



Oregon Council on
Developmental Disabilities

BETTER TOGETHER

February 17, 2021

To: Chair Power and Members of the House Judiciary Civil Law Subcommittee

From: Leslie Sutton, Executive Director, Oregon Council on Developmental Disabilities

RE: Alternatives to Guardianship – Two Emerging Alternatives and One Issue to Watch

Chair Power and Members of the Committee:

The Oregon Council on Developmental Disabilities works to create change so that people with intellectual and development disabilities (IDD) can live full lives as valued members of their communities. Two out of three of our Council members are people with IDD or family members of people with IDD.

The DD Council envisions an Oregon where people with disabilities have choice and control over their lives. Everyone can make decisions – and we all do it every day. We recognize that sometimes all people, including people with disabilities need support to make decisions so we can meet our goals and remain healthy, safe and free from exploitation.

Appointing a guardian is a serious matter – and has significant, long-term consequences for the person, their sense of self-determination and their rights. Oregon law requires that a person be given the chance to try less restrictive alternatives before restricting a person’s rights through guardianship.

Today, I will outline two emerging alternatives to guardianship:

- Supported Decision Making where a supporter helps a person with a disability evaluate information, make their own decisions and communicate that decision, and
- Health care advocates for people with intellectual or developmental disabilities, as outlined in ORS 127.765.

I will also outline one issue to watch in guardianship:

- The “school to guardianship pipeline” and the impact of granting guardianships over people with disabilities when they are only 18 years old.

Emerging alternative to guardianship: Supported Decision Making

Alternatives to guardianship may look different for each person to accommodate their life stage, goals and the way they make decisions. Increasingly, we see a supported decision-making

arrangement with a trusted person can be a useful way to for the person experiencing disability to get help making decisions, without giving up their rights.

In Supported Decision Making, a person uses a trusted friend or family member in their life to help them understand, evaluate and communicate their decisions. Everyone uses supports like this in their life and this takes practice. For people with disabilities, this is a paradigm shift away from doing things “for” people with disabilities to supporting and working “with” people with disabilities to have their own voice and control in their life.

Supported Decision-Making can positively impact the self-determination, health and well-being of Oregonians experiencing disability. According to the 2018 report from the National Council on Disability, people who make their own decisions have better outcomes, are more independent and integrated into their communities, better employed, healthier, and better able to recognize and resist abuse.^{1 2}

The most famous example of Supported Decision Making is the Jenny Hatch story. In 2012 Jenny Hatch, a woman from Virginia, won a landmark legal battle protecting her right to make her own life decisions using Supported Decision Making. Jenny’s legal battle started when her guardians made her quit a job she loved and move out of her home and into a series of group homes against her wishes. Jenny brought her guardians to court where the judge ruled in her favor. The judge ruled that after one year of supported decision making, Jenny’s guardianship would terminate, and she would regain all decision-making authority over her life. This was the first legal case where Supported Decision Making was ordered as an alternative to full guardianship.

Jenny Hatch has paved the way for people with disabilities to use Supported Decision Making as a way to terminate or avoid guardianship in many states, including Oregon. There is a growing number of cases from around the country where guardianship has been terminated or a petition denied because options for Supported Decision-Making have been identified and recognized by a court as an important accommodation that allows a person to continue making their own decisions with support.

Supported Decision Making has been best practice for supporting people with disabilities for decades. Other states, the Uniform Guardianship, Conservatorship and other Protective Arrangements Act and the American Bar Association House of Delegates Resolution all elevate Supported Decision Making as a viable alternative to guardianship. Importantly, Supported Decision Making is one of the priorities of the Oregon Self Advocacy Coalition, a coalition of 18 local groups of people with IDD around Oregon.

¹ See [“Beyond Guardianship: Towards Alternatives That Promote Greater Self-Determination.”](#) Report from the National Council on Disability at p. 131 (March 22, 2018).

² Exercising decision-making skills leads to greater self-determination and the opportunity to control things in life that are important. People with greater self-determination are healthier, more independent, better able to recognize and resist abuse, and have greater psychological health. Wehmeyer, Palmer, Rifenbark, & Little 2014; Powers et al., 2012; Khemka, Hickson & Reynolds 2005; Wehmeyer & Palmer, 2003; Shogren, Wehmeyer & Shwartz, 1997 & 1998; Wehmeyer, Kelchner, & Reynolds 1996)

In Oregon, we are getting closer to using Supported Decision Making routinely. SB 1606 in the first Special Session of 2020 explicitly requires hospitals to recognize the role of support people to help a person make and communicate health care decisions. There needs to be more recognition of Supported Decision Making in Oregon law, including explicitly mentioning it as an alternative to guardianship.

Emerging Alternative to Guardianship: Health Care Advocate for People with IDD:

Many people experiencing IDD do not use guardians, however, they may need more formalized support when it comes to healthcare so they can successfully navigate our complicated health care system. Often, the medical community standards require a “decision maker” for people with disabilities due to their perceived inability to understand medical decisions, give consent or communicate in traditional ways.

A great example of needing a Health Care Advocate is from one of our Oregon DD Coalition Partners, Partnerships in Community Living (PCL). A person PCL supports needed oral surgery. The only way he could communicate that need was through behavior and actions. The dentist refused to perform surgery without his consent and did not feel the person could provide consent. The person’s Health Care Advocate was able to provide consent and he was able to have the pain-relieving procedure.

SB 1039 in 2019 amended ORS 127.765 to allow for a Health Care Advocate for people with IDD. This formalized processes that were already in place in the IDD system in statute. A summary includes:

- A Health Care Advocate may be appointed by the person and their DD services planning team to make certain health care decisions on behalf of the person if:
 - ✓ The person has an intellectual or developmental disability (defined by state law);
 - ✓ The person is enrolled in services through Oregon’s Office of Developmental Disabilities Services; and
 - ✓ A court or attending physician has determined the person cannot make certain health care decisions.
- The person, with their Individualized Service Plan (ISP) team, may appoint an HCA.
- The HCA’s authority is withdrawn if the person objects.
- Significant health care decisions must be discussed with ISP team.
- The HCA terminates after one year and must be renewed if still needed beyond that time.

With the use of Health Care Advocates, people with IDD have been able to get the support they need for health care while retaining all their other rights and avoiding guardianship.

Key issue to watch in guardianship trends: School to Guardianship Pipeline

When youth turn 18, including students with disabilities, their educational rights transfer from the parents to the young adult. Too often, we hear that because families do not have enough information or time to practice alternatives to guardianship like supported decision making, they feel their only option is to file for guardianship in order to continue to support their student in making decisions

about school and life. In fact, families report that guardianship is the only option schools share with them about how to support their youth with decision making as an adult.

We do not have data about how many youth end up with guardianships at the age of 18 or upon leaving high school. However, National Core Indicators data has shown that nationally, as many as 58% of youth with IDD between the ages of 18-21 have guardians.³ Many people at this age need support to make decisions, yet 58% of youth with IDD leaving high school will not have the opportunity to make their own important life decisions because they will already have a guardian. That guardianship will likely remain in place for the rest of their life.

There is so much that can happen in a young adult's life as they gain experiences, make mistakes and learn decision making. The traditional guardianship model presumes that a person has no capacity for growth. The options we are talking about presume that a person can build new skills with support and practice. None of us arrive at adulthood fully equipped to manage every decision that comes our way. We all learn as we go, with support from the people and sources we trust. The same should be true for youth with disabilities.

An important thing to consider is if we make all guardianships of people between the ages of 18-25 expire at age 26. At age 26, a new petition for guardianship would have to be filed and considered anew by the court. This would ensure that guardianships only continue for those who truly need it.

Using data from the District of Columbia, The National Council on Disability recommends introducing Supported Decision Making as early as pre-kindergarten to develop decision making and self-advocacy skills in students with disabilities. These skills are essential for supported decision making later in the student's life.⁴

Requiring information about supported decision-making and other alternatives to guardianship as part of the Individualized Education Plan (IEP) meeting whenever post-secondary goals and transition are discussed is also an important tool to ensuring that Oregonian youth have a full opportunity to practice Supported Decision Making and make plans to retain their rights into adulthood.

Thank you for the opportunity to speak with you today.

³ See National Council on Disability "Turning Rights into Reality: How Guardianship and Alternatives Impact the Autonomy of People with Intellectual and Developmental Disabilities." p. 29 June 10, 2019. https://ncd.gov/sites/default/files/NCD_Turning-Rights-into-Reality_508_0.pdf

⁴ Id, p. 61.