## STRATEGIC PLAN

## 2021-2023 AGENCY OF HUMAN SERVICES Autism Workgroup

## **Autism Planning for the Future**

Autism Workgroup, Co-chaired by Molly Bumpas, UVM & Cheryle Wilcox, DMH

Autism touches many of our lives. Approximately one in 59 children in the United States are diagnosed with an Autism Spectrum Disorder. Medicaid funding for autism related services is primarily channeled through the Designated Agencies. There are also a few private providers supporting children with autism in Vermont. The services are family-centered and require significant training and high levels of supervision. As a state, we have much more work to do to build our system of supports related to autism.

To address and highlight these needs, in November 2015, a group of community and state stakeholders started coming together to ask the following: *How do we use our collective resources to move autism services forward for children and their families in Vermont*?

This group is building on the work that was done by the previous Autism Plan Advisory Committee and the Vermont State Autism Plan. Every other month a diverse group of family members, state staff, and community partners come together to talk about gaps, issues and to highlight examples of exemplary work. The group is focusing on three goals identified by this workgroup.

Purpose of Autism Workgroup: This workgroup convenes to use our collective resources to move autism services forward for children and their families in Vermont

## Strategic Plan

Goal	Action Steps	Measuring our success- what is the data telling us?	Deliverables and Timeline	Representatives
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	<ol> <li>YOUNG CHILDREN</li> <li>Identify all evidence-informed options to meet the needs of more families and ways to fund them (e.g., type of interventions, service delivery models, direct services versus caregiver training, etc.).</li> <li>Increase funding for professional training for evidence-based practices with ongoing supervision/mentorship as needed</li> <li>Increase opportunities for family education around ASD, what is available, what can expect from service providers, etc. from diagnosis onward.</li> <li>SCHOOL AGE</li> <li>Help families fill in the gaps in home/community services outside of school supports.</li> </ol>	a. What do families need and what do they feel is missing in their plan of care? b. What is current El model for training providers in ASD best practice? c. Is there a need for regular education opportunities for caregivers in a group format? Who would do this? Live/Zoom?	a. Ask El leaders current El training model/approach for ASD b. Propose a collaborative group to pilot this initiative	Lead: Molly Bumpas  Group Members:  Jennifer Johnson  Philip Eller  Danielle Howes  Lana Metayer  Melanie Hall  Brian Marrier  Diane Bugbee  Lyn Ujlaky  Emerson Wheeler
		school AGE  a. Can the ACT 264 process be used for children who have service gaps? Are the right people "at the	school AGE  a. Gather information on how ACT 264 process is used currently.  b. Investigate possible collaboration between private ABA providers and school	

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	YOUNG ADULT TRANSITION  1. Identify the systems of care for children versus adults and how they interface. Can we increase this collaboration? Improve this transition process for families and their children.	table" in these meetings?  b. Can service provision occur in after school settings for children who need it? (ABA, social communication, etc). Can private providers pair with schools to use after school programs as a setting?  c. Can staff for these community supports be found by coordinating with undergraduate/graduate programs in the area?—will need to address transportation. Also think about high school students (voc. Tech program)—with college students they come and go. Group programming support.	administrators/after school program representatives  c. If a setting is viable, team with local colleges (UVM, Champlain, St. Michael's, etc.) to establish a staffing source  YOUNG ADULT TRANSITION  a. Identify important stakeholders and form a subcommittee  b. Gather information from invested parties (families, autistic adults, adolescent and young adult services directors/providers) to determine a collaborative path forward	

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B. Increase access to assessments, supports and services up and through transition to adulthood.	<ol> <li>Seek funding to do an RFP to address the following areas (Cheryle to research):         A. Resource Map: Create a comprehensive view of the resources collectively across the state for children, youth and their families.         B. Survey: Gather information about access and supports from caregivers about their experience with providers to inform system improvement needs. Could do the survey ourselves and then have someone analyze the information. It could be very helpful to have support for survey design.         </li> </ol> <li>Gap Analysis: Determine services and supports that exist (or don't) across the State so we know where our gaps are and can make recommendations to address this. What is the need and ideally how many staff in each area are needed?</li>	a. Can systems increase collaboration? Ideas include VT Autism Task Force and DAIL. b. What might the Lifesource training being provided to VFN bring to this process?  a. Active website with resources available on it-how to get in, contact person, how it is funded, possible grants and funding available. Include organizations that may be private pay, how do we know more about these and learn the models-how do we make those supports accessible also—regardless of income status. Ask Liliane if this fits with what she is doing and timeline.  b. Survey sent out to families-be clear about	1. January 2022 2.	Lead: Cheryle Wilcox  Group Members:  Julie Smith  Alex Langevin  Cammie Naylor  Danielle Kent  Sara Stowell  Hanna Wagner  Dr. Elizabeth Forbes  Jamie Rainville  Valerie Wood  Matt Habedank

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	<ul> <li>Planning considerations:</li> <li>Add in age of child, region of state</li> <li>Survey monkey link so it can be collated</li> <li>Can be anonymous unless they want to put their name</li> <li>Send through VFN, Front Porch Forum ad, Facebook, DAs, Education—we know it is a convenient sample and that is ok.</li> <li>Do we want to look at waiting lists, possible services that can be offered, how is workforce effecting access?</li> <li>Be careful about using plain language to describe services, check reading level</li> <li>We want to keep this as short and easy as possible.</li> <li>For families where English is not their first language</li> <li>Could we consider a focus group?</li> <li>Do we have any grad students who could do qualitative interviews?</li> <li>How do we most effectively get parent feedback?</li> <li>Should we provide a one-pager that says: Common struggles and common services that can help so they can adequately answer questions</li> <li>Look at having the link open for months and reviewing mid-way to see if we are getting what we need.</li> </ul>	barriers and how do we tackle those?  c. Families are able to find an evaluation site that offers diagnosis evaluations that are covered by insurance and/or are within a reasonable traveling distance.  d. Measure how access has increased How do we do that?		<ul> <li>Kathryn         Workman</li> <li>Mary-Graham         McDowell</li> <li>Danielle Brier</li> </ul>

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	<ol> <li>Parent/Family "Survey" questions: Pre-COVID:         <ol> <li>What was recommended when you received the diagnosis? What did you receive?</li> <li>Were you offered OT, Speech, One-to-one services? If so, were the services consultation, parent training, school, direct 1:1 behavioral intervention?</li> <li>Did you accept the Autism services? If not, why (Barriers to treatment)?</li> <li>Where were the majority of Autism services offered/delivered? Clinic, home, community</li> <li>Where do you prefer Autism services delivered? Clinic, home, community</li> </ol> </li> </ol> <li>Do you feel there has been progress since Autism services began?</li> <li>Do you feel like you are receiving the correct services? Which services are most valuable?</li> <li>Post COVID: Add questions about covid-how did at home learning go?</li>			
	<ul> <li>Collect Data and Information from the following:         <ul> <li>https://sites.ed.gov/idea/idea-files/2021-spp-apr-and-state-determination-letters-part-b-vermont/</li> <li>a. EDUCATION</li> <li>b. Survey schools to gather more information</li> </ul> </li> </ul>			

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	1. Number of children on IEPs in schools with an ASD. 2. Number of children on 504 3. Survey schools to describe autism services. 4. Maybe offer a grid with a range of supports and services to check off and then ask if they check yes what that looks like. c. DESINGATED AND SPECIALIZED SERVICE AGENCIES d. PRIVATE PROVIDERS  3. Possible coordinated effort for part-time service staff from related graduate programs			
ADDITIONAL FOCUS AREAS TO CONSIDER				
Educate Community about inclusion and neurodiversity				Danielle Kent