



Executive Office

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MEMORANDUM

To: DDSO Directors
Executive Directors, Voluntary Residential Agencies

From: Helene Desanto, Acting Deputy Commissioner

Subject: Informed Consent for Willowbrook Class Members Fully Represented by the Consumer Advisory Board (CAB)

Date: September 30, 2011

This is to reissue information related to the process to be utilized to secure informed consent for “professional medical treatment” for Willowbrook class members who are fully represented by the Consumer Advisory Board.

Effective November 23, 2005, OPWDD's regulation on informed consent for medical treatment 14 NYCRR 633.11 was amended to include the seven member Consumer Advisory Board (CAB) on the list of surrogate decision makers. As a result, the CAB has been authorized to make informed consent decisions for a class member who is not able to make the informed medical decision for her or himself and has no other identified surrogate. As defined in Section 633.9, “professional medical treatment” is 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.

Please note that informed consent for a proposed medical treatment must be sought from this list in the order stated: 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 any other actively involved adult family member; or the CAB for class members it fully represents.

When CAB is the identified surrogate for a class member, please utilize the *Dental Consent Overview* or *Medical Consent Overview* with the *CAB Informed Consent Submission Checklist*, depending on the procedure. Please continue to use the current version, which is dated April 15, 2009. These forms and all supporting documentation continue to be submitted to Antonia Ferguson, Executive Director of the CAB, at the CAB Central Office, located at 1050 Forest Hill Road, Staten Island, NY 10314. In addition, the DDSO Director continues to be informed at the time the compiled information is submitted to Ms. Ferguson and until consent is signed or declined, as detailed below:

- The agency faxes the *CAB Informed Consent Submission Checklist (Revised 4/15/09)* to the DDSO Director immediately after mailing ~ DDSO will enter date of receipt in Box 1.
- The agency immediately notifies the DDSO Director should the information packet be returned for resubmission, or when the signed or declined consent form is received from CAB on behalf of the class member ~ DDSO will enter date consent confirmed in Box 3.

- The agency maintains a detailed chronology of contacts following submission of its request for informed consent, with both the CAB representative and CAB Central Office in Staten Island, including dates of verbal or phone contact, questions raised by the CAB and follow up actions taken by the agency. Written correspondence should be utilized to confirm multiple verbal or phone contacts.
- The DDSO contacts the originating requestor as reflected on the *CAB Informed Consent Submission Checklist (Revised 4/15/09)* for any informed consent submission still pending after 30 business days. If signed or declined consent has already been secured, the DDSO notes this on its copy of the *CAB Informed Consent Submission Checklist*. If the request is still outstanding, the DDSO Director contacts Ms. Ferguson to ascertain the status of the submission.

The following will facilitate CAB consideration of requests for informed consent for class members:

- Review submissions for completeness. Incomplete packets or the use of forms from the Surrogate Decision Making Committee (SDMC) **are unacceptable** when seeking informed consent from the CAB for a class member and **will be returned to the originating requestor**. In such instances, the CAB review will initiate its review upon receipt of the *CAB Informed Consent Submission Checklist, Medical or Dental Consent Overview*, and all supporting documentation at the CAB Central Office in Staten Island. Piecemeal submission will delay the review process.
- Keep the local CAB representative informed. The local CAB representative must be immediately contacted when professional medical treatment is recommended, and updated throughout the process. Advance notice should be given to the local CAB representative of related appointments so that, if possible, they can make arrangements to attend.
- Work closely with the local CAB representative when expedited decisions, defined as within 8 business days of submission, are needed. Advise the local CAB representative immediately, and reflect this need on the *CAB Informed Consent Submission Checklist* and cover letter. In addition, remember to provide the medical recommendation and justification on the *Medical or Dental Consent Overview* form.
- Seek a second opinion for medical/dental treatment when questions can be anticipated. Please include all applicable documentation from these medical/dental consultations to facilitate the CAB review.
- Ensure documentation reflects the following statements:
 1. The class member lacks capacity to give consent for the proposed medical treatment and the basis for the statement, such as an Individualized Services Plan (ISP), Comprehensive Functional Assessment (CFA), or recent assessment by a qualified examiner.
 2. The class member is fully represented by the Consumer Advisory Board. There should be no known health care agent, legal guardian, or available family member authorized under Public Health Law or OPWDD regulation to consider granting informed consent. If such a person exists, there is a need to document the efforts undertaken to determine that such a person 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.” IF an alternative surrogate consent decision maker, as identified above, is available and objects to the proposed treatment, the proposed treatment over objection must proceed as a court application.

Note: please submit only those pertinent pages of the ISP or CFA, not the full document.

- Implement a review protocol for requests for informed consent that includes sign off from administrative or medical supervisory staff. This sign off will be reflected on the *CAB Informed Consent Submission Checklist* and *Medical or Dental Consent Overview*.
- The primary health services contact (RN or MD) must be available to respond to CAB questions, and take steps promptly to facilitate CAB's communication directly with the health care provider who is proposing the treatment, for explanation and clarification of the request. The secondary contact is designated by the requesting provider as the service coordinator/case manager, residential director or other agency designee. It is never the local CAB representative. All communication with the primary health services contact and secondary contact must be reflected in the chronology maintained by the agency requesting informed consent.
- All inquiries on the status of a request for informed consent should be directed to the local CAB representative. If unavailable, a message for the representative should be left at the CAB Central Office in Staten Island at (718) 477-8800. These contacts must be reflected in the chronology maintained by the agency requesting informed consent.

If Ms. Ferguson and the Board have no questions, the signed or declined consent continues to 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. In expedited situations, the CAB will fax the signed consent to the designated person. On an exception basis only, the 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.

To facilitate dissemination of this important information, this memorandum and all attachments can be accessed on the OPWDD website at the following address: http://www.opwdd.ny.gov/hp_cabconsent_index.jsp. In addition, the *CAB Informed Consent Submission Checklist* and *Medical or Dental Consent Overview* forms may be accessed in "writable" PDF format on the website at the above address.

Egregious or repeated failure to follow the above protocol and/or obtain informed consent in a timely manner on behalf of a class member will result in referral to OPWDD Division of Quality Management (DQM) for possible certification review.

Please continue to contact your local CAB representative should you have questions or need clarification on the CAB review process. Lori Lehmkuhl, OPWDD Willowbrook Liaison, is also available to provide general assistance and to clarify DDSO participation in the process. Ms. Lehmkuhl can be reached by telephone at (518) 473-6026. Thank you.

Attachments:

DDSO Director Fax Listing

Frequently Asked Questions (FAQ) September 30, 2011

CAB Informed Consent Submission Checklist dated 4/15/09

Medical Consent Overview (Revised 4/15/09) ~ Dental Consent Overview (Revised 4/15/09)

Brochure: *Informed Consent for "Professional Medical Treatment" for Willowbrook Class Members Fully Represented by the Consumer Advisory Board* Updated September 30, 2011

cc: OPWDD Leadership Team