


Catholic Charities Disabilities Services
Agency Standard and Procedure

Standard Category	Residential
Standard Title	Health Care Decision Making
Regulations	Health Care Decisions Act 14 NYCRR 633
Original Issue Date	February 23, 2016
Latest Revision Date	
Number of Pages	4
Attachments	"Health Care Choices: Who Can Decide" OPWDD February 2012
Approved by: Anne Ogden, Executive Director	

Standard: Catholic Charities Disabilities Services (CCDS) recognizes that each individual has the right to manage the provision of his or her own health care to the extent possible. Decisions regarding health care will be in compliance with all applicable laws and regulations.

Procedure:

Guidance

1. OPWDD has published a document entitled "Health Care Choices: Who Can Decide?" which summarizes all pertinent law and regulation regarding health care. Staff will use this as a resource to guide them in assisting individuals regarding health care decision making.

Article 17A Guardians

2. Unless specifically prohibited by the court, an Article 17 A guardian has the authority to make all health care decisions that the individual could make if they had capacity, provided, however, that any decision regarding end of life treatment (issuance of a DNR/DNI, etc.) must be made in compliance with the requirements of the Health Care Decisions Act.

Health Care Plan

3. As part of the annual planning process, the individual and nurse, with input from his or her family or guardian, and with the assistance of the treatment team, will develop a health care plan which will provide the individual with as much control over his or her health care as they desire, depending upon their ability and legal authority to do so.
4. In the course of developing this plan, the individual will be asked whether or not they like their medical providers, whether or not they are comfortable with their medications, what their health goals are, and any other appropriate questions. From this information a health care plan will be developed.
5. This plan will be documented in the Nursing Care Plan, Residential Habilitation Plan, or Individual Services Plan (ISP) depending upon the goals of the plan.

Consent

6. "Informed consent" is required for professional medical treatment.¹ While "consent" is needed for routine or emergency treatment, "informed consent" is not required.
7. If an individual is 18 years or older and has the capacity to understand and can make thoughtful decisions regarding proposed professional medical treatment, the individual's informed consent is required.
8. For those individuals without a guardian with the authority to make health care decisions, within 180 days of admission or within 180 days of the effective date of this standard, the treatment team will determine if the individual has the capacity to give informed consent. The determination will be documented in the individual's record.
9. If the treatment team cannot determine if the individual has the capacity to give informed consent or if there is some question as to whether or not the individual has the capacity, a properly credentialed psychologist or psychiatrist will be designated to do the evaluation of capacity. This evaluation will be documented in the individual's record.
10. If an individual does not have the capacity to give informed consent, a surrogate will be identified by the treatment team in accordance with regulations.

¹ Professional Medical Treatment is defined as a medical, dental, surgical or diagnostic intervention or procedure in which a general anesthetic is used or which involves a significant invasion of bodily integrity requiring an incision or producing substantial pain, discomfort, debilitation or having a significant recovery period, or any professional diagnosis or treatment to which informed consent is required by law.

11. Regardless of capacity, an individual can at any time refuse any medical procedure. CCDS will ensure that all appropriate protections will be provided to the individual following his or her refusal.

Health Care Proxy

12. A health care proxy is a document created by an individual which names another person as his or her health care agent to have the authority to make health care decisions if and when the individual is determined to be incapable of making health care decisions.
13. The health care agent has the authority to make any and all health care decisions on the individual's behalf that the person could make if he or she had capacity, provided, however, that any decision regarding end of life treatment (issuance of a DNR/DNI, etc.) must be made in compliance with the requirements of the Health Care Decisions Act.
14. The agent's authority begins when a determination has been made by the attending Physician that the individual lacks capacity to make a health care decision.
15. To be able to create a health care proxy, the individual only has to understand that he or she is giving another person, the health care agent, the authority to make medical decisions when he or she is not capable of making these decisions.
16. Individuals may not appoint any member of the Board of Directors, employee of CCDS, or physician affiliated with CCDS as a health care agent.
17. For those individuals who have not executed a health care proxy or are without a guardian, within 180 days of admission or within 180 days of the effective date of this standard, the treatment team will determine if the individual has the requisite understanding to execute a health care proxy. The determination will be documented in the individual's record.
18. If the treatment team cannot determine if the individual has the requisite understanding to execute a health care proxy or if there is some question as to whether or not the individual has the requisite understanding, a properly credentialed psychologist or psychiatrist will be designated to do the evaluation of understanding.
19. While not required, an individual, with assistance if necessary, may write his or her wishes regarding specific health care decisions, including but not limited to artificial nutrition and hydration, blood transfusions, artificial respiration, antipsychotic medication, surgical procedures or dialysis, in the health care proxy.

20. The establishment of any health care proxy will be in compliance with all applicable law and regulation.
21. On an annual basis the clinical team will ask those individuals who are eligible to establish a health care proxy if they want to exercise that right. The conversation will be documented in the individual's record.

Life Sustaining Treatment

22. All decisions involving the withholding or withdrawal of life sustaining treatment, including Do Not Resuscitate (DNR) orders, must comply with the processes outlined in the Health Care Decisions Act and described in the attachment to this Standard.



NYS Office For People With Developmental Disabilities

Putting People First

HEALTH CARE CHOICES: WHO CAN DECIDE?



INFORMED CONSENT FOR MEDICAL TREATMENT

HEALTH CARE PROXIES

HEALTH CARE DECISIONS ACT FOR PERSONS WITH MENTAL RETARDATION

LIVING WILLS

FEBRUARY 2012

Andrew M. Cuomo
Governor



Laurie A. Kelley
Acting Commissioner

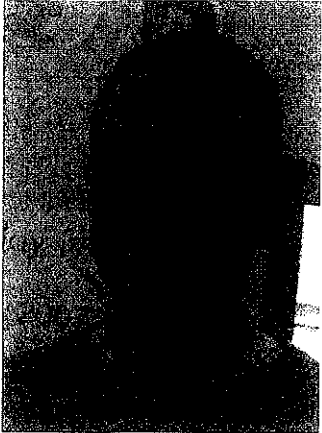
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HEALTH CARE CHOICES: WHO CAN DECIDE?

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INTRODUCTION



The purpose of this booklet is to familiarize you with health care decision options that are available in New York State to assist you in choosing the kind of care you want in the event that you are no longer capable of making your own health care decisions.

The first section of the booklet outlines the circumstances in which informed consent is required for medical treatment, as well as who may provide such consent if the individual is unable to provide his or her own consent.

The second section of the booklet deals with health care proxies. A health care proxy is a document created by a person (the principal) which names another person as his or her health care agent to have the authority to make health care decisions if and when the principal is determined to be incapable of making medical care decisions for himself or herself. Immediately following this section, on pages 9-12, is a health care proxy form, instructions and additional information which was reproduced from the NYS Department of Health web site.

The third topic of the booklet is the Health Care Decisions Act for Persons with Mental Retardation. The Health Care Decisions Act became effective on March 16, 2003, and made explicit the authority of an Article 17-A guardian of the person to make health care decisions for a person with mental retardation. For the first time, this authority specifically included the ability to make a decision to withhold or withdraw life-sustaining treatment, if certain statutory criteria were met. Since 2003, the Health Care Decisions Act has been amended to apply to corporate guardians, as well as guardians of persons with certain developmental disabilities. A subsequent amendment extended the framework for making decisions to withhold or withdraw life-sustaining treatment to qualified family members pursuant to a prioritized list in OPWDD regulation section 633.10. The most recent amendments added the Willowbrook Consumer Advisory Board (CAB) and Surrogate Division Making committee (SDMC) to the list of authorized surrogates in the HCDA.

In addition, the law has changed regarding the issuance of Do Not Resuscitate (DNR) orders. As of June 1, 2010, the HCDA process must be followed for all decisions involving the withholding or withdrawing of life-sustaining treatment, including DNR orders. As a result of this change, there is now one set of medical criteria and one surrogate list for all such decisions. DNR orders issued prior to June 1, 2010 remain effective.

The final health care decision option outlined in the booklet is Living Wills. A living will is a document that provides specific instructions about health care treatment. It is generally used to declare wishes to refuse life-sustaining treatment under specific circumstances that may arise in the future. It does not appoint a "health care agent" and does not replace a health care proxy. It is generally used when a person wants to make his or her wishes known concerning health care, but does not have someone available to act as health care agent.

INFORMED CONSENT FOR MEDICAL TREATMENT

WHEN IS INFORMED CONSENT NECESSARY?

The OPWDD regulation contained in 14 NYCRR section 633.11 sets forth the procedures for obtaining informed consent for "professional medical treatment." The term "professional medical treatment" is defined in section 633.99, as follows: "A medical, dental, surgical or diagnostic intervention or procedure in which a general anesthetic is used or which involves a significant invasion of bodily integrity requiring an incision or producing substantial pain, discomfort, debilitation or having a significant recovery period, or any professional diagnosis or treatment to which informed consent is required by law."

It should be noted that informed consent is not required for medical treatment which does not meet this definition (generally considered to be either routine or emergency treatment). However, if the person or someone authorized to speak on behalf of the person, objects to proposed medical treatment which does not require informed consent, he or she must be advised of the right to appeal pursuant to section 633.12.

WHAT HAPPENS IN AN EMERGENCY?

With respect to the provision of emergency medical treatment, section 633.11 provides that: "Medical, dental, health and hospital services may be rendered to a person of any age without seeking informed consent when, in the physician's judgment, an emergency exists creating an immediate need for medical attention. In such cases, the supplier of the proposed professional medical treatment may accept the authorization of the chief executive officer of the individual's residential facility to render such professional medical treatment."

Accordingly, in cases of emergency medical treatment, the DDSO director or the Executive Director of the agency which operates the home in which the person resides, or his or her designee, may authorize the provision of medical treatment. However, a director may not provide informed consent for non emergency medical professional treatment for a resident.

Section 2504(4) of the Public Health Law defines "emergency" as "the person is in immediate need of medical attention and an attempt to secure consent would result in delay of treatment which would increase the risk to the person's life or health."

WHEN CAN AN INDIVIDUAL PROVIDE HIS OR HER OWN CONSENT?

If the person is 18 or older and has the capacity to understand appropriate disclosures regarding proposed professional medical treatment, the person's informed consent is required.

We would only look to an authorized surrogate to provide informed consent on the person's behalf if it has been determined that the person lacks the requisite capacity to make an informed decision with respect to the proposed professional medical treatment.

WHO MAY PROVIDE INFORMED CONSENT FOR A MINOR?

If the person is under 18 years old, the following surrogates, in the order stated, are authorized to provide consent:

- (1) a legal guardian with authority to consent to health care
- (2) an actively involved¹ spouse
- (3) a parent
- (4) an actively involved adult sibling
- (5) an actively involved adult family member²
- (6) a local commissioner of social services with custody over the person pursuant to the social services law or family court act (if applicable); or
- (7) a surrogate decision-making committee (SDMC) or a court

WHO IS AUTHORIZED TO PROVIDE INFORMED CONSENT FOR AN ADULT WHO LACKS THE CAPACITY TO PROVIDE HIS/HER OWN CONSENT?

If the person is 18 or older, but lacks capacity to understand appropriate disclosures regarding proposed professional medical treatment, informed consent shall be obtained from one of the surrogates listed, in the order stated:

- (1) a legal guardian with authority to consent to health care or the person's duly appointed health care agent or alternate agent
- (2) an actively involved spouse
- (3) an actively involved parent
- (4) an actively involved adult child
- (5) an actively involved adult sibling
- (6) an actively involved adult family member
- (7) the Consumer Advisory Board for the Willowbrook Class (only for class members it fully represents); or
- (8) a surrogate decision-making committee (SDMC) or a court

Consent is to be sought from surrogates on these two lists in the order stated.

WHAT HAPPENS IF THE AUTHORIZED SURROGATE IS NOT AVAILABLE?

If the first surrogate on either list is not reasonably available and willing, and that surrogate is not expected to become reasonably available and willing to make a timely decision given the person's medical circumstances, application shall be made to the next surrogate on the list, in the order of priority stated.

WHAT IF THERE IS MORE THAN ONE SURROGATE WITHIN A CATEGORY?

If more than one party exists within a category on either list utilizing the standard of active involvement, consent shall be sought first from the party with a higher level of active involvement. When the parties within a category are equally actively involved, consent shall be sought from any of such parties.

1. *Actively involved is defined as: "Significant and ongoing involvement in a person's life so as to have sufficient knowledge of the person's needs."*

2. *Family member is defined as: "Any party related by blood, marriage, or legal adoption."*

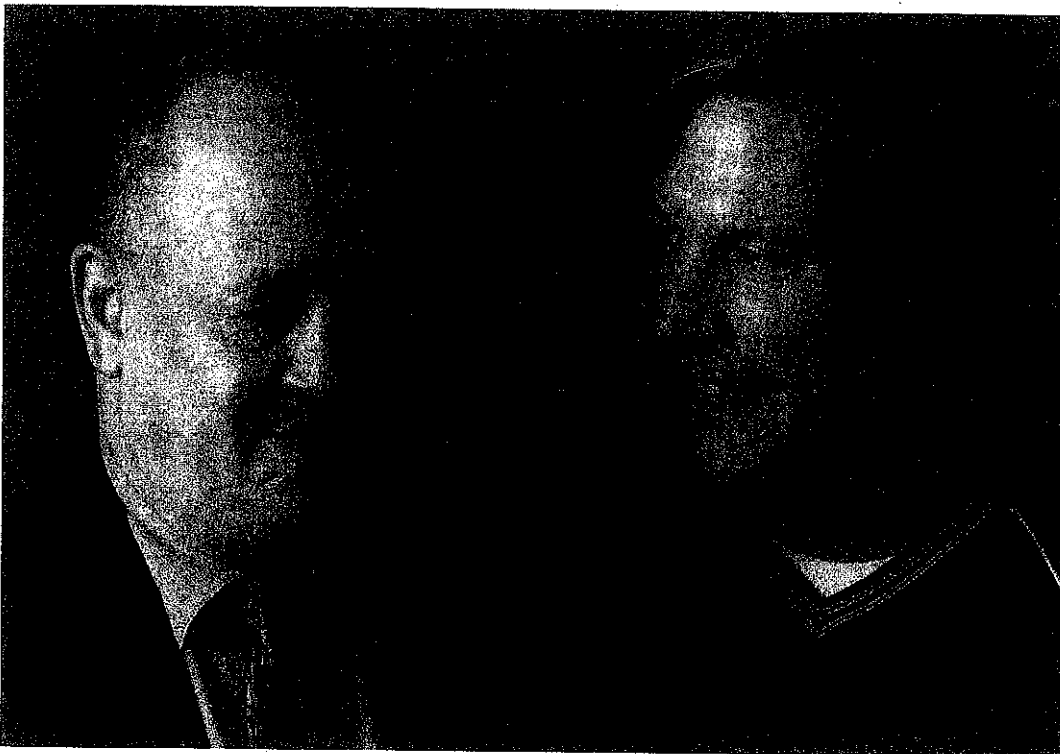
WHAT IF THE AUTHORIZED SURROGATE OBJECTS TO THE PROPOSED TREATMENT?

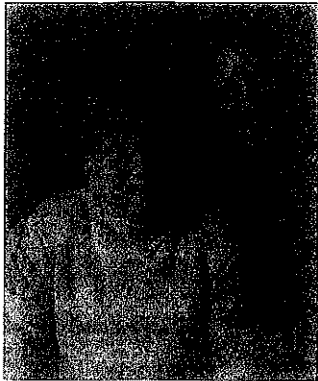
If the first reasonably available and willing surrogate listed objects to the proposed treatment, consent shall not be sought from other surrogates on the lists. If the agency considers the proposed treatment to be in the best interest of the person, application may be made to a court or, if the surrogate does not object to a SDMC proceeding, to the SDMC. Notice of any such application shall be given to the objecting party.

WHAT IF THE PERSON'S CAPACITY TO CONSENT TO THE PROPOSED TREATMENT IS UNCLEAR?

If it is not clear whether a person has the capacity to understand appropriate disclosures regarding proposed professional medical treatment, the Chief Executive Officer of a facility shall either:

- (1) prepare and file a declaration with a surrogate decision-making committee; or
- (2) obtain an independent written opinion of the person's capacity to understand appropriate disclosures regarding proposed professional medical treatment, and to give or withhold informed consent thereto. The consultant shall be either a NYS licensed psychologist or psychiatrist holding current and appropriate licensure, have experience in treating persons with developmental disabilities, and not 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, guardian or correspondent.





HEALTH CARE PROXIES

WHAT IS A HEALTH CARE PROXY?

A health care proxy is a document created by a person (the principal) which names another person as his or her health care agent to have the authority to make health care decisions if and when the principal is determined to be incapable of making medical care decisions for himself or herself.

WHO MAY CREATE A HEALTH CARE PROXY?

A person does not need to have the capability of making and understanding all medical care decisions for himself or herself in order to be able to make a health care proxy. A person simply has to understand that he or she is giving another person (the health care agent) the authority to make medical care decisions on his or her behalf if and when he or she is not capable of making these decisions.

The determination of the person's understanding should be documented in the person's record, preferably in the form of an evaluation or assessment by a psychologist. In the event that a guardian of the person has been appointed, consideration should be given to appointing the same person (guardian) as the health care agent.

No one may create a health care proxy for another person!

HOW IS A HEALTH CARE PROXY CREATED?

The health care proxy must be signed and dated by the person in the presence of two adult witnesses who must also sign the proxy. Assistance may be provided to the person in completing the health care proxy form. Another party may sign and date a health care proxy for the person if the person is unable to do it and instructs that party to do so in the presence of two adult witnesses. In this case, the witnesses must also sign the proxy and state that the person appeared to execute the proxy willingly and free from duress.

A party appointed as an agent cannot act as a witness to the execution of a health care proxy.

If the person resides in an OPWDD operated or certified facility, at least one witness must be someone who is not affiliated with the facility in which the person resides. In addition, at least one witness must be a NYS licensed physician or a clinical psychologist who either:

- (1) is employed by a DDSO; or
- (2) has been employed for at least two years in an OPWDD operated or certified facility¹;
or
- (3) has specialized training and two years experience serving persons with developmental disabilities; or
- (4) has at least three years experience serving persons with developmental disabilities¹

The health care proxy must sufficiently identify the principal and the agent and it must clearly indicate the principal's intent to give the agent authority to make health care decisions. It may be, but is not required to be, in the form of the sample health care proxy which follows this section².

¹ NYS licensure is required for clinical psychologists to qualify in these two categories.

² The Health Care Proxy Form, Instructions and Information Sheet which appear on pages 10-13 of this booklet were reproduced from the NYS DOH website.

WHAT AUTHORITY DOES THE HEALTH CARE AGENT HAVE?

A health care agent has the authority to make any and all health care decisions on the principal's behalf that the principal could make if he/she had capacity. This authority can be limited by adding express limitations to the health care proxy.

A principal, with assistance if necessary, may write his or her wishes regarding specific health care decisions in the health care proxy. Alternatively, a principal may simply appoint the health care agent and trust that the agent will make all health care decisions in accordance with the principal's wishes or, if these wishes are not known, in the principal's best interest.

A principal may write or have written in a proxy his or her health care wishes regarding, but not limited to, the following:

- (1) artificial nutrition and hydration;
- (2) blood transfusions;
- (3) artificial respiration;
- (4) antipsychotic medication;
- (5) surgical procedures;
- (6) dialysis

The only exception to the agent's general health care decision making authority is, if a principal does not make known to the agent his or her wishes about artificial nutrition and hydration (nourishment and water provided by feeding tube), a health care agent does not have the authority to consent or refuse nutrition and hydration on the principal's behalf.

WHEN DOES THE HEALTH CARE AGENT'S AUTHORITY BEGIN?

A person who is capable can execute a health care proxy at any time. However, the health care agent's authority begins when a determination has been made that the principal lacks capacity to make a health care decision.

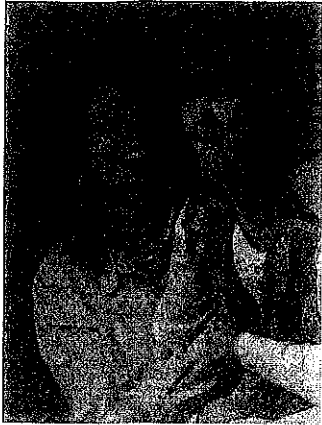
Such a determination is to be made by the attending physician, to a reasonable degree of medical certainty. The determination shall be in writing and must contain the attending physician's opinion regarding the cause and nature of the principal's incapacity, as well as its extent and probable duration. The determination is required to be included in the principal's medical record.

For a decision to withdraw or withhold life-sustaining treatment, the attending physician who makes the determination that a principal lacks capacity to make health care decisions must consult with another physician to confirm the determination. Such consultation must also be included in the principal's medical record.

In addition, if the attending physician determines that a principal lacks capacity because of a developmental disability, the attending physician must be, or must consult with, for the purpose of confirming the determination, a licensed physician or a clinical psychologist:

- (1) who is employed by a DDSO; or
- (2) who has been employed for a minimum of two years to provide services in an OPWDD-operated or certified facility³; or

³ NYS licensure is required for clinical psychologists to qualify in this category.



- (3) who has had specialized training in developmental disabilities and at least two years of experience serving persons with developmental disabilities; or
- (4) who has at least three years of experience serving persons with developmental disabilities.³

A physician who has been appointed as a principal's agent cannot make the determination of the principal's capacity to make health care decisions.

Notice of a determination that a principal lacks capacity to make health care decisions must promptly be given to the following parties:

- (1) to the principal, orally and in writing, where there is any indication of the principal's ability to comprehend such notice;
- (2) to the agent;
- (3) if the principal is in or was transferred from an OPWDD operated or certified facility, to the DDSO Director or Executive Director of the agency operating the residence; and
- (4) to the guardian or committee of, or conservator for, the principal.

The attending physician must confirm the principal's continued incapacity before complying with an agent's health care decisions, other than those decisions made at or about the time of the initial determination. The confirmation must be stated in writing and included in the principal's medical record.

In the event the attending physician determines that the principal has regained capacity, the agent's authority shall cease, but shall recommence if it is subsequently determined that the principal no longer has the capacity to make health care decisions.

CAN ANYONE OBJECT TO AN AGENT'S HEALTH CARE DECISION?

Yes, the principal. Notwithstanding a determination that a principal lacks capacity to make health care decisions, when a principal objects to the determination of incapacity or to a health care decision made by an agent, the principal's objection or decision shall prevail unless the principal is determined by a court to lack capacity to make health care decisions.

ARE THERE ANY RESTRICTIONS ON WHO MAY BE A HEALTH CARE AGENT?

Yes. Generally, persons living in OPWDD certified or operated facilities may not appoint any member of the governing body (Board of Directors), any officer, a chief executive officer, an employee of the facility or a physician affiliated with the facility as their health care agents.

DOES A HEALTH CARE PROXY REMAIN EFFECTIVE IF THE PERSON MOVES?

Yes. It remains effective until it is revoked by the principal. A principal may revoke a health care proxy by notifying an agent or health care provider, orally or in writing, or by any other act indicating a desire to revoke the proxy. A health care proxy is also revoked when the principal executes a subsequent health care proxy.

³ NYS licensure is required for clinical psychologists to qualify in this category.

Health Care Proxy

(1) I, _____
hereby appoint _____
(name, home address and telephone number)

as my health care agent to make any and all health care decisions for me, except to the extent that I state otherwise. This proxy shall take effect only when and if I become unable to make my own health care decisions.

(2) **Optional: Alternate Agent**
If the person I appoint is unable, unwilling or unavailable to act as my health care agent, I hereby appoint _____
(name, home address and telephone number)

as my health care agent to make any and all health care decisions for me, except to the extent that I state otherwise.

(3) Unless I revoke it or state an expiration date or circumstances under which it will expire, this proxy shall remain in effect indefinitely. *(Optional: If you want this proxy to expire, state the date or conditions here.)* This proxy shall expire *(specify date or conditions):* _____

(4) **Optional:** I direct my health care agent to make health care decisions according to my wishes and limitations, as he or she knows or as stated below. *(If you want to limit your agent's authority to make health care decisions for you or to give specific instructions, you may state your wishes or limitations here.)* I direct my health care agent to make health care decisions in accordance with the following limitations and/or instructions *(attach additional pages as necessary):* _____

In order for your agent to make health care decisions for you about artificial nutrition and hydration *(nourishment and water provided by feeding tube and intravenous line)*, your agent must reasonably know your wishes. You can either tell your agent what your wishes are or include them in this section. See instructions for sample language that you could use if you choose to include your wishes on this form, including your wishes about artificial nutrition and hydration.

(5) Your Identification (please print)

Your Name _____

Your Signature _____ Date _____

Your Address _____

(6) Optional: Organ and/or Tissue Donation

I hereby make an anatomical gift, to be effective upon my death, of:
(check any that apply)

Any needed organs and/or tissues

The following organs and/or tissues _____

Limitations _____

If you do not state your wishes or instructions about organ and/or tissue donation on this form, it will not be taken to mean that you do not wish to make a donation or prevent a person, who is otherwise authorized by law, to consent to a donation on your behalf.

Your Signature _____ Date _____

(7) Statement by Witnesses (Witnesses must be 18 years of age or older and cannot be the health care agent or alternate.)

I declare that the person who signed this document is personally known to me and appears to be of sound mind and acting of his or her own free will. He or she signed (or asked another to sign for him or her) this document in my presence.

Date _____ Date _____

Name of Witness 1 (print) _____ Name of Witness 2 (print) _____

Signature _____ Signature _____

Address _____ Address _____

Health Care Proxy Form Instructions

Item (1)

Write the name, home address and telephone number of the person you are selecting as your agent.

Item (2)

If you want to appoint an alternate agent, write the name, home address and telephone number of the person you are selecting as your alternate agent.

Item (3)

Your Health Care Proxy will remain valid indefinitely unless you set an expiration date or condition for its expiration. This section is optional and should be filled in only if you want your Health Care Proxy to expire.

Item (4)

If you have special instructions for your agent, write them here. Also, if you wish to limit your agent's authority in any way, you may say so here or discuss them with your health care agent. If you do not state any limitations, your agent will be allowed to make all health care decisions that you could have made, including the decision to consent to or refuse life-sustaining treatment.

If you want to give your agent broad authority, you may do so right on the form. Simply write: *I have discussed my wishes with my health care agent and alternate and they know my wishes including those about artificial nutrition and hydration.*

If you wish to make more specific instructions, you could say:

If I become terminally ill, I do/don't want to receive the following types of treatments....

If I am in a coma or have little conscious understanding, with no hope of recovery, then I do/don't want the following types of treatments:....

If I have brain damage or a brain disease that makes me unable to recognize people or speak and there is no hope that my condition will improve, I do/don't want the following types of treatments:....

I have discussed with my agent my wishes about _____ and I want my agent to make all decisions about these measures.

Examples of medical treatments about which you may wish to give your agent special instructions are listed below. This is not a complete list:

- artificial respiration
- artificial nutrition and hydration (nourishment and water provided by feeding tube)
- cardiopulmonary resuscitation (CPR)
- antipsychotic medication
- electric shock therapy
- antibiotics
- surgical procedures
- dialysis
- transplantation
- blood transfusions
- abortion
- sterilization

Item (5)

You must date and sign this Health Care Proxy form. If you are unable to sign yourself, you may direct someone else to sign in your presence. Be sure to include your address.

Item (6)

You may state wishes or instructions about organ and /or tissue donation on this form. New York law does provide for certain individuals in order of priority to consent to an organ and/or tissue donation on your behalf: your health care agent, your decedent's agent, your spouse, if you are not legally separated, or your domestic partner, a son or daughter 18 years of age or older, either of your parents, a brother or sister 18 years of age or older, a guardian appointed by a court prior to the donor's death.

Item (7)

Two witnesses 18 years of age or older must sign this Health Care Proxy form. The person who is appointed your agent or alternate agent cannot sign as a witness.

About the Health Care Proxy Form

This is an important legal document.

Before signing, you should understand the following facts:

1. This form gives the person you choose as your agent the authority to make all health care decisions for you, including the decision to remove or provide life-sustaining treatment, unless you say otherwise in this form. "Health care" means any treatment, service or procedure to diagnose or treat your physical or mental condition.
2. Unless your agent reasonably knows your wishes about artificial nutrition and hydration (nourishment and water provided by a feeding tube or intravenous line), he or she will not be allowed to refuse or consent to those measures for you.
3. Your agent will start making decisions for you when your doctor determines that you are not able to make health care decisions for yourself.
4. You may write on this form examples of the types of treatments that you would not desire and/or those treatments that you want to make sure you receive. The instructions may be used to limit the decision-making power of the agent. Your agent must follow your instructions when making decisions for you.
5. You do not need a lawyer to fill out this form.
6. You may choose any adult (18 years of age or older), including a family member or close friend, to be your agent. If you select a doctor as your agent, he or she will have to choose between acting as your agent or as your attending doctor because a doctor cannot do both at the same time. Also, if you are a patient or resident of a hospital, nursing home or mental hygiene facility, there are special restrictions about naming someone who works for that facility as your agent. Ask staff at the facility to explain those restrictions.
7. Before appointing someone as your health care agent, discuss it with him or her to make sure that he or she is willing to act as your agent. Tell the person you choose that he or she will be your health care agent. Discuss your health care wishes and this form with your agent. Be sure to give him or her a signed copy. Your agent cannot be sued for health care decisions made in good faith.
8. If you have named your spouse as your health care agent and you later become divorced or legally separated, your former spouse can no longer be your agent by law, unless you state otherwise. If you would like your former spouse to remain your agent, you may note this on your current form and date it or complete a new form naming your former spouse.
9. Even though you have signed this form, you have the right to make health care decisions for yourself as long as you are able to do so, and treatment cannot be given to you or stopped if you object, nor will your agent have any power to object.
10. You may cancel the authority given to your agent by telling him or her or your health care provider orally or in writing.
11. Appointing a health care agent is voluntary. No one can require you to appoint one.
12. You may express your wishes or instructions regarding organ and/or tissue donation on this form.

HEALTH CARE DECISIONS ACT FOR PERSONS WITH MENTAL RETARDATION

WHAT IS THE HEALTH CARE DECISIONS ACT?

It is a law which became effective in March, 2003 and made explicit the authority of Article 17-A guardians of the person to make health care decisions for persons with mental retardation, including decisions to withhold or withdraw life sustaining treatment if certain statutory criteria were met.

Previously, before an Article 17-A guardian would be appointed for a person with mental retardation or a developmental disability, a licensed physician and licensed psychologist or two licensed physicians would be required to certify that the person was incapable of managing themselves or their affairs because of mental retardation or a developmental disability, and that their condition was permanent or likely to continue indefinitely.

Under the Health Care Decisions Act, the physician and psychologist or two physicians must also determine whether the person with mental retardation or a developmental disability has the capacity to make health care decisions. This means having the ability to understand and appreciate the nature and consequences of health care decisions, including the benefits and risks of and alternatives to any proposed health care, and to reach an informed decision.

Unless specifically prohibited by the court, the Article 17-A guardian of a person with mental retardation or developmental disabilities will have the authority to make all health care decisions that such person could make if they had capacity. This includes decisions to withhold or withdraw life-sustaining treatment.

In addition, the Court of Appeals has determined that the provisions of the Health Care Decisions Act are applicable to Article 17-A guardians regardless of when they were appointed. Thus, it is not necessary for previously appointed guardians to have their guardianships amended to include the authority established by the Health Care Decisions Act.

WHAT AMENDMENTS HAVE BEEN MADE TO THE ORIGINAL LAW?

Under the original law, corporate guardians were prohibited from making decisions to withhold or withdraw life-sustaining treatment. However, this prohibition was subsequently removed, giving corporate guardians the same authority as other 17-A guardians.

Secondly, the applicability of the original law was limited to Article 17-A guardians of the person for persons with mental retardation. It was subsequently amended to apply to persons with developmental disabilities which either include mental retardation or result in similar impairment of intellectual functioning or adaptive behavior.

The most significant amendments have been with respect to the expansion of the list of authorized surrogates for the purposes of making a decision to withhold or withdraw life-sustaining treatment. The current list of authorized surrogates is as follows:

- (1) Article 17-A guardian
- (2) an actively involved¹ spouse
- (3) an actively involved parent
- (4) an actively involved adult child

1. *Actively involved* is defined as: "Significant and ongoing involvement in a person's life so as to have sufficient knowledge of the person's needs."

- (5) an actively involved adult sibling
- (6) an actively involved adult family member²
- (7) The Consumer Advisory Board for the Willowbrook Class (only for class members it fully represents); or
- (8) a surrogate decision-making (SDMC) or a court

Consent must be sought from an appropriate surrogate in the order stated.

ARE THERE ANY STANDARDS FOR THE SURROGATE TO FOLLOW?

The surrogate is required to base all advocacy and health care decision-making solely and exclusively on the best interests of the person with mental retardation or developmental disabilities and, when reasonably known or ascertainable with reasonable diligence, on the wishes of the person with mental retardation or developmental disabilities, including moral and religious beliefs.

An assessment of the best interests of the person with mental retardation or developmental disabilities shall include consideration of five factors:

- (1) the dignity and uniqueness of every person;
- (2) the preservation, improvement or restoration of the health of the person;
- (3) the relief of the suffering of the person by means of palliative care (care to reduce the person's suffering) and pain management;
- (4) the unique nature of artificially provided nutrition or hydration, and the effect it may have on the person; and
- (5) the entire medical condition of the person.

In addition, a surrogate's health care decisions may not be influenced by a presumption that the person with mental retardation or developmental disabilities is not entitled to the full and equal rights, equal protection, respect, medical care and dignity afforded to other persons, nor by financial considerations of the surrogate.

WHAT ABOUT DECISIONS REGARDING LIFE-SUSTAINING TREATMENT?

Specifically with respect to life-sustaining treatment, (LST), the surrogate has an affirmative obligation to advocate for the full and efficacious provision of health care, including life-sustaining treatment. Life-sustaining treatment means medical treatment **including cardiopulmonary resuscitation and nutrition and hydration provided by means of medical treatment**, which is sustaining life functions and without which, according to reasonable medical judgment, the patient will die within a relatively short time period. Cardiopulmonary resuscitation is presumed to be life sustaining treatment without the necessity of a medical judgment by an attending physician.

As indicated by the language in **BOLD**, the definition of LST for purposes of the HCDA has been amended to include DNR. As a result, there is no longer a separate process for obtaining a DNR order. All decisions involving the withholding or withdrawal of LST must comply with the process set forth in the HCDA, which is summarized below. In addition, a checklist which outlines the necessary steps in the process appears on pages 18-19 of this booklet.

2. Family member is defined as: "Any party related by blood, marriage, or legal adoption."

WHAT IS REQUIRED FOR A SURROGATE TO MAKE A DECISION REGARDING LST?

If a surrogate makes a decision to withdraw or withhold life-sustaining treatment (including DNR) from a person with mental retardation or developmental disabilities, the attending physician must confirm that the person lacks capacity to make health care decisions. The attending physician who makes the confirmation is required to consult with another physician or licensed psychologist to further confirm the person's lack of capacity. Either the attending physician or the consulting physician or psychologist must possess specialized training or have experience in providing services to people with mental retardation or developmental disabilities.

In addition, the attending physician, with the concurrence of another physician, must determine to a reasonable degree of medical certainty that **both** of the following conditions are met:

- (1) the person with mental retardation or developmental disabilities has a medical condition as follows:
 - (a) a terminal condition, which means an illness or injury from which there is no recovery and which reasonably can be expected to cause death within one year; or
 - (b) permanent unconsciousness; or
 - (c) a medical condition other than such person's mental retardation or developmental disabilities which requires life-sustaining treatment, is irreversible and which will continue indefinitely; **and**
- (2) the life-sustaining treatment would impose an extraordinary burden on the person, in light of:
 - (a) the person's medical condition, other than the person's mental retardation or developmental disabilities; and
 - (b) the expected outcome of the life-sustaining treatment, notwithstanding the person's mental retardation or developmental disabilities.



In the case of a decision to withdraw or withhold artificially provided nutrition or hydration, one of the following additional factors must also be met:

- (1) there is no reasonable hope of maintaining life; or
- (2) the artificially provided nutrition or hydration poses an extraordinary burden.

The surrogate may express a decision to withdraw or withhold life-sustaining treatment either orally or in writing. If done orally, it must be stated to two persons 18 years of age or older, at least one of whom is the person's attending physician. If done in writing, it must be dated and signed in the presence of one witness 18 years of age or older who must also sign the decision, and presented to the attending physician.

The attending physician must then either issue an order in accordance with the surrogate's decision and advise the responsible staff members, or promptly object to the surrogate's decision.

WHO RECEIVES NOTIFICATION ABOUT DECISIONS REGARDING LIFE-SUSTAINING TREATMENT?

The law provides that at least 48 hours prior to the implementation of a decision to withdraw life-sustaining treatment, or at the earliest possible time prior to the implementation of a decision to withhold life-sustaining treatment the attending physician must notify the following parties:

- (1) the person with mental retardation or developmental disabilities, except if the attending physician determines in writing after consulting with another physician or licensed psychologist that, to a reasonable degree of medical certainty, the person would suffer immediate and severe injury from such notification.
- (2) if the person is in or was transferred from an OPWDD operated or certified residential facility, the Executive Director of the agency operating the facility and the Mental Hygiene Legal Service (MHLS).
- (3) if the person is not in and was not transferred from such a facility, the Commissioner of OPWDD, or his or her designee¹.

WHO MAY OBJECT TO A GUARDIAN'S OR QUALIFIED FAMILY MEMBER'S DECISION REGARDING LIFE-SUSTAINING TREATMENT?

The law establishes seven categories of people who may object to a Surrogate's decision to withhold or withdraw life-sustaining treatment:

- (1) the person with mental retardation or developmental disabilities on whose behalf the decision was made²;
- (2) a parent or adult sibling who either resides with or has maintained substantial and continuous contact with the person with mental retardation or developmental disabilities;
- (3) the attending physician;
- (4) any other health care practitioner providing services to the person with mental retardation or developmental disabilities;
- (5) the Executive Director of the agency operating the facility in which the person resides;
- (6) if the person is in or was transferred from an OPWDD operated or certified residential facility, MHLS;
- (7) if the person is not in and was not transferred from an OPWDD operated or certified residential facility, the Commissioner of OPWDD, or his or her designee.

Any of the listed parties may object either orally or in writing.

An objection by any of the listed parties will result in the suspension of the surrogate's decision, pending judicial review, except if the suspension would be likely to result in the death of the person with mental retardation or developmental disabilities. If the surrogate's decision is suspended following an objection, the objecting party is required to notify the surrogate and the other parties who could have objected to such decision.

¹ Pursuant to the OPWDD regulation at section 633.10(a)(7)(iii), the Commissioner has designated the DDSO directors to receive these notifications.

² Although the legislature did not specify the process of assisting a person who wishes to make an objection, it is our position that the person could tell anyone they object, and that other person should assist in making the objection known to the attending physician, guardian or qualified family member and all other parties.

WHAT ARE THE OBLIGATIONS OF HEALTH CARE PROVIDERS?

A health care provider is required to comply with the health care decisions made by a surrogate in good faith pursuant to the law, to the same extent as if the decisions had been made by the person with mental retardation or developmental disabilities if he or she had capacity.

However, a private hospital would not be required to honor a decision which is contrary to a formally adopted written policy of the hospital expressly based on religious beliefs or sincerely held moral convictions central to the hospital's operating principles.

ARE GUARDIANS AND QUALIFIED FAMILY MEMBERS PROVIDED WITH IMMUNITY?

Yes. Surrogates cannot be subjected to criminal or civil liability as long as they make a health care decision reasonably and in good faith pursuant to the law.

HCDA – Required Steps

Medical decisions which involve the withholding or withdrawing of life sustaining treatment (LST) for individuals with DD who lack capacity and do not have a health care proxy must comply with the process set forth in the Health Care Decisions Act for persons with MR (HCDA) [SCPA § 1750-b (4)]. Effective June 1, 2010, this includes the issuance of DNR orders. This document sets forth the required steps to comply with the HCDA. Documentation for each step must be included in the individual's medical record.

Step 1–Identification of Appropriate 1750-b Surrogate from Prioritized List.

- (1) 17-A guardian
- (2) actively involved spouse
- (3) actively involved parent
- (4) actively involved adult child
- (5) actively involved adult sibling
- (6) actively involved family member
- (7) Willowbrook CAB (full representation)
- (8) Surrogate Decision Making Committee (MHL Article 80)

Step 2–1750-b surrogate makes decision to withhold or withdraw LST, either orally or in writing.

Note: Decision must clearly specify the LST that is requested to be withdrawn or withheld.

Decision made orally (to attending physician and one other person over age 18.)

Decision made in writing (must be dated, signed by surrogate, signed by 1 witness and given to attending physician).

Step 3–Confirm individual's lack of capacity to make health care decisions.

Attending physician's determination must include his/her opinion regarding the cause and nature of the person's incapacity, its extent and probable duration. Either the attending physician or the concurring physician or licensed psychologist must: (a) be employed by a DDSO; or (b) have been employed for at least 2 years in a facility or program operated, licensed or authorized by OPWDD; or (c) have been approved by the commissioner of OPWDD as either possessing specialized training or have 3 years experience in providing services to individuals with DD.

Step 4- Determination of Necessary Medical Criteria.

Two physicians must determine to a reasonable degree of medical certainty that both of the following conditions are met:

- (1) the individual has one of the following medical conditions:
 - (a) a terminal condition; or
 - (b) permanent unconsciousness; or
 - (c) a medical condition other than DD which requires LST, is irreversible and which will continue indefinitely

AND

- (2) the LST would impose an extraordinary burden on the individual in light of:
 - (a) the person's medical condition other than DD and
 - (b) the expected outcome of the LST, notwithstanding the person's DD

If the 1750-b surrogate has requested that artificially provided nutrition or hydration be withdrawn or withheld, one of the following additional factors must also be met:

- (a) there is no reasonable hope of maintaining life or;
- (b) the artificially provided nutrition or hydration poses an extraordinary burden.

Step 5 - Notifications.

At least 48 hours prior to the implementation of a decision to withdraw LST, or at the earliest possible time prior to a decision to withhold LST, the attending physician must notify the following parties:

the person with DD, unless therapeutic exception applies

if the person is in or was transferred from an OPWDD residential facility: Facility Director and MHLS

if the person is not in and was not transferred from an OPWDD residential facility: the director of the local DDSO

Step 6 - Objections

- (1) If no objection is received, or all notified parties have responded that they do not object, the surrogate's decision shall be implemented
- (2) If there is an objection (oral or written) the surrogate's decision shall be suspended and
 - (a) dispute mediation – may be requested by objecting party or surrogate (other than SDMC). This is non-binding mediation. Party requesting mediation must provide notifications. If objection is withdrawn, surrogate's decision shall be implemented.
 - (b) court review – may be requested by: the surrogate; attending physician; director of residential facility; MHLS or OPWDD Commissioner or designee. Court decides whether or not surrogate's decision should be implemented.

**State of New York
Department of Health**

**Nonhospital Order Not to Resuscitate
(DNR Order)**

Person's Name _____

Date of Birth ___ / ___ / ___

Do not resuscitate the person named above.

Physician's Signature _____

Print Name _____

License Number _____

Date ___ / ___ / ___

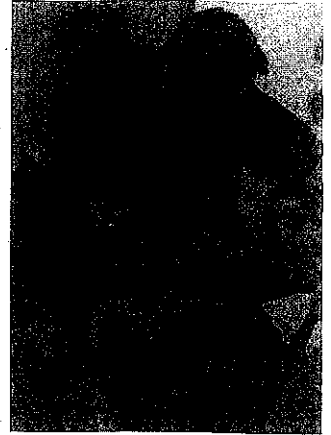
It is the responsibility of the physician to determine, at least every 90 days, whether this order continues to be appropriate, and to indicate this by a note in the person's medical chart. The issuance of a new form is NOT required, and under the law this order should be considered valid unless it is known that it has been revoked. This order remains valid and must be followed, even if it has not been reviewed within the 90-day period.

LIVING WILLS

WHAT IS A LIVING WILL?

A living will is a document that provides specific instructions about health care treatment. It is generally used to declare wishes to refuse life-sustaining treatment under specific circumstances that may arise in the future. It does not appoint a "health care agent" and does not replace a health care proxy. It is generally used when a person wants to make his or her wishes known concerning health care, but does not have someone available to act as health care agent.

In contrast, the health care proxy allows a person to choose someone he or she trusts to make treatment decisions on his or her behalf. Unlike a living will, a health care proxy does not require a person to know in advance all the types of decisions that may arise in the future. Instead, a person's health care agent can interpret his or her wishes as medical circumstances change, and make decisions a person could not have known would have to be made. However, a person can include instructions in a health care proxy if he or she wishes to do so. A health care proxy is just as useful for decisions to receive treatment as it is for decisions to stop treatment. If a person has a health care proxy, but also has a living will, the living will can provide instructions for the health care agent, and will guide his or her decisions.



GLOSSARY

Agent, health care. An adult to whom authority to make health care decisions is delegated pursuant to a properly executed health care proxy.

Article 17-A guardian. A guardian appointed pursuant to Article 17-A of the Surrogate's Court Procedure Act (SCPA). SCPA section 1750 covers guardianship of persons with mental retardation; section 1750-a covers guardianship of persons with other developmental disabilities. Under either section, the Surrogate's court may appoint a guardian of the person, of the property or of both the person and the property. If guardianship is being sought for the purpose of obtaining the authority to make health care decisions on behalf of the person, guardianship of the person is needed. Parents have the primary right to be appointed guardians of their children. Other than parents, no one has priority under Article 17-A to be appointed guardian. The guardian may be a sibling, another relative, a friend or a qualified organization (corporate guardian).

Available, reasonably. A surrogate to be contacted can be contacted with diligent efforts within a reasonable time by an attending physician or other party seeking to obtain informed consent for the purposes of section 633.11, or a DNR decision pursuant to section 633.18.

Board, Consumer Advisory (CAB). A seven member board established in conformance with the requirements of the Willowbrook Consent Judgment.

Capacity. The ability to adequately understand and appreciate the nature and consequences of professional medical treatment and DNR orders, including the benefits and significant risks and alternatives to such treatment so as to be capable of making a decision thereto in a knowing and voluntary manner. A person's decision relative to the proposed professional medical treatment or proposed DNR order shall not, in and of itself, be the exclusive basis for the determination of capacity.

Care, health. Any treatment, service or procedure to diagnose or treat an individual's physical or mental condition.

DDSO. Developmental Disabilities Service Office is the local administrative unit of OPWDD. The governing body of a DDSO is the central office administration of OPWDD. The DDSO director is its chief executive officer.

Decision, health care. Any decision to consent or refuse to consent to health care.

Decision, capacity to make health care. The ability to understand and appreciate the nature and consequences of health care decisions, including the benefits and risks of, and alternatives to, any proposed health care, and to reach an informed decision.

Involved, actively. Significant and ongoing involvement in a person's life so as to have sufficient knowledge of the person's needs.

Member, family. Any party related by blood, marriage or legal adoption.

Mental Hygiene Legal Service (MHLS). An agency of the Appellate Division of the State Supreme Court which provides legal services, advice and assistance to persons with developmental disabilities, pursuant to Article 47 of the Mental Hygiene Law.

Order, do not resuscitate (DNR). Instructions not to attempt cardiopulmonary resuscitation in the event a person suffers cardiac or respiratory arrest. Such instructions may cover any cardiopulmonary resuscitation measures or may be limited depending on the scope of the consent.

Order, non-hospital DNR. A do not resuscitate instruction issued for a person who is not a resident of a developmental center; or instructions issued for a person in a developmental center, hospital, psychiatric center or residential health care facility which is to take effect only after the person leaves such a facility.

Physician, attending. As used in connection with DNRs, health care proxies or the Health Care Decisions Act, the physician selected by, or assigned to, a person in a developmental center, hospital, psychiatric center, residential health care facility, or any facility certified or operated by OPWDD who has primary responsibility for the treatment and care of that person. Where more than one physician shares such responsibility, any of such physicians may act as the attending physician pursuant to these sections.

Principal. For purposes of health care proxies, a person who has executed a health care proxy.

Proxy, health care. A document delegating the authority to make health care decisions, executed in accordance with applicable requirements.

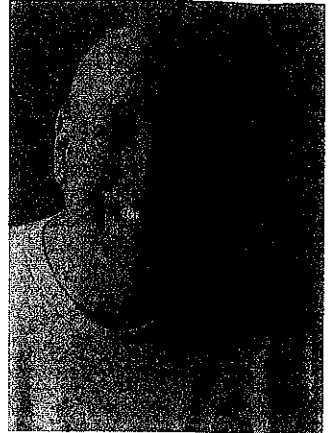
Resuscitate, order not to (DNR orders). Instructions not to attempt cardiopulmonary resuscitation in the event a person suffers cardiac or respiratory arrest. Such instructions may cover any cardiopulmonary resuscitation measures or may be limited depending on the scope of the consent.

Resuscitation, cardiopulmonary (CPR). Any measures to restore cardiac function or pulmonary function in the event of a cardiac or respiratory arrest such as manual chest compression, mouth-to-mouth rescue breathing, intubation, direct care injection, intravenous medications, electrical defibrillation, and open chest cardiac massage. For purposes of DNRs, cardiopulmonary resuscitation shall also include the transfer of a person to another facility if solely for the purpose of providing cardiopulmonary resuscitation. Cardiopulmonary resuscitation shall not include measures to improve pulmonary and cardiac function in the absence of an arrest.

Surrogate. For the purposes of 633.11 and 633.18, a party designated to act in the place of a person receiving services by the provisions of the respective regulations.

Treatment, capacity to understand appropriate disclosures regarding proposed professional medical. The ability to adequately understand and appreciate the nature and consequences of such professional medical treatment, including the benefits and significant risks and alternatives to such treatment so as to be capable of making a decision thereto in a knowing and voluntary manner. A person's decision relative to the proposed professional medical treatment shall not, in and of itself, be the exclusive basis for the determination of capacity.

Treatment, professional medical. A medical, dental, surgical or diagnostic intervention or procedure in which a general anesthetic is used or which involves a significant invasion of bodily integrity requiring an incision or producing substantial pain, discomfort, debilitation or having a significant recovery period, or any professional diagnosis or treatment to which informed consent is required by law.



PLACES TO OBTAIN ADDITIONAL INFORMATION

- 1) NYS Office For People With Developmental Disabilities (OPWDD)
44 Holland Avenue
Albany, New York 12229
www.opwdd.ny.gov
- 2) NYS Commission on Quality of Care and Advocacy for Persons with Disabilities (CQC)
 - a) CQC Legal Services Bureau
401 State Street
Schenectady, New York 12305
518-388-1270
www.cqc.ny.gov/homepage.htm
 - b) CQC Surrogate Decision-Making Committee
401 State Street
Schenectady, New York 12305
518-388-2820
www.cqc.ny.gov/sdmc.htm
- 3) NYS Department of Health www.health.ny.gov

Persons with developmental disabilities seeking additional information regarding these issues are urged to contact:

- a) their service coordinators;
- b) their local self-advocacy association; or
- c) a local ombudsperson



For further information, please check the OPWDD Website:

www.opwdd.ny.gov

A publication of NYS OPWDD Communications Office
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