



May 4, 2021

Testimony Before the House Committee on Human Services re: Act 243 - An act relating to the Working Group on Services on Adults with Autism

Thank you for inviting Vermont Family Network (VFN) to speak on the needs of families who have an adult child with Autism Spectrum Disorder (ASD).

My name is Karen Price and I work at VFN as the Co-Director of Family Support. VFN is the federally designated Parent Training and Information (PTI) Center, the Family to Family Health information Center and the Vermont chapter of both Family Voices and Parent to Parent USA. We have been supporting families for more than 30 years. VFN Family Support Consultants are skilled parents of children with disabilities who support families in accessing services for their children with disabilities and special health needs from birth through adulthood in health, education, and in the community. VFN operates a statewide telephone helpline, provides in-person (now virtual) support to families, and attends meetings with parents. VFN also administers social media groups for parents of young and adult children and a website of family-friendly resources. We provide written materials, and conduct training on a broad range of topics of interest to families and professionals who work with children with disabilities.

Parents value our support as peers. We walk the walk with other parents. I myself am the parent of a 23-year-old son who was diagnosed with ASD and an intellectual disability at the age of five when he outgrew the developmental delay diagnosis. He received special education services and respite services through his childhood. Just a month ago, we finally received a genetic diagnosis for his disability - Koolen-de Vries Syndrome, a diagnosis that didn't exist during the first years of his life when we looked for answers. The diagnosis of ASD isn't a straightforward diagnosis. My son manifests the characteristics of ASD - lifelong deficits in social interaction, communication and behaviors, and his needs are still the same now as they were before his diagnosis. Others with genetic diagnoses like Angelman Syndrome, Fragile X, or Down Syndrome may likewise display ASD symptoms. Currently, it is estimated that approximately different 1000 genes are involved under the umbrella of ASD. I have concerns that Act 243 is too narrowly defined. The needs of individuals who qualify for adult services, whether the diagnosis is autism, ASD or intellectual

disability with deficits in adaptive living skills, overlap but also vary widely between individuals.

Families of adult children with ASD and/or intellectual disabilities have expressed frustration with the lack of resources/services in these broad areas:

In-person support - Direct support workers, case managers, employment support and respite support are in constant shortage with a high level of staff turnover. Staff available are often not trained to support individuals with more intensive behavior, communication, or mental health needs.

Programming - There is a dearth of social, recreational and employment opportunities.

Living options - The shared living provider model is the only option that families have been offered. This model of adult foster care is not what many families want for their adult children.

Lack of transparency and communication - Families feel in the dark and are challenged in navigating in the developmental disabilities services world.

I can speak to my experience after my child left the school system shortly before his 22nd birthday in August 2019. He, and we as his parents, fell off a cliff. He went from a full schedule of structured learning and social activities to a fragmented patchwork of caregivers and services with little life structure. He qualified for 25 hours of services a week and a respite budget. He never received more than 12-15 hours of services a week and we didn't even touch the respite budget as we couldn't find any one to work those hours. The little structure he had was the continuation of his job of just three hours a week that the school had set up for him. Then the pandemic happened seven months later, and we chose to stop his in-person services for health and safety reasons. It was also during this time that his epilepsy took a downturn which compounded the difficulties of life for him. He requires 24 hours of supervision a day, seven days a week.

The one upside of the pandemic was the acknowledgement of the caregiving roles that parents of adult (and young) children with disabilities play which resulted in directly paying parents through the difficulty of care payments. Parents of children with disabilities, for most part, would vastly prefer the services of competent, reliable professional caregivers. In reality, this has not been available. Parents have expressed that the paid caregiver provision for parents be made permanent, as it is in several other states.

I realize that this bill cannot be passed this legislative session. Parents of adult children feel the urgency of time passing. Our biggest fear is what will happen to our vulnerable and/or high needs adult children when we are no longer here. I appreciate the acknowledgement of this Committee that this is an area of great need. Parents know the needs of their adult children, some of whom may not have the voice or ability to communicate those needs. We know what the gaps are and can bring to the table ideas and possible solutions. We fear that a work group, consisting of more professionals than family members and individuals with disabilities, will only succeed in admiring the problems that we live with and know all too well day after day. Given the wide continuum of needs, I would recommend that the state engage with many families of adult children with ASD and intellectual disabilities. The sooner, the better.

Thank you.

Karen Price
Co-Director of Family Support - Education
Project Director, Parent Training & Information Center
Vermont Family Network
Karen.Price@vtfn.org
Ph: 1-802-876-5315
1-802-556-1850