

Supported Decision-Making

Presentation to the Joint Task Force on Hospital Discharge Challenges

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What is supported decision-making?

- A decision-making process in which a person gets support from family, friends and others they trust to:
 - Gather information and understand options
 - Evaluate options
 - Communicate decisions to others
- The person remains the decision-maker.
- Important reasonable accommodation that may be necessary to access goods and services and to enjoy existing rights.



Background

Supported decision-making has been best practice for supporting people with disabilities for decades.

Research shows people with disabilities who are supported to make their own decisions:

- Have better outcomes
- Are more independent
- Better integrated into their communities
- Better employed
- Healthier
- Better able to recognize and resist abuse

Sources: [“Beyond Guardianship: Towards Alternatives That Promote Greater Self-Determination.”](#) Report from the National Council on Disability, p. 131 (March 22, 2018); also Khemka, Hickson and Reynolds, 2005; O’Connor & Vallerand, 1994; Wehmeyer & Schwartz, 1998.

Federal regulations (42 CFR 441.301(c))

Federal regulations governing services and supports for people with disabilities recognize supported decision-making, informed choice, person-centered planning and more:

- Medicaid: home- and community-based services (HCBS) in APD, used by ODDS.
- WIOA: Vocational Rehabilitation
- IDEA: education system
- ABLE
- American Disabilities Act/Olmstead

Example: Person-centered planning through ODDS and Medicaid HCBS

- Individual leads the person-centered planning process where possible.
- Individual's representative should have a participatory role, as needed and as defined by the individual.
- In addition to being led by the individual receiving services and supports, the person-centered planning process:
 - i. Includes people chosen by the individual.
 - ii. **Provides necessary information and support to ensure that the individual directs the process to the maximum extent possible and is enabled to make informed choices and decisions.**

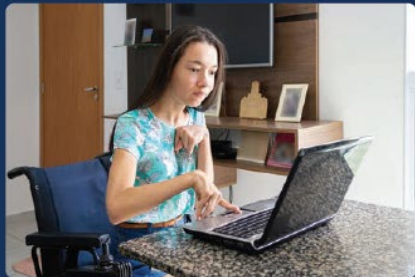
Oregon-specific policies regarding decision-making supports



- Support person to make their own decision to the extent possible.
 - Narrowly tailor appointment of surrogate, if one is necessary, to meet specific support needs.
 - Even with an appointed surrogate, the surrogate has an obligation to support the person to make decisions to extent possible.
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- Surrogate must base decisions on what the person would want, including what we know about the person's preferences or what a similarly situated person would want.
 - May make decisions based on best interest if preferences are unknown or unreasonably dangerous. ORS 125.315(1)(h)

ODHS supported decision-making brochure

Continuum of decision-making supports



- ☑ There are many types of decision-making support. These support options can be used alone or in combination with other types of support.
- ☑ The option that allows you to retain more of your rights is always explored and used before more restrictive options.
- ☑ Even if you use a more restrictive support option, such as a guardianship or conservatorship, you must be supported to make your own decisions.



Available in six languages at <https://sharedsystems.dhsoha.state.or.us/DHSForms/Served/de3991.pdf>

Decision-making supports

Continuum of decision-making supports from least restrictive to most restrictive:

- Supported decision-making
- Release of information
- Case management and social services
- ABLE account
- Money management assistance
- Joint bank account
- Rep payee
- Health care representative, power of attorney or a trust
- Health care advocate for people using ODDS' services
- Guardianship or conservatorship

Health care representative (HCR): Appointed in an HCR form, advanced directive or statutory default

127.635 Withdrawal of life-sustaining procedures; conditions; selection of health care representative in certain cases; required consultation. (2) If a principal's condition has been determined to meet one of the conditions set forth in subsection (1) of this section, and the principal does not have an appointed health care representative or applicable valid advance directive, the principal's health care representative shall be the first of the following, in the following order, who can be located upon reasonable effort by the health care facility and who is willing to serve as the health care representative:

- a) A guardian of the principal who is authorized to make health care decisions, if any;
- b) The principal's spouse;
- c) An adult designated by the others listed in this subsection who can be so located, if no person listed in this subsection objects to the designation;
- d) A majority of the adult children of the principal who can be so located;
- e) Either parent of the principal;
- f) A majority of the adult siblings of the principal who can be located with reasonable effort;
or
- g) Any adult relative or adult friend.

Note: There is nothing similar for long term services and supports.

Designated representative

411-004-0010(3) "Designated Representative" means:

- (a) Any adult, such as a parent, family member, guardian, advocate, or other person, who is:
 - (A) Chosen by the individual or, as applicable, the legal representative of the individual;
 - (B) Not a paid provider for the individual; and
 - (C) Authorized by the individual or, as applicable, the legal representative of the individual to serve as the representative of the individual or, as applicable, the legal representative in connection with the provision of funded supports.
 - (D) The power to act as a designated representative is valid until the individual modifies the authorization or notifies the agency that the designated representative is no longer authorized to act on his or her behalf.
- (b) An individual or the legal representative of the individual is not required to appoint a designated representative.

Oregon-specific policies regarding decision-making supports

Oregon law requires less restrictive alternatives be explored before guardianship.

- ORS 125.055(2)(i)((A)

Often, families unnecessarily turn to guardianship or other more restrictive options because they do not know supported decision-making is an option.

Structures and frameworks for supported decision-making exist within social service delivery systems but are commonly not recognized as an accommodation by other entities like courts, doctors, schools, banks, etc.

Supported decision-making legislation

Supported decision-making is increasingly recognized under federal and state law.

[Indiana](#) (2019)

[Rhode Island](#) (2019)

[North Dakota](#) (2019)

[Nevada](#) (2019)

[Washington](#) (2019)

[Maine](#) (2018)

[Tennessee](#) (2018)

[Alaska](#) (2018)

[Delaware](#) (2016)

[Wisconsin](#) (2018)

[Texas](#) (2015)



Recent Changes: Explicitly recognizing supported decision-making in Oregon law

SB 1606: First special session, 2020

- Specifically recognizes the right to have a support person present while in the hospital.
- A support person is explicitly recognized as a right or accommodation to gain access to already existing right to healthcare and to help ensure effective communication with the patient.

SB 2105: 2020

- Requires schools to provide training and information regarding supported decision-making.

U.S. Health and Human Services notice of proposed rule-making (NPRM)

1. Supported decision-making is recognized in the NPRM as a reasonable accommodation that may be needed to access healthcare and human services.
2. Incorporation of ADA/Olmstead Integration Mandate
 - i. Existing Section 504 regulation requires programs and activities to be administered in the most integrated setting appropriate to the needs of the person with a disability.
 - ii. Proposed rule incorporates language reflecting principles established through Supreme Court and other significant court decisions that require the provision of community-based services to persons with disabilities when such services are appropriate, the affected persons **do not oppose** community-based treatment, and the placement in a community setting can be reasonably accommodated.

Guidance from U.S. Health and Human Services: Discharge planning and care coordination

- Unreasonable segregation of individuals with disabilities is a form of discrimination prohibited by Title II of the Americans with Disabilities Act.
- If emergencies strain services, individuals who live in community-based settings may need to temporarily access supports or medical care in institutional settings.
- However, the priority should always be to support adults with disabilities in community-based settings using person-centered planning.
- When admission to an institutional setting is unavoidable, it should be considered temporary and include immediate plans to return them to the most integrated setting.
- People should never be institutionalized unnecessarily.

Tools and resources

- [ODHS supported decision-making website](#)
- [ODHS supported decision-making brochure](#): available in six languages
- [Oregon WINGS](#): Oregon Guardianship Workgroup (train the trainer on continuum of supports)
- [Oregon SB 2105 fact sheet](#): 2021 regular session

Facilitation tools

- [Example agreements](#)
- [ABA Practical Tool](#)
- [LifeCourse](#)
- [POLST Guide](#)

LifeCourse Stoplight tool

- Identifies areas where person wants support and who they want to have support them in different areas.
- May translate to written supported decision-making agreement.

CHARTING THE LIFECOURSE | EXPLORING DECISION-MAKING SUPPORTS

This tool was designed to assist individuals and supporters with exploring decision making support needs for each life domain.


Individual: _____


Person completing this form: _____


Relationship to individual (circle one): ☐ Self ☐ Family ☐ Friend ☐ Guardian ☐ Other: _____


How long have you known the individual? _____

For each question below, mark the level of support you need when making and communicating decisions and choices in the Charting the LifeCourse life domains.


 I can decide with no extra support

 I need support with my decision

 I need someone to decide for me

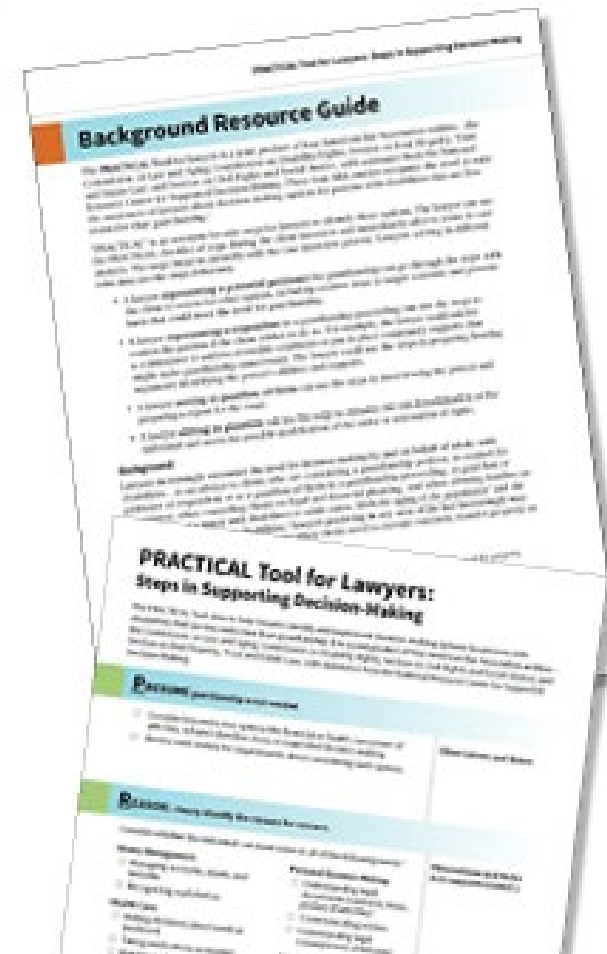
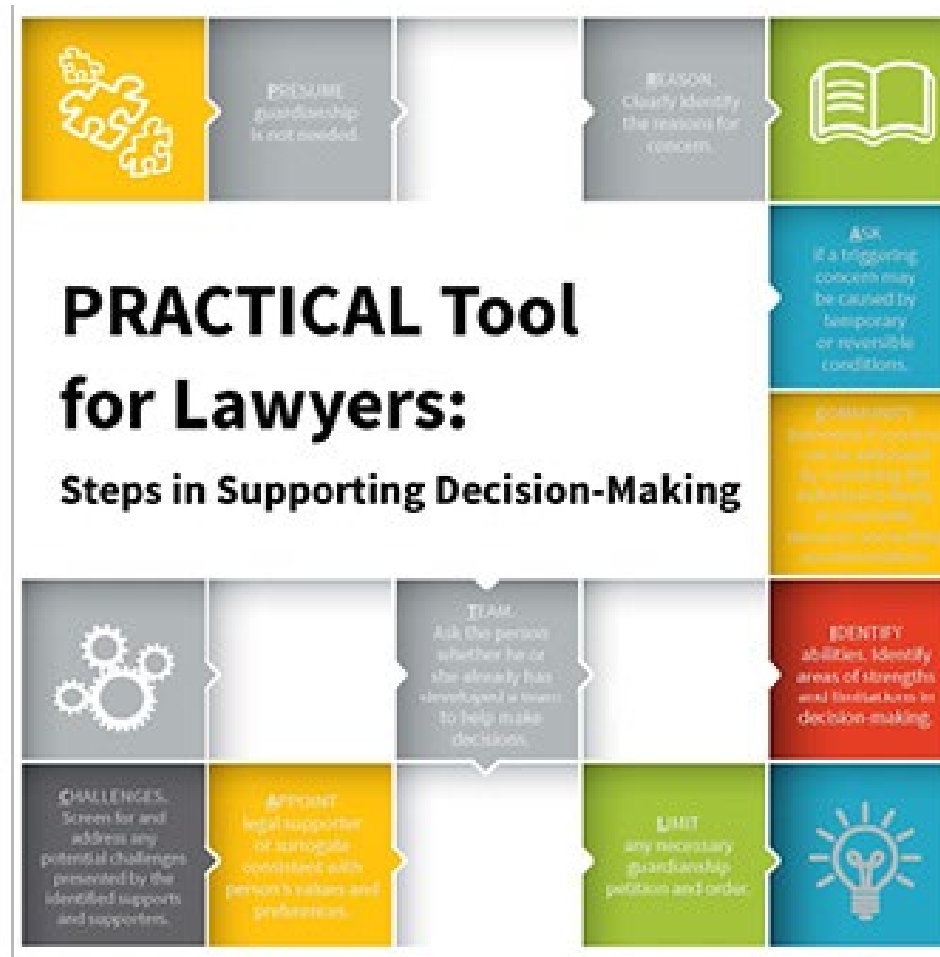
 **Daily Life & Employment**

Can I decide if or where I want to work?			
Can I look for and find a job? (read ads, apply, use personal contacts)			
Do I plan what my day will look like?			
Do I decide if I want to learn something new and how to best go about that?			
Can I make big decisions about money? (open bank account, make big purchases)			
Do I make everyday purchases? (food, personal items, recreation)			
Do I pay my bills on time? (rent, cell, electric, internet)			
Do I keep a budget so I know how much money I have to spend?			
Am I able to manage the eligibility benefits I receive?			
Do I make sure no one is taking my money or using it for themselves?			

 **Healthy Living**

Do I choose when to go to the doctor or dentist?			
Do I decide/direct what doctors, medical/health clinics, hospitals, specialists or other health care providers I use?			
Do I make health/medical choices for my day-to-day well-being? (check-ups, routine screening, working out, vitamins)			
Do I make medical choices in serious situations? (surgery, big injury)			
Do I make medical choices in an emergency?			
Do I take medications as directed or follow a prescribed diet?			
Do I understand the reasons why I take my medication?			
Do I understand the consequences if I refuse medical treatment?			

ABA PRACTICAL Tool





Questions?

Thank you

