



Alternatives to Guardianship: Empowering Individuals Through Supported Decision Making

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ADVANCING JUSTICE. ADVOCATING INCLUSION.



Disability Rights New Jersey

We are NJ's designated protection and advocacy agency:

- PROTECTION - Each state designates an agency to receive federal funds to investigate and monitor facilities where individuals with disabilities are located to ensure that they were not the subject of abuse and neglect.
- ADVOCACY - To advocate for the civil, legal and human rights for individuals with disabilities
 - Represent clients with disabilities in legal matters
 - Provide information, referral, and technical assistance
 - Engage in outreach, training, education of self-advocates

Our mission is to preserve and advance the human, civil, and legal rights of persons with disabilities.



Learning Objectives

- ❖ Understand the decision-making spectrum
- ❖ Understand what guardianship is and why it should be considered a last resort
- ❖ Discuss alternatives to guardianship, included supported decision-making
- ❖ Explore your role in empowering people with disabilities, promoting self-determination, and preventing unnecessary guardianship



Self-Determination

- The ability to determine your destiny
- Identifying goals and determining how to reach those goals
- This does not mean the individual must make decisions without the input from others (e.g., parents, friends)
- These skills take time to develop for everyone

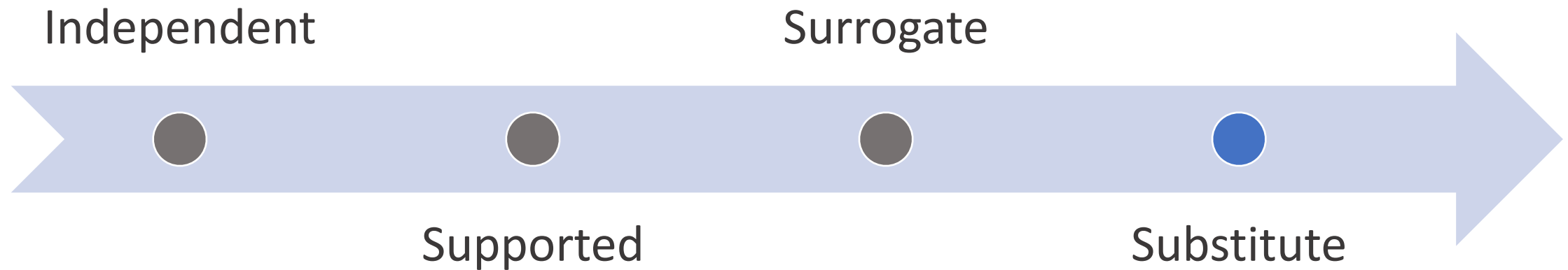


What is Capacity?

- General Test: Does the person have the capacity to make responsible decisions, not whether the person's decisions are *in fact* responsible
- Adults **are presumed legally competent unless adjudicated “incapacitated”** by a court
- No single definition
- Just because someone is older and/or has a disability, does not mean they lack capacity



Continuum of decision-making





Guardianships: True or False?

- Every person with a cognitive impairment needs a guardian.
- In order to get medical information about a family member with a disability, family members need to have guardianship.
- A guardianship lasts only as long as the guardian's lifespan.
- A guardianship is a deprivation of a person's legal rights.

False

False

False

True



Guardianship

- **Guardianship**- a legal structure allowing *a court-appointed individual* to make legal decisions for the person subject to guardianship (“ward” or “person subject to guardianship”)
- A person seeking guardianship over another person must file a complaint with supporting documentation, alleging the other person is incapacitated.
- The person challenging the other person’s capacity has the burden of proving specific incapacity by clear and convincing evidence



Types of Guardianship: Subject Areas

- If the court decides the person is “incapacitated,” the court will appoint a guardian
 - Guardianship of the person: guardian responsible for personal affairs
 - Guardianship of estate: guardian responsible for financial affairs
 - Guardianship of person and estate: guardian is responsible for both

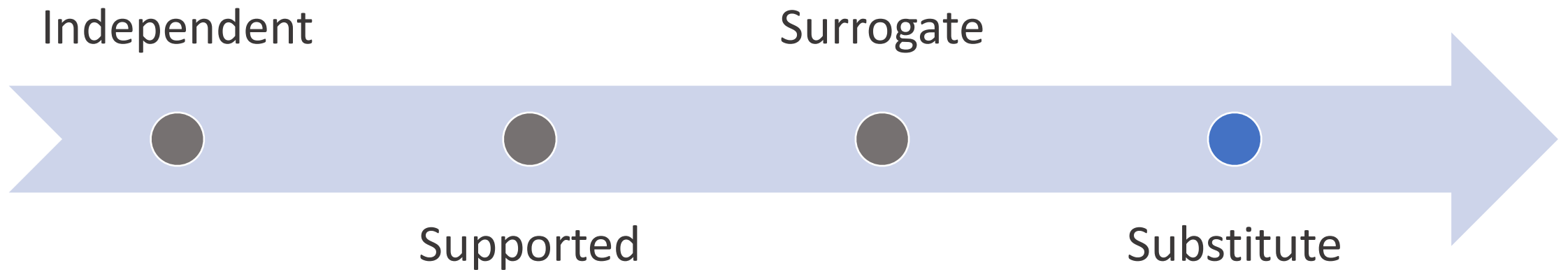


Guardianship: Key Definitions and Scope

- N.J.S.A. 3B:1-2 “Incapacitated Individual” defined
 - An individual who is impaired by reason of mental illness or intellectual disability to the extent that the individual lacks sufficient capacity to govern himself and manage his affairs
- N.J.S.A. 3B:12-24.1 General and Limited Guardianships:
 - General: shall exercise all rights and powers of the incapacitated person
 - Limited: if an individual lacks capacity in some, but not all tasks necessary to take care of himself, court can appoint a limited guardian and shall make specific findings regarding the individual's capacity including which areas the person retains sufficient capacity to manage



Continuum of decision-making



Guardianship: Person Seeking Guardianship Over Another Person



NJ Court Rule 4:86-2: supporting documentation includes affidavits or certifications from 2 physicians; or 1 physician and 1 licensed practicing psychologist

- Stating, among other things, their opinion of the extent to which the “alleged incapacitated person” is unfit to govern themselves and to manage their affairs, and, if applicable, the extent to which the “alleged in capacitated person” retains sufficient capacity to retain the right to manage specific areas.



Guardianship: Person Seeking Guardianship Over Another Person

NJ Court Rule 4:86-10: when a person is seeking guardianship over a person is **eligible for and/or receiving services from DDD**, the supporting documentation is different. It must include only 1 affidavit or certification from a psychologist or physician, and 1 of the following:

- An affidavit or certification from a CEO, medical director, or other officer having admin control over a DDD program where the individual is receiving functional or other services, or
- An affidavit or certification from a designee of DDD having person knowledge of the functional capacity of the individual, or
- An affidavit or certification from a practicing physician or psychologist; or
- A copy of the individualized education Program including medical or other reports prepared no more than 2 years before filing the complaint; or
- An affidavit or certification from a licensed care professional having personal knowledge of the functional capacity of the individual



Guardianship: Rights of Person Subject to Guardianship

- NJ Court Rule 4:86-7(a)
 - Right to be treated with dignity and respect
 - Right to privacy
 - Right to equal treatment under the law
 - Right to have personal info kept confidential
 - Right to communicate privately with an attorney or other advocate
 - Right to petition the court to modify or terminate the guardianship, including the right to meet privately with an attorney or other advocate to assist with this legal procedure, as well the right to petition for access to funds to cover legal fees and costs; and
 - Right to request the court to review the guardian's actions, request removal and replacement of guardian, and /or request that the court restore rights



Guardianship: rights of person subject to guardianship

- Case law: *Matter of M.R.*, 135 N.J. 155 (1994)
 - General incompetence does not mean incompetent for all purposes; the person can still make choices about specific matters
 - Guardianship does not remove a person's ability to choose where they live



Guardianship: Powers and Duties of Guardian

- N.J.S.A. 3B:12-57 (g) (excerpt)
 - Guardian shall give “due regard” to the preferences of the person subject to guardianship, if known or otherwise ascertainable upon “reasonable inquiry”
 - Guardian shall encourage the person subject to guardianship to participate with the guardian in the decision-making process to the maximum extent of the person’s ability in order to
 - encourage the person to act on their own behalf whenever able to do so, and to
 - develop or regain higher capacity to make decisions in those areas in which the person is in need of guardianship services, to the maximum extent possible



Guardianship: Termination

- NJ Court rule 4:86-7(b)
 - The person subject to guardianship, or an interested person on their behalf, can start a new court action (filing a complaint) to seek return to full or partial capacity. This complaint must also be accompanied by 1 affidavits (physician or psych) explaining that the person is no longer incapacitated or has return to partial capacity.
 - There is no separate rule for people eligible for or receiving DDD services to terminate
- NJ Court Rule 4:86-7(c)
 - The person subject to guardianship, or an interested person on their behalf, may seek review of a guardian's conduct and/or review of a guardianship by filing a motion setting forth the facts



Guardianship: Termination

- N.J.S.A. 3B:12-64 The authority and responsibility of a guardian will terminate upon:
 - Death, resignation, or removal of the guardian
 - Death of person subject to guardianship
 - Entry of judgment adjudicating the restoration of competency or termination of guardianship for other reasons



What guardianship is not

- Absolute control/removal of all rights
- All-seeing and all-knowing
- a Magic Wand
- Yours to control
- Easy to undo



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Less Restrictive Alternatives to Guardianship



- Supported Decision-Making, including formalized supported decision-making agreements
- Advanced Directive/Living Will
- Healthcare Proxy
- Psychiatric Advanced Directive/PAD
- Medical Orders: DNR, DNH, POLST
- Powers of Attorney
- Representative Payee (SSA benefits)
- Joint ownership



Context-Specific Tools To Support Decision-Making without Guardianship

- Designated representatives are a useful tool for accessing services such as Medicaid or Vocational Rehab.
- Releases of information.
- Transition Age Supports
- Job coaching can be available through DVRS, or through Pre-employment transition services, which also include job exploration and assistance with applications.



Supported Decision Making Agreements

- Family, friends, natural supports
- Social services agency or caseworker
- Physician or social worker

- Some states have laws about supported decision making
 - New Jersey does not
- Still, people can use the model forms to enter into a supported decision-making agreement
- The agreement can be used in court as a less restrictive alternative to guardianship



Formal Decision-Making Arrangement

- The Decider
- The Supporter
- The Process
- The Communicator

See some examples at:
supporteddecisionmaking.org

Supported Decision Making



ADDA Quality Trust Sample Supported Decision-Making Agreement

Supported Decision-Making Agreement

This agreement must be used on oral or written communication to all parties to the agreement in the presence of a witness. The form of communication will be appropriate to the needs and preferences of the person whose disability.

My name is: _____

Today's date is: _____

I want to have people I trust help me make decisions. The people who will help me are called **supporters**. I can say what and help my supporters will help me. If I want supporters to help me make choices about money, I will sign a different agreement, called "Supported Decision-Making Agreement for Finance."

Supporters

My supporters are _____

Supporter #1

Name: _____

Address: _____

Phone Number: _____

Email address: _____

I want this person to help me with:

(check all that apply below or for write)

☐ Making choices about food, clothing, and where I live

☐ Making choices about my health

☐ Making choices about how I spend my time

☐ Making choices about where I want

Names specific people to act as "supporters" in specific areas

ADDA Quality Trust Sample Supported Decision-Making Agreement

My supporters are not allowed to make choices for me. To help me with my choices, my supporters may:

- help me find out more about my choices;
- help me understand my choices so I can make a good decision for me;
- help me tell other people about my decision.

I am including the following forms to this agreement:

(check yes or no for each choice below)

Yes / No A form that lets my supporters access my medical records (HIPAA Authorization)

Yes / No A form that lets my supporters use my school information (authorization to disclose educational information)

this supported decision-making agreement starts right now and will continue until the agreement is stopped by me or my supporters.

Signature of adult with a disability

I am signing this supported decision-making agreement because I want people to help me make choices. I know that I do not have to sign this agreement. I know that I can change this agreement at any time.

My signature: _____

My printed name: _____

My address: _____

My phone number: _____

My email address: _____

Explicitly states the supporter cannot make decisions for the person, but will help the person understand and communicate decisions

Signature of person naming the supporters

ADDA Quality Trust Sample Supported Decision-Making Agreement

CONSENT OF SUPPORTERS

I, _____, consent to act as _____'s supporter under this agreement. I understand that my job as a supporter is to honor and express his/her wishes. My support might include giving this person information in a way he/she can understand; discussing pros and cons of decisions; and helping this person communicate his/her choice. I know that I may not make decisions for this person. I agree to support this person's decisions to the best of my ability, honestly, and in good faith.

Signature of supporter: _____

Date: _____

I, _____, consent to act as _____'s supporter under this agreement. I understand that my job as a supporter is to honor and express his/her wishes. My support might include giving this person information in a way he/she can understand; discussing pros and cons of decisions; and helping this person communicate his/her choice. I know that I may not make decisions for this person. I agree to support this person's decisions to the best of my ability, honestly, and in good faith.

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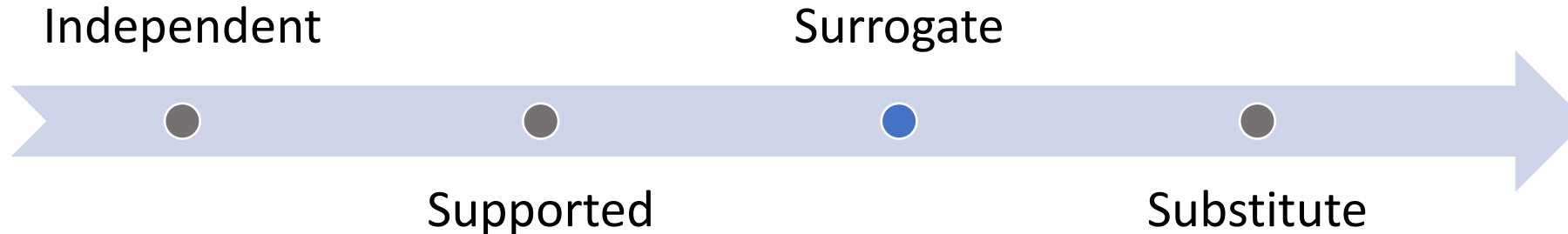
Date: _____

Consent of the people acting as supporters



Surrogate Decision Making

- Advance Directives
 - Proxy Directives
 - Instruction Directives
 - Practitioner Orders of Life Sustaining Treatment (POLST)
- Representative Payee
- Power of Attorney





Advance Directives: Proxy Directives and Instruction Directives

- **Proxy directive:** also known as Durable Power of Attorney for Healthcare or Healthcare Proxy
- **Instruction directive:** also known as a Living Will
- Becomes effective upon incapacity to make a particular healthcare decision (a determination made by physician- N.J.S.A. § 26:2H-60)
- Sometimes combined in one document
- Only one person may serve as a healthcare proxy, but can appoint alternates in the event health care proxy resigns, is incapacitated themselves, or dies



Representative Payee

- A person appointed by the Social Security Administration office to receive federal income benefits on someone else's behalf, when the person is unable to manage funds personally
- Decision is made by agency upon review of court determinations, medical evidence, and other evidence
- Legal guardian, spouse, other relative, custodial friend, institution, other
- Individuals are susceptible to fraud, misuse of funds, conflict of interest



Powers of Attorney

- A written authorization for one individual (**agent** or **attorney-in-fact**) to act on behalf of another individual (**principal**) for the purposes set forth in the document
- An attorney-in-fact has a fiduciary duty to the principal, and to the guardian of the property of the principal if the principal has been adjudicated as incapacitated person, to act within the powers delegated by the power of attorney and solely for the benefit of the principal. N.J.S.A. 46:2B-8.13(a)



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How can you help people with disabilities exhibit self determination?

- Your loved one should be leading their own meetings and be at the center of the discussions to the extent of their abilities. Direct questions from others that your family member can answer to your family member.
- Do your best to let your loved one decide. Indecision does not mean incapacity.



How can you help people with disabilities avoid unnecessary guardianship?

- If your loved one is able to express preferences and make some decisions for themselves, explore the alternatives to guardianship we discussed.
- Know your loved one's rights – push back on providers who tell your family member that you need to have guardianship to be involved in their case or care.



We're Here to Help:



ADVANCING JUSTICE. ADVOCATING INCLUSION.

New Jersey's designated Protection and Advocacy agency under federal law.



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