

Outreach, Education and Workforce Development Committee

Outreach, Education and Workforce Development Subcommittee Members: George Africa, Anne Barbano, Cindy Cole, Linda Luxenberg, Linda Mulley, Margaret Novotny, Patty Prelock, Pam Reed, Nancy Richards, Gigi Weisman and Katie Willard representing: families, higher education, special education, speech and language pathology and school psychology

The Outreach, Education and Workforce Development Subcommittee studied the information gathered from two instruments: The five public forums on Autism and a survey monkey designed to gather information from families and professionals working and living with individuals diagnosed with Autism Spectrum Disorder (ASD). Our operational definition of Autism Spectrum Disorder included diagnoses along the continuum to include: Pervasive Developmental Disorder, Autism, High Functioning Autism and Asperger's Disorder throughout the lifespan. The moving testimonies from the five community forums inspired us to take action for this population that has been so underserved, and which is growing by the day. The data collected from the 512 respondents (104 parents and 408 professionals) from the survey monkey informed our recommendations for your consideration.

Expertise:

The committee learned from the data collected that professionals in Vermont are sadly lacking in the level of expertise required to work with this population. The complexity of autism requires a high level of specific training, supervision and competence. Data collated from the survey monkey and the community forums report a significant lack of adequate levels of expertise among the professionals working with individuals with ASD across the lifespan in Vermont. Parents reported that in their experience, professionals working with their children were not adequately trained. For example, they reported that the following professionals had “inadequate or some training in ASD”: **85%** of daycare providers, **90%** of general educators, **100%** of school counselors, and **100%** of job coaches. In addition, **86%** of school administrators were perceived as having inadequate or only some degree of training. Even more significant, were the responses from professionals who indicated that they had “inadequate to some training” for the ASD population: **44%** special educators, **77%** general educators and **78%** job coaches. In addition, **45%** of dentists surveyed felt that their training was inadequate for individuals with ASD. A growing problem for individuals with ASD involves community members (e.g., correctional facilities, law enforcement, librarians, etc.) who have little or no awareness of ASD and how it impacts their interactions/communication with those individuals.

Those most in need of knowledge or results-oriented or evidence-based practice have acknowledged their limited knowledge base and skill level in those interventions. For example, 73% of professionals reported none to moderate levels of familiarity of characteristics of ASD. In addition, only 13% of professionals that responded to the survey rated their level of familiarity with Applied Behavior Analysis (ABA), the most extensively researched practice, as adequate for using this intervention effectively. See attached survey monkey for further analysis of that data.

Equitability

Equitability includes funding, accessibility (state and district), and coordination of services. Due to the rural nature of the state of Vermont, equitability is a widespread issue. From the onset of the diagnosis, through the educational and community experiences, this committee found dramatic inequities in services, accessibility to quality training opportunities, programming and funding. For example, two services that are required to directly address the core deficits of ASD could not be accessed (69% of parents reported being unable to access social skills training and 49% were unable to access functional life skills training). As more research is conducted, new information in the treatment of individuals with ASD becomes available. Even those who are considered to have expertise in this field must continue to have opportunities to keep up with improvements in the field.

Infrastructure:

The top priority identified by our committee was creating an infrastructure for training and education to increase the effective practices and expand capacity for all who work with children and their families with ASD. Training and education must be developed that recognizes methodologies and best practices across the lifespan. Training and education also must be tied with funding sources. One parent from the Public Forums summed up our needs for quality services and providers as, "Essential! Requires funding and training."

Offering training and education opportunities across disciplines are an immediate necessity. It was clear that all professionals and parents on our committee recognized the need to increase more long term training, mentorship, and supervision to ensure what is learned is truly applied. Everyone was in agreement that intensive training and education needed to be offered at all levels of practice from beginners to the most experienced. ASD is a life long learning experience and as one speaker from the public forum stated:

We must "...train a cadre of people who will be able to support the individuals with ASD throughout the community and their lifespan; ongoing support and training must be an overarching system to make changes"

Further, we need to expand the definition of professionals and caretakers working with ASD who need access to training and education opportunities to include: medical doctors, public safety officers (state police, corrections, and sheriffs), related services (occupational therapists, physical therapists, speech and language pathologists), psychologists and mental health counselors, education and human service administrators, educational staff (principals, regular and special education teachers, daycare providers, adult services, vocational specialists, employers, autism specialists, autism behavior specialists, para-educators/behavior interventionists, personal care assistants, and respite workers. parents, families, educational surrogates, guardians, and foster parents.

The infrastructure for training and education must be available across all regions of Vermont. We can capitalize on existing technologies and systems through interactive sites, universities and state colleges, human service agencies, hospitals, private and public schools, advocacy groups, and individuals to host and support training and education opportunities.

While we have some of the foundational trainings in place, we need to increase the type and level of trainings and coursework. We need to provide financial support for families and professionals to attend trainings, and maintain their engagement in addressing the needs of this population so that capacity is not only increased, but maintained. This committee has concluded that the present system of care and support for individuals diagnosed with ASD is in dire need of change.

Vermont prides itself as being a state which celebrates the diversity of its citizens. In order to fully embrace its population of individuals of all ages with autism spectrum disorder, which includes Asperger's Syndrome, Vermont must provide the expertise and training sited in this document. It is the civil right of each individual with autism spectrum disorder to be given the support necessary to be a contributing member able to share his or her gifts and talents with the greater community of Vermont.

Supporting documents attached:

White paper

Video tapes of forums

Autism center report

Meeting notes

50 page forum document

US Department of Education Vermont-Rural Autism Project final performance reports

North Carolina State job description

Example of a schedule of an Autism Summer Institute workshop

Following are our specific recommendations:

Question One: How do we insure public dissemination of helpful information?

Present Challenges:

Accessibility: The ways in which parents, professionals and others seek and receive information through quality sources/resources are not viable or accessible to all stakeholders (including medical, education, vocational, service providers, care providers, law enforcement members, emergency room staff and other community members) leading to an inefficient use of time and resources. There are neither adequate nor equitable resources to address diagnosis, treatment and the support needed for caregivers. Resources are not coordinated or readily available.

Facts/ summary of key findings with age focus and themes noted as needed:

A variety of institutions and organizations offer trainings within Vermont although attendance is dependent upon location, availability of caregivers and funds.

Challenges: Training does not typically apply to the expansive range of knowledge (beginning, intermediate, etc.) and experience required of those caring for individuals with ASD. Stakeholders need guidance as to the quality of trainings and the instructor's experience.

Recommended Actions:

- Regional resource centers for individuals with ASD, families, professionals and community members (e.g., police officers, emergency room staff, employers, etc.) that includes high quality written material, an informational phone line and an opportunity for individualized guidance with funding provided by federal and state entities.
- Utilize technology to develop and share information such as trainings and power point presentations and the media to launch a formal campaign to educate the public about ASD and Vermont's resources.
- Communicate effectively the roles and responsibilities of professionals and organizations serving individuals with ASD and their families.
- Provide an opportunity for teams to learn about best practices and plan for implementation (structure similar to the BEST Institute).

Question Two: How do we provide sufficient numbers of trained professionals?

Present Challenges:

Funding: Inadequate funding limits the efficiency and effectiveness of trainings to ensure Vermont's workforce attain the skills needed for teaching our autism population. In addition, support for staff to attend the limited trainings is sorely lacking across agencies.

Accessibility: Trainings are often limited to select geographical settings that limit access and attendance from personnel in more remote parts of the state. There is a limited number of qualified trainers and because of the demographics of the workforce, Vermont loses newly educated professionals to states that can compete with better salaries and/or that have accredited programs in place with educational incentives.

Quality Training: There is a lack of sufficient interdisciplinary training and funding in higher education to support the development of multiple disciplines (i.e., developmental pediatrics, neurology, geriatrics nursing, nutrition, psychology, psychiatry, social work, speech-language pathology, occupational therapy, physical therapy, general and special education) that can benefit individuals with autism spectrum disorders. There is also a lack of extrinsic incentives for completing a training program (time and cost) in autism spectrum disorders because it does not lead to certification or licensure. The spectrum of autism is one where individual needs differ from one another yet there is little diversity of training in the state that identifies educators' specific training with age groups, cognitive function, social needs, language level, adaptive behavior and motor skills.

Facts/ summary of key findings with age focus and themes noted as needed:

The following is what we know of professionals who have been or are receiving intensive training in autism:

- 12 individuals finishing the first cohort of the Higher Ed Collaborative Autism Case Manager Training Program.
- 50 individuals trained through the VT Rural Autism Project, although some have left Vermont.
- 17 Board Certified Behavior Analysts in VT.
- 3 Relationship Development Intervention (RDI) trainers
- 3 Developmental pediatricians with challenges in recruitment because of noncompetitive salaries and benefits.

Challenges: There is a statewide shortage of Occupational Therapists and Speech-Language Pathologists. The statewide survey of parents and professionals on issues of autism services, training, supports and needs revealed a general lack of expertise to address the complex needs of individuals with ASD even by those professionals with credentials in their areas of expertise (e.g., behavioral specialists, speech-language pathologists).

Families often are responsible for securing and training respite and personal care staff, acting as their child's case manager. A statewide survey of parents and professionals indicated that 45.5% of families use Personal Care Services. Personal care was rated as the highest percent of all services that families access. As parents/ guardians are learning themselves about their children's educational programs and medical needs, there is limited support from professionals.

Recommended Actions:

- Support for training new and experienced professionals on the job that would encourage their commitment to stay in Vermont and work with individuals on the autism spectrum. Supports must include scholarship money for academic training and for mentorship and supervision provided by experienced professionals.
- A system needs to be put in place to identify the available workforce and to monitor recruitment, training and retention of the workforce across the state and relevant agencies. Of the professionals responding to the statewide survey of autism services, training, supports and needs, 72.2% recommended the provision of a mentoring program with experts in ASD coaching targeted professionals as the most effective strategy for establishing trained professionals to work with individuals with ASD. These professionals (63.4%) also recommended the creation of trainer models with individuals with expertise in ASD training local professionals.
- Expanding the Governor's Next Generation Initiative to include human services.
- Supported employment must be a priority, funding and training employers and vocational rehabilitative staff to effectively implement vocational training for individuals with autism. Other states' models (e.g., TEACCH/North Carolina) should be reviewed to examine and evaluate ways vocational gaps can best be addressed here in Vermont.
- A requirement for higher education, across colleges and schools (College of Medicine, College of Art and Sciences, College of Nursing and Health Science, College of Agriculture and Life Sciences, College of Education and Social Services) to train and

work collaboratively with multiple disciplines that can benefit students with autism spectrum disorders.

Question Three: What types of training, educational and technical assistance resources are needed?

Present Challenges:

Continuum of Trainings: There is not sufficient variety or intensity in the types of trainings available for people working with individuals with Autism Spectrum Disorders (ASD) from birth to adult. There is a lack of intensive and advanced trainings available for professionals and parents, and a limited number of experts in the state dedicated to provide trainings specific to autism. Trainings that increase awareness in the community for others that will encounter individuals with ASD on a less regular basis (e.g., first responders, police, lawyers, judges, dentists, nurses, etc.) are rare. Trainings are inconsistently available, and many trainings offered do not clearly define the instructional level (i.e., introductory, intermediate, advanced).

Generalization/Follow-through: There is a significant lack of efficient or effective ways to provide ongoing consultation, support, mentorship and supervision for people that have completed trainings. The teams working with individuals with ASD are often not trained at the same level or in the specific methodologies or programs specific to the individuals with whom they work.

Facts/Summary of Key Findings:

Autism is a field of study that requires competence. There are at least 24 different types of methodologies/programs in the state that have been reported to be effective in working with an individual with ASD, and at least 22 different disciplines noted to be working with individuals with ASD. The most common types of training, educational and technical assistance resources currently available are at the introductory or intermediate level, and occur through workshop or conference models. Trainings at all levels are typically brief with no mechanism in place for sufficient pre-service or follow-through with the teams working with individuals with ASD. A limited number of agencies/organizations in the state (i.e., Washington County, ALMC, Howard Center) provide training via consultation.

Challenges: Trainings are not sufficiently widespread, easily accessible geographically, financially, or at the level of intensity to establish and sustain a skill or competency level necessary to benefit individuals with ASD across the lifespan. Further, trainings across treatment methodologies used in ASD are limited, and not all disciplines working with individuals with ASD are being trained adequately.

Recommendations:

- Establish regional model demonstration sites where teams and individuals (including families) can be trained in a range of effective strategies, programs, and methodologies. These sites need to be staffed by people from various disciplines who have the level of expertise needed to train others. Sites could be available based on specialties that others could observe. Internships for students in university/college training programs could be available at these sites.
- Set up a model in which interdisciplinary teams of experts can consult to schools or other settings that support individuals with ASD to provide ongoing support, guidance, training, and resources.
- Regions should consider defining teams to establish and maintain a certain level of competency to benefit individuals with ASD.
- Create a task force to consider a train the trainer model. The task force should define the level of expertise needed for the person delivering the training and include the mentorship/support needed to make this effective.
- Reference the Primary Service Provider Model currently being implemented in the Family Infant and Toddler Program as an example of an effective interdisciplinary training model that has shown positive effects for children birth to three.
- Ensure the inclusion of perspectives/voices of individuals with ASD in all trainings; trainings need to occur in multiple formats to reach different types of learners.
- Establish a systematic way, such as the proposed Regional Autism Centers, for all training opportunities, materials and resources to be accessible.
- Create an initiative in higher education across the state to require a minimum of one course in autism for all disciplines.

Question Four: Who should have the responsibility for developing training, educational and technical resources?

Present Challenges:

Coordination: Currently, a number of private and public agencies offer trainings, however there is not one centralized agency responsible for creating and managing a strategic plan for awareness and training of pertinent topics for a variety of levels of service providers, parents and individuals with a diagnosis on the autism spectrum. A coordinated vision or framework for training and resources does not exist at this time.

Accessibility: Currently, training and resources are not readily accessible geographically or financially to those in need. Dissemination of information about training and resources is inadequate and uncoordinated at the present time. Results gleaned from the Autism Community Forums and Statewide survey support this finding.

Accountability: Currently, there are not guidelines to ensure that a provider has adequate training to provide a certain service to professionals, children, youth, adults and family consuming services for individuals with ASD.

Facts/ summary of key findings with age focus and themes noted as needed:

There are a variety of trainings and courses available through Vermont Department of Education and Vermont Department of Disabilities, Aging and Independent Living as well as private agencies and the Higher Education Collaborative. The Autism Summer Institute has just completed its tenth course. These trainings cover a variety of topics addressing a range of developmental needs for families and individuals diagnosed with Autism. The courses range from information dissemination to focused awareness to a graduate level course of study.

Challenges: Currently, there is not a vision or mission in the field of study of autism and its effects on individuals and families in our State. Courses are offered inconsistently and are attended by those who are able to receive notification of the event. The courses are not offered in an equitable way throughout the State and many are unable to access the courses due to an inability to have release time from other responsibilities and/or funding and transportation.

Recommended Actions:

A central organization should be designated to develop a framework for training that addresses the needs of families, professionals, individuals and businesses working with those diagnosed or supporting individuals with autism. Specifically, a designated central organization such as the Agency of Human Services should hire an executive director and appoint an advisory board that represents all stakeholders. This director would then hire specialists and develop a coordinated training and outreach program that reaches all areas of the State. Further, money should be available to free people up to get trained or assistance. The framework for training should address diagnosis, treatment at different developmental levels, parenting, education, health, vocational training and independent living skills.

Coursework should be offered throughout the State with financial support to aid those who need help with tuition and release time from other responsibilities to attend important trainings. Information about course offerings should be made accessible to all stakeholders. Finally, a task force (including families, educators, medical professionals, related service providers, mental health agencies) should examine the viability of a certification system to designate those who have completed a certain level of professional training so that consumers can be ensured of a certain level of competency.

Specifically:

- A centrally located organization comprised of a team who can develop and deliver training, educational and technical supports to include specialists in the areas of education, special education, communication, behavioral specialists, vocational training, and independent living is needed to build capacity for regionally based programs.

- Funding should be allocated to support Higher Education Collaborative to develop undergraduate, graduate and continuing education courses to address training needs of parents and professionals.
- Funding should be allocated to support a bi-yearly institute (e.g., similar to the BEST spell out these because no glossary model with involvement from Agency of Human Services, Department of Education and Higher Education) where teams comprised of schools, businesses, service providers, parents and employers can come together in teams organized around individuals or groups of individuals diagnosed with autism to be trained and to have time to plan and expand the capacity of their respective systems.
- Consider creating a pool of money, which can be accessed by application to private agencies providing support for peer training, parent support, and self-advocacy (e.g., Green Mountain Self Advocates)
- Develop a communication and dissemination system utilizing new, existing or currently being developed (i.e. statewide broadband access) technologies to communicate availability of trainings including families, individuals, education professionals, medical professionals, mental health professionals, corrections, and public safety personnel.
- Define the competencies and experience expected of professionals (such as behavioral specialist, communication specialist, autism specialist, etc.) to provide best practices to individuals with ASD across the life span and across settings.