

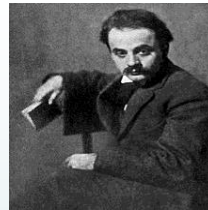
Ethical Concepts of Surrogate Decision-Making



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Our very lives depend on the ethics of strangers, and most of us are always strangers to other people—Bill Moyers

Safeguarding the rights of others is the most noble and beautiful end of a human being.—Kahlil Gibran

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A FIDUCIARY IS....

- someone who acts in place of another
- exercises the highest duty of care
- Serves in either a voluntarily or involuntary arrangement

GUARDIANSHIP IS.....

- an involuntary fiduciary arrangement imposed by a court
- a highly restrictive fiduciary arrangement
- a fiduciary arrangement of last resort

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Ethical Principles of Guardianship

- A guardian treats the person with dignity
- A guardian *involves* the person to the greatest extent possible in all decision making
- A guardian selects the option that places the fewest restrictions on the person's freedom and rights
- A guardian identifies and advocates for the person's goals, needs and preference
- A guardian maximizes the *self-reliance and independence* of the person.

-National Guardianship Association

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Guardianship: The Downsides

- ▶ overuse, misuse, overly broad, lacking in nuance
- ▶ complete civil disenfranchisement in most extreme form
- ▶ stigma, stereotypes, presence of person often unacknowledged.
- ▶ anti-therapeutic—reduces overall wellbeing by undermining whatever autonomy can be rightly exercised
- ▶ dynamic versus static impairments; not always considered.
- ▶ move toward capacity (alcoholism, TBI as person recovers) verses move away from capacity (neurodegenerative disease)
- ▶ resorting to guardianship for people with cognitive disabilities does not strike an appropriate balance but unjustly tips scales in favor of protection

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Guardianship Tensions: the Balancing Act

- ▶ There is an inherent conflict between the responsibilities of a guardian and supporting the values and wishes of the person.
- ▶ Guardians must be given education to understand and monitor for ongoing issues that arise between the difficult balancing act of preserving autonomy and ensuring safety.



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Guardianship proceeding

- Always requires a court action
- Requires two physicians or a physician and a psychologist who have examined the person within 30 days
- Filed in: family must be served
- Person is entitled to have any attorney representing them. In most cases the attorney is appointed by the court
- Two questions for the Court:
 - a.) Is the person incapacitated, and
 - b.) Who should be the guardian

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A Serious Action with Serious Consequences

- The rules governing guardianship matters are established to protect the alleged incapacitated persons from wrongly being declared incapacitated and having their rights taken away.
- In their *parens patriae* role, courts are the guardians of personal rights and they have a special responsibility to protect the rights of the alleged incapacitated. *In re M.R.*; *In re Conroy*.
- So severe is the consequence of taking away constitutionally protected individual rights that courts must not permit that to occur unless there is a showing by clear and convincing evidence that the alleged incapacitated person needs to be stripped of those rights for his or her own safety and protection, and that there is no less restrictive alternative. *In re M.R.*, 135 N.J. 155 (1994); *In re Conroy*, 98 N.J. 321 (1985); *In re Macak*, 377 N.J. Super 167 (App. Div 2005).

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Types of Guardianship/Scope of Relief

- An action for guardianship of an alleged incapacitated individual is governed by statute and court rule. *N.J.S.A. 3B:12-24 to -29; R. 4:86(1)-(8)*.
- A person is incapacitated if (s)he "is impaired by reason of mental illness or mental deficiency to the extent that [s]he lacks sufficient capacity to govern [her]self and manage [her] affairs." *N.J.S.A. 3B:1-2*.
- Where appropriate pre-need documents have been executed but cannot be implemented, a guardianship may be necessary.
- Temporary Guardian—limited to 45 days unless court specifies otherwise or unless court extends for good cause.
 - Appropriate when there is a risk of substantial harm during course of guardianship, such as a threat to safety and well-being, physical and mental health, risk of waste or loss of property.
 - Not an adjudication of incapacity.
 - Requires notice.

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Who can be appointed?

- Statute provides that letters of guardianship shall be granted in following order:
 - Spouse or domestic partner, providing that same is living with incapacitated person at the time the incapacitated arose
 - Heirs or friends of incapacitated person
 - If no spouse, heirs or friends then first consideration must be given to the Office of the Public Guardian for those aged 60 and older; and
 - Such other proper person.

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Surrogate medical decision-making

- An adult has the right to make decisions about his/her own healthcare
- In the absence of ability to give informed consent, surrogate exercises that right on behalf of the adult
- Important New Jersey surrogate decision making cases: *In re Conroy* 98 N.J. 321, 486 A.2d 1209 (1985), *In re Jobes*, 108 N.J. 394 (1987), *In re Peter*, 108 N.J. 365 (1987)
- **Substituted Judgment**: Decision-maker must take into account the patient's general value system and personal beliefs as well as previously made statements about medical treatments. The decision maker is to "stand in the patient's shoes" and make the decision the patient would make in the same situation, if able



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2021: Guardianship Goes Multi-Media



And gains national attention...

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2021: "I Care A Lot" Film
(A "Professional" Guardian Horror Story)



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All of this suggests the need for us to consider alternatives to guardianship.....



.....both Traditional and Newer

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Traditional Alternatives

Durable Financial Power of Attorney

- Grants legal rights to another to make financial decisions
- Remains in effect if Principal becomes Incapacitated
- Can be Revoked
- Must have Capacity to Execute
- Disadvantage: Can be used by bad actors as a "license to steal"

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Traditional Alternatives

Representative Payees

- For those unable to Manage Social Security or VA Benefits
- Benefit funds must be used for Basic Needs
- Apply to Government Agency and Provide Yearly Accounting

Trusts

- A Legal Plan of placing funds in the control of a "trustee" for beneficiary
- The Individual Funding the Trust (Grantor) may direct Trustee how funds may be spent
- Trustee can be institutional (e.g. a Bank)

Joint Bank Accounts

- To Address Difficulties with Money Management

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Traditional Alternatives

Advance Directive for Healthcare

- Proxy Directive: Names Surrogate Decision Maker
- Instruction Directive: Tells physicians whether and when to withhold or withdraw treatment
- Can be revoked
- Must have capacity to execute
- Disadvantage: Proxy may become unable to service.
- Cover specific categories of decisions, may not cover others

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Other Court-Ordered Protective Arrangements for Adults

- Conservatorship is a voluntary legal arrangement designed to provide surrogate decision-making for an individual who is unable to manage his or her property. A conservatorship cannot be imposed over the objection of the individual. A conservatorship is also supervised by the Court.
- Protective arrangements without appointment of a guardian may be ordered by court.

Reasons for protective arrangements may include urgent need for care or dissipation of asset. N.J.S.A. 3B:12-2 outlines matters within protective arrangement.

Some possible transactions encompassed in a protective arrangement may include sale of property, entry into contract, or establishment of trust

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- Limited Guardian- may be appointed by the Court upon finding that individual lacks capacity to do **some** but not *all* tasks necessary to care for himself. N.J.S.A. 3B:12-24.16.

In a limited guardianship, subject areas where individual **does** have capacity to manage will be specifically noted in order (medical, financial, residential).

- Special Medical Guardian may be appointed where life-threatening health situation exists and patient incapable of giving **informed consent** to medical treatment.

Usually commenced by hospital when consent to treatment is needed

Under special circumstances, the Court may accept an oral complaint and telephone testimony.

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- Ageism can influence whether a guardianship is imposed.
- For example, many individuals exhibit dangerous behaviors such as excess drinking, driving under the influence, drug experimentation, walking alone at night, speeding, unsafe sexual experiences, and the like.
- Such behaviors in the young are called youthful indiscretions and may be the stuff of nostalgia in later life.
- Such behaviors in later life often result in a petition of guardianship for an elderly person.
- **Consider whether other supports might be put into place before you file.**

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Office of the Public Guardian

- Administratively located within Department of Human Services but independent of any supervision or control by department ("in but not of")
- Majority of protected individuals come from hospitals, nursing homes, adult protective services.
- Available 24/7
- Staff includes care managers, nurses, investigators, attorneys, accountants and administrative staff.
- OPG has an interdisciplinary approach to managing each client's guardianship



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Medical Decision-Making Issues at OPG

- Daily team meetings to make medical decisions.
- Guardian of the person must act consistently with the terms of previously executed powers of attorney for health care or advance directives pursuant to *N.J.S.A. 26:H-53* unless revoked or altered by the court. *N.J.S.A. 3B:12-56* and *57*.
- In most cases, Court revokes advance directives in OPG Order. OPG strongly considers directives within such writings and weights circumstances accordingly.

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The Office of the Public Guardian Elder Financial Abuse Initiative

- Increased prevalence of guardianships commenced due to financial exploitation
- Underserved population by law enforcement due to difficulty of proofs/dementia
- DOJ-VOCA Grant for Underserved Victims
- Convicted of felonies; recovered funds through restitution and civil settlements.

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NEWER ALTERNATIVES

GUARDIANSHIP REFORM: BUILDING A MORE ETHICAL MODEL

The Fourth National Guardianship Summit: May 2021

Stakeholders gathered to discuss the current state of the nation's adult guardianship system and develop recommendations for reform and improvement around the theme of maximizing autonomy.

Workgroups convened to make recommendations in the following areas:

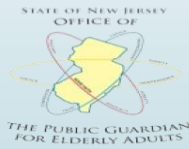
- Protective Arrangements and Pipelines.
- Monitoring and Abuse.
- Fiduciary Responsibilities and Tensions.
- Court Improvement Programs.
- **Supported Decision Making.**



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Office of the Public Guardian

"Maximizing capacity, preserving dignity"



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Supported Decision Making

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What if . . .

- Concerns about your health or safety were determined to be more important than your personal history, beliefs, heritage and preferences?
- You were not included in discussions about where you live, what medical treatment you receive, and how your money is spent?

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When denied self-determination, people can:

- “[F]eel helpless, hopeless, and self-critical” (Deci, 1975, p. 208).
- Experience “low self-esteem, passivity, and feelings of inadequacy and incompetency,” decreasing their ability to function (Winick 1995, p. 21).



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People with disabilities with greater self determination are

- More independent
- More integrated into their communities
- Healthier
- Better able to recognize and resist abuse



Powers et al., 2012; Shogren, Wehmeyer, Palmer, Rifenbark, & Little 2014; Wehmeyer & Schwartz, 1997 & 1998; Wehmeyer & Palmer, 2003; Khemka, Hickson & Reynolds 2005; Wehmeyer, Kelchner, & Reynolds 1996

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AUTONOMY

- Determination of one's own fate or course of action without compulsion
- Autonomy is the basis for informed consent, truth-telling, and confidentiality.

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Ethical Principles

Medical Ethics

- **Autonomy**
- Beneficence
- Non-Maleficence
- Justice / Equity

NASW

- **Self-Determination**
- Confidentiality
- Informed Consent

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NASW Code of Ethics



1.02 Self Determination

Social workers respect and promote the right of clients to self determination and assist clients in their efforts to identify and clarify their goals. Social workers may limit clients' right to self determination when, in the social workers' professional judgment, clients' actions or potential actions pose a serious, foreseeable, and imminent risk to themselves or others.

- NASW Code of Ethics

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N.J. Guardianship Statutes

- **The guardian shall encourage the ward to participate with the guardian in the decision-making process to the maximum extent of the ward's ability**, in order to encourage the ward to act on his own behalf whenever able to do so; and to develop or regain higher capacity to make decisions in those areas in which he is in need of guardianship services, to the maximum extent possible.

■ N.J.S.A. 3B:12-57(g)

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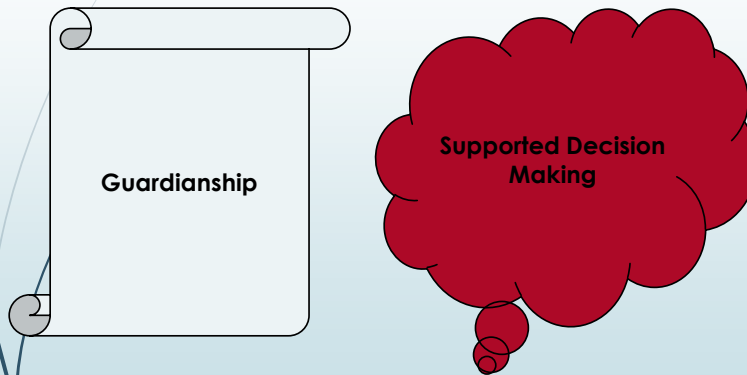
Nursing Facility Regulations

- **The NF shall notify each resident of his or her right under State law to make decisions concerning his or her medical care and his or her right to formulate an advance directive** in compliance with the New Jersey Advance Directives for Health Care Act, 26:2H-53 et seq., and the advance directive provisions of the Omnibus Reconciliation Act of 1990, effective December 1, 1991 and Department of Health and Senior Services licensing requirements at 8:39-9.5.

■ N.J.A.C. 8:85-1.17(c)

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Decision Making: A Paradigm Shift



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Surrogate Decision Making v. Supported Decision Making

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Supported Decision Making Compared to Guardianship

The key distinction:

Substitute Decision Making keeps the focus on the surrogate (guardian): the **surrogate makes the decision** for the PWD, even if he/she consults extensively with the person (as he/she should)

Supported Decision Making keeps the **focus on the PWD** as the decision maker, even if the PWD needs extensive support in communicating that decision

-Dinerstein, 2014

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What do people with disabilities want in their lives?

What do people with disabilities want?	Overall n = 827	Person w/ DD n = 36	Family Member n = 464	Professional n = 327
Dignity & Respect	48%	56% ←	38%	61%
Safety & Security	47%	31%	52% ←	41%
Consistency & Stability	44%	22%	48% ←	42%
Competent Support	44%	28%	51% ←	37%
Choice & Control	42%	28%	34%	54%
Happiness	37%	53% ←	38%	35%
Meaningful Activities	36%	19%	42% ←	28%
Housing	35%	31%	43% ←	25%
Relationships	30%	25%	27%	36%
Be Valued	28%	44% ←	23%	35%
Employment	27%	39% ←	30%	21%
Community Inclusion	23%	19%	21%	27%
Independence	22%	47% ←	18%	25%
Opportunities to Grow	17%	22%	18%	14%
Lives like people without disabilities	15%	31%	13%	16%

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Americans with Disabilities Act

- Titles of the ADA
 - I – Employment
 - II – Public Entities
 - III – Public Accommodations
 - IV – Telecommunications
- Modifications in policies and procedures
- Public accommodations must make reasonable modifications in policies, practices, and procedures that deny equal access to individuals with disabilities.

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The United Nations Convention on Rights of Persons with Disabilities (CRPD)

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CRPD Article 12

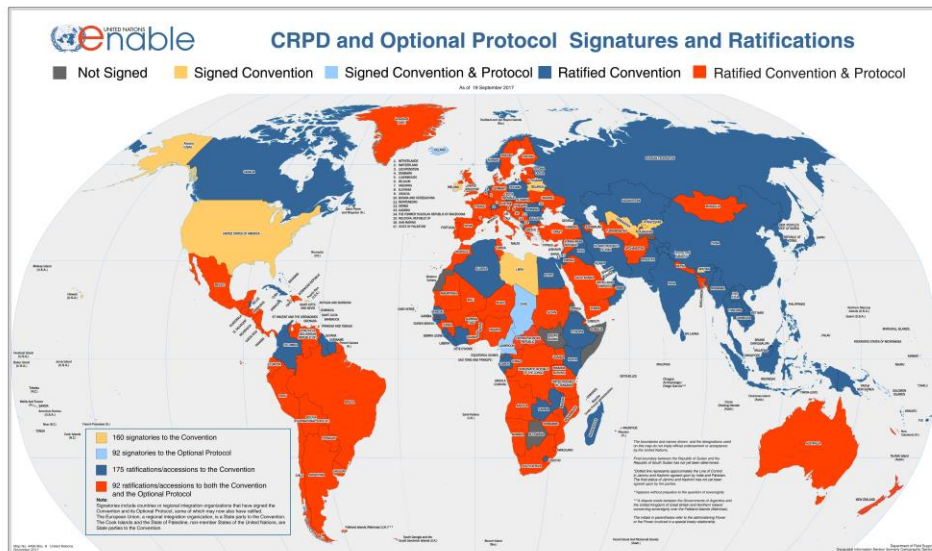
People with disabilities:

- “have the right to recognition everywhere as persons before the law.”
- “enjoy legal capacity on an equal basis with others in all aspects of life.”

State parties shall:

- **“take appropriate measures to provide access by persons with disabilities to the support they may require in exercising their legal capacity.”**
- “ensure that all measures that relate to the exercise of legal capacity provide for appropriate and effective safeguards that prevent abuse in accordance with international human rights law.”

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Justice for Jenny

APRIL 2008- Jenny Hatch begins working at Village Thrift.

LATE 2011 TO MARCH 2012- Jenny Hatch is living with a family friend, according to court records.

MARCH 9, 2012- Jenny Hatch gets into a bicycle accident, injuring her back. Police say she veered into the side of a car that honked as it passed her.

MARCH 19, 2012- Jenny Hatch leaves the hospital and moves in with Kelly Morris and Jim Talbert, who own Village Thrift, where Jenny works.

MAY 9, 2012- Jenny Hatch leaves the couple's home and moves into a group home. The couple said the arrangement was supposed to be temporary and was necessary for her to qualify for a Medicaid waiver.

JULY 1, 2012- Jenny Hatch has received a Medicaid waiver that will provide a host of in-home and community-based services.

AUG. 6, 2012- Jenny Hatch returns to live with Kelly Morris and Jim Talbert.

AUG. 8, 2012- Jenny Hatch's mother, Julia Ross, and stepfather, Richard Ross, file for guardianship.

AUG. 27, 2012- Newport News Circuit Court Judge David F. Pugh places Jenny Hatch under temporary guardianship and she returns to live in a group



<https://www.youtube.com/watch?v=iKpIR1MpCkE>

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What Is Supported Decision Making?

Supports and services that help an adult with a disability make his or her own decisions, by using friends, family members, professionals, and other people he or she trusts to:

- Help understand the issues and choices;
- Ask questions;
- Receive explanations in language he or she understands; and
- Communicate his or her own decisions to others.

(See, e.g., Blanck & Martinis 2015; Dinerstein 2012; Salzman 2011)

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One Size Does Not Fit All

- Supported Decision-Making “solutions also are different for each person.
- Some people need one-on-one support and discussion about the issue at hand. For others, a team approach works best.
- Some people may benefit from situations being explained pictorially. With supported decision-making the possibilities are endless.”

Administration for Community Living, “Preserving the Right to Self-determination: Supported Decision-Making”



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Supported Decision Making Can Be Used

- To help the person understand all components of the plan
- To help the person prioritize what is important to him/her
- To help the person build a network of supporters for the plan and beyond
- To help the person communicate and implement his or her choices

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Supported Decision Making Network

A Supported Decision-Making Team can include:

- The Person
- The Person's chosen Friends, Family, Professionals
- Case Manager
- Providers
- Advocates
- Anyone Else who Can Contribute

A Supported Decision-Making Team can be different depending on the decision to be made.

If decision-making capacity lessens (for example, as dementia progresses), a history of practicing supported decision making will prepare team members

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Supported Decision Making – An Example

- Identify problem that requires a decision
- What kinds of support does the individuals need to make decisions?
- Assure individual that there is more than one way to deal with the problem
- Determine individual's preferred approach to receiving information
- List options (including taking no action)
- Discuss pros and cons of options
- Explore individual's expectations
- Explore individual's concerns (fears)

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Supported Decision Making - An Example

- Ensure individual has understood the information
- Provide explicit opportunities to ask questions
- Determine individual's preferred level of involvement in decision making
- Indicate need to make a decision
- Indicate need to review the decision

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When Do I Want Support?

When Do I Want Support?






Check the boxes to say if you need support in each area.

You do not have to check a box for every category.

When you check the  "I can do this with support" box, you should think about who you might want to support you and what kind of support you need.




You can use the information in this form to help you fill out a Supported Decision-Making Agreement.

	I can do this <u>alone</u> . 	I can do this <u>with support</u> . 	I need <u>someone else</u> to do this for me. 
COMMUNICATION			
Telling people what I want and don't want			
Telling people how I make choices			
Making sure people understand what I am saying			
PERSONAL CARE			
Choosing what I wear			
Getting dressed			
Choosing what to eat, and when to eat			

<https://www.aclu.org/other/when-do-i-want-support>




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When Do I Want Support?

	I can do this <u>alone</u> . 	I can do this <u>with support</u> . 	I need someone <u>else</u> to do this for me. 
Taking care of my personal hygiene (for example, showering, bathing, brushing teeth)			
Remembering to take medicine			
STAYING SAFE			
Making safe choices around the house (for example, turning off the stove, having fire alarms)			
Understanding and getting help if I am being treated badly (abuse or neglect)			
Making choices about alcohol and drugs			
HOME AND FRIENDS			
Choosing where I live			
Choosing who I live with			
Choosing what to do and who to see in my free time			
Keeping my room or home clean			
Finding support services and hiring and firing support staff			
HEALTH CHOICES			
Choosing when to go to the doctor or the dentist			




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When Do I Want Support?

	I can do this <u>alone</u> . 	I can do this <u>with support</u> . 	I need someone <u>else</u> to do this for me. 
Making medical choices in everyday situations (for example, check-up, medicine from the drug store)			
Making medical choices in serious situations (for example, surgery, big injury)			
Making medical choices in an emergency			
PARTNERS			
Choosing if I want to date, and who I want to date			
Making choices about sex			
Making choices about marriage			
Making choices about birth control and pregnancy			
TRAVEL			
Traveling to places I go often (for example, getting to work, stores, friends' homes)			
Traveling to places I do not go often (for example, doctors' appointments, special events)			
JOBS			
Choosing if I want to work			
Understanding my work choices			

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When Do I Want Support?

	I can do this <u>alone</u> . 	I can do this <u>with support</u> . 	I need someone <u>else</u> to do this for me. 
Choosing classes or training I need to get a job I want, and taking these classes			
Applying for a job			
Going to my job every work day			
MONEY			
Paying the rent and bills on time			
Keeping a budget so I know how much money I can spend			
Making big decisions about money (for example, opening a bank account, signing a lease)			
Making sure no one is taking my money or using it for themselves			
BEING A CITIZEN			
Signing contracts and formal agreements			
Choosing who to vote for and voting			
OTHER (write any other choices or activities here)			

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Brainstorming Guide:How Are We Already Using Supported Decision-Making?

Supported Decision-Making can sound like a new, foreign idea. But most families, people with disabilities, and advocates are already using supported decision-making, even if they don't call it that. In fact, most people *without* disabilities are also already using supported decision-making!

Supported decision-making means helping a person understand, make, and communicate her own decisions. This will look different for everyone.

This tool can help people brainstorm ways that they are already using supported decision-making, and think about new ways supported decision-making could help the person with a disability learn to make her own safe, informed choices.

How to use this tool:

- Go through each area of the individual's life. Brainstorm whether you work together to make choices in this area. You might not yet be using supported decision-making in all of these fields. If you think of supports you could start using, write these down too.
 - *If you are considering conservatorship:* supported decision-making can sometimes be formalized into arrangements that prevent the need for conservatorship. For example, the person with a disability could sign a form to let you access her medical records so you can make health decisions together.
 - *If you are planning for the future:* this tool can help you think about ways to learn and practice decision-making. Learning to make good choices is a skill, and people can learn to make better, safer, and more informed choices with practice and support.
 - *If a lawyer, doctor, school official, banker, or anyone else is worried that the person with a disability cannot make her own decisions:* this tool can help you explain to the person the ways in which the decisions of a person with a disability are informed and safe.

<http://supporteddecisionmaking.org/node/388>

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Brainstorming Guide to Supported Decision-Making

How does the person with a disability manage his money?

- ▶ If no one ever talks about money with the person with a disability and they do whatever they want, that's not supported decision-making.
- ▶ If someone takes all of the person's money and gives him no choices about how it's spent, that's not supported decision-making either.
- ▶ Anything else - opening a joint bank account, making a budget together, having an SSrep payee and then discussing how to spend money - is supported decision-making.

How we work together to help the person with a disability member manage his/her money:

Additional supports that we might want to start using (examples include: appointing a representative payee, opening a joint bank account, making and implementing a budget together, taking a money management course):

How does the person with a disability make healthcare decisions?

- If he makes his own decisions without talking to anyone else, that's not supported decision making.
- If someone else makes all of the person's medical choices for him without discussing his preferences and opinions, that's not supported decision-making, either.
- Anything else - attending medical appointments together, explaining healthcare choices in plain language, sharing access to medical records - is supported decision-making.

How we work together to help the person with a disability make healthcare choices:

Additional supports that we might want to start using (examples include executing a HPAA authorization to share medical records, attending medical appointments with a supporter, providing complicated health information in simplified plain language):

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Brainstorming Guide to Supported Decision-Making

How does the person with a disability decide where she lives and who she lives with?

- If she makes her own choices without consulting any friends, family, or other resources, that's not supported decision-making.
- If someone else makes all living choices for the person with a disability without talking to her or considering what she prefers, that's not supported decision-making.
- Anything else - visiting possible homes together, making lists of pros and cons, setting up "trial runs" visiting different homes, meeting possible roommates, discussing support staff needs - supported decision-making.

How we work together to help the person with a disability make choices about where he/she lives:

Additional supports that we might want to start using (examples include working with Regional Center staff to find housing options, discussing priorities in housing):

How does the person with a disability decide what to do during the days?

- If she does whatever she feels like and no one ever discusses her work, activities, or social life with her, that's not supported decision-making.
- If someone else decides what she should do and who she should see and forces her to do it regardless of what she wants, that's not supported decision-making.
- Anything else - helping the person find a job based on her interests, responding to her preferences about what she does every day, teaching her to take transit to get where she wants to be, talking about safety, consent, and choice in relationships, helping her think about different options and decide which is the best fit for her - is supported decision-making.

How we work together to help the person with a disability decide how to spend his/her time:

Additional supports that we might want to start using (examples include help finding and applying for jobs, help learning to take public transportation, setting up "trial runs" or internships in workplaces):

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