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February 16, 2022, Human Services Committee Testimony By Max Barrows

Issues Impacting the Lives of People with Developmental Disabilities Living in Vermont

I am Max Barrows. I'm a person on the Autism spectrum. I work for Green Mountain Self-Advocates as the Outreach Director. We will address four areas of concern: The need for more funding for residential services, Vermont being out of compliance with CMS rules, Our commitment to Peer Supports and Inclusion and The Supervision and Quality of Developmental Services.

We support the call for more funding for residential services. There are more than 1,500 people receiving developmental services who live with their families. People without disabilities typically move out of their parents house when they are in their 20s. Not so for us, we only get residential services when our: parents die, move out of state, or we go into crisis and our families are no longer able to take care of us.

We call on you to form a planning committee to explore more residential service options for people with developmental disabilities. The committee should include a majority of people with developmental disabilities. We will know that things are really changing when the people who have the most to lose, us, are the ones who are making the decisions. We need fair, objective, and clear rules to decide who will get these new services. We need to know how much it will cost. And, most importantly, services must embrace the spirit of the Americans with Disabilities Act and they must comply with federal rules for HCBS funding.

Speaking of federal rules, in January of 2014, CMS implemented new rules for Home and Community Based Services. Vermont is out of compliance in several crucial areas. In 2014 and before, all across the country, state DD agencies formed groups with service recipients to plan how they would implement the new HCBS rules. The rules specifically require an inclusive planning process. But, not in Vermont. Our state officials opted to spend the last 8 years in private discussions with CMS arguing why the new rules did not apply to Vermont. As you recently learned, the feds have issued their final decision. Vermont does have to follow the HCBS rules. We at Green Mountain Self-Advocates are eager to get to work to develop our transition plan.

The HCBS rules require conflict free case management. We need to have a neutral person, not working for our service provider, to talk to about: eligibility for services, what my options are for getting services, planning for my services using person centered planning, and how things are going with our services. And we need someone on the outside to contact when we have a complaint. The Choices for Care program has an Ombudsman program. We do not understand why people getting developmental services are not included.

I want to conclude with remarks about inclusion, peer support, and quality of services. GMSA knows full inclusion is sometimes tough to do, but it is possible. There are thousands of people with significant disabilities living productive, full inclusive lives. When we are integrated into society, given appropriate support, people in the community see what we have to offer.

We prefer individualized services. But if you must have group living situations, please, no gated communities. No large residential programs for more than 6 people. These are examples of segregation. You are taking a community of people and you are

shunning them from the rest of society. You're putting them in a separate box from the rest of society without the same freedoms.

We've heard that some families that have a lot of money do not want their sons or daughters living with shared living providers who often are working class and may live in a trailer. But honestly, it is not about how much you spend on the house where we live, it is about the services we get where we live. We've seen some shared living providers who provide services worth a million dollars and we've also seen some programs in million dollar homes that provide lousy, and at times, harmful services to people with disabilities. Whatever you decide to do, please focus on the quality of services and real non-biased ways to evaluate the quality of our services.

Finally, we want to thank you for using Covid money to fund peer support. Please continue to include people with developmental disabilities in ongoing initiatives to fund peer support. In Washington DC, they are training people with developmental disabilities to be direct support professionals. In many states, for example, Michigan, Connecticut, Pennsylvania, there are peer mentor programs using HCBS dollars to pay people with developmental disabilities to teach and support each other. Other states recognize and support the unique value of peer support. Other states have also realized this is an important way to address the workforce crisis issues. And, getting advice from a peer can be an important part of Vermont's mandate to create a case management system that is conflict free.

Thank you for listening to my introduction of topics to be addressed by 6 others from Green Mountain Self-Advocates. Each person will speak for less than 5 minutes. I am glad to call on a person when it is their turn and I will be helping a few of my peers to testify.