



April 3, 2019

To: Senator Gelser, Chair, Senate Committee on Human Services

From: Joanne Fuhrman, Oregon Developmental Disabilities Coalition

RE: SB 1039 – Health Care Representatives for People Experiencing Intellectual or Developmental Disabilities

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Senator Gelser and Members of the Committee:

My name is Joanne Fuhrman and I am the CEO and Founder of Partnerships in Community Living, Inc. (PCL). PCL is a private non-profit organization and has been a partner with the State of Oregon for over 32 years providing supports at home, work, and in their communities for over 300 adults, children, and families who live and thrive with Intellectual and Developmental Disabilities (I/DD). PCL provides these services in eight counties including Marion, Polk, Benton, Josephine, Jackson, Linn, Yamhill, and Lane.

Thank you for this opportunity to speak on behalf of the Oregon Developmental Disabilities Coalitions (DD Coalition) in support for SB 1039.

The DD Coalition is a group of approximately 36 organizations across Oregon that promote quality services, equality, and community integration for Oregonians with Intellectual and Developmental Disabilities (IDD) and their families. We also have individual members who are self-advocates and family members.

The DD Coalition believes that Oregon is strongest when all people exercise self-determination, choice, and control in their lives. We also recognize that sometimes people with disabilities need decision-making support to meet their goals and remain healthy, safe, and free from exploitation. In these cases, we support the least restrictive alternatives to guardianship. We take guardianship very seriously because it restricts fundamental rights of a person experiencing disabilities, often permanently.

We support SB 1039 because it aligns Oregon law with current practice that we know is a viable alternative to guardianship for people experiencing IDD who need health care decision making support while acknowledging and remaining in place their right and ability to maintain self-determination and control over all other aspects of their lives. For people who need support making health care decisions, the Office of Developmental Disability Services has had a process in place that has been used successfully for many



years. The current process allows the person supported to appoint a Health Care Representative. SB 1039 expands this vital support to people who may not be able to clearly appoint their own health care representative by providing an option for the person's Individual Support Plan team (ISP) to identify and appoint a Health Care Advocate to fulfil the role. The appointed Health Care Advocate will be empowered to make important health care decisions with and/or for the person supported.

Health Care Representatives have had proven benefits for the people we support. Many of the people who have chosen PCL to support them are their own guardians and enjoy, like the rest of us, the ability to live everyday lives embracing self-determination. However, often when it comes to health care, they need additional support to navigate and understand the very complicated health care system. In many cases, the medical community standards require they have a "decision maker" due to their perceived inability to understand the decision they are consenting to or the person's untraditional communication methods. In these cases, the Health Care Representative process has been invaluable and in many cases lifesaving. Extending this support to those who also need the help of their ISP team to appoint an advocate only enhances our ability to facilitate the best health care possible for people with I/DD.

In one recent case, a person we supported was experiencing significant dental pain and needed oral surgery. The only way he had to tell us he was in pain was through aggressive and self-injurious actions. The Dentist could not perform the surgery without his consent and while those who work with him every day knew he understood and was requesting relief, the Dentist did not feel he could provide consent. Luckily, he had a Health Care Representative who could step in and provide this consent for this important procedure relieving him of significant pain.

For people with I/DD, having a compassionate and caring Health Care Representative or Health Care Advocate, as outlined in SB1039, makes all the difference throughout someone's life: from support in managing everyday health decisions to serious diagnosis's. Last year John, a person who PCL was honored to support for 30 years, was diagnosed with terminal cancer. He also had a Health Care Representative who had been in his life for many years. This advocate was with him every step of the way helping with decisions and making sure he got the best health care possible and that his wishes were honored throughout the process - from the beginning of the treatment to his final days with hospice. He was a proud man who had spent many years in institutions. Since leaving Fairview, he took great pride in being in charge of his life. The health representative process allowed him to maintain the pride he felt being his "own boss." It also allowed him to get the help he needed to remain living in his home and make health decisions that allowed him to pass at home surrounded by the people he loved.



Oregon DD  
Coalition

Advancing Opportunities

Please approve SB1039 and **expand this important support** to all people who live with Intellectual and Developmental Disabilities.

