Submitter: Amanda Siebe

On Behalf Of:

Committee: Senate Committee On Rules

Measure: SB1089

I am an injured worker living with Complex Regional Pain Syndrome from an on the job injury. Even though I'm supposed to be covered by workers compensation, their constant denials and dragging of their feet has left me depending on OHP for a lot of my care. I've seen the short-comings of our current system. A system that allows patients to fall below the line of coverage because they are too sick in OHP doesn't cover their condition. People with disabilities who cannot function outside their homes without the assistance of a mobility or accessibility device, having those adaptive devices denied because, for a group of doctors sitting in a room who will never be in my shoes decided that just surviving inside your home is a good enough quality of life. It's not. We need a governing body that is composed not just of out-of-touch doctors and invested parties, but patients and real people. People who can look at the situation as a who and always err on the side of the patient and quality of life rather than on profits. We need a governing body to hold the program accountable and ensure patients are protected, but that body cannot be composed of the same greedy & heartless jerks that would trap a disabled person in their home, starving to death, because they cannot get outside of their home to function, go to the store, or even see a doctor. Our first priority needs to be to the patients. No one should be 'too sick' or 'too disabled' to receive services. We need a board who will assess people as individuals and take the whole body, including mental and emotional health, into account. Universal healthcare needs to be represented by a board that is not just accountable to Oregonians, but is comprised of them. And not just doctors, nurses, therapists, etc. But by patients. Patients know this program inside and out because we depend on it to survive, so we should be included in a \*real\* capacity, with an equal voice and footing. That's the only way to keep from turning what could be an amazing program into a giant clusterf\*ck that doesn't work, provides crappy sub-par care, and leaves people to suffer. Accountability is key.