

Increasing Self-Determination Through Less Restrictive Alternatives to Adult Guardianship

(from [MSW Capstone Project](#) in Spring 2024)

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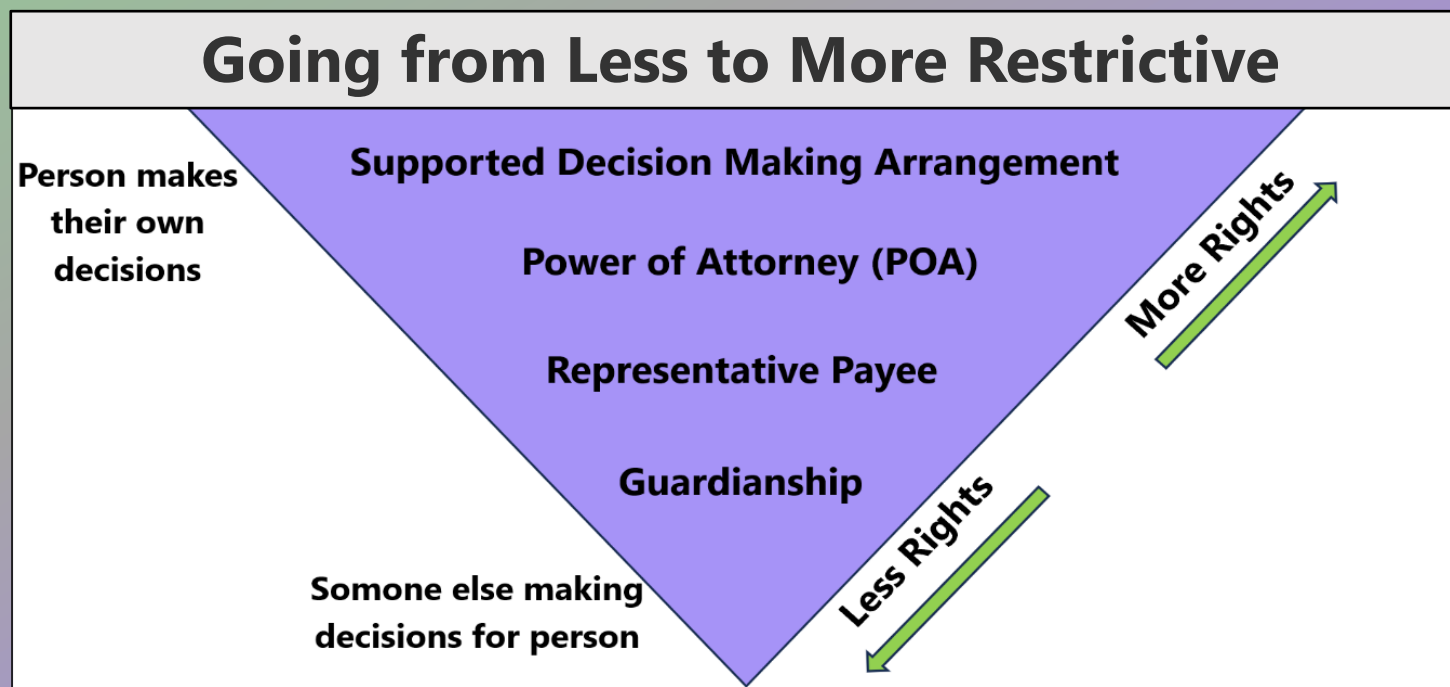
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Impacts of Self-Determination on Health

- There are a growing number of studies highlighting how much self-determination increases an individual's biopsychosocial health (short-term and long-term).
 - In one study of 145 young adults with disabilities, they were evaluated to measure self-determination and quality of life after one year. Results found positive correlations between self-determination and quality of life and that self-determination has an immediate and long-lasting impact on quality of life (Chao, 2017).
 - Another longitudinal study examined the relationship between self-determination and quality of life for 34 youth or young adults with disabilities. Those with high levels of self-determination reported higher perceptions of satisfaction with both personal development and personal fulfillment over time (McDougall et al., 2010).
 - A meta-analysis of research of the topic references several studies of around 5,000 individuals with intellectual disabilities, and found correlations with increasing levels of self-determination and increasing levels of life satisfaction/quality of life (Wehmeyer, 2020).

Decision-Making Protective Arrangement Impacts on Self-Determination

- One study found that those with severe mental illnesses who were appointed a guardian to make decisions for them (often referred to as a “substitute decision maker,” experienced negative impacts on relationships, increased experiences of stigmatization, and had strong desires to restore their decision-making rights (Law et al., 2023).
- Nationally, there are many states asking to prioritize less restrictive alternatives to guardianship to be “tried and exhausted” before implementing guardianship (Shotwell, 2022). In Washington State, the Revised Code of Washington states that a guardian should only be appointed after less restrictive alternatives have been thoroughly tried (RCW 11.130.265).



Considering Less Restrictive Alternatives to Guardianship

- Guidance from American Bar Association's [PRACTICAL](#) decision-making tool, suggests:
 - Start with a presumption that guardianship is not needed and to consider least restrictive decision-making arrangements first.
 - The most current decision-making protective arrangements in Washington State include statutes that need to be met:

Representative (Protective) Payee: The Social Security Administration appoints a person or organization to manage the person's SSI and benefits.	SSA Information Statute: WAC 388-460
Supported Decision-Making (SDM) Agreement: document that identifies the person or people they want to support them and the kinds of decisions they want support to make. More information will be provided below.	SDM Guide SDM Agreement Template Statute: RCW 11.130.700
Power of Attorney (POA): POA can be limited to one topic (ex: money or disability services), <u>or</u> limited to one decision (ex: buying a house), or broad covering all decisions. However, POA for health care must be separate.	POA Documents Statute: RCW 11.125
Guardianship: if needed, consider limiting recommendation of guardianship to what is absolutely necessary , such as: <ul style="list-style-type: none">• Only specific property/financial decisions• Only personal/health care decisions• Only specific personal/health care <u>decisions</u>• Only property/finances	DCYF Policy Statute: RCW 11.130

Note: additional alternatives such as a Trusts, Directives, etc., can be found at: [NAMI website](#).

How this Applies to the Population

- In Washington State, there are a significant amount of youth with disabilities in foster care with DCYF who transition to in-home or out of home adult services with the Developmental Disabilities Administration (DDA).
- As of 2022, there were 48,358 DDA clients, **11,641 of those clients had been assigned a guardian**, 7,410 had a parent as guardian, 2,323 had another family member as guardian, and 1,918 had someone who wasn't a family member as guardian (Developmental Disabilities Administration, 2022).
- In this same DDA report to the legislature, it was reported that there are still many unmet decision-making needs for DDA clients in facilities. It was recommended that guardianship options be simplified, and other less restrictive arrangements utilized more.
- In DCYF's 2023 report on Extended Foster Care and guardianships for Children and Youth in Out-of-Home Care, there were 777 young adults exiting extended foster care in 2022, and 7.3% of children and youth exited out-of-home care, into guardianship. (Department of Children Youth & Families, 2022).
- Youth aging out of foster care experience an increased risk for homelessness, young parenthood, low educational attainment, high unemployment rates, and abuse (Rosenberg & Abbott, 2019). This is regardless of disability, so when a youth is experiencing both, it is easy to see that putting a guardian in place is likely done with the best intentions.

Barriers to Less Restrictive Alternatives

- Lack of education/direction on less restrictive protective arrangements, and recommendation that all professionals working with disabled clients receive education on impacts of guardianship (Costanzo, 2022).
- Supporters rarely explain the potential consequences of guardianship or provide information on less restrictive alternatives. A study found that of all options, guardianship is consistently & frequently discussed, & less restrictive alternatives were rarely discussed. SDM was the least discussed (Jameson et al., 2015).
- Study examining perspective of 117 school professionals working with special education students. Results found incongruency between professional's values on decision making and the reality of practice. Despite valuing the importance of less restrictive alternatives to guardianship, less than half reported having received training in the last 3 years on self-determination or alternatives to guardianship (Plotner, 2022).
- Society generally values safety over choice & neurotypical decision making, which, helps to create a "deep-rooted paternalistic culture," in America, which makes it difficult for many to embrace SDM (Zhang, 2019).
- Lack of social worker involvement in supporting with decision-making arrangements, due to legal nature.
- Lack of DCYF policy to explore less restrictive options. Social workers entrenched in a "paternalistic" culture and already familiar with status quo (guardianship). A current lack of clear directions on less restrictive options, and many being unaware of SDM, due to how new this alternative is.
- Concerns for potential abuse and exploitation using SDM. In response to this concern
 - A study on a SDM pilot program in New York concluded that client's using SDM had more safe people in their life as supports and reduced the risk of abuse and exploitation (Hamilton, 2023 & Pell, 2019).
 - Conceptually, if SDM is constructed well, it would create more "checks and balances." (Kohn et al., 2012).

My Proposed Intervention:

The Supported Decision-Making Toolkit

- **Purpose:**

- To increase education and contentionsness on the importance of self-determination and less restrictive alternatives to guardianship.
 - Additional information will be provided on SDM, as it is a newer alternative.
- Provide resources & tools to assess decision-making support needs (emphasizing client input) & matching to the most appropriate decision-making arrangement(s).
- As a tool to involve other social workers supporting the client (WISe, school, etc).
- As a tool to inform AAG or attorney (if needed), to better assess the most appropriate arrangement.
- To utilize decision making arrangements in a way that should maximize self-determination, while still meeting health and safety concerns.

Decision Making Toolkit

Drafted by Johnny Hanson

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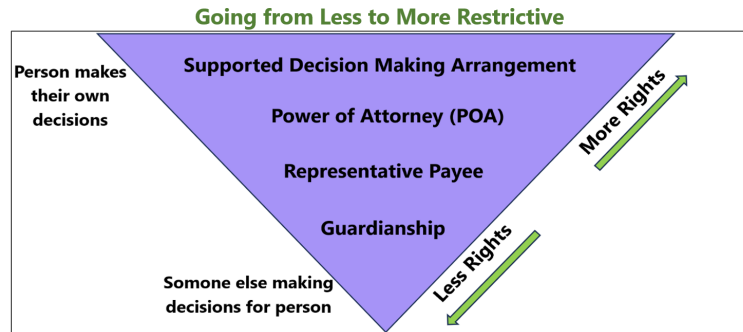


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[Supported Decision Making Agreement Template Form](#)
(separate document also available)

[Additional Resources on Less Restrictive Alternatives to Guardianship](#)

Why Consider Less Restrictive Alternatives to Adult Guardianship?

(see [additional resources](#) for list of studies mentioned below)

Understanding the Impact of Self-Determination on Health

According to [Self-Determination Theory](#), short and long-term biopsychosocial health are linked to self-determination (having more choices in life). Several recent peer reviewed studies have found positive correlations between increased self-determination and short and long-term improvements on quality of life, personal development, and personal fulfillment ([Chao, McDougall](#)). In contrast, those with mental illnesses who were [appointed a guardian to make decisions for them, experienced negative impacts](#) on relationships, increased experiences of stigmatization, and the desire to restore their decision-making rights.

Importance of Less Restrictive Alternatives to Guardianship on Self-Determination

Nationally, there are many states asking to prioritize less restrictive alternatives to guardianship to be ["tried and exhausted"](#) before implementing guardianship. In Washington State, the [Revised Code of Washington](#) states that a guardian should only be appointed after less restrictive alternatives have been thoroughly tried. Despite growing research and state laws, studies show social workers are prioritizing guardianship for those they support, and [rarely discussing or utilizing less restrictive alternatives to guardianship](#).

Barriers to Less Restrictive Alternatives

Society generally values safety over choice and neurotypical decision making, which, helps to create a ["deep-rooted paternalistic culture,"](#) in America, which makes it difficult for many to fully embrace less restrictive alternatives, like [supported-decision making \(SDM\)](#). Studies found although school social workers valued less restrictive alternatives to guardianship, [less than half reported that it was being put to practice](#). Hesitancy to utilize SDM due to concerns around the potential for abuse and exploitation. This is in part due to past cases of guardians or conservators exploiting and/or abusing those they are making decision for, including the famous case of [Brittany Spears](#). Recent research on clients utilizing SDM found that clients had [reduced risk of abuse and exploitation under SDM](#), due to having [more people supporting them](#) and likely the increased "checks and balances." It is important that an SDM agreement be constructed in a way that [minimizes risk for exploitation and abuse](#).

Balancing Health/Safety with Self-Determination When Choosing Arrangements

Ethics of social work dictate that social workers (including school social workers) balance between acting on behalf of vulnerable people (safety) and supporting self-determination (choice). [Social workers should be more involved in helping transition-age students with disabilities find protective arrangements that promote self-determination](#) as much as possible. This tool is designed to help social workers make that balance, by assessing decision-making support needs (including client input) and matching to the most appropriate decision-making arrangement. That decision-making arrangement should ideally maximize self-determination, while meeting health and safety concerns.

Making bad decisions does not mean someone cannot make decisions!

Guide to Assessing Less Restrictive Alternatives to Guardianship

The following is provided for informational purposes only, and is not intended as legal advice

Questions to Consider When Thinking About a Chapter 11 (Adult) Guardianship

(People to include in conversation: the youth (as they are able and want to), parents (if they maintain parental rights), other family members, close friends or advocates, court appointed special advocate (CASA) or attorney for the youth, current caregiver, DCYF social worker, DDA Case Manager, Tribe (if appropriate)

- How does the youth communicate her or his needs?
- How does the youth receive and comprehend information?
- Does the youth have a basic understanding of money? Making healthcare decisions?
- Is the youth able to sign a lease and understand what that means?
- Can a Supported Decision-Making (SDM) Agreement meet youth's needs per [Chapter 11.130 RCW](#)?
- If not, why?
- Can a representative payee meet the youth's needs? If not, why?
- Can a Power of Attorney meet the youth's needs as [Chapter 11.125 RCW](#)? If not, why?
- Can another protective arrangement meet youth's needs per [Chapter 11.130 RCW](#)? If not, why?
- Does the youth want a guardian?
- What does the youth require a guardian for?
- Does the youth learn new skills that could reduce the need for a guardian?
- Is court intervention necessary to determine decision-making arrangements?

Considering Less Restrictive Alternatives (guidance from American Bar Association [PRACTICAL](#) tool)

- Start with a presumption that guardianship is not needed. Consider least restrictive means first.
 - Review information and statutes for requirements on less restrictive alternatives, such as:

Representative (Protective) Payee: The Social Security Administration appoints a person or organization to manage the person's SSI and benefits.	SSA Information Statute: WAC 388-460
Supported Decision-Making (SDM) Agreement: document that identifies the person or people they want to support them and the kinds of decisions they want support to make. More information will be provided below.	SDM Guide SDM Agreement Template Statute: RCW 11.130.700
Power of Attorney (POA): POA can be limited to one topic (ex: money or disability services), or limited to one decision (ex: buying a house), or broad covering all decisions. However, POA for health care must be separate.	POA Documents Statute: RCW 11.125
Guardianship: if needed, consider limiting recommendation of guardianship to what is absolutely necessary , such as: • Only specific property/financial decisions • Only personal/health care decisions • Only specific personal/health care decisions • Only property/finances	DCYF Policy Statute: RCW 11.130

If it is unclear what level of support a youth may need, it may be helpful to review existing documents that may contain information relevant to a youth's decision-making capacity. These might include: *Psychological Assessment, Functional Assessment, Individualized Education Plan, Speech/language Assessment, Assistive Technology Assessment, DDA Person Centered Service Plan. Also consult with agency/regional AAG, or see [additional resources](#) for more supports or consultation.*

Decision Making Support Tool

This form was designed based on information from the American Bar Association's [PRACTICAL](#) tool on decision making. The PRACTICAL tool was created with support from the Commission on Law and Aging, Commission on Disability Rights, Section on Civil Rights and Social Justice, and Section on Real Property, Trust and Estate Law, with assistance from the National Resource Center for Supported Decision-Making.

This form was designed to support clients and supporters with assessing decision making support needs.

Name of Individual: _____

Name of person completing this form: _____

Relationship to individual: _____

For each domain below, mark the level of support the individual needs when making and communicating decisions and choices.

Money Management	I can decide with no extra support	I need support to make my own decision	I need someone to make decision for me
Managing accounts, assets, & benefits			
Recognizing Exploitation			
Other:			

Notes:

Healthcare	I can decide with no extra support	I need support to make my own decision	I need someone to make decision for me
Making decisions about medical treatment			
Taking medications			
Maintaining hygiene and diet			
Avoiding high-risk behaviors			
Other:			

Notes:

Relationships	I can decide with no extra support	I need support to make my own decision	I need someone to make decision for me
Behaving appropriately with friends, family, and workers.			
Making safe decisions about sexual relationships			
Other:			
Notes:			
Community Living	I can decide with no extra support	I need support to make my own decision	I need someone to make decision for me
Living independently			
Maintaining habitable conditions			
Accessing community resources			
Other:			
Notes:			
Personal Decision Making	I can decide with no extra support	I need support to make my own decision	I need someone to make decision for me
Understanding legal documents (contracts, leases, powers of attorney)			
Communicating wants and needs			
Understanding legal consequences of behaviors.			
Other:			
Notes:			

Employment	I can decide with no extra support	I need support to make my own decision	I need someone to make decision for me
Finding, gaining, & retaining employment			
Other:			
Notes:			
Personal Safety	I can decide with no extra support	I need support to make my own decision	I need someone to make decision for me
Avoiding common dangers			
Recognizing and avoiding abuse			
Knowing what to do in an emergency.			
Other:			
Notes:			
Other Decision Making	I can decide with no extra support	I need support to make my own decision	I need someone to make decision for me
Notes:			

Example use: Review substitute decision making needs (red/most restrictive) and assess which less restrictive alternatives could meet that need. For example, if client needs substitute decision making for medical and finances and supports with other decisions (blue), start with a viable substitute decision making option, that could be a POA for Healthcare and a rep payee. Then you could draft an SDM agreement for the remaining supported decision-making (blue).

Communication assistance for clients (to capture their voice):

- Online Choice Board: <https://app.cboard.io/>
- Augmentative and Alternative Communication (AAC) Apps: "Verbal Me" and "Visuals2Go"

Supported Decision Making (SDM) Agreement Guide

The following is provided for informational purposes only, and is not intended as legal advice

What is an SDM Agreement?

- For adults with disabilities who need assistance with decisions regarding daily living.
- A written agreement between an individual and a supporter or supporters, where a **court petition is not needed**.
- The individual can act and make decisions without having the supporter assist them.
- The supporter can only take actions to obtain information that the agreement authorizes.
- The individual or the supporter can end the agreement at any time.

Supporter Responsibilities (should be tailored for client, but general responsibilities include):

1. Explaining the individual's options/choices and the good and bad consequences and responsibilities for their options.
2. Obtain information that could include medical, psychological, financial, educational, or treatment records.
3. Assist the individual in understanding information they obtain.
4. Assists in communicating information for others to understand the individual.

A Supporter CANNOT Be:

- An **employer or employee** of the adult with a disability, unless the person is an **immediate family member** of the adult with a disability.
- A **person directly providing paid support services** to the adult with a disability, unless the person is an **immediate family member** of the adult with a disability.
- An individual against whom the person with a disability **has obtained an order of protection from abuse**, or an individual who is the subject of a civil or criminal order prohibiting contact with the adult with a disability.

SDM Agreement Form Rules:

- Has to be in writing (see [SDM template](#))
- Needs either two witness signatures (witnesses can't be paid providers or a supporter, or employee or agent of a supporter, must understand individual's type of communication) OR a notary signature (check local banks, libraries, or look online)
- General form is in the statute ([11.130.745](#)) and should be individualize to the client and situation.
- Either party can terminate at any time

Additional SDM Resources:

- [Northwest Justice Project Guide to SDM](#)
- [SDM Sample Template](#)
- [Supported Decision Making in WA State | Informing Families](#)
- [Washington | National Resource Center \(supporteddecisionmaking.org\)](#)
- [Client Stories Utilizing SDM](#)
- [SDM Personal Experience Video on Vimeo](#)

Additional Resources for Support

Support Resources on Less Restrictive Alternatives & Supported Decision Making

- [Center for Transition to Adult Health Care for Youth with Disabilities](#)
- [The Arc Flyer on Decision Making Supports](#) (also contact: futureplanning@thearc.org)
- [SDM in WA | Informing Families](#)
- [Washington | National Resource Center \(supporteddecisionmaking\)](#)
- [Client Stories Utilizing SDM](#)
- [Parent & Teacher Tips Sheet on Decision Making](#)
- [PAVE: Supported Decision Making](#)
- [Office of Public Guardianship](#)

Policies

- DCYF Policy: [4340. Guardianships | Washington State Department of Children, Youth, & Families](#)
- State Policy: [Chapter 11.130 RCW: Uniform Guardianship, Conservatorship, and Other](#)
- Wash. Rev. Code [RCW 11.130.265: Basis for appointment of guardian for adult. \(wa.gov\)](#)
- Wash. Rev. Code [RCW 11.130.700: Definitions. \(wa.gov\)](#)

Research Articles

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SUPPORTED DECISION-MAKING AGREEMENT

Appointment of Supporter(s)

I, _____ (name of supported adult), make this agreement of my own free will.

I agree and designate the following supporter (**Supporter #1**):

Name: _____ (name of supporter)

Address: _____ (address of supporter)

Phone number: _____ (phone number of supporter)

Email address: _____ (email address of supporter)

is my supporter.

Supporter #1 may help me with making everyday life decisions relating to the following (check as many boxes as you want):

- Obtaining food, clothing, and shelter.
- Taking care of my health.
- Managing my financial affairs.
- Other matters: (specify).

Supporter #1 is not allowed to make decisions for me. To help me with my decisions, my supporter may:

1. Help me access, collect, or obtain information that is relevant to a decision, including medical, psychological, financial, educational, or treatment records;
2. Help me understand my options so I can make an informed decision; and
3. Help me communicate my decision to appropriate persons (circle yes or no for each choice below):

(Yes/No) A [release](#) allowing my supporter to see protected health information under the Health Insurance Portability and Accountability Act of 1996, P.L. 104-191, is attached.

(Yes/No) A release allowing my supporter to see educational records under the Family Educational Rights and Privacy Act of 1974, 20 U.S.C. Sec. 1232g, is attached.

Supporter #3 may help me with making everyday life decisions relating to the following (check as many boxes as you want):

- Obtaining food, clothing, and shelter.
- Taking care of my health.
- Managing my financial affairs. f
- Other matters: (specify).

Supporter #3 is not allowed to make decisions for me. To help me with my decisions, my supporter may:

1. Help me access, collect, or obtain information that is relevant to a decision, including medical, psychological, financial, educational, or treatment records;
2. Help me understand my options so I can make an informed decision; and
3. Help me communicate my decision to appropriate persons (circle yes or no for each choice below):

(Yes/No) A release allowing my supporter to see protected health information under the Health Insurance Portability and Accountability Act of 1996, P.L. 104-191, is attached.

(Yes/No) A release allowing my supporter to see educational records under the Family Educational Rights and Privacy Act of 1974, 20 U.S.C. Sec. 1232g, is attached.

I agree and designate the following supporter (**Supporter #2**):

Name: _____ (name of supporter)

Address: _____ (address of supporter)

Phone number: _____ (phone number of supporter)

Email address: _____ (email address of supporter)

is my supporter.

Supporter #2 may help me with making everyday life decisions relating to the following (check as many boxes as you want):

- Obtaining food, clothing, and shelter.
- Taking care of my health.
- Managing my financial affairs.
- Other matters: (specify).

Supporter #2 is not allowed to make decisions for me. To help me with my decisions, my supporter may:

1. Help me access, collect, or obtain information that is relevant to a decision, including medical, psychological, financial, educational, or treatment records;
2. Help me understand my options so I can make an informed decision; and
3. Help me communicate my decision to appropriate persons (circle yes or no for each choice below):

(Yes/No) A release allowing my supporter to see protected health information under the Health Insurance Portability and Accountability Act of 1996, P.L. 104-191, is attached.

(Yes/No) A release allowing my supporter to see educational records under the Family Educational Rights and Privacy Act of 1974, 20 U.S.C. Sec. 1232g, is attached.

I agree and designate the following supporter (**Supporter #3**):

Name: _____ (name of supporter)

Address: _____ (address of supporter)

Phone number: _____ (phone number of supporter)

Email address: _____ (email address of supporter)

is my supporter.

Effective Date of Supported Decision-Making Agreement: This supported decision-making agreement is effective immediately and will continue until _____ (insert date) or until the agreement is terminated by my supporter or me or by operation of law.

Signed this ___ (day) day of _____ (month), _____ (year)

Consent of Supporter

I, _____ (name of supporter), acknowledge my responsibilities and consent to act as a supporter under this agreement.

(Signature of supporter)

(Printed name of supporter)

Supported adult _____

(Signature of supported adult)

(Printed name of supported adult)

(Signature of witness #1)

(Printed name of witness #1)

(Signature of witness #2)

(Printed name of witness #2)

Notarization

State of Washington

County of _____

I certify that I know or have satisfactory evidence that _____ is the person who appeared before me, signed above, and acknowledged that the signing was done freely and voluntarily for the purposes mentioned in this instrument.

Date

Signature of Notary
NOTARY PUBLIC for the State of Washington.
My commission expires _____

SDM Form is outlined by: [RCW 11.130.745](#)

Conclusion and Potential for Project

Ethics of social work dictate that social workers (including school social workers) balance between acting on behalf of vulnerable people (safety) and supporting self-determination (choice). Social workers should be more involved in helping transition-age students with disabilities find protective arrangements that promote self-determination as much as possible (Smith-Hill, 2023).

Social workers play critical roles in supporting clients with decision-making arrangement and need to feel confident providing information/resources without crossing any legal boundaries.

Increasing awareness and utilization of less restrictive alternatives, could lead to snowball effect of competency and utilization of less restrictive alternatives. It is my hope that in turn, could lead to DCYF policy changes on adult guardianship, to prioritizing less restrictive alternatives, that could further enhance use not just at DCYF, but collaborating organizations.

This toolbox should help social workers make that balance of maximizing self-determination, while meeting health and safety concerns, and should in turn, help this vulnerable population with smoother transitions to adulthood, and to increase the quality of their life.

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Supportive Resource Links for Less Restrictive Alternatives

- [Center for Transition to Adult Health Care for Youth with Disabilities](#)
- [The Arc Flyer on Decision Making Supports \(also contact: \[futureplanning@thearc.org\]\(mailto:futureplanning@thearc.org\)\)](#)
- [SDM in WA | Informing Families](#)
- [Washington | National Resource Center \(supporteddecisionmaking\)](#)
- [Client Stories Utilizing SDM](#)
- [Parent & Teacher Tips Sheet on Decision Making](#)
- [PAVE: Supported Decision Making](#)
- [Office of Public Guardianship](#)
- [Alternatives to Guardianship – NAMI Southwest Washington \(namiswwa.org\)](#)
- [Northwest Justice Project Guide to SDM](#)
- [Another SDM Agreement Sample Template \(NW Justice Project\)](#)
- [Supported Decision Making in WA State | Informing Families](#)
- [Washington | National Resource Center \(supporteddecisionmaking.org\)](#)
- [Client Stories Utilizing SDM](#)
- [SDM Personal Experience Video on Vimeo](#)

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Thank you!

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