

Hello,

I am the Burlington-based parent of a 24-year-old man with a developmental disability (DD), in our son's case, autism spectrum disorder and intellectual disability, who also lives in Burlington. I am also a member of the parent-led Developmental Disability Housing Initiative (DDHI) which successfully advocated for Act 126 last session.

My son needs stable, supported housing for his lifetime. He enjoys a relatively full life, but his housing situation provides no stability. Currently, he resides in a transitional, therapeutic group home in a temporary program intended for stabilization, which will finish near the end of this calendar year for a total of three years. During the pandemic, our son's anxiety and OCD led him to exhibit unsafe behavior in our home community, so it was necessary for him to move to this staffed, therapeutic residential setting, essentially a temporary group home. It literally saved us all.

Our family and others like ours, with loved ones with developmental disabilities, need access to permanent, supported congregate living situations, such as the supported group home models that exist in many other states such as Pennsylvania where our family lived before relocating to Vermont.

However, lifetime "group homes" have been non-existent in Vermont, unlike in many other states where they provide important alternatives to living with family. In Vermont, the only alternative to living with aging family members has been Shared Living Providers (SLPs), known by many families as "foster care" (but often described by agencies as the more inviting sounding "professional roommates") for people with developmental disabilities. Those living situations can change at any time a shared living provider decides they can no longer offer residential support, thus leaving our loved ones without stability, as many in our community experience. There is also insufficient training provided for shared living providers with very little oversight, as we know from recent news stories of neglect and abuse.

Also, while that paradigm may work for some, there are approximately 50% fewer shared living providers since the pandemic, further limiting housing options for our population. Meanwhile, most with DD live at home with aging parents who are not paid for their caregiving, and often must work fewer hours in paid work, if we can work at all, due to the caregiving needs of our loved ones.

Our son wants to have more independence, to live with peers just like many other young people prefer and are able to experience. However, his high energy and at times complex behavioral support needs call for frequent supervision. Rather than live with family, as he desires to have more independence like most young people, or one shared living provider, his supervision and care are best spread among multiple staff, some of whom can be shared with other DD individuals, during a 24-hour period, who work at different times vs. one caregiver.

With the new Act 186, group home-type residences are now allowed to be developed in Vermont, but without the robust commitment of resources to make change happen at the rate that is needed, the true support that our families require to meet the actual daily, supported, stable, residential needs our loved ones, among the most vulnerable Vermonters, deserve in order to have a full, stable life, like the rest of the population.

Thank you very much for listening to our needs.

Donna C. Roberts, M.S