

Reference Information and Frequently Asked Questions on the Consumer Advisory Board (CAB)

Willowbrook References:

Appendix H of the Willowbrook Permanent Injunction 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 of the Willowbrook Permanent Injunction 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-representative or advocate for class members who are not non-correspondent class members. The CAB also has “the responsibility to evaluate alleged dehumanizing practices and violations of individual or legal rights with regard to any and all members of the plaintiff class.”

OMRDD References:

OMRDD policy and procedures defines correspondent as follows:

Someone (not on staff of the facility) who assists a person in obtaining necessary services, participates in the person’s program planning process as a member of the person’s program planning team, and who receives notification of certain significant events in the life of that person. The fact that a correspondent is providing advocacy for a person as a correspondent does not endow that party with any legal authority over the person’s affairs.

Per *Community Policy CPI, Placement of People in the Community*, a correspondent is, in the first instance, a parent or legal guardian, as listed in the person’s program plan. (A copy of CPI can be found in the OMRDD reference booklet *Community Placement Procedures*, better known as the “*Green Book*.”)

OMRDD Memoranda issued by Litigation Support Services; *Willowbrook Active Representation*, dated 10/23/2009; and *CAB Communication Protocol*, dated 9/4/02.

Power point presentation: “*Advocacy, The Advocate and Willowbrook Active Representation.*”

Frequently Asked Questions

What is the Consumer Advisory Board (CAB)?

The CAB is a seven-member board comprised of parents, siblings and advocates that provides 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. The CAB may also act as co-representative for class members who have a correspondent. There are also local representatives who are assigned throughout the state to carry out the mission of the CAB. These local CAB representatives perform their day-to-day functions under the direction of an Executive Director and three regional Assistant Directors. The CAB was established in 1975 on consent of the parties to litigation on behalf of approximately 5,400 current and former residents of the Willowbrook Developmental Center.

What is the role of the Board?

The Board, through the local CAB representatives, gives or denies consent for placement or movement opportunities, and psychotropic medication and behavior management plans, after consultation with residential and day program teams and prescribing psychiatrists for individuals, as appropriate. Similarly, the CAB representative acts for the Board, to give or deny consent for a variety of matters, including but not limited to camp, Special Olympics, minor medical and dental procedures and photographs/films, videotaping. Local associates represent the Board in utilizing the appeal mechanism if there is a disagreement with the overall plan of care and services.

Following revisions to 14 NYCRR 633.11 that took effect November 23, 2005, the CAB is authorized to provide informed consent for Willowbrook class members who are not able to give informed consent on their own behalf, and for whom there is no legal guardian, health care agent or other actively involved family member to act as surrogate decision maker. If a family member is available and willing to give consent on behalf of a class member, the CAB will not review a request for informed consent.

It should also be noted that the CAB is available to serve as the 17A guardian for class members. In the event that guardianship is being considered for a class member who does not have an actively involved family member willing to serve as guardian, the CAB should be considered for guardianship.

What is the role of the local CAB representative?

Local CAB representatives attend team meetings and advocate on behalf of their class members, evaluate and recommend proposed placements or movement opportunities for Board consideration, follow up on identified problems, and ensure that the class member they represent has appropriate services. Along with the team, CAB representatives assist in the development of individual program plans, ensure that services are being provided consistent with the plan, make site visits to the day program and to the residence. CAB

representatives review and sign, or seek revisions of, statements of resident rights, notices of appeal, money management forms, etc.

When the CAB is the authorized surrogate for informed consent, the local CAB representative should be contacted immediately whenever professional medical treatment is recommended, and involved throughout the review process. The local CAB representative should also be notified when an expedited decision is needed, defined as within eight calendar days of submission. The local CAB representative reviews information to be submitted to the Board and ensures that the request is complete, with supporting documentation. If Ms. Ferguson and the Board have no questions, the signed consent is forwarded via regular mail directly to the primary health services contact, with a copy to the local CAB representative. All inquiries on the status of a request for informed consent are to be made to the local CAB representative.

Who may serve as active representative for a class member?

If a parent or legal guardian is not available to provide active representation, an alternate family member may be identified, or referral must be made to the CAB. No friend or interested party may serve as correspondent for a Willowbrook class member.

How does the team determine if the Willowbrook standard for active representation is met for the class member?

A correspondent may participate with team member(s) and provide input into planning and evaluation in person, by phone, or by correspondence. If participation is made by phone, the team member may call the correspondent, in order not to discriminate against families with limited funds. There must be evidence in the class member's individual record to reflect correspondent interaction with the team on at least an annual basis.

What if family members are not actively representing the class member?

Active representation is foremost for the benefit of the class member. If the family is not meeting the standard of active representation on behalf of the class member, for whatever reason, and the class member is not able to actively represent him or herself, then the class member should be referred to the CAB. Similarly, if guardianship is being considered for a class member who does not have an actively involved family member willing to serve as guardian, the CAB should be considered for guardianship.

What is the protocol used to advise the class member and/or correspondent of the availability of active representation by the CAB?

The service coordinator/case manager should initiate contact to a class member or his or her family using the prescribed letter format, which is adapted to suit the recipient and the situation. The prescribed Response Form Format, which includes active representation options, is used as an attachment to this letter. The response form format must NOT be changed or modified in any way. Copies of the correspondence and completed response

form must be forwarded to DDSO Willowbrook Liaison and the Executive Director of the CAB.

What is the difference between co-representation and active representation for a class member?

When CAB is the active representative, it acts as the correspondent for the class member. In that capacity, the local CAB representative participates in case conferences and visits the day and residential program, and reviews and responds to issues of care and treatment that require written consents. Effective November 22, 2005, the CAB may consent to surgery and general anesthesia when there is no other appropriate surrogate decision maker. When CAB is the co-representative, the local CAB representative advocates on behalf of the class member by attending case conferences and visiting the day and residential program, however, the correspondent retains the responsibility for review and response to issues of care and treatment that require written consent.

What are expectations for a collaborative SCOR visit with the local CAB representative?

When the CAB is involved on behalf of a Willowbrook class member, the local CAB representative should participate in a collaborative SCOR visit once annually. This collaborative SCOR visit can take place at a mutually convenient time; or scheduled in concert with a team meeting convened at the residence when both service coordinator and CAB are in attendance.

If you provide the local CAB representative a copy of the Individual Service Plan (ISP) or equivalent, is it necessary to send a copy to the Central Office of CAB?

ISPs are official communication and must be sent to the Central Office of CAB. It is acceptable to provide the local CAB representative a copy directly, but this is in addition to the copy to the Central Office in Staten Island.

What are the obligations in reporting incidents to the Consumer Advisory Board?

The Central Office of CAB receives all incident reports on behalf of class members. In addition, DDSOs and voluntary agencies must submit minutes of their Special Incident Review Meetings to assist CAB in its implementation of this provision of the permanent injunction. [Please refer to other incident reporting requirements on behalf of class members reflected in the Incident Management section of *Beyond Willowbrook*]

What is the protocol when communicating with CAB?

All official communication with the CAB, both verbal and written, is to be directed to the main office at 1050 Forest Hill Road, Staten Island, NY 10314, (718) 477-8800. Official communication includes notifications that are required by the Willowbrook Permanent Injunction, policy and procedures, and regulations.

Do not send emessages via All-In-One or the Internet to the CAB. These documents are not a substitute for official communication. Similarly, messages on answering machines/voice mail should not be left in lieu of official correspondence notification as indicated above. As indicated on answering machines/voice mail of local CAB representatives, if it is necessary to speak to someone immediately, a call should be placed to the Central Office of CAB at (718) 477-8800. During normal business hours, staff will be available to assist and contact the assigned local representative. After hours and on weekends, the answering machine is checked on a regular basis. If a response is necessary before the next workday, specific information and a request to respond should be included in the message.

The protocol is in place because local CAB representatives are often out of their offices for long periods of time, and the information may require immediate attention. Staff at the Central Office of CAB will review the mail and communicate with local CAB representatives regarding items that require follow up. The protocol does not in any way limit direct communication with local CAB representatives but should expedite appropriate action on behalf of class members. Once notification has been made to the Central Office of CAB as required, communication may also be made directly to the local CAB representative, in person, by phone, or copy of correspondence.

Can email sent via All-In-One or the Internet be used to set up meetings with the local CAB representative?

It is not recommended that email via All-In-One be used to set up meetings due to possible limitations in access by local CAB representatives. When making the arrangements for the meeting, if you cannot reach the local CAB representative in person or by phone, a message is to be left with the Central Office of CAB. During normal business hours, staff will be available to facilitate communication with the assigned local representative. For meetings convened to address an urgent issue or emergency situation, and it is not possible to reach the local CAB representative by phone, a message is to be left with Central Office of CAB; specific information and a request for response should be included in the message. Once a meeting time is confirmed in person or by phone, written confirmation should be directed to the local CAB representative at the Central office of CAB. Communication via the Internet is not secure and should not be used.

Is email sent via All-In-One or the Internet acceptable communication when providing updates related to hospital stays, medical or other clinical appointments, evaluations, team reviews, etc.

Email is not an acceptable means of communication. When CAB is the active representative on behalf of a class member, or provides co-representation, residential notification related to hospital stays for medical or psychiatric care is to be made immediately via phone to the Central Office of CAB. A subsequent phone contact may also be made to the local CAB representative. It is required that CAB receive written correspondence for extended hospital stays (medical) by the 7th day of the hospitalization and within 24 hours for hospitalizations due to psychiatric emergency. The local CAB

representative should receive official communication related to medical or other clinical appointments, evaluations or team review when CAB serves as active representative or provides co-representation. Official communication is either verbal or via letter. Informal email exchange between staff is unofficial communication; these exchanges may be summarized for the local CAB representative as official communication, verbally, or by letter directed to the Central Office of CAB. Informal email exchange is not to be used in lieu of formal team communication for decision making and service review, which would involve the local CAB representative serving as active representative or co-representative on behalf of a class member. When CAB initiates questions on email, response should be via official communication, verbally or by letter directed to the Central Office of CAB.