

May 16, 2019

TO: Representative Andrea Salinas, Chair
House Committee on Health Care
FR: Bob Joondeph, Policy Consultant
RE: Support for SB 1039 with -2 amendments

Disability Rights Oregon (DRO) is the designated Protection and Advocacy agency for Oregon. DRO is mandated by federal and state law to advocate for the rights of individuals with disabilities and to investigate complaints of abuse or neglect.

SB 1039 is a key component to assuring that individuals who receive state-funded Intellectual/Developmental Disability (I/DD) services receive timely and adequate health care services, as well. For an individual who does not have an actively engaged family member or guardian and whose ability to understand proposed medical treatment is in question, treatment can be delayed or denied due to an inability to provide informed consent for the treatment.

In past years, DRO has discovered individuals who have not had routine preventative care and non-emergent medical care due to the inability to provide informed consent. In those circumstances, the underlying condition has needed to become emergent before a medical provider will act. The alternative is to go through the expensive, lengthy and intrusive process of obtaining and legal guardian which involves finding someone to act as the guardian.

To protect an individual's civil rights, the -2 amendments recognize that a person should not be forced to undergo treatment without the due process afforded by the guardianship process if they protest any substituted health care decision. A third party may also use the guardianship process if they want to assert greater control of an individual. However, in many cases, a court or guardian will lack an understanding of the individual's unique needs and circumstances that can be provided by a service team made up of those with the most direct contact with the person.

For these reasons, DRO believes that SB 1039 and administrative rules that will be crafted for implementation, will strike the correct balance between honoring individual rights and the need to avoid medical neglect of individuals who have questionable capacity to provide informed consent for medical treatment. With proper training and oversight, surrogate medical decision making is well-placed within the service plan team when the individual does not protest.

Thank you for this opportunity to testify in support of SB 1039 with the -2 amendments.