

## Autism Planning for the Future

## Meeting Minutes

**Date:** May 6, 2021

10:00-11:00

## Location: Teams

**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?

**Present:** Cheryle Wilcox, Liliane Savard, Molly Bumpas, Joy Wilcox, Kathryn Workman, Lana Metayer, Julie Smith, Cortney Keene, Jamie Rainville, Matt Habedank, Courtney Daffinrud, Diane Bugbee, Philip Eller, Brian Marrier, Jenn Johnson, Beth Forbes, Michael Hoffnung, Hillary Hill, Erika Rojas, Valerie Wood, Sarah Stutz, Alex Langevin

Agenda	Discussion Notes	Next Steps
<b>Welcome!</b>	Thank you to Mary Graham McDowell, our outgoing co-chair and welcome, Molly Bumpas, new co-chair with Cheryle.	
<b>Updates</b> Updates from group members about any legislative information, other workgroups addressing autism services, DVHA, etc.	<p><b>Liliane Savard, Autism Collaborative:</b></p> <ul style="list-style-type: none"> <li>The document sent this week is a working draft for a grant application they are developing for an Engagement award. If you are able to read it and give feedback Liliane welcomes that. A big part of that application is getting support from community partners. If you feel the proposal is connecting to something your organization would like to be involved with, then contact me and we will make a plan to partner on the project. They are gathering letters of support-they can only have 5. Liliane will draft letters so many folks can sign them together (ABA providers, parents)</li> <li>Looking for someone with communication expertise-want to give this to someone from Vermont who is Autistic.</li> <li>Policy brief for reimbursement for services such as Pediatric PT who often are denied unless they carefully craft the goals. I would like the brief to go forward for a demonstration project-where parents can work with the PT to create the goals.</li> </ul> <p><b>Marilyn Mahusky (Vermont Legal Aid):</b></p> <ul style="list-style-type: none"> <li>Legislative Committee on Administrative Rules (LCAR) met today and approved the adoption of special education rule changes. This is very impactful for special education—changes include: <ul style="list-style-type: none"> <li>Overall, the current rules were changed to better align with the federal rules.</li> <li>For this group it is important to note that we were successful in advocating for changes to the adverse effect requirement</li> <li>Functional skills must be considered when looking at impact of disability on educational performance, no longer just academic impact</li> </ul> </li> </ul>	<p>See attached draft language for more details</p> <p>Have Marilyn and VFN come to a meeting to talk more about these details.</p>

	<ul style="list-style-type: none"><li>○ These are really important changes that have been being advocated for, for years.</li><li>○ There is parental input now required.</li><li>○ Effective starting the 2022-2023 school year.</li><li>○ You can see the marked up version here-starts on pg. 501. <a href="https://legislature.vermont.gov/Documents/2022/WorkGroups/LCAR/20-P12%20-%20Special%20Education%20Rules,%20parts%20B%20(ages%20-22)%20and%20C%20(birth%20to%20Age%203)/W~none~20-P12%20-%20Special%20Education%20Rules,%20Parts%20B%20(ages%203-22)%20and%20C%20(birth%20to%20Age%203)~4-14-2021.pdf">https://legislature.vermont.gov/Documents/2022/WorkGroups/LCAR/20-P12%20-%20Special%20Education%20Rules,%20parts%20B%20(ages%20-22)%20and%20C%20(birth%20to%20Age%203)/W~none~20-P12%20-%20Special%20Education%20Rules,%20Parts%20B%20(ages%203-22)%20and%20C%20(birth%20to%20Age%203)~4-14-2021.pdf</a></li></ul> <ul style="list-style-type: none"><li>● There is proposed legislation to form a working group to focus on adults with Autism. Here's a link to the proposed legislation re: adult autism services: <a href="https://legislature.vermont.gov/Documents/2022/Docs/BILLS/H-0243/H-0243%20As%20Introduced.pdf">https://legislature.vermont.gov/Documents/2022/Docs/BILLS/H-0243/H-0243%20As%20Introduced.pdf</a></li></ul> <p><b>Alex Langevin (AOE):</b></p> <ul style="list-style-type: none"><li>● One of the things we were able to put a lot of focus on in past year is deaf and hard of hearing community. This is the year for autism and Alex has been asked to put together a report on what is happening, what the needs are, this is an exciting project to work on. Working on the LCAR rule changes. Mentor programs, educator attraction and retention, moving towards a statewide IEP system, started a task force to figure out how to decrease paperwork for special educators, looking at how to focus COVID funds coming.</li></ul> <p><b>Lana Metayer (parent):</b></p> <ul style="list-style-type: none"><li>● Have used services for a decade for her two boys. Where we are now we have many individuals working with them supporting their needs that they have worked with over the years. The second you leave this bubble it isn't pretty- there is a lack of public understanding and inclusion. Until we have people on board outside of this bubble we won't make the progress we need—camp counselors, friends, employers, sports programs. Outside of the island is a swamp that has a lot of needs. We need to educate the broader community about Autism.</li></ul> <p><b>Valerie Wood (Parent and CDCI):</b></p> <ul style="list-style-type: none"><li>● Have a grant where they have a team that is made up 50% of members who are on the spectrum—they talk a great deal about the cliff that exists as they become adults. What are policies we can craft to increase access for services for adults.</li></ul>	<p>Should Alex need input for the Autism report this group is available for that.</p> <p>Have Jennie Masterson and someone else from DDSD come to this group to talk</p>
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	<p><b>There has been a slow down in seeing individuals who have been diagnosed with autism. This could be due to the following:</b></p> <ul style="list-style-type: none"><li>• Because the CDC has closed down</li><li>• COVID and families being home</li><li>• Daycares being closed</li><li>• There is now a backlog due to all of these factors.</li><li>• Some families may be going to Dartmouth.</li></ul> <p><b>Jenn Johnson (SD Associates):</b></p> <ul style="list-style-type: none"><li>• Windsor School-has been providing in person services since June and is taking new referrals for school and community programming.</li><li>• Montpelier Location- hoping to grow our toddler program taking referrals now! Have 2 toddlers currently, referral process is the same as our Williston location, please go to our website.</li><li>• Williston/NVT- recently had influx of school referrals, taking on 4-5 new students now. This week we are contacting our insurance wait list for early intervention services based out of our office location and plan to be able to take 4-5 children from our waitlist. We had offered a remote parent training to families on our waitlist in March/April but didn't have much interest.</li><li>• We are continuing to pursue school accreditation for our NVT location, however with COVID restrictions the AOE is not able to visit new locations in person and aren't able to do remote visits etc. so we are waiting on next steps in that process.</li></ul> <p><b>Courtney Diffenrud (Kingdom ABH):</b></p> <ul style="list-style-type: none"><li>• They have a new EI clinic located in Williston and provides services to 2–6-year-olds. There is a waiting list already but are accepting referrals.</li></ul> <p><b>Phillip Eller (Vermont Autism Task Force-VATF):</b></p> <ul style="list-style-type: none"><li>• The VATF has highlighted Autism Acceptance Month (note the use of term ‘acceptance’ which goes beyond our historical ‘awareness’ terminology) on our Facebook which I would like to refer everyone to check out. VATF has also been working on updating our Website, and invite all the work group team to review it *<a href="http://Vtautismtaskforce.org">Vtautismtaskforce.org</a> and send me their information and link IF they don’t find themselves on our Resources page. The VATF has been also monitoring and advocating this year with the various statewide groups that impact on the ASD community, e.g., State Board of Education, Act 173 Advisory Group, Special Education Advisory Panel, etc. VATF has also been extensively involved in the AoE Rules changes effort.</li><li>• Would it be possible to get a list of all the professionals, parents, and agencies involved with the IFS Work Group with a brief statement of their work and interests - like in our introductions given this morning? This is something I would like to do a page for on our website.</li></ul>	<p>about what is available so we can better understand where the gaps are in services.</p>
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	<p><b>Jamie Rainville (Vermont Family Network):</b></p> <ul style="list-style-type: none"> <li>• Gaps heard from Families and Professionals: <ul style="list-style-type: none"> <li>○ To expand on what Lana was talking about, I also think there needs to be more training and supports for first responders and police.</li> <li>○ We hear a lot from families that the wait time for getting a diagnosis is really long. I don't think this is a new problem because of COVID. Our intern recently compiled a list of autism services throughout the state that included alternatives for families who were on a long wait list for receiving a dx as well as who are the ABA providers in the state. She had to do a bunch of research to get this list together. It would be great to have a central place that families and organizations like VFN could go, to direct families too. They can see all their options which includes where they can go for a diagnosis and what are the ABA providers in their area. Then families can decide if traveling 3 hours is what they want to do, because their child can be seen 4 months sooner, than that can be their choice. In an ideal world, there would be more options!</li> <li>○ I recently heard from a pediatrician that children with autism should have more care coordination. Sometimes these children don't have the medical complexities that would qualify them for care coordination, but their needs are still really intense and very complex. I think a care coordinator for families would be so helpful!</li> <li>○ To echo others on the call, we get a lot of calls from families that have older children and housing is a huge problem. I think having someone from DDSD on the call would be great. There needs to be more affordable and safe housing options.</li> </ul> </li> <li>• <b>Updates: VFN still has Flutie Funding</b> <ul style="list-style-type: none"> <li>○ Families who have children (from birth to age 22) with an autism diagnosis may request up to \$200 for needed equipment, respite, camp, therapies, emergency childcare, or to attend a conference related to their child's diagnosis. We encourage families from rural areas (e.g. Bennington, Essex, Orleans and Windham counties) to apply. First time applicants will be prioritized for receiving a grant. One grant per household.</li> <li>○ This funding has been awarded to VFN through The Doug Flutie, Jr. Foundation for Autism. Please visit our website to complete an application. If you have questions or need support in completing an application, please email <a href="mailto:laurel.sanborn@vtnf.org">laurel.sanborn@vtnf.org</a> or call 800-800-4005.</li> </ul> </li> </ul>	
<b>Moving forward: Frequency and length of meetings</b>	<p>Should we meet more than every other month? Helps to keep momentum and focus.</p> <p>Decided as a group to meet monthly for an hour and a half.</p>	<p>Cheryle and Molly will schedule monthly meetings for an hour and a half</p>

