ○ I have started conversations with the Vermont Department of Labor about ABA workforce development (we just received a grant for front line staff development) and am hoping to meet with them about clinical development for BCBA's and BCaBA's.
<p>We would like to do a survey to check in about the group direction— what questions should we ask?</p>	<p>Given that we have a large group and not everyone makes it to every meeting, Molly and Cheryle would like to do a short survey to get feedback on our direction as a group:</p> <ol style="list-style-type: none"> 1. What keeps you coming back to the meeting-what do you get out of it that makes it meaningful? 2. Is there an ideal time/availability for the meeting? and length of meeting? In person? Stay virtual? 3. Remind folks of the mission of the group. Does this still work? 4. How can the members of this group further/promote the goals of the strategic plan? <p>Follow up with more ideas post meeting from Valerie Wood:</p> <ul style="list-style-type: none"> • Think about all the meetings you attended this past year. How would rate them on the following (Likert scale 1, Strongly Disagree to 5, Strongly Agree): <ul style="list-style-type: none"> ○ The meetings were beneficial. ○ I felt actively engaged during the meetings. ○ My ideas were respected at the meetings. ○ I was able to meaningfully contribute to our conversations in meetings. ○ I was presented with leadership opportunities through my participation on the committee. ○ I received the right amount of information through my committee participation. ○ The meetings were organized and well coordinated. ○ The agenda material was 'right-sized' for the length of the meetings. ○ The length of the meetings worked well for me. ○ Participating in the meetings was a good use of my time.

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	Qualitative Questions: <ol style="list-style-type: none"> 1. What is your favorite part of the committee? 2. What aspect(s) of the meetings need improvement (if any)? 3. Do you have any other comments you would like to share?
Topics for agenda setting for the next calendar year	<ul style="list-style-type: none"> ○ What do we know about the needs of children with autism and their families? ○ What do we know about the systems ability to meet those needs and what are the gaps? ○ What areas need strengthening to fill those gaps? ○ How do we do advocacy and workforce development. ○ What is the professional development in elementary schools to implement the plans that come from ABA programs? ○ Possibly including someone from CASP joining our meeting to support advocacy efforts and next steps (I am thinking of Judith Ursetti, specifically) or Dan or Lorri Unumb.
Wrap Up and Next Steps	<p>Cheryle and Molly will meet to pull survey together and plan out next year's meeting schedule.</p> <p>Next meeting Friday, December 8th from 10:00-11:30—combined our Nov and Dec. meetings into just one due to holidays</p>