

March 1, 2021

To: Chair Williams and Members of the Oregon House Committee on Human Services

From: Sharon Lewis, Portland, OR

Re: Supported decision making and HB2015

Chair Williams and Members of the Committee:

Thank you for the opportunity to testify today. I am here today as a parent of an adult with intellectual and developmental disabilities who uses supported decision making. I also served as the Commissioner of the Administration on Intellectual and Developmental Disabilities and the Secretary's Senior Disability Policy Advisor in the U.S. Department of Health and Human Services during the Obama Administration. During my federal service, I helped to develop and support the [National Center on Supported decision making](#), worked with multiple stakeholders including the American Bar Association Commission on Law and Aging and the National Guardianship Association to support research and policy development related to supported decision making and alternatives to guardianship.

Supported decision making is pretty simple concept that most people rely upon in our everyday lives. Few of us have ever signed a mortgage or purchased property without the assistance of realtor or a title expert. Most of us rely upon our health care professionals to explain procedures and options before we make decisions about our health care. Many people consult with financial advisors, attorneys, and other experts to break down complex information and make it accessible before making decisions. These are all examples of supported decision making.

Most of us make final decisions about big and important issues in our lives after considering our options and consulting with experts and/or family and friends. We are able to exercise our self-determination and informed choice – even when others may disagree with our judgement. We are afforded the dignity of taking risks, living with consequences, and experiencing the opportunity to make choices that align with our values and preferences.

Far too often, for people with disabilities and older adults, the presumption is that they must be protected from important decisions and choices, and others must substitute their judgement or make decisions in the best interest of the person. This often results in unnecessary rights restrictions, up to and including guardianship. Research has demonstrated that people subject to guardianship experience poorer quality of life outcomes, including “significant negative impact on . . . physical and mental health, longevity, ability to function, and reports of subjective well-being.”¹ National Core Indicators data shows that people with intellectual and developmental disabilities under guardianship are less likely to access some elements of preventative health care, are more socially isolated, and “experience diminished independence and opportunities.”²

¹ Wright, J.L. (2010) Guardianship for your own good: Improving the well-being of respondents and wards in the USA. *International Journal of Law and Psychiatry*, 33(5-6), p.354

² Bradley, V. (2019) Data Brief: What Do NCI Data Reveal About the Guardianship Status of People With IDD? Retrieved from https://www.nationalcoreindicators.org/upload/core-indicators/NCI_GuardianshipBrief_April2019_Final.pdf

Since 2006, the United Nations Convention on the Rights of Persons with Disabilities (CRPD) has recognized that people with disabilities should “enjoy legal capacity on an equal basis with others in all aspects of life.” The CRPD explicitly rejects the traditional legal structure of “best interest” or “substituted judgement” and asks countries to honor the human rights of all people by taking “appropriate measures to provide access by persons with disabilities to the support they may require in exercising their legal capacity.”³

Supported decision making has now been recognized as an effective less restrictive alternative to guardianship in eleven state statutes (and the District of Columbia), and several other states are actively considering legislation.

As a parent, I have personally seen the benefit of using supported decision making, as my daughter described in her testimony. It has provided her the opportunity to maintain control and choice in her life, while still being able to rely upon people she trusts to help her make decisions. It has given her a way to protect herself when she feels pressured into signing documents or engaging in conversations that do not provide her with adequate accessible information and time to process or communicate. It affords her the time and space to exercise informed choice, and to get help when she needs it.

Our supported decision making agreement also gives her the chance to further develop her decision-making skills over time, unlike the assumptions inherent in the determination of “incapacity” at age 18 as many young adults with I/DD experience when parents seek guardianship. We do not presume that the skills my daughter had at age eighteen are the same skills she demonstrates now at age twenty-four, or will have as she continues to grow and learn over her lifetime. Supported decision making allows us to have legal agreements specific to her needs and strengths, and to change the particulars over time. Our agreement sunsets every other year, requiring us to revisit the conversation frequently – without the expense of attorneys and court costs.

Should Oregon include supported decision making in our law, it certainly should not – and cannot – be limited to people based upon a diagnosis or particular type of disability, nor should it exclude people already working with a fiduciary or guardian. All people should have the opportunity to have their human rights respected and their preferences honored, regardless of impairment. All people should be supported to express their likes and dislikes, priorities and choices – including people who rely upon behavior to communicate instead of words, or those who have been determined to experience “incapacity” in some or many domains of decision-making. This is not always comfortable or simple for systems, providers, financial institutions and even families, and it often requires time, patience, trust and understanding – but at the core of self-determination is the opportunity to make choices and have some level of control over one’s life.

As a parent, I can attest that this can be terrifying and frustrating and sometimes simply exhausting. But without the opportunities to exercise decision-making and self-determination at many different levels with the support of people in trusted relationships, my daughter will be far more vulnerable to potential abuse or exploitation by others – especially in the future, when I am not here.

³ United Nations Convention on the Rights of Persons with Disabilities, Article 12 (2006). Retrieved from <https://www.un.org/development/desa/disabilities/convention-on-the-rights-of-persons-with-disabilities/article-12-equal-recognition-before-the-law.html>

HB2015 offers Oregon the opportunity to incorporate supported decision making into our state statutes as an alternative prior to an appointment of a fiduciary, as well as expanding the information for families and people with disabilities about these options, including the important conversations related to the Transfer of Rights at age 18 in the education system.

However, I believe the current draft of the legislation would benefit from further refinement.

Supported decision making is an inclusive and expansive construct, intended to describe a process to determine when help in making decisions is needed and the finding ways to provide that assistance through trusted relationships, without diminishing the rights of the person seeking assistance. In its best forms, it is highly individualized and flexible, and does not require much more than an acknowledgement of the validity of such arrangements in the law as a less restrictive alternative.

The description of supported decision making agreements in a prescriptive manner will make the tool far less accessible and useful to many individuals and families. At the same time, I worry that other important protections, such as strong conflict of interest provisions, are not adequate in the current bill.

I am hopeful that further input from stakeholders and amendments to the legislation could address these outstanding issues, and we can move forward on establishing supported decision making as a legally-recognized alternative to guardianship in Oregon.

Thank you for your time and the opportunity to testify today.