

Supported Decision-Making An Alternative to Guardianship



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Equip for Equality

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Discussion Items

- What is supported decision-making?
- Why consider supported decision-making?
- Who can use supported decision-making?
- How does an adult implement supported decision-making?



The What: Decision-Making

Examples of Decisions:

- Where will I live?
- What activities do I want to do?
- What relationships do I want to build?
- How will my daily needs be met?
- Where will I work?



The What: Decision-Making

- Understand the issue
- Gather Information
- Consider options / consequences
- Exercise choice
- Communicate / implement choice
- Evaluate results



The What: Decision-Making

- “Capacity” to make decisions:
 - The person understands his or her situation;
 - The person understands the risks;
 - With these areas of understanding, the person communicates her decision.



The What: Supported

- Supports: friends, family members, professionals, other trusted individuals
- Process: adult uses supports to effectively access decision-making process
- Maintain: self-determination



The What: Supported Decision-Making

Support to:

- Understand issue / options
- Investigate issue / options
- Weigh pros and cons
- Communicate decision



The Why: Philosophical

Adults have fundamental / constitutional
right to make choices

- Liberty / freedom
- Equality
- Dignity



The Why: Health & Wellness

People with increased self-determination have:

- Improved psychological health and better adjustments to changing care needs.
 - O'Connor & Vallerand, 1994.
- Increased health, welfare and safety.
 - Khemka, Hickson, and Reynolds, 2005.



The Why: Health & Wellness

Continued...People with increased self-determination have:

- Better quality of life, including increased community integration and employment.
 - Rifembark & Little, 2014.



The Why: Health and Wellness

In contrast:

- Denial of self-determination causes “low self-esteem, passivity, and feelings of inadequacy and incompetency.” Winick, 1995.
- Overbroad / undue guardianship can cause “significant negative impact on ... physical and mental health, longevity, ability to function, and reports of subjective well-being.” Wright, 2010.



The Why: Legal

- Guardianship is a legal status that can only be established by court order.
- Court case remains open after guardian in place.
- “Guardianship shall be utilized only as is necessary to promote the well-being of the person with a disability, to protect him from neglect, exploitation, or abuse, and to encourage development of his maximum self-reliance and independence.” 755 ILCS 5/11a-3(b).



The Why: Legal

Consequences of plenary guardianship:

- 625 ILCS 5/6-103(5), SOS shall not issue, renew, or allow retention, drivers license to a person “adjudged to be afflicted with . . . mental or physical disability or disease” who has not been restored to competency.



The Why: Legal

Continued ... consequences of plenary guardianship:

- Potential limitations on access to marriage, reproductive rights, access to money, travel, choice of association;
- Inability to legally contract for basic services.



The Who

Who can use supported decision-making?

- Anyone who needs help making decisions.
- Concept can be combined with other decision-making arrangements.
- Not limited to particular diagnosis or disability.

Look at capacity as a spectrum.



The Who

What if the Adult is without “supporters”?

- Be creative – who is involved in the person’s life?
- What is the individual’s community engagement; meaningful relationships there?
- Options for building decision-making skills?



The How

- Identifying Needs / Abilities
- Identifying Available Supports
- Formalizing Supports



The How: Identifying Needs / Abilities

- Money Management
 - managing bank accounts
 - managing assets
 - managing benefits
 - paying bills / budgeting
 - self-protection / exploitation

Source: ABA Practical Tool for Lawyers: Steps in Supporting Decision-Making,
<http://supporteddecisionmaking.org/sites/default/files/docs/events/PRACTICALGuide.pdf>



The How: Identifying Needs / Abilities

- Health / Health Care
 - medical treatment
 - taking medicine
 - hygiene / dental care
 - diet
 - maintaining healthy habits (substance use, sexual activity)

Source: ABA Practical Tool for Lawyers: Steps in Supporting Decision-Making,
<http://supporteddecisionmaking.org/sites/default/files/docs/events/PRACTICALGuide.pdf>



The How: Identifying Needs / Abilities

- Relationships
 - boundaries (family, friends, romantic, co-workers)
 - marriage / reproduction
- Community Living
 - independence
 - maintaining residence (cleanliness, repairs, security)
 - accessing community (transportation, bank, stores, 911)

Source: ABA Practical Tool for Lawyers: Steps in Supporting Decision-Making,
<http://supporteddecisionmaking.org/sites/default/files/docs/events/PRACTICALGuide.pdf>



The How: Identifying Needs / Abilities

- Personal decision-making
 - understanding legal documents / contracts
 - communicating consent
 - communicating wishes
 - identifying support(s) for decision-making
 - identifying surrogate decision-maker(s)
 - understanding legal consequences resulting from actions (civil laws, criminal laws)

Source: ABA Practical Tool for Lawyers: Steps in Supporting Decision-Making,
<http://supporteddecisionmaking.org/sites/default/files/docs/events/PRACTICALGuide.pdf>



The How: Identifying Needs / Abilities

- Employment / Education
 - finding, obtaining and keeping a job
 - enrolling in school, selecting and succeeding in classes
 - accommodations needed
- Personal safety
 - avoiding danger (community, home)
 - identifying and avoiding abuse by others
 - responding to emergencies

Source: ABA Practical Tool for Lawyers: Steps in Supporting Decision-Making,
<http://supporteddecisionmaking.org/sites/default/files/docs/events/PRACTICALGuide.pdf>



The How: Identifying Supports

- Community Supports
 - Human Services / ARDC
 - Agencies on Aging / Ombuds Programs
 - PAS Agencies
 - Centers for Independent Living
 - Developmental Disability Councils
 - Legal Services



The How: Identifying Supports

- Informal / Natural Supports
 - family members
 - friends
 - neighbors
 - co-workers
 - past providers
 - volunteers



The How: Identifying Supports

- Trained supporters
- Protective measures / accountability
- Abuse / exploitation
 - abuse is not about person with disability
 - abuse is about wrong-doer
 - abuse happens in all settings and all relationships
 - we abuse people by over-protecting them



The How: Identifying Supports

- Accommodations
 - assistive technology
- Communication Techniques
 - using plain language
 - breaking down information
 - using drawings / demonstrative materials
 - organizing field trip / practical experiences



The How: Formalizing Supports

- Informal agreement / no particular format
- Models found at:
 - www.supporteddecisionmaking.org/node/390
 - <https://www.supporteddecisions.org/>



The How: Formalizing Supports

- Model Agreements:
 - name / contact individual supported
 - describes areas where needs supports
 - incorporates other records where needed
 - supporter name / contact
 - sets forth supporter's responsibilities



The How: Formalizing Supports

- Model Agreements (cont'd):
 - sets forth limits on supporter
 - expressly states supporter is not a surrogate decision-maker
 - sets forth effective dates of agreement
 - notarized signature
 - supporter acknowledgement



The How: Formalizing Supports

- Now What?
 - Once agreement is completed, share with those who need to know
 - Doctors, other Service Providers
 - Can be used to demonstrate ability to make decisions / accommodation in place
 - Supporters
 - Others in circle of trust



The How: Formalizing Supports

- One last thing...
 - After creating supported decision-making agreement, review the individual's service plan or any other documents created with the individual's input to make sure that they are consistent with the plan for supported decision-making.



The How: Formalizing Supports

- Other less formal: Modified medical or education release
- Other formal supports beyond supported decision-making: POA, trust, joint accounts, representative payee



The How

Formalizing Supports

- Durable Power of Attorney to transact financial affairs
- Power of Attorney for Health Care
- Mental Health Advance Directives
- Joint bank accounts / Trust where needed



The How: Formalizing Supports

- Representative Payee
 - Established by the SSA if it determines that a PWD is unable to manage his/her social security benefits
 - Rep payee required to spend money first on PWD's living expenses, then other expenses.
 - Rep payee can never spend PWD's SSA benefit for his own benefit.



Guardianship (in brief)

Guardianship = Last Resort, when:

- Despite support, person clearly lacks capacity to make or communicate decisions, and
- Alternatives exhausted, and
 - critical decision, requiring legal authority, to protect from harm, or
 - guardianship necessary to stop abuse or exploitation



Guardianship (in brief)

- Even if guardianship necessary ...
 - Right to be free from overbroad guardianships
 - Limited guardianship favored over plenary
 - Limited guardian of person restricted from acting beyond the areas listed in the court order
 - Limited guardian of the estate has all decision-making other than that retained by the ward
 - Limited guardianship ≠ legal incompetence



Guardianship (in brief)

- Even if guardianship necessary must encourage Individual to:
 - Exercise retained rights
 - Participate to extent possible in decision-making
 - Develop / regain capacity to extent possible

**incorporate supported decision-making into guardianship / limited guardianship



Guardianship (in brief)

- Guardian of Person, 755 ILCS 5/11a-17(e)
 - 1st – make reasonable effort to determine ward’s wishes and make decisions in conformity;
 - 2nd – wishes unknown: make decisions conforming as closely as what the ward, if competent, would have done;
 - 3rd – best interests.
- “The guardian (of the person) **shall** assist the ward in development of maximum self-reliance and independence.” 755 ILCS 11a-17(a).



Guardianship (in brief)

- “In making residential placement decisions, the guardian shall make decisions in conformity with the preferences of the ward unless the guardian is reasonably certain that the decisions will result in substantial harm to the ward or the ward’s estate.” 5/11a-14.1 (emphasis added).
- “A guardian of the person may not admit a ward to a mental health facility except at the ward’s request who has the capacity to consent to the admission.” 5/11a-17(a).



Guardianship (in brief)

- A ward has the right to marry so long as he/she has the mental capacity to understand the nature of marriage.
Larson v. Larson, 1963, *Pape v. Byrd*, 1991.
- A guardian may petition the court for leave to consent to marriage.
- A guardian can go to court and attempt to prevent the marriage.



Guardianship (in brief)

- Guardian of the Estate:
 - Disbursements are made using the best interests standard, but: “The ward’s wishes as best they can be ascertained **shall** be carried out, whether or not tax savings are involved.” 755 ILCS 11a-18(a-5).



Closing Thoughts

Nothing is 100% “safe” – Not guardianship, not powers of attorney, not rep payee-ships, and not supported decision-making.

Nonetheless, decision-making is a skill, and the more an individual practices it, the more they are able to protect themselves.



Resources

- <http://www.supporteddecisionmaking.org/> (National Resource Center for Supported Decision-Making)
- <https://www.supporteddecisions.org/> (Center for Public Representation)
- [https://ncd.gov/publications/2018/beyond-guardianship - toward-alternatives](https://ncd.gov/publications/2018/beyond-guardianship-toward-alternatives) (National Council on Disability)
- https://americanbar.org/groups/law_aging/resources/guardianship_law_practice/ (American Bar Association)