

PROTECTING AND EMPOWERING:

Supported Decision Making, Guardianship and Advance Directives
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Top reasons parents-caregivers give for needing guardianship:

“My child can’t do anything for himself, he needs me to do everything for him”

My doctor wants me to get guardianship so that she can legally continue to talk to me about decisions about my child’s care”

“If my child gets into an accident and ends up in the hospital without me, I don’t want him to become a ward of the state”

“I’m afraid that a (relative/friend) will take all his social security income if he can sign documents for himself”



Parent-Caregiver's Goal:

What is the right balance between the need to protect your loved one and the desire to empower him/her to make decisions that are in his/her best interest, to the best of their ability ?

Protect

- Protect individual's health and finances making decisions on his/her behalf
- Have more control over individual's whereabouts
- Shield individual from dishonest people/people who do not have individual's best interest at heart.



Empower

- Effective decision-making is a skill that can be learned, but only if an individual has the opportunity to make decisions
- Respect their rights to learn from their own mistakes in making decisions

Focus should be on finding the right balance



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Let's Address the Concerns..

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The Arc* Positioning Statement

“People with intellectual and/or developmental disabilities (I/DD) have the same right to, and responsibilities that accompany, self-determination as everyone else. They must have opportunities, respectful support, and the authority to exert control in their lives, to self-direct their services to the extent they choose, and to advocate on their own behalf.”

Including:

- The right to take risks
- The right to choose their own allies
- The right to lead in decision-making about all aspects of their lives

*The Arc is the largest national community-based organization advocating for and with people with intellectual and developmental disabilities (I/DD) and serving them and their families

Supported Decision Making (SDM) is rooted in this principle



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What is SDM?

A *process* by which a person with an intellectual or developmental disability (I/DD) can be supported in making his or her own decisions.

- SDM draws on our common experience of consulting or seeking assistance from others when we make decisions or choices in our own lives.
 - Individual with IDD is called the Decision Maker or DM
 - The DM selects his group of trusted supporters
 - DM specifies how he or she wants to be supported by supporters
 - Decisions are made by DM, supporters are trained to stay in supportive/advisory role
- A “**supported decision-making agreement**” or SDMA is created which spells out the rights and obligations of the parties, including an understanding by supporters that they are to assist the decision-maker, but never to substitute their own decision in lieu of the person wanting the support.
- SDM is currently **not** a legal instrument in NY State
 - legislation in process



When should you start SDM?

- From early childhood!
 - Parents and teachers should encourage their loved ones/students to understand and make decisions
 - “What decisions do you need to make in order to be out the door at 7:00 am?”
 - “What are you going to wear? Why?”
- SDM can be practiced informally
 - Trusted friends and family provide a network of support
- A facilitated SDM project provides a formal structure which ends in a Supported Decision-Making Agreement.
 - A facilitator guides the DM and later on his or her chosen supporters through a process to help define the terms of the SDMA.
 - Supporters may be grouped into teams focusing on specific areas (eg healthcare, finance, employment)

Decision making is an important life skill that gets better with practice, and over time, the DM learns to manage and avoid risks of making poor decisions



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Health Care Protections

	Healthcare Proxy	17 A Guardianship
What it is	Advance directive; allows an individual (the principal) to appoint an agent to legally make healthcare decisions on behalf of principal when principal is incapable of making and executing the healthcare decisions stipulated in the proxy	Legal relationship established by the court in which a person or entity makes decisions on behalf of an individual who is not able to make life decisions on their own.
Established by:	Signed and notarized document by a competent adult. Adult is assumed competent unless declared not to be by court of law. In effect upon signing.	Petition to NY Surrogate court. Long document-intensive process, takes several months
Requirements	Principal does not need to have the capability of making and understanding all medical care decisions for themselves in order to be able to make a health care proxy. Simply must understand that they are giving another person (the health care agent) the authority to make medical care decisions on their behalf if and when they are not capable of making these decisions.	Individual is deemed to be incapable of managing his or her affairs due to a permanent intellectual or developmental disability
Individual's rights	Decision-making rights are not removed from an individual	Transfers almost all decision-making rights from the individual to the guardian, very restrictive.
Ease of being revoked	Revoked from agent by individual (principal) anytime	Intended to be permanent in nature

Guardianship decision clear-cut only in severely disabled situations: inability to understand concept of giving authority to another person and inability to practice SDM even after decisions are broken down into simple steps. An SDM team around healthcare decision making minimizes risk of poor decision making.



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Health Care Decisions Act

- The Health Care Decisions Act is a law that allows specifically authorized surrogates to make health care decisions on behalf of persons with intellectual or developmental disabilities, including the decisions to withhold or withdraw life sustaining treatment if certain statutory criteria are met
 - If guardianship or healthcare proxys are in place, they supersede all others.
 - If not, a process is set in place to locate family members in a defined order of succession

The popular belief that an individual with IDD in an emergency room automatically becomes a ward of the state if guardianship is not in place is false



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Financial Protection

Social Security's Representative Payment Program provides benefit payment management for beneficiaries who are incapable of managing their Social Security or Supplemental Security Income (SSI) payments. A suitable representative payee is appointed by SSA who manages the payments on behalf of the beneficiaries.

Durable Financial Power of Attorney, an advance directive, grants someone (an agent) legal authority to act on an individual's behalf for financial issues (e.g. signing legally binding documents, paying bills). Individual can revoke durable POA from agent at any time.

SSI's representative payee is appointed by an SSA process and not through the guardianship process, so guardianship decisions should not be based on access to SSI concerns. An SDM team around financial decision making, and a durable POA if applicable, can reduce risk of being taken advantage of by dishonest people.



Protecting and Empowering Together

Protect

Advance directives
(HC Proxy or
Durable POA)



Guardianship

Increasing restrictiveness
(to individual with IDD)



Empower

Practice SDM
Practice appropriate life skills

- Consider least restrictive legal protection option to protect individual's human rights
 - Can individual understand decisions when broken down and explained simply?
 - Can individual understand the concept of giving someone else decision-making authority when s/he is unable to make decisions for him or herself?
 - If yes, guardianship may be too restrictive
- Practicing SDM allows DMs to gain confidence while minimizing risk.

Finding the balance allows loved one to be protected from poor decision-making while being empowered to make choices for themselves



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APPENDICES



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17 A Guardianship Requirements

Eligibility Criteria

- Individual cannot make decisions about his or her personal affairs or property by reason of intellectual or developmental disability
- Disability is permanent
- Guardianship is in the best interest of the individual

Documentation Requirements

Maximum document age at filing

Psychological tests – IQ and Adaptive

3 years

Affidavit and affirmation of health professionals

6 months

Petition for guardianship with accompanying affidavits

Certified birth certificate of individual, parent's death certificate if applicable

N/A

Stage	Evaluated by	Possible Outcomes
File Documents	NY Surrogate court clerk (doc review)	Request additional information if documentation incomplete
Hearing	NY Surrogate Court	Petition approved or denied

Challenge:

- Guardianship is not always the right solution- parents need to know all possible solutions to protect their loved ones
- Tests and affidavits can expire



17 A Guardianship Process


4. Guardianship flowchart-pdf.pdf - Adobe Acrobat Pro DC (32-bit)

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Home Tools 4. Guardianship flo... x

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What are the Steps in the Guardianship Process?



Step # 1
OBTAIN psychological evaluations/ diagnostic reports - **Dated within the last 3 years**

Step # 2
BRING Form GMD-2A (Affidavit) to Physician or Licensed Psychologist to be completed and notarized
BRING Form GMD -2B to Physician to be completed - **Both valid for six months**

Step # 3
Obtain **CERTIFIED Birth Certificate of the Respondent - Must have a RAISED Seal**

Step # 4
COMPLETE and NOTARIZE Forms:
GMD-1 - Petition for Appointment of Guardian(s) (in 2 places on forms)
GMD-1A - Affidavit of each Proposed Guardian (separate forms)
GMD-3 - Waiver of Process & Renunciation (only if necessary)
GMD-4- Consent, Oath, & Designation of Standby and 1st and 2nd Standby Guardians

Step # 5
Forms GMD-7 Citation to Show Cause and GMD-8 Notice of Petition
Complete as much as possible & bring to court clerk to complete.

Step # 6
Form OCFS-3909 - Office of Children and Family Services Request for Information Guardianship Form
To be Completed and signed by all proposed guardians and members of proposed guardian's household over 18 years old. **Include addresses for the last 28 years.**

Step # 7
Petitioner Must Bring the Completed Documents to Westchester County Surrogate's Court (111 Dr. Martin Luther King Jr. Blvd) and a Filing Fee of \$20 (Cash, Credit or Money Order) made out to Westchester County Surrogate's Court.

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Some Links For Learning More:

1. 17A Guardianship NY State Site:
<https://nycourts.gov/courthelp/Guardianship/17A.shtml>
2. OPWDD's Healthcare Decisions site, with link to NYS Healthcare proxy form:
<https://opwdd.ny.gov/providers/health-care-decisions>
3. Supported Decision Making NY:
<https://sdmny.hunter.cuny.edu/>
4. Report and Recommendations of Olmstead Cabinet:
<https://www.criminaljustice.ny.gov/opca/pdfs/9-Olmstead-Cabinet-Report101013.pdf>
5. Disability Rights NY Litigation:
<https://ilny.us/phocadownload/conference/2017/litigation-and-legislative-update-article-17a/17-A%20Presentation%20for%20NYAIL%20Conference%20-%20Final%20Draft.pdf>





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