



**DATE:** April 4, 2019

**TO:** Senate Committee on Human Services

From: Lilia Teninty, Director of the Office of Developmental Disabilities

Services, DHS

Subject: SB 1039, Health Care Advocate Bill

## Introduction:

Senate Bill 1039 strengthens support for people with intellectual and developmental disabilities (I/DD) who are unable to make health care decisions for themselves, using principles that align with the history and values of Oregon's I/DD system.

## Background:

Oregon's existing health care representative rule (OAR 411-365) came about to address concerns of the Office of Developmental Disability Services and the I/DD community, following the closure of institutions in the mid-1990s. People with I/DD who were unable to make health care decisions, and who didn't have guardians, were being denied routine procedures like blood draws and antibiotics because no one had the authority to give consent.

## What the bill does:

Senate Bill 1039 affirms support for the process that currently exists for people who need help in making health care decisions in residential settings and expands that assistance to include those in other settings. It also clarifies the roles of the various parties. To qualify for a health care advocate, individuals will be receiving services through Oregon's I/DD system and have an individualized written service plan (commonly known as an ISP), who do not have a guardian or a health care representative to make health related decisions.

Health care advocates may be appointed by the ISP team when individuals are deemed incapable of making health care decisions by a court or health care provider. ISP teams include the person with I/DD, the legal guardian or designated representative, case manager, and other individuals who may be chosen by the person, such as caregivers, friends or family members.

Senate Bill 1039 also specifies qualifications and responsibilities of the health care advocate, training requirements for the ISP team, and sets the parameters of the advocate's authority. The bill includes a dispute resolution process when the individual does not agree with the health care advocate.

## Requested Changes:

The Office of Developmental Disability Services recognizes the institutional knowledge, lived experience and expertise of stakeholders and is why we value the feedback received thus far on SB 1039. Feedback from stakeholders and DOJ has been submitted for an amendment. The amendment requested consists of minor technical changes and other substantive changes which include engaging and informing the individual on the health care decisions being considered; clarifying limits on the decision-making authority of the health care advocate; identifying who qualifies to be a health care advocate and clarifying training requirements.