



Vermont Developmental Disabilities Council

100 State Street, suite 342
Montpelier, Vermont 05633-0206

(802) 828-1310
vtddc@vermont.gov
www.ddc.vermont.gov

Testimony Before the House Committee on Human Services
RE: H. 243 - An act relating to the Working Group on Services for Adults with Autism
April 29, 2021

Thank you, Representative Pugh and committee members for inviting me to speak today about the needs of Vermont adults with a diagnosis of Autism Spectrum Disorder and their family members.

For the record, my name is Kirsten Murphy, and I am the Executive Director of the Vermont Developmental Disabilities Council. For context, DD Councils are created in federal law. There is a DD Council in every state and territory in our country. We are charged with ensuring that people who have a developmental disability and their family caregivers have a voice in creating the policies that impact their services and therefore their lives. We use that voice to protect the right of people with disabilities to make their own choices, and we advocate for supports that enable people with disabilities to live as independently as possible as contributing members of their communities

We receive no State funding, though we operate as a program within state government. Although I am a state employee, the Council has unique permission to speak directly to the legislature on behalf of the Council and the people it serves. To be clear, we do not speak on behalf of the Agency of Human Service.

My own experience as an advocate for people with autism dates back many years now to when I was raising my family just across the border in New Hampshire. I am the proud parent of an adult son and an adult daughter who each have this diagnosis, though they could not be more different one from the other. While they experienced many challenges growing up – including long stays in psychiatric facilities, police interactions, and, for my older child, placement in a therapeutic residential school – they are now independent adults. One is married, both drive, and both are working in careers of their own choosing. My daughter Lynn is a journalist covering progressive movements in central Virginia. My son Josh lives in Seattle where he works as an electrical engineer. He builds and tests defibrillators for a manufacturing firm. Josh does not use expressive language fluently, and when Josh was just ten, I was told by his school district that we

needed to place him in a residential setting where education would focus on basic life skills. Obviously, I resisted this idea.

I can also say that – during the period of about 2006-2008 when there was a lot of attention to addressing the needs of what appeared to be an increasing population of children with autism – I was the only person in the country to sit on not one but two state planning commissions for autism services. In Vermont, I represented a small, non-profit serving Vermonter families in the Upper Valley area; in New Hampshire, where I headed the Commission and authored their white paper, I spoke as a parent.

Merits of H. 243 and family concerns

First, I want to applaud Rep. McFaun for listening with an open mind to Barre-area families and working to address the struggles that they are facing in supporting adults and transition age youth with autism. H. 243 speaks to very real and urgent needs.

Second, I would share that in my experience working with self-advocates and families, stories from lived experience provide an important window into how well service systems are doing. Families are excellent at identifying what they need and what is missing in the supports available to them or to a loved one. Families can also bring fresh ideas to addressing problems. But families are, understandably, not aware of all the levers that government systems can use to help or of the broader context of their personal experiences. This is a place where entities like the Developmental Disabilities Council can help, since we act as a bridge between self-advocate and family members on the one hand, and government agencies and policy makers on the other hand.

Every five years, the DD Council is required to undertake a comprehensive needs assessment that looks at all the various systems – from transportation to early childhood services, from special education to housing – that support people in our state who are impacted by developmental disabilities. This needs assessment informs a set of five-year goals and detailed work plans that our federal partners review annually to gage our progress. We are in the middle of that process, with a final plan due next August.

I have probably spoken with some of the parents that have worked with Rep. McFaun, but I have not had an opportunity to speak with them as a group. I can report that in conducting a series of family focus groups, we often heard about the challenges of supporting adults with communication differences, difficulty in self-regulation, interests and motivations that might strike some of us as quite narrow, repetitive behavior, atypical sensory processing , and a complex cognitive profile – in short, many of the things that might describe a person with autism, though not necessarily only people with autism. We often heard these families express

frustration with the lack of resources available to bring mental health services to people with intellectual and developmental disabilities.

We also heard that families transitioning a son or daughter toward greater independence were not comfortable with the shared living model on which Vermont has relied heavily. This is a generational shift. For people coming back into the community from the Brandon Training School or a segregated education placement, shared living may have been quite attractive. But today, youth with I/DD spend more time in inclusive general education classrooms. They are looking for the next step toward independent adult life, and the last thing they want to do after living at home with their parents, is live with another family.

In addition, in talking with stakeholders from the Agency of Human Services, we heard that our state leaders are well aware of a need to develop more clinical capacity within Developmental Services. Similarly, there has been talk of needing new housing or supported living models for quite a while. In fact, some agencies are supporting promising pilots in both areas – clinical capacity and housing. For lack of funding, however, these initiatives are still at a small scale.

Federal funding

I would like to turn now to abrupt changes happening at the federal level as the new administration establishes itself. In fact, some of these have already happened.

As you may know, the American Rescue Plan Act recently signed by the Biden administration includes a one year “bump” in the federal matching rate for Medicaid-funded Home and Community-based Services (HCBS). While detailed guidance from the Center for Medicaid Services (CMS) is still pending, the net impact for Vermont is estimated to be \$48 million in one-time funds. These funds cannot be used to “supplant existing services,” and they must be invested in HCBS. This represents a unique opportunity to address longstanding challenges faced by the programs that support people in the community. The DD Council held an online Town Hall earlier this week for self-advocates and family members to share their thoughts about how to use this money; nearly 100 people participated.

Let me repeat, this \$48 million is already signed into law.

Several other very promising streams of federal funding for community-based services are in the works. The fiscal impact of these is not clear yet, and some are still only in draft legislation. Money Follows the Person funds, which support people to come out of nursing homes with 100% federal support for their first year was extended through the budget reconciliation process for three more years. The Biden infrastructure bill makes huge investments in people with disabilities, though we don’t know if these provisions will survive negotiations in Congress. Most promising of all, legislators are introducing the HCBS Access Act, which would end the

institutional bias in Medicaid funding that renders nursing home care an entitlement but HCBS an optional service. The Access Act not only makes HCBS *mandatory*, it funds states to make this transition and greatly increases support for the workforce that delivers these essential services.

H. 243 in the current policy environment

As you can see, there has been a lot that has taken place since H. 243 was drafted, with likely more to come before next session.

My concern with H. 243 is this: On the one hand, it is too narrowly focused on one diagnostic category; and on the other hand, the label of autism does not by itself indicate that a specific set of services or solutions are needed.

The clinical definition of Autism Spectrum Disorder is that it is a complex developmental disability with “persistent challenges” – meaning lifelong difficulties – in three areas: (1) social interaction; (2) communication, including deficits in expressive language and trouble interpreting non-verbal communication; and (3) repetitive behaviors, including verbal tics and motor mannerisms like hand flapping, and restricted interests, for example a fixation on dinosaurs or vacuum cleaners. You can think of each of these three areas as presenting on a spectrum. So, for example, a person may have relatively strong language skills but difficulty negotiating social situations; this describes my oldest child. Or a person may be very limited in their speech abilities and display some atypical movements but have strong social instincts; this is my middle child.

In addition, Autism Spectrum Disorder is often comorbid with other diagnoses. Thirty-one percent of people with autism also have an intellectual disability. For reasons not known, 26% have epilepsy. Mental illness, gastro-intestinal disorders, and allergies are also common.

People with autism do not present uniformly. As I said, my own son and daughter could not be more different one from the other. Moreover, there are others within the Developmental Services System and outside of it with challenges similar to the ones experienced by the families who have championed this bill; but their family member has another diagnostic label --- for example, fetal alcohol syndrome or an intellectual disability with a co-occurring mental illness. Expertise in autism is a part of the greater clinical capacity needed to serve the people in the Developmental Services System today, but it is not the only skill set needed. Similarly, the desire for other housing models reaches far wider than the autism community. It is a need voiced by self-advocates and families with a wide range of conditions.

Vermont’s Department of Disability, Aging, and Independent Living (DAIL) has existing capacity to pull in self-advocates and families as advisors. Both the Division of Developmental Disability Services and DAIL have standing committees, and there are several stakeholder groups working on payment reform within the Developmental Services System. Finally, the Division of

Developmental Disability Services is already actively engaged in a process to revise its System of Care Plan, which is how the Vermont statute that created the Developmental Services System ensures that there is a regular examination of the Division's practices and priorities.

Given the federal funding changes in play, the legislature may wish to direct AHS to increase engagement with individuals and families. Your committee or individual legislators here may wish to engage DAIL over the summer to understand how the funding environment is evolving. At some critical point, AHS and the legislature will – at a minimum -- need to come to agreement as to whether any of the \$48 million can and should be invested in a way that has cost implications for the State of Vermont in subsequent years (for example, using some funds to permanently adjust wages for frontline workers).

In summary, H. 243 has tapped into important questions, but it may not lay out the best mechanism for addressing these concerns.

Again, I would like to thank Rep. McFaun and your committee for thinking proactively about these issues.