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Vermont House Human Services Committee - February 4, 2025

H. 13 - An act relating to Medicaid payment rates for home- and community-based service providers and designated and specialized service agencies.

My name is Max Barrows, and I live with my parents in Worcester, VT. I have been the Outreach Director for Green Mountain Self-Advocates for 17 years. I am a person with an intellectual and developmental disability, and I am on the autism spectrum. I receive Developmental Services.

In my role, I mentor people with intellectual disabilities who are part of local peer support groups across Vermont. A quick lesson on self-advocacy, the first step to speaking up for yourself is understanding your disability. To know what you do well and what you need help with. For example, I can easily say, "I have autism." But admitting when I don't understand something is harder. I worry that people might think I'm not smart. Many of us find it easy to talk about what we can do independently, but it takes courage to be honest about what we need help with.

Building trust with a new support person takes time. My confidence grows when I have a strong, familiar team that listens to and supports me. Losing trusted support staff can be devastating. I rely on my team for advice and reassurance. My emotional well-being, physical health, and success at work all depend on having a consistent, reliable, and stable support system.

In April 2022, the workforce crisis directly impacted my life. My support person, who had worked with me for over six years, had to leave for a higher-paying job to support his family. I was fortunate to have a supportive family—my dad, a retired teacher, stepped in as my volunteer support person. Because of him, I was able to continue working successfully.

What you need to know is that for 13 months, I had no support staff. Eventually, I switched to a different agency in my county—one that was more accountable and met my needs. But I am not the only one who has gone a long time without services. The system is under pressure.

Many people with disabilities experience high stress because staff leave so often. Just when we build a strong relationship with a support worker, they leave for a higher-paying job. This is painful and sets us back.

Thank you for your hard work in writing and working to pass H. 13. This bill is an important step toward making funding for Developmental Disabilities Services (DDS) fair, stable, and data-driven. The way I see it, H. 13 will ensure we get the services we need, pay providers fair rates based on real costs and improve tracking of how public money is spent.

Other states and some of Vermont's other Medicaid programs adjust payment rates each year based on real costs. H. 13 establishes a clear and fair process for setting rates for home- and community-based service providers and designated and specialized service agencies. We truly appreciate the committee's efforts to stabilize our service system.

For the past five years, many of us have struggled without staff due to COVID-19 and the workforce crisis. This has made self-advocacy harder. The ripple effect is that now some of us hesitate to speak up when staff are disrespectful

because we fear that if we do, we might lose our staff and go back to having no support at all.

H. 13 is not just about funding—it's an investment in people with developmental disabilities. It will increase access to job support, which is essential for economic independence. Right now, the State reports that 48% of people receiving services have jobs and pay taxes. But many want to work and cannot because of a lack of support. Others work only a few hours a week but want to work more. When we work, people see our skills and contributions. Stabilizing pay rates for support staff is a smart investment because the more we work, the less we rely on government benefits like Social Security and the more we make real contributions to our communities.

In closing I will quote my co-worker Kris Medina who receives developmental services. "Life after the pandemic has been challenging for me. I use supported typing to communicate, and I only have one support person to be my typing partner. I barely get out of the house to work and contribute to my community compared to my funded support hours. (Kris gets less than 50% of the hours he is actually funded to receive.)

My fellow typing brothers of my peer support group are in a similar situation. The impact not having trained staff has on my life means I cannot have independence and autonomy. Time without staff is time without communication. So losing a staff person is like locking up my voice and throwing away the key. I want to have full control of my life with supportive staff. I need good staff to work and access my community."

Thank you for taking the time to listen to our concerns. We understand that you have many priorities and are working hard to support the needs of so many people.

We appreciate your proactive efforts to pass H. 13 and improve the services that people with disabilities rely on. Thank you for your dedication and commitment to making a difference.