

-
- Active Representation
 - Informed Consent for "Professional Medical Treatment" when CAB fully represents the Class Member
 - Willowbrook Considerations: Do Not Resuscitate (DNR), Do Not Intubate (DNI), Life Sustaining Treatment (LST)

Active Representation

Important Reference: Willowbrook Active Representation

- Correspondence dated 9/30/2011 posted on the *Beyond Willowbrook* website
- Updates prior memoranda related to sign off on movements, plans of care and treatment on behalf of Willowbrook class members

Active Representation

Is...

- Per the Willowbrook Permanent Injunction,
 - ✓ Correspondent participation with the program planning team in planning and evaluating the person's plan of services; and/or visits the class member at least annually

Is not...

- Merely signing consent forms sent through the mail or receiving phone calls initiated by staff with no other involvement

Representation is first and foremost for the class member

If the family is not meeting the standard of active representation, for whatever reason, and the class member cannot self-advocate, then the class member should be referred to CAB

Active Representation Status: **Self-advocate**

- A class member who self-advocates acts as his or her own correspondent
 - ✓ A class member who self-advocates may also have co-representation from a family member or the CAB
- As a self-advocate, the class member gives his or her own consent for movements, release of information, participation in activities, routine medical/dental care, etc.
- The class member who self-advocates may also sign for invasive medical/dental treatment when determined to be capable of making the decision at hand

When a class member is not a self advocate...

- The correspondent would be either...
 - ✓ A parent or legal guardian
 - ✓ Alternate family member
 - ✓ The Consumer Advisory Board (CAB)

Active Representation Status: Family full representation

- A parent/family member may act as the class member's correspondent
 - ✓ The parent/family may also elect to have co-representation from the CAB
- As the correspondent, the parent/family member gives consent for movements, release of information, participation in activities, routine medical/dental care, etc.
- The parent/family member acting as correspondent is also able to sign for invasive medical/dental treatment

Active Representation Status: CAB co-representation

- CAB staff attend team meetings and visit programs
- CAB is notified along with the self advocate/family of significant events, including medical, injuries and incidents
- The self-advocate/family retains its responsibility as correspondent, to review and respond to issues that require written consent, including informed consent
 - ✓ Therefore, CAB staff do NOT sign plans of care or give consent for care and treatment for class members they co-represent

Active Representation Status: CAB full representation

- The Board acts as correspondent for the class member
- The Board provides informed consent for surgery and/or other invasive treatments; or end of life decisions
- On behalf of the Board, local CAB representatives...
 - ✓ attend team meetings and advocate for the class member
 - ✓ visit the class member
 - ✓ make recommendations to the Board
 - ✓ ensure that the class member is receiving appropriate services, and that services are consistent with his/her plans;
 - ✓ follow up on identified problems; and
 - ✓ report to the Board

Remember: When CAB fully represents a class member...

- The Board acts as correspondent/ surrogate for the class member
- The local CAB representatives provide the eyes/ears/voice for the Board but are NOT the correspondent/surrogate
- If a surrogate name is needed for any form or document, enter Consumer Advisory Board (CAB)

Willowbrook Concerns



The Willowbrook parties feel that OPWDD is not ensuring active representation for class members

- ✓ They feel MSCs and program staff are obliged to be knowledgeable regarding active representation status for each class member
- ✓ They feel providers are not taking timely steps to involve CAB when class member family members retire/relocate out of state/age and/or die

Willowbrook Concerns



The parties feel that the DDSOs and agencies do not understand the role of CAB and the different functions of the local representatives and the Board itself

- ✓ The local representative serves as the point person for DDSOs and voluntary agencies BUT the BOARD is the deciding body
- ✓ For example, when surrogate name is requested, enter "Consumer Advisory Board," never name of local representative

Willowbrook Expectations...



- Teams should discuss active representation status for each class member at the semi-annual update and annual review
- The plan of services should reflect whether the class member self-advocates or whether family member(s) or the CAB serve as sole advocate or co-representative on their behalf
- If family is involved, the plan of services and follow up documentation should include the frequency of visits and/or participation with team members

Active Representation Monitoring

- OPWDD has developed the **WillowBrook CAB Active Representation** data system to maintain information on CAB involvement on behalf of class members
 - ✓ Service coordination/case management providers are to report active representation status to the DDSO Willowbrook liaisons quarterly along with caseload reporting

When offering CAB to correspondents...

The Willowbrook CM/SC should adapt 1 of 2 sample letter formats with prescribed attachments, located at http://www.opwdd.ny.gov/willowbrook/hp_willowbrook_activerep.jsp

- 1st letter format is used when CAB is "no rep"
- 2nd letter format is used when CAB already provides co-representation

Attachments:

1. ACTIVE REPRESENTATION RESPONSE FORM
 - ✓ Note: Active Representation options **CANNOT** be changed
2. Responsibilities of Correspondent
3. Definition of Willowbrook Active Representation

When offering CAB to correspondents...

- The DDSO Willowbrook liaison and CAB Executive Director should be cc'd on the correspondence to the correspondent
- Copies of the completed response form should be forwarded to the DDSO Willowbrook Liaison and CAB Executive Director

Informed Consent When CAB Fully Represents the Class Member

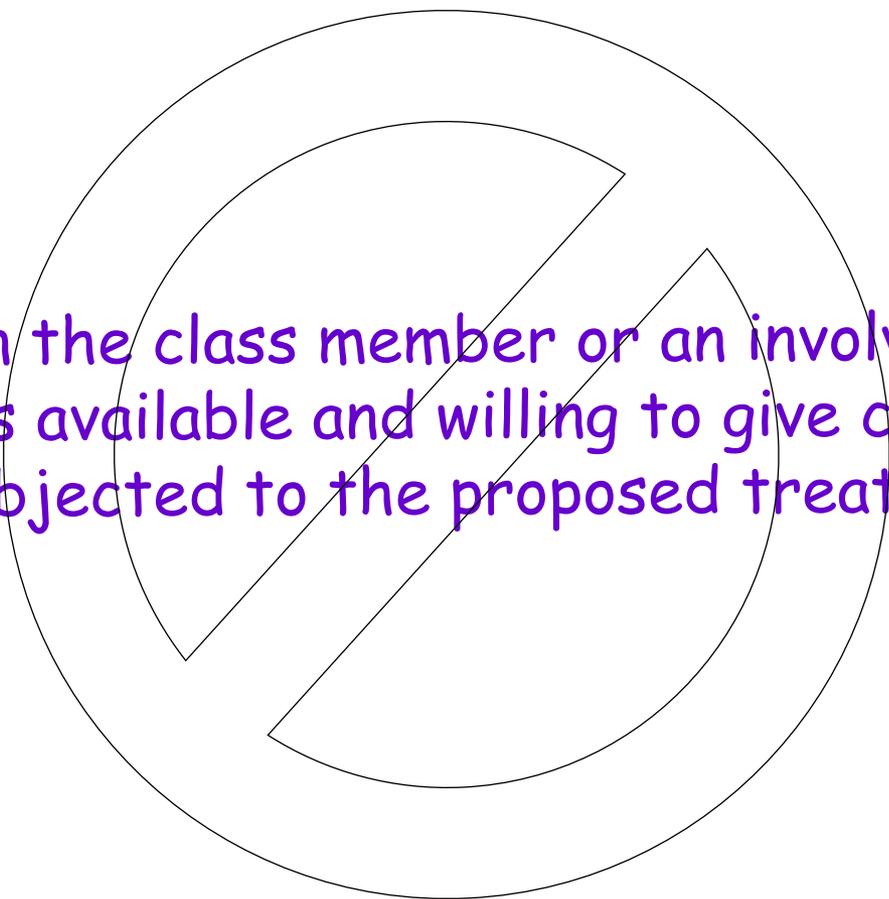
Effective 11/23/2005...

- OPWDD's regulation on informed consent for medical treatment 14 NYCRR 633.11 was amended to include CAB on the list of surrogate decision makers
- CAB is authorized to make informed consent decisions for a class member who is not able to make the informed medical decision and has no other identified surrogate
- The following is the order for surrogates:
 - ✓ a legal guardian or health care agent;
 - ✓ an actively involved spouse;
 - ✓ an actively involved parent;
 - ✓ an actively involved adult child;
 - ✓ an actively involved adult sibling;
 - ✓ or actively involved adult family member;
 - ✓ or the CAB for class members for whom it fully represents; OR
 - ✓ a surrogate decision-making committee (SDMC) or a court

CAB is **NOT** authorized to give informed consent for class members...

- who are able to give informed consent on their own behalf;
- who have a legal guardian, health care agent [person appointed pursuant to a health care proxy executed by the individual] or other actively involved family member to act as surrogate decision maker; or
- when CAB provides co-representation.

CAB will **NOT** give informed consent...



...when the class member or an involved family member is available and willing to give consent or has objected to the proposed treatment

When CAB is the identified surrogate for a class member...

- Depending on the procedure, the provider submits either the **Dental Consent Overview or Medical Consent Overview**, AND **CAB Informed Consent Submission Checklist**
- Current forms dated [4/15/09] and available on OPWDD's website at http://www.opwdd.ny.gov/hp_cabconsent_index.jsp
- The compiled information is submitted **via paper mail** to Antonia Ferguson, Executive Director of the CAB, at 1050 Forest Hill Road, Staten Island, NY 10314

Requesting agencies are expected to...

- Implement a review protocol for requests for informed consent, which includes sign off from administrative or medical supervisory staff
 - ✓ sign off is to be reflected on the **CAB Informed Consent Submission Checklist** and **Medical /Dental Consent Overview**
- Maintain a detailed chronology of contacts following submission of its request for informed consent, with local CAB reps and CAB Central Office in SI
 - ✓ include all dates of verbal or phone contact, questions from CAB and follow up actions taken by the agency

Requesting agencies are expected to...

- Respond timely to all questions and requests for information from the CAB.
 - ✓ Remember ~ All responses to questions and requests for information must be reflected in the chronology.
- Notify CAB of date of procedure/ treatment AND forward results/findings to the Executive Director of the CAB, 1050 Forest Hill Road, Staten Island, NY 10314



Requesting agencies are expected to...

- Notify DDSOs of all requests for informed consent to CAB:
 - ✓ Fax the **CAB Informed Consent Submission Checklist** to the DDSO Director immediately after mailing ~ DDSO enters date received in Box 1
 - ✓ Notify the DDSO Director immediately when the information packet is returned for resubmission, or when the signed or declined consent form is received from CAB ~ DDSO enters date consent confirmed in Box 3

Requesting agencies are expected to...

- Keep the DDSO informed of status of request
 - ✓ DDSO needs to know if request for informed consent is still pending after 30 business days
 - ✓ If signed or declined consent has been secured, DDSO will note on its copy of the **CAB Informed Consent Submission Checklist**
- If the request is still outstanding, the DDSO Director or designee will contact Ms. Ferguson to ascertain the status of the submission

WHEN will requesting agencies hear from CAB?

- As a rule, CAB will complete a regular review, when all required documentation is submitted, within 21 business days.
- Expedited decisions will be made within 8 business days of submission when all required documentation is submitted.

HOW will requesting agencies hear from CAB?

- Once all questions are fully addressed and information received, the signed or declined consent will be forwarded via regular mail directly to the originating requestor as reflected on the **CAB Informed Consent Submission Checklist** along with the local CAB representative
 - ✓ On an exception basis only, CAB will fax the copy directly to a provider if a faxed consent is accepted by the health care provider, i.e., hospital, clinic, physician, etc.

What if an alternate surrogate exists?

- 633.11 allows the requesting agency to seek consent from the next highest surrogate if the authorized surrogate is “not reasonably available and willing, and is not expected to become reasonably available and willing to make a timely decision given the person’s medical circumstances.” However, the agency must document the efforts made to contact the surrogate
- IF a surrogate refuses to provide the requested consent and the agency believes the proposed treatment would be in the person’s best interest, the agency should apply for court authorization for the proposed treatment



What happens in an emergency?

- For 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 treatment may accept the authorization of the chief executive officer of the person’s residential facility to render treatment
- Public health law defines “emergency” as when a person is in immediate need of medical attention and an attempt to secure consent would result in delay of treatment that would increase the risk to the person’s life or health”



What happens in an emergency? continued

- Before declaring an “emergency”, the hospital/physician will attempt to reach out to the appropriate surrogate to obtain informed consent
- For a member fully represented by the CAB, the hospital/physician would reach out to CAB Central Office in Staten Island, to give notice of the situation
- If the CAB cannot be reached or cannot provide consent given the circumstances, the treatment should be provided on an “emergency” basis.
- Some hospitals/physicians will simply provide such treatment; others will seek the director’s authorization pursuant to Section 633.11



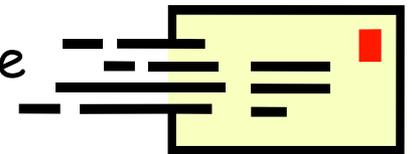
What happens when urgent care is needed?

- Urgent care is needed when a condition occurs suddenly and unexpectedly; requires prompt diagnosis or treatment; and in the absence of immediate care, the individual could reasonably be expected to suffer chronic illness, prolonged impairment or require a more hazardous treatment.
- When a class member fully represented by CAB is in the hospital and requires urgent care:
 1. Contact CAB directly by telephone at 718-477-8800
 2. Primary health contact completes the **Medical Consent Overview** form; faxes to the CAB Staten Island Office at 718-477-8805
 3. All questions on the **Overview** form should be answered to prevent delays; however, responses to some questions will be abbreviated since CAB will obtain supplemental information directly from the physician via telephone



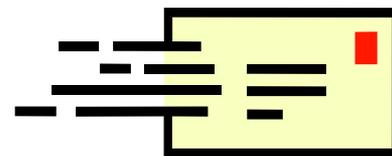
TIPS to facilitate requests for CAB informed consent

- Do not use SDMC forms ~ they will be returned to the originating requestor.
- Failure to submit all required documentation delays the review, and will result in the return of the information packet to the originating requestor for resubmission.
- Piecemeal submission will also delay the review process.
- For expedited requests only, fax submissions will be accepted
 - ✓ Please confirm that the pages received are legible



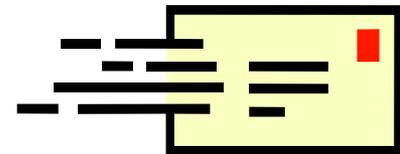
TIPS to facilitate requests for CAB informed consent

- If sedation or anesthesia is required, include an explanation including type of anesthesia and risk/benefit information
- Always include recent annual medical assessment and laboratory reports
- Provide a listing of current medication ~ remember name and dosage
- Any known medication or food allergies
- Don't forget weight information for the past year



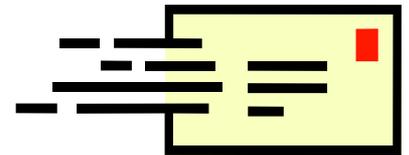
TIPS to facilitate requests for CAB informed consent

- Include a statement from the ISP/CFA or a recent assessment by a qualified examiner that confirms:
 - ✓ the class member lacks capacity to give informed consent for the proposed medical treatment and the basis for the statement
 - ✓ no health care agent, legal guardian, or actively involved family member is available to grant informed consent
 - ✓ the class member is fully represented by the Consumer Advisory Board



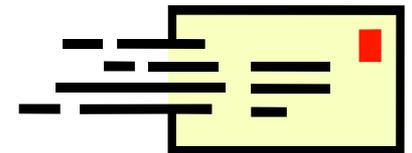
TIPS to facilitate requests for CAB informed consent

- Work with local CAB representative immediately when professional medical treatment is recommended, and communicate throughout the process
- Give advance notice to local CAB representative of related appointments so that, if possible, they can attend
- Remember to request a status from the local CAB representative



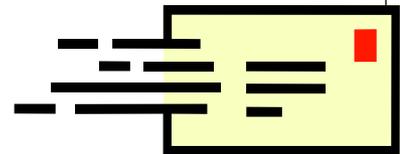
TIPS to facilitate requests for CAB informed consent

- If an expedited decision is needed [within 8 business days of submission], inform the local CAB representative, and reflect on the *CAB Informed Consent Submission Checklist* and cover letter
- Remember to provide the medical recommendation/justification for the expedited review



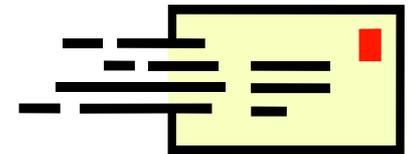
TIPS to facilitate requests for CAB informed consent

- Ensure that the primary health services contact (RN or MD) is available to respond to CAB questions.
- Ensure prompt response to CAB's inquiries from the health care provider proposing the treatment
 - ✓ The secondary contact is designated by the requesting agency ~ it may be the service coordinator/case manager, residential director or other agency designee. It is helpful if the secondary contact is aware and knowledgeable of the submission
 - ✓ The local CAB rep is NEVER the secondary contact



TIPS to facilitate requests for CAB informed consent

- Seek a second opinion for medical/dental treatment when questions can be anticipated
- Include all applicable documentation from these medical/dental consultations to facilitate the CAB review



What if...

...there is known family who is not the correspondent for the class member and has not been active in care and treatment?

- A non-correspondent family member may be initially passed over in the chain of surrogate decision makers. However, the provider **must** include the name, address and telephone number of any known family member in its request to CAB for informed consent.



What if...

...there is a family member who has served as correspondent for the class member with CAB co-representation; however, the family is no longer involved and no other family is immediately available to serve as correspondent?

- Immediately submit a written request for full representation to the Executive Director CAB. CAB is unable to give informed consent until it serves as the full representative.
- If an alternate family member subsequently indicates a willingness to serve as correspondent, the issue of co-representation would be revisited.



What if...

...the class member has served as his/her own correspondent with no CAB involvement; however, the individual is no longer able to provide his/her own informed consent and no other family is immediately available to serve as correspondent?

- If the class member has not executed a health care proxy, immediately submit a written request for full representation to the Executive Director CAB. CAB is unable to give informed consent until it serves as the full representative.
- If an alternate family member subsequently indicates a willingness to serve as correspondent, the issue would be revisited.



Is informed consent required for IV sedation for dental services?

- Dental procedures performed under general anesthesia must go before the CAB for informed consent.
- For dental procedures that require informed consent in which IV sedation is required, the informed consent provided by CAB will cover both the procedure and IV sedation.
- The local representative on behalf of CAB is able to provide consent for routine dental procedures when IV sedation is required.



Does the primary health services contact have to be available during evening hours?

- Agencies must ensure the primary health services contact (RN or MD) is available by telephone to respond to CAB questions, and facilitate CAB's communication directly with the health care provider proposing treatment
 - ✓ These telephone calls will be scheduled with notice during day or evening hours
- Include all communication by the primary health services contact in the chronology maintained by the requesting agency



Is informed consent required for presentation when it is required to perform the proposed medical or dental treatment?

- Informed consent for presentation is included in CAB's informed consent for the underlying professional medical treatment.
- Once the procedure/treatment is completed, are there other steps to be taken to finalize documentation?
 - ✓ The primary health services contact should forward the results of the procedure to the Executive Director of the CAB, 1050 Forest Hill Road, Staten Island, NY 10314.



Is it routine care or professional medical treatment?

- Venipuncture, suturing of lacerations and catheterization of the bladder are routine.
- Radiology procedures not involving contrast are routine; however, radiology procedures involving contrast with radiopaque dyes or contrast media require informed consent due to the risk of allergic reaction.
- Sigmoidoscopies, colonoscopy and endometrial biopsies require informed consent due to the risk of perforation.



Is it routine care or professional medical treatment?

- Biopsies of suspicious skin lesions that involve scraping are routine; however, those involving excision procedures would require informed consent due to the risk of bleeding and infection, and due to the cuts that compromise body integrity.



Is it routine care or professional medical treatment?

- Reduction and casting of fractures depends on the situation. If considered an emergency, care would be covered under Public Health Law 2504. Routine recasting does not require informed consent.
- If a break has not healed well and internal fixation is required, informed consent is needed for this surgical procedure.



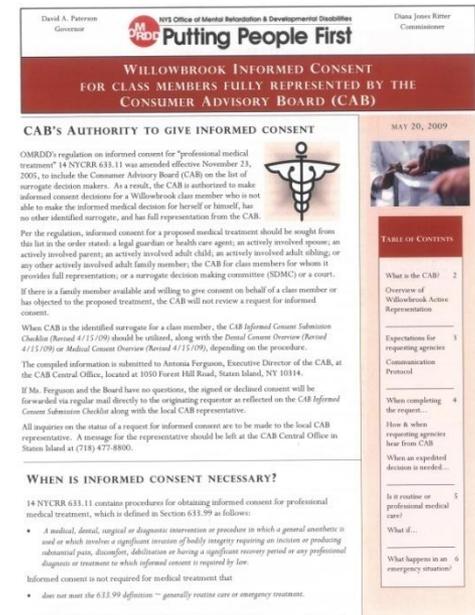
Is it routine care or professional medical treatment?

- Aspiration or injection of joints, tendons, or cysts that involve a fine needle biopsy do not require informed consent.
- Surgical biopsies; fine/core needle biopsies, i.e., breast, liver; and transurethral biopsies of the bladder requires informed consent due to the invasive nature of the procedures.
- Insertion of a central venous catheter for venous access requires informed consent due to the intrusive nature of the catheter.



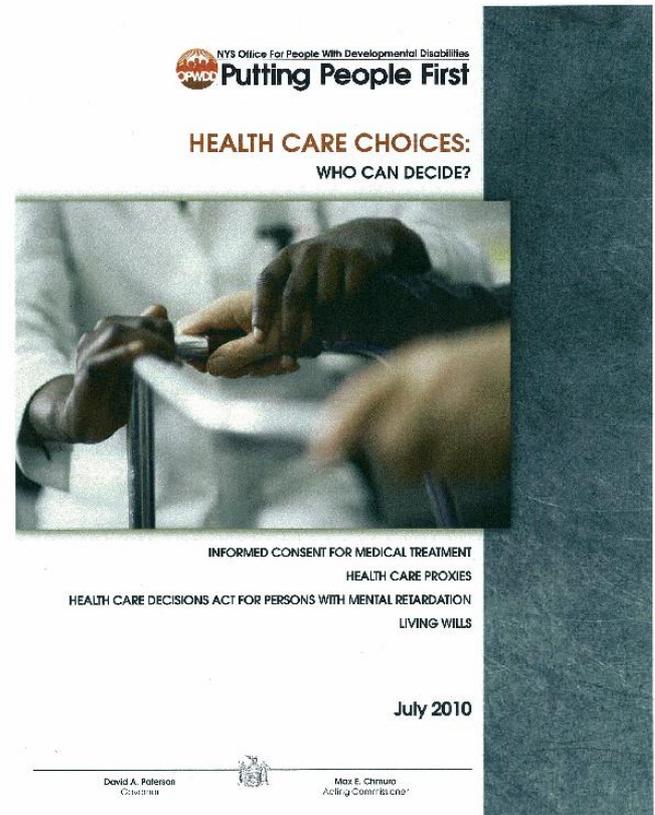
For more about Willowbrook informed consent...

- Reference the document, **Willowbrook Informed Consent for Class Members Fully Represented by the Consumer Advisory Board, last updated September 30, 2011**
- Available on OPWDD's website as follows:
 - Go to <http://www.omr.state.ny.us/>
 - Select "News & Publications"
 - Select "Publications"
 - See "CAB Informed Consent"



Another important resource for health concerns...

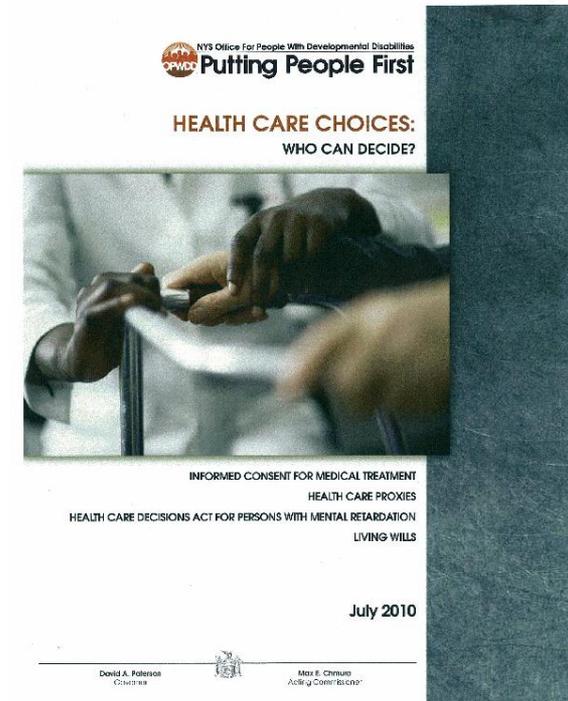
- Reference the document, **HEALTH CARE CHOICES: WHO CAN DECIDE?**, issued March 2011 to learn about...
 - ✓ Informed consent for professional medical treatment
 - ✓ health care proxies
 - ✓ DNR Orders
 - ✓ Health Care Decisions Act for Persons with Mental Retardation
 - ✓ Living Wills



Willowbrook Considerations ~
Do Not Resuscitate (DNR), Do Not Intubate
(DNI), Life Sustaining Treatment (LST)

CAB is now an authorized surrogate for DNR/DNI/LST

- Effective 6/1/10, the Health Care Decisions Act (HCDA) process was changed for all decisions involving the withholding or withdrawing of life-sustaining treatment, including
 - ✓ Do Not Resuscitate (DNR),
 - ✓ Do Not Intubate (DNI) or
 - ✓ Life Sustaining Treatment (LST)
- HCDA created one set of medical criteria and one surrogate list for all such decisions, which includes CAB for class members fully represented by the CAB
- Access additional information at http://www.opwdd.ny.gov/health/images/hp_fhcda_memo.pdf



What is life-sustaining treatment?

- Life sustaining treatment means medical treatment **including CPR and artificial nutrition and hydration** which is sustaining life functions and without which according to reasonable medical judgment, the patient will die within a relatively short time period



Prioritized Surrogate List

- ✓ Article 17-A guardian
- ✓ Qualified family member [14 NYCRR section 633.10(a)(7)(iv)]
 - Actively involved spouse
 - Actively involved parent
 - Actively involved adult child
 - Actively involved adult sibling
 - Actively involved adult family member
- ✓ CAB
- ✓ Surrogate Decision-Making Committee

Steps in securing DNR Orders and Life Sustaining Treatment (LST)

- Step 1-Identification of Appropriate 1750-b Surrogate from Prioritized List
 - ✓ Should be the signer for the class member
- Step 2-1750-b surrogate makes decision to withhold or withdraw LST, either orally or in writing.
- Step 3-Confirm individual's lack of capacity to make health care decisions.
- Step 4- Determination of Necessary Medical Criteria.
- Step 5- Notifications
- Step 6- Objections

When is CAB the 1750-b surrogate?

- When CAB is the 17A guardian
- When CAB provides full representation for a class member

Remember: CAB is NOT the 1750-b Surrogate when CAB provides co-representation

- ✓ In these instances, the local representative is NOT the authorized Surrogate and cannot consent to DNR, DNI, LST but should be kept informed throughout the process



How will CAB make a request for DNR/DNI/LST?

- The process begins with a conversation or series of conversations between the class member, CAB as 1750-b surrogate, and qualified, trained health care professional
 - ✓ This minimally includes diagnosis, progress, objectives for care, treatment preferences, CAB position on DNR, DNI, LST
- When CAB is 1750-b Surrogate, the request will be made in a letter issued by Antonia Ferguson, Executive Director
 - ✓ In lieu of a letter, the request may be made orally in extenuating situations, i.e., a weekend or holiday



What documentation is required?

- The MOLST LEGAL REQUIREMENTS CHECKLIST for Individuals With Developmental Disabilities is completed first and must accompany the MOLST or DOH Nonhospital Order
 - ✓ MOLST = Medical Orders for Life Sustaining Treatment
 - ✓ The MOLST LEGAL REQUIREMENTS CHECKLIST confirms that the appropriate statutory standards have been met per the Health Care Decisions Act (HCDA)
- A Nonhospital DNR order may be documented on either the DOH Nonhospital DNR form or on the MOLST



When should the MOLST be used?

- The MOLST is an optional form and best used when the person has serious health conditions
- The MOLST is the only authorized form in NYS for documenting both DNR and DNI orders.
- Use of the MOLST should be seriously considered when a decision has been made to withhold or withdraw LST other than CPR



Is a DNR/DNI/LST Order transferable between home and hospital?

- When a class member is admitted to the hospital with a DOH Nonhospital DNR Order, it will be reviewed by the hospital physician
 - ✓ A new order will be needed when the class member returns home
- A DNR issued on a MOLST form is transferable between settings
 - ✓ The MOLST form is effective in hospitals, nursing homes, community settings
 - ✓ Review and renewal of the DNR must be done upon discharge from the hospital and reflected in Section F of the MOLST



Who fills out the MOLST form?

- A blank MOLST form should never be sent to the 1750-b Surrogate
- It is only appropriate to complete the MOLST after the MOLST LEGAL REQUIREMENTS CHECKLIST has been completed
 - ✓ After the MOLST Legal Requirements Checklist has been completed, the 1750-b Surrogate will determine whether or not they want the MOLST completed
 - ✓ If the physician will not fill out the form, a staff shall be designated to complete the MOLST to reflect the decision of the 1750-b Surrogate for the subsequent signature of the physician



For more information on Willowbrook services

Go to OPWDD's Beyond Willowbrook website

Powerpoint:

Overview of Services for Willowbrook Class Members

Accessed at

http://www.opwdd.ny.gov/willowbrook/hp_willowbrooktraining.jsp