Submitter: Lynn Russell

On Behalf Of:

Committee: Senate Committee On Human Services

Measure: SB576

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Dear Senators,

I am writing to share my strong support for SB576. My biracial son Liam is 18 years old and has a neuromuscular condition called Spinal Muscular Atrophy Type 2. I am writing this letter with his permission. A full-time power wheelchair user, he is in his first year at Oregon State University (OSU). He lives in the dorms, where his peer aides assist him with Activities of Daily Living (ADLs) and Instrumental Activities of Daily Living (IADLs). He has recruited, interviewed, and trained his staff in addition to being a full-time college student. Liam studies hard, makes mistakes, and learns. He meets new people, gets sick, and is tired of dining hall food, like first-year students all over this country—but he is also navigating and advocating for himself within complex systems: higher education, insurance, medical appointments, hospital stays, and, more recently, the Aging and People with Disabilities (APD) program. But he is not an older Oregonian; he is a young adult filled with possibility and dreams.

Like many first-year college students, the arc of his future lies ahead—promising, uncertain, hopeful. Now in his second term at OSU, Liam is considering switching his focus from bioengineering to ecological engineering, both fields that demonstrate his commitment to making the world a better place. And yet who knows what the next several years will bring? He may change his major again, but I know he has much to offer with his brilliant mind and courageous heart. I am not worried about that. Liam lives an interdependent life where he both gives and receives help.

Being disabled is no easy feat in a system and society predicated on the pathologizing medical model of disability. The focus on deficits and limitations perpetuates impossible, inequitable choices. Liam currently participates in the Independent Choices Program (ICP) through APD and has secondary insurance through Oregon Health Plan (OHP). As a current student who does not yet work, he is only eligible for these programs and services if his assets are $2K or less. When Liam begins working, he will be allowed $5K in assets through the Employed Person with Disability (EPD) program. Let these numbers sink in for a moment: to be eligible for services that maintain his independence and quality of life, he cannot have more than five thousand dollars in assets. Liam cannot pursue gainful employment—employment that ultimately gives back to others-–without being punished by discriminatory, unjust systems. These arbitrary caps on income and assets create and maintain obstacles for disabled people. These systemic, ableist barriers discourage and prevent people like Liam from leading full lives with work they care about with the supports and services they need.

Please do not limit or dictate Liam’s bright future with outdated ideas that devalue the humanity and capability of disabled people. Do not force him to choose between meaningful employment and necessary, sometimes life-saving, healthcare and critical long-term services. Please support SB576 and allow Liam—and many other disabled Oregonians—to thrive: whole, equal, and respected.

Thank you,

Lynn Russell
Corvallis, Oregon