



Executive Office

44 Holland Avenue
Albany, NY 12229-0001

TEL: 518-473-1997
FAX: 518-473-1271
TTY: 866-933-4889

www.opwdd.ny.gov

MEMORANDUM

To: DDSO Willowbrook Liaisons

From: Lori Lehmkuhl, OPWDD Willowbrook Liaison *LL*

Subject: Willowbrook Active Representation

Date: September 30, 2011

This is to update prior memoranda related to sign off on movements, plans of care and treatment on behalf of Willowbrook class members.

As you know, if a person with developmental disabilities is not able to advocate on their own behalf, OPWDD Policy and Procedures requires that he or she has a correspondent, defined as a person (not on staff of the facility) who assists him/her in obtaining necessary services, participates in his/her program planning process as a member of the program planning team, and receives notification of certain significant events in the life of that person. The Willowbrook Permanent Injunction provides for active representation as follows:

- Appendix H defines active representation for class members as participation with the interdisciplinary team in planning and evaluating the individual development plan and/or visits between the correspondent and the individual class member at least annually. Merely signing consent forms sent through the mail or receiving phone calls initiated by facility staff with no other involvement does not constitute active representation.
- Paragraph 7 provides for the Consumer Advisory Board (CAB) to provide necessary and appropriate representation and advocacy services on an individual basis for all Willowbrook class members who do not have correspondents, as long as any class member lives. CAB can also act as co-correspondent or advocate for class members who are not non-correspondent class members. Therefore, for class members who do not self-advocate, the correspondent would be his/her parent, involved family member, or the CAB.

The following situations may be found for class members:

- A class member may represent him/herself, and in such instances, the class member gives consent for movements, release of information, participation in activities, routine medical and dental care, behavior management including medication, etc. In addition, the class member may sign for invasive medical/dental treatment when determined to be capable of making the decision at hand.
- A class member may represent him/herself, with co-representation from a family member. In such instances, the class member continues to give consent as indicated above.
- A family member may serve as correspondent for a class member, and fulfill the responsibilities of the correspondent as described in OMRDD Policies and Procedures.
- A class member may represent him/herself, and may ask CAB for co-representation. Similarly, a family member may elect to have co-representation from the CAB on behalf of a class member. In such instances,

the CAB staff participate in case conferences and visit the home and day program. However, when CAB co-represents with the class member or family, the class member or family retain the authority to give consent for movements, release of information, participation in activities, routine and major medical and dental care, behavior management including medication, etc. Therefore, CAB staff do NOT sign plans of care or give consent for care and treatment for class members they co-represent.

- If the CAB fully represents the class member, CAB staff act as the correspondent and review and respond to issues of care and treatment that require written consents, including but not limited to movements, release of information, participation in activities, routine medical and dental care, behavior management including medication, etc. Effective November 22, 2005, the CAB may also consent to surgery and general anesthesia for a class member when there is no other appropriate surrogate decision maker.

Attached are two letter formats to be used when advising families of the availability of the CAB for Willowbrook class members. Please use Sample Letter Format #1 when advising of the availability of the CAB on behalf of Willowbrook Class Members who have full active representation by family. Sample Letter Format #2 is to be used to offer full representation from the CAB when CAB is already providing co-representation. Each letter is to be adapted to suit the recipient and situation, but must contain all the information. Note that the prescribed Active Representation Response Form that is used as an attachment has been tailored to suit each letter format. The Active Representation Response Form must not be changed or modified in any way. Copies of the correspondence and completed response form must be forwarded to the DDSO Willowbrook liaison and the Executive Director of the CAB.

In order to facilitate compliance with the Permanent Injunction, team meetings on behalf of class members should include confirmation of active representation status, and the plan of care is to prominently reflect current information on active representation status, specifically, whether the class member represents him/herself, or whether family member(s) or the CAB serve as sole advocate or co-representative on their behalf.

Please forward this information to service coordination staff and program managers who are responsible for planning for class members. You may also contact me at (518) 473-6023 for additional assistance or clarification in this matter.

Thank you.

Attachments:

Sample Letter Formats #1 and #2

Active Representation Response Form

Responsibilities of Correspondent/Definition of Willowbrook Active Representation