

April 28, 2025

TO: Rep. Bowman, Chair; Rep. Drazan, Vice-Chair; Rep. Pham, Vice Chair, and the House  
Committee on Rules  
Oregon State Capitol  
900 Court St. NE  
Salem, OR 97301

Dear Chair Bowman and Vice Chairs Drazan and Pham,

My name is Gabrielle Guedon, and I am from Newberg. I lead a group called the Oregon Self Advocacy Coalition (OSAC), which is a group fighting for the rights of people with intellectual and developmental disabilities (IDD). Like all of OSAC's members, I am a person with a disability. We are an organization led by individuals with disabilities. I am writing to you about House Bill 3838, because OSAC objects to an HCBS Workforce Standards Board that has no guaranteed representation from people with disabilities who receive services.

People with disabilities deserve a voice in the services that impact their lives, and HB 3838 takes that away. Both the original bill and the "Dash 3 Amendment" provide for only two people on the Board who "represent the interests" of those receiving services. Notice that it is not "those receiving services", so it could be whoever the Board or the Governor thinks "represents our interests." We represent our interests.

I have used home-care workers like Direct Support Professionals and Personal Support Workers at different times in my life, and these workers are really impactful for me. They support cleaning my house, organizing, and dealing with other situations. Due to my disability, some things are hard for me and, if I stopped taking medications, my body would deteriorate. My home-care workers help with day-to-day issues, take me to medical appointments, and in emergencies I can contact them right away. I have joint issues that make it hard for me to bend and do certain tasks, and they can help with those things. I mention all that because individuals with IDD or other disabilities have very specific kinds of barriers. It's important that the Board have input directly from those actually receiving services when developing workforce standards.

We care about these workers, and the provider agencies too. I think it's important to include us when workforce standards are created because we know how valuable workers are and how valuable what they do is. They deserve to get paid the correct amount of money. Making these decisions without us would be so impactful on our lives, and a Board without self-advocates with disabilities will not understand. They will not understand how certain standards or decisions about services impact our daily lives, our independence, and our home-life.

We value service providers or employers more than they know. The services they make possible are the difference between having a full life and not having independence. They also give us the opportunity to have normal relationships with our families, so we don't have our parents doing everything when we need support.

The number one goal should be what's needed for people with disabilities. An HCBS Workforce Standards Board without people with disabilities would most likely lose sight of that goal. In terms of safety standards, we are the ones who may experience the abuse or neglect that the Board will develop standards around. When workers have to go "hands on", for example, we understand the risk of harm that is created for both the worker and the person receiving services. People with disabilities are just as likely to get hurt as the person working with us. Without us they won't get the full perspective needed for better safety standards and will base it only on their own experience. The Board will focus on workplace safety without people with IDD even in the room. Their "workplace" is our "home." We can give perspective to those making up the standards who otherwise won't fully understand what should happen in our homes.

The needs of providers and workers will become more important than the needs of the individuals receiving services. We are too often left out of policy decisions because we are the ones receiving services. It tells us we are not as important. It impacts the fullness of the community not to have the input from people with IDD. Policy makers leave us out of conversations because they think "we're just ... this," or "we're just ... that," or "we're just ...", not important? As persons with disabilities are left out of decisions that effect our lives, we are made to feel less than, not as important, and not as valuable.

HB 3838 is about our whole lives, our independence, and what goes on in our homes. It's wrong to make choices about the people impacted without them. They should be engaging with us, but the process that went into creating this Board is a process without us, and without us—it is not for us.

Sincerely,

Gabrielle Guedon  
Executive Director  
Oregon Self-Advocacy Organization