

Deciding About Guardianship

Moving from Pediatric to Adult Health Care
Continuing Education Module



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✓ Learn ✓ See ✓ Do

Skills for Moving from Pediatric to Adult Health Care

- Scheduling an Appointment
- Getting Health Insurance
- Deciding About Guardianship
- Speaking up at the Doctor's Office
- Understanding Your Disability
- Managing Medications
- Keeping a Health Summary
- Looking into Service Coordination
- Setting Health Goals
- Finding Community Resources

Welcome!

This education module provides information that families and professionals can use to help youths who have developmental disabilities to decide about guardianship.

Deciding About Guardianships: Skill attainment for this topic is defined when the adolescent or young adult is able to:

- ✓ State what a health care guardian does
- ✓ Be aware of alternatives to health care guardianship
- ✓ Define a Circle of Support for him/herself
- ✓ Name his/her health care guardian and/or carry documents that provide this information, if applicable
- ✓ Complete a health care proxy, if applicable

This continuing education module is part of a 10-unit curriculum that was developed for families, health care providers, service coordinators and other professionals who would like to facilitate the transition from pediatric to adult health care for youths who have developmental disabilities. Adolescence and young adulthood is a time of tremendous change, not just physically, but also in terms of social and emotional development, and due to transitions in services, supports and health care providers. The Healthy Transitions curriculum provides a context for mutual understanding and collaboration during this complex time.

The curriculum is organized around 10 key skills that youths need to develop in order to transition to adult health care. The skills are not sequential. They can be developed over time, between the ages of 14-25 years. The Healthy Transitions checklist (see "script pad") can be used to track accomplishments. Each module provides strategies that families and professionals can use to help youths to develop a particular skill. The curriculum emphasizes self-determination and the active involvement of young adults who have developmental disabilities in their own health care.

The modules begin with a vignette that illustrates a transition "success story". This is followed by didactic information and a list of references and resources for skill development. A table with "tips for collaboration" lists concrete steps that youths, families, service coordinators, and health care providers can take in order to facilitate the transition process. A self-assessment quiz is included at the end of each module.

In addition to the Continuing Education Modules, the Healthy Transitions project offers Lessons Plans, Videos and a Moderator Guide for educators that can be used in group settings with young adults. Our website also features a secure network of personal health sites called **MY PLACE** that link youths to a personal transition team for care coordination, planning, and setting priorities during the transition to adulthood.

Please visit us at HealthyTransitionsNY.org to find out more. We welcome feedback!

Nicole

Nicole is a 24 year old woman with cerebral palsy who recently established medical care with a new physician. At the initial visit she explained that she does not require health care guardianship because she understands and can make decisions about her own health care. She does have a Health Care Proxy and a Durable Power of Attorney that she put into place with her parents. She has these documents at her parent's house, but hasn't given copies to her doctor yet.



Nicole has a good relationship with her family and has developed a Circle of Support, which is a group of friends and relatives who help her with day-to-day issues related to her physical disability. Nicole chose to list her parents and several members from her Circle of Support on the HIPAA consent form. This way office staff can legally discuss Nicole's health information with people who assist Nicole with managing her health needs.

Deciding about Guardianship

Learning Objectives:

1. Define guardianship.
2. Name six alternatives to guardianship.
3. Describe the pros and cons of guardianship under Article 17-A of the New York State Surrogate's Court Procedure Act versus Article 81 of the New York State Mental Hygiene Law.
4. List key issues addressed by the Health Care Decisions Act for Persons With Mental Retardation (HCDA) and the Family Health Care Decisions Act (FHCDA).
5. Define health care proxy.



Guardianship and Health Care Transition

Making a decision about guardianship is essential to the health transition process. When a youth who has a developmental disability is unable to make health care decisions independently, there are several options to consider and procedures to follow in order to obtain legal guardianship. It is important to make these decisions before the youth's 18th birthday. This is because an 18 year old is considered a legal adult in New York State unless actions are taken to establish guardianship. In other words, guardianship is not automatic. The process of establishing guardianship can be daunting for some families, but it is essential because guardianship guarantees advocacy. Once obtained, guardianship papers should be kept in a wallet so that they can be presented at all health care encounters. Guardianship papers are as important as an insurance card when patients with developmental disabilities enter the adult health care system.

This unit provides information and strategies that health care providers, service coordinators, family members and other caregivers can use to help youths to decide about guardianship.

What is guardianship?

All persons have a right to make decisions. If a person cannot make decisions because of mental incapacity or a developmental disability, the law can take away or "limit" a person's right to make decisions, and appoint someone else to make decisions. This is called guardianship.

Several types of guardianship are recognized by New York State. *Guardianship of the Property* applies to decisions related to financial matters. *Guardianship of the Person* applies to decisions related to personal life, such as where one lives, what health care is provided, and where one works or goes to school. *Limited guardianship* applies to some, but not all, decisions related to personal life. *Health care guardianship* is an example of a limited guardianship.

Guardianship is Not Automatic In New York State an individual is considered to be a legal adult at age 18. If health care guardianship has not been established, parents may be surprised to learn that they cannot legally communicate with health care providers about their adult child without the written permission of the young adult patient. This is because the *Health Information Portability and Accountability Act (HIPAA)* states that at age 18 years, youths who are capable of understanding the **HIPAA** privacy form must give written consent in order for records to be shared with others. If a youth cannot understand the **HIPAA** consent form, then legal guardianship should be established. There are two types of guardianship in New York State, **Article 17-A of Surrogate's Court Procedure Act** and **Article 81 NYS Mental Hygiene Law**:

Article 17-A of Surrogate's Court Procedure Act Most applications for this type of guardianship can be completed with or without an attorney. The process typically includes an informal hearing with the Surrogate's Court Judge. After reviewing the application, medical certifications from two physicians or one physician and one psychologist, and with approval from the Office of Child and Family Service, the Surrogate's Court Judge will confirm the appointment of the guardian. The following forms are required for establishing guardianship under 17-A:

- **Petition for Appointment of Guardian**
- **Affidavit of Proposed Guardian**
- **Birth Certificate**
- **Request for Information Guardianship Form**
- **Certification of Examining Physician or Licensed Psychologist**
- **Certification of Examining Physician**
- **Citation**
- **Notice of Petition**

The website for the New York State certified courts system includes links to all of these forms and a helpful checklist that can be used to walk a family through the process: <http://www.nycourts.gov/forms/surrogates/guardianship.shtml>. Once the forms have been submitted and reviewed by the court, a guardian and a stand-by guardian are then legally designated by the court. These guardians can be:

- **Friend**
- **Family member**
- **Individual identified by court**
- **Agency**
- **State**

When deciding who will be named as guardian and who will be named as stand-by guardian, it is helpful for families to consider both the immediate and long-term future.

Guardianship may occasionally be an adversarial process when the person deemed in need of a guardian does not want to cooperate or agree to the process. In such circumstances, a *guardian ad litem* is appointed by the Surrogate's Court Judge to represent the individual's rights. The *guardian ad litem* has the opportunity to call expert witnesses and cross-examine the petitioner and the experts.

Establishment of guardianship under 17-A of the Surrogate's Court Procedure Act typically takes 4-6 months and costs \$20. It is the most commonly used mechanism for establishing guardianship for individuals with developmental disabilities in New York State.

Article 81 NYS Mental Hygiene Law An attorney is always necessary for establishing guardianship under Article 81 NYS Mental Hygiene Law. This type of guardianship involves specific time frames set by law, appointment of a court evaluator, a full hearing in front of a Judge, and very detailed financial reporting to the Court. It also requires bonding of the guardian and a trustee.

A *stand-by guardian* is also designated by the court. The standby guardian has authority to assume the responsibilities of the guardian in the event of death or disability of the appointed legal guardian. The qualifications of both the guardian and the standby guardian must be reviewed and approved by the New York State Office of Child and Family Services. Establishment of guardianship under Article 81 of the New York State Mental Hygiene Law is a lengthy process that includes a functional assessment and specific restrictions so that accountability of the guardian is assured.

The table on page 6 summarizes key differences between guardianship under Article 17-A of the Surrogate's Court Procedure Act and guardianship that is established under Article 81 of the New York State Mental Hygiene Law. Regardless of the type of guardianship that is established, it is important to know that guardianship does not have to be permanent. A re-determination hearing can be scheduled at any time. At this hearing the guardian must show why an individual still needs a guardian. If a guardian breaks the law or does not act in the best interest of an individual, the Court can revoke guardianship.



Options for Establishing Guardianship in NYS

17A Surrogate Court Procedure Act	Article 81 NYS Mental Hygiene Law
• Generic	• Individualized
• Standard forms	• Based on functional assessment
• Attorney not required	• Attorney required
• Quick	• Greater accountability

Filing Procedures

<ul style="list-style-type: none"> Requires a diagnosis of Developmental Disability and/or Mental Retardation made by two physicians or one physician and one certified licensed psychologist. 	<ul style="list-style-type: none"> Requires “Developmentally Disabled” or “Mentally Incapacitated” diagnosis. Physician may be required to testify in court.
<ul style="list-style-type: none"> Can obtain forms and instructions from local Surrogate’s Court, or on the Internet: http://www.nycourts.gov/forms/surrogates/guardianship.shtml 	<ul style="list-style-type: none"> Requires assistance by experienced legal counsel who has taken the necessary court training. Attorney fees accrue.
<ul style="list-style-type: none"> Filing fee currently is \$20 statewide. Additional certifications cost \$6. 	<ul style="list-style-type: none"> Begins with filing Petition with show cause order and \$270 filing fee. Very specific time requirements must be met.
<ul style="list-style-type: none"> If disabled individual lives in a group home, a report is required by the attorney from NYS Mental Hygiene Legal Services. 	<ul style="list-style-type: none"> Court evaluator is appointed to give report to Surrogate. Court requires full hearing with notice to all necessary parties.
<ul style="list-style-type: none"> Occasionally, the Surrogate’s Court may appoint an <i>ad-litem</i> guardian (temporarily) to determine whether guardianship is necessary. 	<ul style="list-style-type: none"> Court appointed guardian and/or trustee must be bonded and file annual financial reports with the court during disabled person’s life time. <p>New petition is required to appoint standby guardian.</p>



Alternatives to Guardianship

Alternatives to guardianship that are recognized by the legal system include:

Durable Power of Attorney

This is a legally executed and witnessed document that allows an individual to designate a competent adult to act on one's behalf. It is typically put into place in order to manage finances and insurance matters. In New York State, a Durable Power of Attorney does not pertain to health care decisions but can be used to request medical records, obtain bills, and submit health insurance forms. The permission can be granted for a specific, limited purpose and period of time or for much broader purposes such as handling all financial affairs for an unlimited period of time. A durable power of attorney remains in effect even when the individual's ability to make decisions is impaired by health or mental incapacity. It is important to note that a power of attorney is not recognized by the Social Security Administration. Individuals who help to manage these funds must be designated as a representative payee (see below).

Representative Payee

This is a legally executed and witnessed document that is required by the Social Security Administration for the designation of a person to act as agent for SSI, SSDI, Medicare & Medicaid benefits. This designation requires approval from the Social Security Administration.

Adult Protective Services

When there are concerns about abuse or neglect, the Court may appoint a guardian with Adult Protective Services to protect the safety and interests of the individual who has a developmental disability. The New York State Commission on Quality of Care and Advocacy for Persons with Disabilities is the oversight agency for incident reporting for both the New York State Office of Mental Health and Office of Mental Retardation and Developmental Disabilities. Programs operated or certified by these agencies are required to report allegations of abuse and neglect to the Commission by calling 1-800-624-4143.

Alternatives to guardianship that are not recognized by New York State's legal system and do not substitute for legally executed documents that express an individual's wishes or need, are nevertheless important to include in discussions of guardianship. The following alternatives to guardianship may be appropriate for some individuals in order to meet his/her goals for self-determination:

- **Advocate:** A friend or family member who provide assistance or guidance.
- **Circle of support:** a group of friends and family members that help an individual with developmental disability to make plans.
- **Micro-board:** a group of friends and family that act as advisors. The individual with a developmental disability makes final decisions as "chairman of the board."
- **Autonomy:** A young adult independently makes decisions regarding his/her health care.

Autonomy

Autonomy is certainly appropriate for some youths who have developmental disabilities. If an individual has the mental capacity to understand the issues of his or her own daily life and health care, then guardianship is not needed. If there is conflict or uncertainty regarding the individual's decision-making ability, a *guardian ad litem* can be assigned to represent the individual in a determination process under 17-A of the Surrogate's Court Procedure Act.

For situations or conditions that preclude autonomous decision making, such as acute illness or progressive mental infirmity, individuals who are autonomous may be able to execute legal documents to designate agents to act on his or her behalf, and still stay in control of his or her own decision making.

This can be accomplished with the use of Health Care Proxies, Living Wills, and provisions of recent legislation under the **New York State Health Care Decisions Act for Persons with Mental Retardation (HCDA)** and the **Family Health Care Decisions Act (FHCDA)**. An excellent overview, with forms and legal briefs that may be helpful to attorneys and families regarding these issues is available on the OPWDD website at http://www.omr.state.ny.us/health/hp_health_carechoices.jsp.

Health Care Proxy

A Health Care Proxy is a legally signed and witnessed document that allows an individual to appoint someone he or she trusts, for example, a family member or close friend, to make health care decisions when that individual loses the ability to communicate those decisions independently. Hospitals, doctors and other health care providers must follow the agent's decisions as if the individual were speaking directly. Within the health care proxy, an individual can add his or her own express wishes (for example, limiting the amount of exploratory or invasive surgery or kinds of medications the person will or will not take). The individual can also include choices regarding advanced directives, Do Not Resuscitate, type of care, location of service, health care providers and limitations on services. Finally, the Health Care Proxy can also be used to document instructions with regard to organ and/or tissue donation.

A health care proxy form can be obtained from the NYS Department of Health website http://www.health.state.ny.us/professionals/patients/health_care_proxy/about.htm. It does not have to be drafted by an attorney. The health care proxy form must be signed, dated and witnessed by two individuals other than the individual who is designated as the health care agent. The form becomes effective only when the individual cannot express his or her own wishes independently. It must then be presented to the individual's health care providers. The health care proxy agent should have an original signed copy and be able to present this document as needed. A signed health care proxy form is not going to benefit the person if no one knows that it exists or where it is located. It is important to remember that an authorized "proxy" is only requested if it has been determined that the person lacks the capacity to make an informed decision regarding his/her medical treatment. If the person is 18 or older and has the capacity to understand the information that his or her doctor is discussing regarding proposed medical treatment, the person's informed consent is required.

Living Will

A living will is a document that provides specific instructions regarding specific situations or types of health care treatment. It is generally used to document that an individual does not wish to receive life-sustaining treatment. If a person has a health care proxy as well as a living will, the living will can provide instructions for the health care agent that will guide his or her decisions.

Health Care Decisions Act for Persons with Mental Retardation:

The **Health Care Decisions Act for Persons with Mental Retardation (HCDA)** gives guardians of individuals with mental retardation the authority, subject to strict protections, to withhold or withdraw life-sustaining treatment. A related law for New Yorkers who do not have a developmental disability called the **Family Health Care Decision Act (FHCDA)** was enacted in March 2010. It is anticipated that the two laws will eventually be merged. Both laws allow family members or legal guardians to make health care decisions, including Do Not Resuscitate decisions, on behalf of patients who are unable to make such decisions independently and who do not have an advanced care directive or health care proxy in place that documents their wishes. Both laws apply only to family members or legal guardians, not close friends.

The decision making under **HCDA** is limited to medical procedures or interventions that require informed consent, including decisions regarding life-sustaining treatments, and Do Not Resuscitate (**DNR**) orders. For **DNR** orders, the **HCDA** requires documentation that the life sustaining treatment would impose an extraordinary burden on the individual. The medical criteria for **DNR** under this law do not specifically include medical futility, but are broad enough to encompass this concept. The

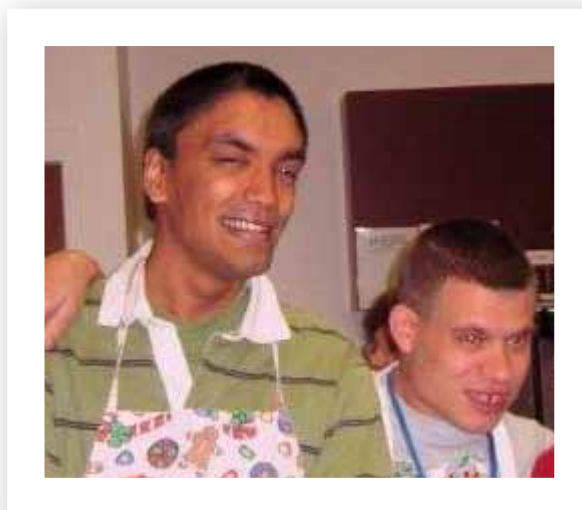
documentation process outlined above must be followed for all decisions involving the withholding or withdrawal of life sustaining treatment, including **DNR** orders. In other words, the **HCDA** stipulates that one set of medical criteria and one surrogate list are used for all such decisions.

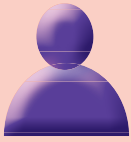
The **HCDA** also provides guidelines for decision making regarding individuals who do not have a 17_A guardian, an actively involved family member, or a so called consumer advisory board. In such situations, if it is not clear whether a person has the capacity to understand the medical information provided by his or her doctor and to give informed consent, then, by law, the Chief Executive Officer of a facility where the medical treatment is to take place shall either (a) prepare and file a declaration with a surrogate decision-making committee (if one has been established at that health care location; or (b) obtain an independent written opinion from a consultant who is able to evaluate the person's capacity to understand the medical information provided by his or her doctor regarding the proposed medical treatment. The consultant shall be either a NYS licensed psychologist or psychiatrist who has experience in treating persons with developmental disabilities. This consultant cannot be an employee of the facility. After considering the consultant's opinion, the Chief Executive Officer must determine whether or not the person possesses capacity to understand the appropriate disclosures and to give or withhold informed consent thereto. Both the consultant's opinion and the Chief Executive Officer's decision shall be documented in the person's record and communicated to the person and his or her parent, other nearest relative, or guardian.

HCDA applies only to procedures that require informed consent, and does not apply to routine care or emergency medical circumstances. It's important to note also that the **HCDA** does not supersede directives that are documented in a health care proxy or decisions that are made by a court appointed legal guardian. New York State still encourages (and prefers) that all individuals who are capable of signing a health care proxy do so. More information about the **Health Care Decisions Act for Persons with Mental Retardation** is available on the Internet at http://www.omr.state.ny.us/hp_healthtext.jsp.

In Summary

Decision making regarding guardianship is a very important component of health care transition. This should take place well before the 18th birthday of an adolescent who has a developmental disability. Two options for establishing guardianship are available in New York State: **Article 17 A of the Surrogate's Court Procedure Act** and **Article 81 of the New York State Mental Hygiene Law**. Youths should be aware of alternatives to guardianship, and should understand the rationale and scope of guardianship, if this is established. For young adults who are capable of making health care decisions, a health care proxy is recommended.





Adolescent/ Young Adult

Gather your Circle of Support to talk about guardianship, and decide if legal guardianship is needed for making health care decisions. Discuss the alternatives to guardianship.

Think about the people you know who might be able to look out for your interests as your health guardian.

If the guardianship process has been initiated and you feel this is not needed, request a guardian *ad litem* to speak for you in court.



Family

Start the process when your son or daughter turns 17 years old. Try to submit all paperwork to the Court at least 6 months *before* his/her 18th birthday.

Schedule a medical appointment to discuss guardianship with your child's physician. Bring the physician affidavit form for the guardianship application to the visit and review it together. Be sure to ask that the form be notarized before the doctor sends it back to you. Provide a return envelope.

Do not hesitate to contact the local Court to ask for information or to have specific questions answered. The paperwork may seem daunting. If you need help ask for it.

Think about the person who should be listed as your adult child's health care guardian, both now, and 10-20 years into the future. Be sure to list an alternate guardian.



Health Care Providers

Do not assume that health guardianship is established.

Remind family members that decisions regarding guardianship should be made well before age 18 years.

Explain that at age 18 years, the HIPAA law requires written consent by the youth for physician-parent communication, unless guardianship is in place.

Promptly sign, and notarize affidavit forms to establish legal guardianship for the Court.

Discuss the health care proxy with young adult patients who make health care decisions autonomously.

Ask youths who are autonomous whether they would like to list members of their Circle of Support on the HIPAA consent form.



Service Coordinators

Discuss alternatives to guardianship with youth.

Assist families with submission of guardianship paperwork to the Court well before the youth's 18th birthday.

If the guardianship process has been initiated inappropriately, request that a guardian *ad litem* be assigned to speak for the youth in Court.

References and Resources

Article 17-A Guardianship Forms and Procedures

Information and forms regarding Article 17-A Guardianship from the New York State Unified Court's System.

<http://www.nycourts.gov/courts/3jd/surrogates/guardianship.shtml>

Guide to Adult Guardianship: Article 81 of the NYS Mental Hygiene Law

Guide prepared for the New York State Office of Children and Family Services by the Brookdale Center for Healthy Aging & Longevity of Hunter College Sadin Institute on Law, Public Policy & Aging and The New York State Law Revision Commission (2005).

<http://www.ocfs.state.ny.us/ohrd/materials/151670.pdf>

Health Care Choices

A web-resource maintained by the New York State Office of Mental Retardation and Developmental Disabilities that provides up to date legal information about Informed Consent for Medical Treatment, Health Care Proxies, Do-Not-Resuscitate (DNR) Orders, the Health Care Decisions Act for Persons With Mental Retardation, and Living Wills.

http://www.omr.state.ny.us/hp_healthtext.jsp

Planning for the Future

A 94-page guide for families that addresses all aspects of future planning, including guardianship. This PDF document can be downloaded in Spanish or English from the website of the New York State Developmental Disabilities Planning Council (6th edition, published in 2006).

http://www.ddpc.state.ny.us/publications/childcare_education/planning_for_the_future_2006.pdf

New York State Commission on Quality of Care and Advocacy for Persons with Disabilities

Information, forms, technical assistance, and legal briefs relevant to guardianship.

<http://www.cqcapd.state.ny.us/default.html>

New York State's Health Care Proxy

English and Spanish language forms and information about New York State's Health Care Proxy from the New York State Department of Health.

http://www.health.state.ny.us/professionals/patients/health_care_proxy/intro.html

Quiz

1. An individual who has a developmental disability cannot apply for a limited guardianship.
 - (a) True
 - (b) False

2. Which of the following is an alternative to guardianship that is NOT recognized by the legal system:
 - a) Durable Power of Attorney
 - b) Adult Protective Services
 - c) Representative Payee
 - d) Circle of Support

3. The following is NOT true regarding guardianship under Article 81 of the New York State Mental Hygiene Law:
 - a) It is based on a functional assessment
 - b) An attorney is required
 - c) It requires bonding of the guardian
 - d) Cost is minimal

4. Decision making under The Health Care Decisions Act for Persons With Mental Retardation (HCDA) and The Family Health Care Decisions Act (FHCDA) is limited to family members or a guardian and applies to medical procedures or interventions that require informed consent, including decisions regarding life-sustaining treatments, and Do Not Resuscitate (DNR) when a patient who does not have a health care proxy is incapacitated.
 - (a) True
 - (b) False

5. A Health Care Proxy is a legally signed and witnessed document that allows an individual to appoint someone he or she trusts to make health care decisions when that individual loses the ability to communicate those decisions independently.
 - (a) True
 - (b) False

Answer key: 1(b); 2(d); 3(d); 4(a); 5(a)

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