**AHS: Autism Planning Workgroup**

**Co-chairs: Diane Bugbee (DAIL) and Cheryle Bilodeau (DMH)**

**Priority Goals and Action Steps**

*Last updated 11-16-2017*

| **Goal**  | **Action Steps** | **Prioritized Action Steps**  | **Notes from previous meetings** |
| --- | --- | --- | --- |
| 1. ***All children in Vermont receive effective, individualized, intervention services consistent with the National Research Council (NRC) recommendations from 2001 as soon as the diagnosis of ASD is seriously suspected.***

**Tenet’s that support success:**1. Digestible scope – incremental change, esp. if tied to larger initiative/infrastructure/outcome we have to do anyways
2. There is a clear entity or entities responsible (some entity needs *primary* responsibility)
3. Clear parameters to define responsibility and functions.
4. Parameters need to be mandated and funded
5. Need a champion (individual or group) willing to advocate and hold the entity accountable
6. Expertise to provide technical support to get the work done

**Group Members:** * Danielle Howes
* Valerie Wood
* Molly Bumpas
 | 1. Coordinate advocacy efforts regarding accessibility and payment for ASD services
	1. Make advocacy materials and resources available to parents
	2. Legislative action to bring notice that private insurers need to be held accountable for paying for ABA services/supports. Raise consciousness in the legislature about early intervention cuts.
	3. Ensure Medicaid contract negotiators understand ASD services are outside the medical model. Include consultation with providers and families on day-to-day realities
	4. Making chart of private insurance appeal process and caps
	5. Information gathering if there’s been a successful appeal of caps so far
	6. Would legislature be helpful with this?
	7. Guide for parents in how to successfully challenge this
2. Coordinate the service system for autism supports in the home, school and community
	1. Educate parents about range of service options including families whose child is diagnosed at a later age
	2. Educate parents about their rights
3. Identify range of interventions and best practices specific to ASD and create clinical guidelines to ensure interventions are within best practices and within the natural and least restrictive environment for the child. How are we certain that best practices are followed?
	1. Have a multidisciplinary internal review board to look at practices in Vermont
	2. How will we measure fidelity to clinical guidelines?
	3. Who will develop clinical guidelines?
	4. How will we know clinical guidelines are being followed?
4. Figure out what types of funding sources could be available. Including ABA and other practices such as ESDM and other promising practices not currently reimbursable through the state plan.
	1. Who? Autism Work Group
	2. When? December 2016
	3. How will we know? 1. No or minimal waitlists for families. 2. Documentation of best practices and their components (see MTSS field guide-Jim Calhoun)
	4. As appropriate, align best practices with family preferences. Who? Vermont LEND??
	5. Acknowledge that we need to leverage current system capacity for individualized behavioral supports as we build future system capacity.
 | 1. Coordinate the service system for autism supports in the home, school and community
	1. Map what is available, where and who is in charge of it.
	2. Educate parents about range of service options including families whose child is diagnosed at a later age
	3. Educate parents about their rights
	4. Identify the barriers to treatment in the current system and ways to overcome them…
2. Identify range of interventions and best practices specific to ASD and Create clinical guidelines to ensure interventions are within best practices and within the natural and least restrictive environment for the child. How are we certain that best practices are followed?
	1. Have a multidisciplinary internal review board to look at practices in Vermont
	2. How will we measure fidelity to clinical guidelines?
	3. Who will develop clinical guidelines?
	4. How will we know clinical guidelines are being followed?
3. Advocacy and funding go hand in hand
 | * Baseline community education-treating everyone equally/fairly, does not mean treating everyone the same
* Each CIS region has a trained person in these intervention models. Look at occurrence rate of 1 in 65 births diagnosis to determine the number of folks needed statewide. Each region needs equity of access. Access issues:
	+ Reimbursement rates
	+ Lack of providers for the service.
* Capacity needs to be responsive to the emerging needs in regions.
* Research-based – we need this to assure that it works.  Eclectic approaches don’t have this.  ESDM and VB-MAPS also have evidence that is more current than ABA even.  It is about measuring what you do!  Use data to show the child is making progress.
* This is a matter of supervision! It isn’t enough to know how to use an approach.  You need to do so with consistency and fidelity, while also making conditional discriminations.
* Does every child we see who gets a diagnosis of autism need ABA?  Need to be more discerning and individualized about what we provide.
* Consider: what are the other models we want to do, and how can we access Medicaid funding for this?  ESDM can be done and bill the ABA codes… however, you need the certified/credentialed BCBA’s to supervise the work.
* School contracts are more profitable (mixture of funding – Part B and Medicaid):
* Rate/day
* Staff turnover has less impact on these because we have to meet our contractual obligations
* Insurance programs (straight Medicaid):
* We can only bill when we see the child
* Staff turnover
* CDC contract (combo of Title V and Medicaid):
* If a child no-shows, contract still pays a portion
* How could we think about creating funding that is more secure – blending Medicaid with other funds that allow some degree of flexibility like a contract would?
* Are there programs who do this that we can learn from?
* Can Global Commitment savings be accessed – investment dollars?
* We need real ‘money’ people helping tease this out to think creatively about what could be possible.
* How would security in the money help staffing capacity?
* We currently grow from within the company to grow pro staff – we give tuition assistance to help them gain their certification.
* There is nowhere to pull BCBA’s from…
* Are there any Institutes of Higher Ed offering training?  Do any of them have grants to help with tuition reimbursement?
* Can the State apply for any grants (like Title IV-E) to pay for tuition reimbursement with an obligation to work in the field for a while afterwards.
* Who can help consider this??? Professional grant-writers??? Where do we find the grants???
* Medicaid Advisory Board, Green Mtn Care Board, could help us consider this.
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| 1. ***Professionals who provide services to individuals with ASD will demonstrate competencies that reflect the experience needed when working with individuals on the spectrum. Training will be available to all professionals for building capacity to meet the needs of individuals with ASD and their families.***

**Group members:** * Danielle Bragg
* Hillary Hill
* Matt Habedank
* Adam Poulin
* Julie Smith
* Joy Wilcox
* Meg Mayo
* Chris Kane
 | 1. Develop competencies for educators and interventionists
	1. CIS providers
	2. Family directed staff (PCA, respite)
	3. Private providers
	4. School professionals
		1. Spec ed
		2. General education
		3. Admin.
		4. Para educators
		5. OT, PT, SLP
2. Develop education and resource materials for community members and support personnel who interact with children and youth with autism. Include the following:
	1. Caregiver affect
	2. Do no harm
	3. Safety
	4. Interactions
	5. Relationships
	6. Support or reinforce prosocial behaviors
	7. Early childhood development
	8. Typical childhood development
	9. Core knowledge/skills supporting positive behavior and inclusion

For the following groups: 1. Local Police Depts.
2. DCF-FSD staff, foster parents
3. First responders (ER, hospital staff)
4. Dr’s, nurses, medical students, dentist
5. After school programs
6. Early care and educational programs
 | a.) Is it worth cross checking with other groups/depts. to find out if there are overlapping efforts? 1. What systems are in place to ensure that entities outside of schools adhere to and train to these competencies as well – do oversight systems need to be looked at for this either – example of SLP, OT, PT is discussed?
2. It will be important to tend to requirements of providers—what are the competencies? Work with appropriate people to build standards. Not necessarily put in job description but they are trained to an expectation.
3. Make educational competencies accessible via funding
4. Review these competencies to determine who should be done with them

b.) Take an inventory of gaps. Identify training needs based on this and build on current resources. 1. Work with higher education programs to offer degree programs and incentives to keep trained people in Vermont.
2. Increase capacity BCBA/autism supports to provide in person intervention
3. In the interim, investigate increasing access in underserved areas through the use of technology such as telemedicine.
4. creating/finding a training system that would result in staff being “Autism informed”, much like the trauma-informed system
 | * BCBA’s—RBT, standards for competencies, could we establish for the state? There are standards and a licensing process.
* Schools will struggle with kids who come in without getting treatment – will show up as high needs
* Need education and dialogue to make sure resources are directed to where they are most needed
* There is a huge variation across schools and districts in what an actual title means and what level of training is tied to the title/credential
* Realistic limitation that if legislation is passed to require oversight of Autism intervention, other advocacy groups will want the same thing for their kids – possibly more realistic to ensure that they honestly represent their capacity
	+ Joy works on the governor’s council to attempt to address some of these concerns
* Provision of ABA services to kids without ASD – SD serves some of these kids through Medicaid, NCSS does under the IFS umbrella
* Discussed training—are there some core skills for any provider that could help anyone interacting with children/youth on the spectrum (such as Mental Health First Aid). Do we have two levels: one for people interacting with individuals and one for people making decisions about services. Create a day-long training people can access-offer it in each county
* Share information about different assessments
* Importance of collaborations with others—Let’s Grow Kids, Patty Prelock (CS at UVM), PCC, CHSN, Vermont Family Network, Vermont afterschool
* What do we use for outcome assessments? And how do we show outcomes?
* Discussed telehealth-would that expand access?
* Question: Is the Autism Task Force still meeting?
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| 1. ***Educational services that provide the full range of continuum of supports and services will be available to students with ASD throughout Vermont.***

**Group Members:*** Kirsten Murphy
* Lana Metayer
* Philip Eller
* James Calhoun
* Miriam Novotny
* Michelle Irish
 | 1. Increase collaboration between AOE and AHS
	1. Gather more information about the availability of services to assist in the reintegration of kids who have been placed out of district and are ready to come home
	2. Identify availability of afterschool/community supports
	3. Work with AOE about special education vs. time in the classroom
2. Explore rule making around adverse effect
 |  | * Consideration of the functional aspects of SpEd eligibility re: Adverse Effect is already a part of their schools’ best practices, as being promoted by the Stakeholders Group trainings
* Philip shared copies of the documents that the Vermont Autism Task Forces is distributing to various legislators for the proposed legislation pertaining to Adverse Effect. It essentially eliminates the Gate 2 and replaces it with (4) “Adverse effect” means, for students of legal school age, having a negative impact.” (5) “Educational Performance’ means, for students of legal school age, performance in academic and functional areas both within the general curriculum and in areas necessary to access public education and gain functional independence later in life, including but not limited to socio-emotional development, communication, reasoning and problem solving, civic and social responsibility, and self-help skills.” This language is included in a 6-page paper, written for VATF by a lawyer from Autism Speaks; it contains four pages of background and rationale and two pages of legislation language.
* Also being shared with legislators is a one-page summary of the adverse effect issue and a one-page copy of the New Hampshire special education eligibility criterion (that says nothing about adverse effect).
* Philip also shared a side-by-side comparison of the Federal IDEA language about eligibility with the Vermont regulations (created by Sherrie Brunelle of the Disability Law Project of the VT Legal Aid Society). Philip emphasized that part of the rationale/need to revise the present Adverse Effect rule is because it is discriminatory, as it applies the eligibility critieria of SLD to all 13 categories of special education including autism. While the state has not yet had a law suit brought by a parent based on this discrimination, it is always an expensive possibility.
* Notes from Jim Calhoun following the 1/17 meeting
	+ Do we have information regarding the number of children being served in New Hampshire under special education and disaggregated by disability category?
	+ It is important for us to encourage inclusion of social skills and social inferencing in the MTSS model. Changing adverse effect influences tier 3 intervention models, but the capacity of a school system should include a universal social curriculum (tier 1) and more specialized skills (tier 2) training like social inferencing regardless of eligibility distinctions. This would provide a balanced approach to meeting the needs of children on the autism spectrum (and others) by strengthening the entire system of supports available in a school.  The is a field guide put out by UVM AND Vermont Reads that reviews the components of an MTSS educational model. This field guide will be reviewed in the future and social skills and social inferencing should be included.
* Discussed training—are there some core skills for any provider that could help anyone interacting with children/youth on the spectrum (such as Mental Health First Aid)
* Importance of collaborations with others—Let’s Grow Kids, PCC, etc.
* What do we use for outcome assessments? And how do we show outcomes?
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