

Testimony--
Tracey Bowen

My name is Tracey Bowen. I live in Arlington, Vermont, with my husband, whose family has lived in the area for ___ generations. We have nine-year-old twins, a girl and a boy. Our son has autism and other medical disabilities that have required numerous surgical interventions. He has significant challenges within school, at home and in the community related to social skills, cognition, and anxiety, which present in behaviors such as aggression, anxiety, elopement and wandering.

His local doctor, psychologist, the developmental pediatrician, and chair of Boston Children's Hospital Autism Program have recommended that he receive ABA therapy at school, at home, and in the community. In spite of these experts' recommendations, we have had to advocate for years to receive any services, which are currently limited to the school setting. And the services provided at school were not simply provided. --We have struggled financially to pay fees for legal action necessary to compel the school to provide services, and to keep them in place.

What we have seen is that these programs delivered in school are WORKING. I am happy to share that since beginning treatment with certified ABA therapists in his school last April, my son has been medically stable for one year. And, he went from being a child who was frequently restrained on a daily basis to one of six lead roles in the elementary school musical in November. What a difference well-trained, certified support can make in the quality of his life! Unfortunately, when school ends at 2:45, my son does not leave his autism there.

My son desperately needs professional support to help him cope with the the world outside of school. He struggles to remain calm when he is overwhelmed by the way his neurological system processes sensory stimuli. He needs more help than our family alone can provide. We have been on waiting lists: 4 years for services through United Counseling Service, and 7 months SD Associates, yet we are told by both agencies that they have neither the staff nor the funding mechanisms to provide support at this time.

During every moment we wait, our son's safety and well-being are in jeopardy. Although his school situation has improved immensely, his peers still remember past behaviors when he was crying out for help. And while we hope these situations in school will fade from students' memories, they continue to reappear in the wider world, where he has no support beyond our family. Last August a woman at the town pond publically called my son an "f-bomb" autistic nightmare and told other families not to allow their kids play with my son. This was, according to her, based on "stories everyone in the community knows that school can't do anything with him." Last fall the Arlington Youth Soccer Club director and coaches refused to allow my son to join the fourth grade team, citing a problem he had in kindergarten, three years prior, and "the stories that come home through a coach's son through school."

Public incidents out in the community color how the world looks at my son. In an article which I am including in our handouts, our Bennington Police Chief described having to send his police officers to the emergency room with young children on the spectrum who are out of control. I have had to take my child home from the ER without treatment for a broken elbow and lacerations because the staff can't figure out how to treat him when he is fully panicked in response to danger and pain.

Recently a leader of a Cub Scout troupe defamed him as a child who requires police intervention. You can understand why my son does not get invited for playdates. Other children get to have fun and thrive in community situations, but this has remained beyond our reach.

For these reasons, we have been told to consider "outplacing" him in a residential therapeutic environment. However, there are no such facilities in the state of Vermont.

Imagine being told that in order to allow your child to feel safe and function in his home and community, you must send him OUT of his community. And that currently no step-down system to integrate him back into his community exists.

I believe that my son deserves to grow up in his home town with his sister and parents. I think you would agree that any child with an intact, loving family deserves to remain in that family.

I've given some examples of how Vermont's need for community autism services has impacted my child. As a family, we lose faith when we are asked to leave churches libraries, coffee shops, and stores when our child melts down. Our son is treated like an outsider.

Vermont should not reinforce a system of "haves" and "have nots" within our state, nor should its citizens have to turn to other states for services we can't receive right here. We have been living in the trenches too long without support.

Thank you for the opportunity to express the dire need our family and others face every day. I implore you to stand up for these forgotten children, who don't seem to fit in with any available program or service. We CAN create the supports they need, but until we have the will to confront lack of awareness and funding reform, Vermont, touted as one of the best places to raise children, will continue to turn their back on children like my son.