



**Office for People With
Developmental Disabilities**

Overview of Services for Willowbrook Class Members

December 2015

Willowbrook opened in October 1947



Willowbrook was a big campus setting with a large number of people who were isolated from community life



Willowbrook and institutions
like it used to focus on beds,
not people



Willowbrook Important Dates!!

- ✓ March 17, 1972
Class-action lawsuit filed against NYS in federal court
- ✓ May 5, 1975
Willowbrook Consent Decree became effective
- ✓ February 25, 1987
Federal Court approves Willowbrook "1987 Stipulation" that sets forth guidelines for class member community placement
- ✓ September 17, 1987 ~ A promise fulfilled ~
Willowbrook Developmental Center "officially and forever closed"
- ✓ March 11, 1993 ~
Willowbrook Permanent Injunction replaces Willowbrook Consent Decree and all other prior orders in the Willowbrook litigation



Willowbrook Guiding Principles

- ✓ Protection from harm
- ✓ High quality and appropriate services
- ✓ Community based, integrated services



Willowbrook Expectations

- ✓ Compliance with applicable state and federal regulations, OPWDD policies and procedures
- ✓ Compliance with the Willowbrook Permanent Injunction



Those Currently Involved in the Willowbrook Case

Willowbrook Attorney's

- New York Civil Liberties Union (NYCLU)

Beth Haroules & Lisa Laplace: lead Willowbrook attorneys for allegations of abuse/neglect AND guardianship petitions

125 Broad Street, 19th Floor

New York, NY 10004

phone (212) 607-3300

fax (212) 607-3318



Willowbrook Attorney's

- New York Lawyers for the Public Interest (NYLPI)

Roberta Mueller: lead Willowbrook attorney for due process notification AND death notices

151 W. 30th Street, 11th Floor

New York, NY 10001-4007

phone (212) 244-4664

fax (212) 244-4570



Consumer Advisory Board (CAB)

Established in 1975, CAB is a seven member board of parents, siblings and advocates

Ann Nehrbauser, Chairperson

Antonia Ferguson, CAB Executive Director

1050 Forest Hill Road,
Staten Island, NY 10314
phone (718) 477-8800
fax: (718) 477-8805

Local representatives communicate with Ms. Ferguson, 3 assistant directors and the Board



CAB dual role for class members

“In loco parentis”

- ✓ Latin for "in the place of a parent"
- ✓ CAB may provide full representation for non-correspondent class members; co-representation with the self advocate or with family; or no representation

Systemic monitoring

- ✓ The CAB Staten Island Office reviews ALL incident reports and Special Incident Review Meeting minutes to ensure the rights of all class members

Commissioner's Task Force on Willowbrook

- ✓ Serves as an advisory group to the OPWDD Commissioner; participants include parents, advocates, people receiving services, CAB, Willowbrook attorneys
- ✓ Meets quarterly with OPWDD Commissioner/ other OPWDD staff
- ✓ Utilizes subcommittees for the following areas: Monitoring; Case Management/Service Coordination; Incident Review; Health & Wellness; Behavior Management and Positive Behavioral Supports

Independent Evaluator for the Willowbrook Class

Ronnie Cohn, Independent Evaluator for the Willowbrook Class

Hudson Valley DDSO ~ Westchester Office.

220 White Plains Road, Suite 675

Tarrytown, NY 10591

(914) 332-8964; fax: (914) 332-8024

- ✓ Serves as staff to the Commissioner's Task Force on Willowbrook
- ✓ Monitors class members on Attachment 1
- ✓ Coordinates Willowbrook community audit
- ✓ Provides additional monitoring at the request of the Willowbrook attorneys
- ✓ Monitors any class member on Appendix C who are deemed “as if on Richmond Complex”.



OPWDD Contacts

Helene DeSanto, Administrative Liaison to the Willowbrook Parties, Service Delivery and Integrative Solutions

44 Holland Avenue, 4th Floor, Albany, NY 12229; (518) 474-9897

Elizabeth Matthews, OPWDD Office of Counsel

25 Beaver Street, NY, NY 10004; (646) 766-3203

Lori Lehmkuhl, OPWDD Willowbrook Liaison

Statewide responsibilities related to Willowbrook class members;
44 Holland Avenue, 4th Floor, Albany, NY 12229; (518) 473-6026

DDSO Willowbrook Liaisons

Each district has its own liaison addressing Willowbrook matters



Eligibility and Permanent Injunction Status

What Makes Someone A Willowbrook Class Member?

An individual is not a class member simply having lived at Willowbrook State School

Membership includes:

- ✓ All 5,343 individuals on the rolls of Willowbrook State School at the time the lawsuit was filed (March 17, 1972)
- ✓ Additionally, by court order, 104 individuals who were on community status on March 17, 1972 and documentation confirms that they returned to Willowbrook or another related facility



Monitoring Categories from the Permanent Injunction:

Attachment 1

- ✓ Class members who were not in qualifying community placements as of 12/31/1992
- ✓ Class members are monitored by the Independent Evaluator until deemed to have successfully transitioned to community services



Monitoring Categories from the Permanent Injunction:

Attachment 2

Class members deemed appropriate for continued stay in long-term care facilities to receive intensive medical care that cannot be provided in a community-based setting

Since 3/11/1993, placement in a long-term care facility would consider:

- ✓ medical fragility;
- ✓ complexity and frequency of skilled nursing procedures required;
- ✓ need and availability of appropriate medical crisis intervention personnel;
- ✓ transportation difficulties due to fragility;
- ✓ complexities of a feeding tube, including frequency of changing/suctioning and observation needs;
- ✓ unavailability in ICFs of 24-hour nursing or other specialized services needed by the class member

Monitoring Categories from the Permanent Injunction

Appendix C

- ✓ Class members living on Richmond Complex as of 3/11/93 for whom the teams agreed were appropriate for continued stay
- ✓ Class members with significant challenging behaviors still living in non-qualifying settings on 12/31/1992; all but one currently reside in community homes
 - ✓ Non-qualifying settings are residences on a campus or capacity exceeding 30 beds

Active Representation

Important Reference: Willowbrook Active Representation

- ✓ Correspondence dated 9/30/2011 posted on the *Beyond Willowbrook* website, accessed at http://www.opwdd.ny.gov/willowbrook/images/hp_willowbrook_active_rep09311.pdf
- ✓ 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



Active 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-advocacy

- ✓ 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, a class member gives his or her own consent for movements, release of information, participation in activities, routine medical/dental care, etc.
- ✓ A class member who self-advocates may also sign for invasive medical/dental treatment when determined to be capable of making the decision at hand
- ✓ Encourage class member who self-advocates to do a Health Care Proxy

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

(Please note that CAB should be notified of the death of any class member, regardless of what the individuals correspondent status is)



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 CM/SC 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 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”
- ✓ CAB has agreed that “if” a name is required you may put in the local CAB representatives name



Willowbrook Expectations:

Active Representation Monitoring

- ✓ 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:
 - ✓ frequency of visits and/or participation with team members

Willowbrook Expectations:

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



CAB Communication Protocol

CAB Communication Protocol

Official communication with the CAB, both verbal and written, is directed to the CAB Staten Island Office

Official communication includes notifications required by the Permanent Injunction, policies and procedures, and regulations

- ✓ Plan of services, i.e., the ISP or CFA; all due process notification, i.e., 30-day notice, and letters documenting temporary moves, emergency moves and time limited services elsewhere; incident reporting; meeting related correspondence, i.e., invitations and confirmations; requests for psychotropic medication/behavior plans; etc.



CAB Communication Protocol

If you need to speak to a local CAB representative immediately, call the CAB Staten Island Office at (718) 477-8800:

- ✓ During normal business hours, staff will contact the assigned local CAB or advise accordingly
- ✓ After hours and on weekends, the answering machine is checked regularly

If a response is necessary before the next workday, specific information and a request to respond should be included in the message



Revised: CAB Communication Protocol

Email is NOW official communication

- ✓ You may use email to schedule meetings:
 - ✓ To schedule meetings you may email the CAB rep directly.
 - ✓ However when you need immediate assistance you must call the CAB main office on Staten Island.
 - ✓ ISPs may be scheduled via email.

Email exchange is not to be used in lieu of formal team communication for decision making and service review



CAB Electronic Communication

OPWDD and CAB have agreed upon a protocol when sending official communication electronically

CAB has three “virtual” mailboxes

- The CAB has gone to electronic files, efficiencies are in time, paper and postage.
- All documents should be sent to one of the following email addresses:
 - ✓ OPWDD.CAB@opwdd.ny.gov
 - ✓ OPWDD.CABINCIDENTS@opwdd.ny.gov
 - ✓ OPWDD.SM.CAB.IMCREQUESTS@opwdd.ny.gov
- At no time should notifications required by the Permanent Injunction be sent to local CAB reps directly, via email or to their offices.
- All communication should be directly emailed to CAB Main Office, to Ms. Antonia Ferguson’s attention.



Approved for CAB Electronic Transmission

TO OPWDD.CAB@OPWDD.NY.GOV

- ✓ Plans of care, i.e., CFAs and ISPs along with related documents for all class members represented or co-represented by CAB
- ✓ Also, as email attachments:
 - death notification/Report of Death
 - meeting related correspondence, i.e., invitations and confirmations
 - requests for psychotropic medication/behavior plans
 - referral letters/referral packets
 - informational letters to families re CAB representation
 - all due process notification, including 30-day notices, and letters documenting temporary moves, emergency moves and time limited services elsewhere
 - routine consents, i.e., photos, camp, etc.
 - Willowbrook “Other” Notifications (new yellow “Cheat Sheet”)
 - **NEW: Requests for Informed Consent**



Approved for CAB Electronic Transmission

OPWDD.CABINCIDENTS@OPWDD.NY.GOV

- ✓ Incident Review Committee Minutes
- ✓ 147 Incident Reporting
- ✓ 148 Incident Reporting
- ✓ 30 day updates on investigations

(**Only** send via paper mail or fax **IF** agencies do NOT have secure email to send these documents electronically)



Recently Approved for CAB Electronic Transmission

OPWDD.SM.CAB.IMCREQUESTS@OPWDD.NY.GOV

Requests for Informed Consent for “professional medical treatment”

- ✓ May now be sent electronically.
- ✓ Only send via paper mail to the CAB Staten Island Office “if” you do not have secure email.



Expectations for Willowbrook Case Management/Service Coordination (CM/SC)



Legal Obligations for Willowbrook CM/SC

- ✓ OPWDD is legally bound to comply with requirements outlined in the Willowbrook Permanent Injunction (PI)
- ✓ The PI guarantees class members certain rights and sets standards for care, including case management services
 - ✓ Case management obligations are detailed in Paragraph 8 and Appendix I as well as subsequent orders of the court



Per Paragraph 8, OPWDD shall continue to provide class members with case management/service coordination services, as defined in Appendix I

FUNCTIONS WITHIN APPENDIX I INCLUDE...

Advocacy

Assessment

Program Plan Development

Recordkeeping

Coordination

Linking, Support

Monitoring/Follow up

Discharge of services

Case Manager Reporting



From a Willowbrook perspective, CM/SC is critical to successful implementation of the Willowbrook entitlements for services

- ✓ Promote self advocacy, self direction and choice
- ✓ Advocate and arrange for services that are accessible, community-based, comprehensive and culturally appropriate
- ✓ Monitor the quality of services and programs provided to the class member through measures of individual satisfaction
- ✓ Monitor compliance of the services and programs with Willowbrook requirements and entitlements AND with state and federal laws and regulations



Expectations for Willowbrook CM/SC

CASELOAD: NO GREATER THAN 1:20 RATIO EQUIVALENT

EXPERIENCE: MUST BE A QIDP (QUALIFIED INTELLECTUAL Disability PROFESSIONAL)

- ✓ QIDP standards defined in 14 NYCRR 690.99 AC

FUNCTIONAL INDEPENDENCE:

- ✓ Service coordinators must have an “arms length” relationship from program operations within the voluntary agency
- ✓ CM to class members in ICFs must not be provided by the voluntary residential provider



What Is A QIDP?

- ✓ Qualified Intellectual Disabilities Professional (QIDP) standards are defined within regulation 14 NYCRR 690.99 AC.
- ✓ Information regarding the qualifications for a QIDP can be found in ADM#2009-05 on the OPWDD website at <http://www.opwdd.ny.gov/wt/memoranda/index.jsp>
- ✓ It is not sufficient that staff are supervised by a QIDP. Each case manager/service coordinator serving even one class member must comply with the QIDP standard.

What is Functional Independence?

Appendix I stipulates...

OPWDD Vendor Manual revised 6/20/11 prohibits...

...that a class member/class member correspondent may choose a functionally independent CM/SC

Functional independent CM/SC means that, if employed by the same agency that provides residential/day services, the CM/SC is organizationally separate from these services

...“Conflict of interest”

To avoid a potential conflict of interest and promote the independence of the service coordinator, staff providing direct services to a person cannot also serve as that person’s service coordinator [i.e., residence managers, clinicians, habilitation staff, FC liaisons, direct support staff]



Expectations Willowbrook CM/SC:

Case load Calculation

When even 1 class member is served on caseload, caseload compliance is calculated using the approved court ordered work standards:

- ✓ .5 when a class member resides in VOICF and served by a DDSO or voluntary case manager
- ✓ .5 when a class member resides in an SOICF and served by a voluntary case manager
- ✓ 1 when a class member resides in an SOICF and served by a state case manager
- ✓ 1 for individuals in any other living arrangement
- ✓ 1 for non class individuals receiving PCSS when a class member is served on caseload

When calculating Willowbrook caseload compliance...

FTE = amount of time a case manager/service coordinator is employed by the DDRO or agency

CMFTE = amount of time assigned to the CM/SC function



When calculating Willowbrook caseload compliance...

Staff FTE=1 and CMFTE=1 can carry 20 work units [using the court-ordered work standards of 1 or .5]

When staff work less than full time as a case manager/service coordinator [CM FTE <1], the CM FTE is prorated and work units adjusted accordingly

- ✓ half time [.5 CM FTE] can carry 10 work units
- ✓ quarter time [.25 CM FTE] can carry 5 work units
- ✓ When CM FTE <1, non-case functions must be included on the caseload report

DDSO Liaison Role in Caseload Compliance

- ✓ Receives quarterly compliance reports from DDRO and voluntary agencies
- ✓ Ensures all current caseload assignments for class members are entered in TABS
- ✓ Reports DDRO caseloads to the OPWDD Willowbrook Liaison
- ✓ When an agency or DDRO service coordinator/case manager does not meet the 1:20 court-ordered ratio or QIDP experience standard, ensures development of a plan of compliance with time frames for implementation



Recent Changes That Support Voluntary Agency Implementation of Willowbrook CM/SC



- ✓ During the 2010 MSC Redesign, OPWDD heard concerns regarding the inequity of compensation for MSC services delivered to Willowbrook class members vs. non-class individuals
- ✓ In addition, there was noted to be no way for voluntary agencies to provide case services to class members if not included in MSC
- ✓ DDSOs have had difficulty in ensuring consistency within voluntary agencies when providing case services to class members

OPWDD Response to Concerns

- ✓ Increased **reimbursement** for Willowbrook class members receiving MSC
- ✓ **Regulatory changes** to support **Willowbrook Case Services (WCS)** for class members living in ICF programs
- ✓ Application of the increased Willowbrook MSC rate for class members receiving case management when the class member is not eligible for MSC



Willowbrook Reimbursement Effective 4/1/2015

- \$480.97 – Willowbrook MSC
 - this enhanced Willowbrook MSC rate supports class members receiving MSC and results in a comparable annual revenue that an MSC without class members on caseload can generate
- \$480.97 – Willowbrook SC (WSC)
 - this enhanced Willowbrook WSC rate also supports case management to class members living in nursing homes or who otherwise are not eligible for MSC
- \$240.49 – Willowbrook Case Services (WCS)
 - this rate is equivalent to one-half the enhanced Willowbrook MSC rate



Willowbrook Case Services (WCS)

- ✓ Traditionally, in an ICF/DD setting, QIDPs deliver case management services to the individuals residing there.
- ✓ For class members, DDRO case managers have provided additional court ordered services required per the Willowbrook Permanent Injunction, Appendix I, which defines case services for class members.
- ✓ By promulgating emergency regulations, OPWDD is increasing the ICF/DD rate in order to provide a mechanism to sufficiently compensate the ICF/DD for payments to service coordination providers that will be providing these additional court-ordered services.

Willowbrook Service Coordination (WSC)

- ✓ Reimbursement equal to Willowbrook MSC for class members living in nursing homes or who otherwise are not eligible for MSC
- ✓ WSC does not include class members living in ICFs and receiving WCS
- ✓ Agencies must confirm with DDROs those class members receiving WSC who reside in nursing homes so that steps are taken to **bypass the payment edit** that denies state paid service coordination if an individual has Medicaid
- ✓ Similarly, agencies must confirm with DDROs those class members served who are not eligible for MSC and receiving WSC

For more information on Willowbrook MSC/WSC/WCS

GO TO OPWDD'S BEYOND WILLOWBROOK WEBSITE ON CASE
MANAGEMENT/SERVICE COORDINATION

POWERPOINT:
WILLOWBROOK
SERVICE COORDINATION/CASE MANAGEMENT TRANSITION

ACCESSED AT
[HTTP://WWW.OPWDD.NY.GOV/WILLOWBROOK/HP_WILLOWBROOK_CM_TRANSITION.PDF](http://www.opwdd.ny.gov/willowbrook/hp_willowbrook_cm_transition.pdf)



Willowbrook CM/SC Service Expectations

Expectations Willowbrook CM/SC:

Face to Face Contact

Face-to-face contacts must be made monthly at either the residence or day services location...

- ✓ There is discretion as to the location of the face-to-face contact but a class member must be seen at both locations over the course of each quarterly period
- ✓ There is no exception to the monthly face-to-face requirement for class members
- ✓ No monthly billing without face-to-face contact

Expectations Willowbrook CM/SC:

Monthly Documentation

The Willowbrook CM/SC keeps a list of dates of monthly contact and dates of attendance at team meetings, which shall be available to plaintiffs and CAB upon request.

- ✓ The Willowbrook CM/SC prepares case notes that conform to:
 - For WCS/WSC, use WCS/WSC10b, Case Note for Class Members Living In ICF/DDs, Placed in Nursing Homes or Otherwise Ineligible for MSC services
 - For MSC, continue to use MSC10b, Medicaid Service Coordination Notes (same as for non-class if MSC)

Expectations Willowbrook CM/SC:

CM/SC Training

- ✓ MSC/WSC/WCS adhere to all training obligations for MSCs serving at least one class member on caseload
- ✓ Willowbrook training obligations include attendance at the OPWDD-approved core service coordination training within 6 months of assuming case management responsibilities; attendance at 15 hours of professional development during every training year; as well as training and understanding of incident management requirements outlined in Part 624.

Expectations Willowbrook CM/SC:

On-site access to DQI Reports at programs

In order to improve the overall effectiveness of service coordinators as advocates (effective 7/15/99 and reissued **6/5/2013**) DDSOs and providers of services certified by OPWDD maintain copies of the most current DQI inspection reports on site...

- ✓ DQI reports include Statements of Deficiencies (SODs), plans of corrective actions (POCAs) and/or exit summary forms
- ✓ DDROs maintain copies of family care certification reports centrally for the district

MSCs/WCSs/WSCs all have access to and should take full advantage of reviewing all DQI reports. Information may be shared with advocates as appropriate

Service Coordination Activity Plan

Required for class members receiving MSC

- ✓ Should be an attachment to the ISP
- ✓ Describes certain short-term service coordination activities that are most important to the person.
- ✓ Tracks activities to achieve valued outcomes or other objectives

NOT required for WSC or WCS



Service Coordination Activity Plan continued

- ✓ Timeframes for completion ~ within 60 days of enrollment into the MSC program
- ✓ Review at least every six months but activities may be added at any time
- ✓ The review of the Activity Plan must be referenced in the MSC case notes

Service Coordination Activity Plan continued

Best Practice

- ✓ Complete immediately following ISP or other team review ~ serves as a way to track agreements from the meeting
- ✓ The Activity Plan may also be modified, updated following a meeting with the individual and advocate or after an important life changing event



Activities for the Activity Plan

Activities may include:

- Arrangements for new life experiences
- Follow up with a provider about a current issue or problem
- Discovering new ways to promote community inclusion
- Learning more about the person
- Resolving a difficult situation
- Identifying ways to help the person contribute at work, home and in the community

Activity Plan is NOT designed to reflect:

- Ongoing services that are part of the routine maintenance of a person's ISP
- Required MSC activities
- Completion of required monthly notes or required MSC forms
- Writing, reviewing or updating the ISP, and convening ISP or other required meetings

Service Coordination Observation Report (SCOR):

Required for Willowbrook class members who:

- ✓ receive MSC/WCS and live in OPWDD certified residences, including family care homes, IRAs, SOICFs, VOICFs, CRs

NOT required for Willowbrook class members who:

- ✓ receive WSC who live in DCs or nursing facilities or non-certified OPWDD residences (ISS)



SCORs for Class ~ When?

In a meeting convened 4/11/05 between OPWDD and the Willowbrook parties [including CAB], it was agreed that the SCOR is...

- ✓ Minimally required one time in a six month period, i.e., two times a year
- ✓ Also completed any time the MSC/WSC/WCS observes a significant issue in the home related to health, safety or the environment

The MSC/WSC/WCS should always have a SCOR form when they make a visit to a home where a SCOR is required



SCORs for Class ~ Collaborative Visits?

It was also agreed that when a SCOR is required, the MSC/WSC/WCS will participate in a collaborative SCOR visit with the local program associate once annually when CAB is involved on behalf of the class member

- ✓ at a mutually convenient time OR
- ✓ at a team meeting convened at the residence when both service coordinator/case manager and CAB are in attendance



SCORs for Class ~ Follow up?

Ensure that corrections are made by the residential agency within reasonable time frame

- ✓ What is considered “reasonable” will vary

Report delays in correction to the supervisor

- ✓ Supervisor should contact residential agency regarding unresolved issues, or provide other follow up to facilitate corrections if delays are noted
- ✓ Check back with supervisor to ensure that follow up has occurred
- ✓ Another option: report to DQI for Immediate Jeopardy [IJ] or ID Imminent Danger [ID]. The service coordinator should NOT leave the site until someone comes to rectify the issue

Beware of repeat SCOR citations, either the same issue or related



Beyond the SCOR, look out for...

- ✓ Offices in common space such as dining rooms, living/recreation rooms, hallways ~ find furniture that blends with the décor
- ✓ Postings: Staff communication can go in binders, not posted on walls or cabinets. Don't post menus, feeding protocols, schedules ~ remember privacy
- ✓ NO freezers in the dining room
- ✓ Misfit Window Treatments – Take time to shorten window treatments or raise the curtain rod







For more information on Willowbrook SCORs and Activity Plans

**GO TO OPWDD'S BEYOND WILLOWBROOK WEBSITE
ON CASE MANAGEMENT/SERVICE COORDINATION**

POWERPOINTS:

- *MSC Activity Plan Best Uses*
- *You need a good eye to get a good SCOR*

**ACCESSED AT
[HTTP://WWW.OPWDD.NY.GOV/WILLOWBROOK/HP_
WILLOWBROOK_CASEMGMT.JSP](http://www.opwdd.ny.gov/willowbrook/hp_willowbrook_casemgmt.jsp)**



If the class member changes MSC/WSC/WCS vendor...

- ✓ The sending agency should ensure that the receiving agency knows about class status and requirements for caseload ratio, experience and functional independence
- ✓ The sending agency should confirm that compliant choices are offered
- ✓ The sending agency should notify the DDSO Willowbrook liaison of the change

DDSO Liaison Role in Vendor Change

When a class member or his/her correspondent requests a change in vendor, the DDSO's CM/SC Coordinator should consult with the DDSO's Willowbrook Liaison who will provide guidance on CM/SC vendors able to accommodate Willowbrook entitlements for services



Habilitation and Community Inclusion

Willowbrook Expectation for Day Services

Per the Willowbrook Permanent Injunction, class members are to receive meaningful, full day habilitative programming and services appropriate to their individual needs each day during week days.



Willowbrook Expectations for Habilitative Services

Daily/weekly/yearly routines

- ✓ that mirror a typical home/work situation and include participation in normative activities

Unique approaches to people

- ✓ not as just a member of a group where all are treated the same

Team decisions regarding removal of services

- ✓ never discontinue services by simply removing from the ISP or plan of care; such decisions are made at a team meeting with the participation of the class member or his/her active representative

Valued Outcomes/Objectives

There should be valued outcomes [or objectives] and scheduled activities that are...

- ✓ consistent with the person's capacity
- ✓ meaningful and challenging
- ✓ relate to his/her assessed needs
- ✓ Focus on maintaining skill levels of aging population

Methods to achieve valued outcomes [or objectives] should be known to staff and implemented as designed

- ✓ The class member should be actively involved in accordance with the schedule
- ✓ Staff should interact with the class member in an active or passive (but appropriate) manner

Meaningful activities are NOT...

...busy work activities designed to keep a person occupied



Long-term relevance...

Valued outcomes [or objectives] and scheduled activities should be relevant to the long-term view of the class member:

- ✓ Look for appropriately high (but realistic) expectations for outcomes
- ✓ Look to develop achievable goals for our aging population who may be losing skills
- ✓ Low expectations may result in fewer opportunities offered to the person and less growth than possible



Functional...

The total program should be designed to develop functional skills that move the class member toward independence and maintenance

- ✓ Independence = skill development AND activities related to communication, socialization, autonomy, decision-making, etc.
- ✓ Even if the class member will not achieve total independence in an, i.e., taking their own medication, they need to learn to be as independent as possible by doing parts of the task, i.e., perhaps pouring their own water



Service Planning

Objectives, valued outcomes and activities for the class member should be age-appropriate and sufficient in number/scope to ensure that he/she receives appropriate day services

- ✓ The amount of time scheduled for an activity is adequate for learning AND is implemented
- ✓ The setting and materials used are appropriate to the learning situation and person
- ✓ Group size should be as small as possible as appropriate to the activity.
- ✓ Special programs/services are provided as necessary

Think about...

Do staff members make decisions about activities based upon their own values rather than the choices of the individuals served?

Does the program have mechanisms to ascertain the individual's preferences for activities?

- ✓ How do individuals indicate their preferences?
- ✓ Do staff understand and act upon those choices?



Think about...

Are individuals practicing skills (such as cooking, making purchases, table-setting, etc.), or do they “learn” a skill never to use it again?

Are the habilitative activities designed to reach the chosen outcomes?

Are services and activities based upon preferences as well as needs?

Are habilitation activities individualized?

- ✓ Are all individuals “learning” the same skills regardless of their interests, preferences and capabilities?
- ✓ Are skills being modified to meet the needs of our aging population?



Willowbrook Expectations for Community Inclusion

- ✓ Individual strategies based on capabilities, needs and preferences are incorporated into the person's plan of services
- ✓ Variety that provides a rhythm of life based on the activities the class member enjoys
- ✓ Frequency as often as possible based on need and preference
- ✓ Group size as small as possible as appropriate to the activity
- ✓ Opportunities to individualize and personalize activities with community members
- ✓ Documentation to confirm implementation

Remember to reference the
Guidelines for Willowbrook Community Inclusion (9/30/2011)



Community Inclusion Is...

Activities from both the home and day services that ensure the person

- ✓ Uses facilities that are typically used by community members;
AND
- ✓ Interacts with people who are not paid staff and who do not have a disability

*Remember that recreation experiences,
while appropriate and useful at times,
do not meet the definition of community inclusion*



Community Inclusion Is Not...

- ✓ Taking people around to community places in large groups
- ✓ Bringing community members into segregated programs in large groups



Inclusion documentation should reflect...

Within the strategy

- ✓ limitations that impact the class member's frequency, i.e., clinical concerns, weather restrictions, health issues, preferences, etc.

Within the documentation

- ✓ Breakaways, i.e., if the class member arrives to an activity together with other people, and then splits up into smaller groups or goes out as individuals upon arrival at the destination.
- ✓ Weather conditions, clinical concerns, weather restrictions, health issues, preferences, etc. that impacted on the class member's participation in a planned community experience.



Willowbrook CM/SC role with inclusion

- ✓ Advocate for a rhythm of life for the class member based on the things he/she enjoys
- ✓ Advocate for regular experiences, community relationships, family connections
- ✓ Review documentation
- ✓ Suggest new community experiences when appropriate

Willowbrook Expectations for Refusals

- ✓ Look at patterns of refusals
- ✓ Convene a team meeting to discuss and document community options being refused, reasons for refusals and new options to explore
- ✓ Ensure counseling and alternatives consistent with preferences and interests



Assessment, Planning and Other Service Considerations

Willowbrook Expectations for Planning/Assessment

Class members must have an annual plan of services based on current and appropriate assessment information

- ✓ The ISP and required attachments represent the plan of services for class members enrolled in MSC or HCBS Waiver services
- ✓ For class members in ICF programs, the CFA represents the plan of services

Whether an ISP or CFA, Willowbrook parties look for valued outcomes or objectives that exceed skill or ADL development



Considerations for Class Member Plan of Services

Whether an ISP or CFA, the annual plan should reflect whether the class member self-advocates or whether family member(s) or the CAB serve as full or co-representative

- If family is involved, include the relationship, contact information, frequency of visits and/or participation with team members
- Guardianship arrangements should also be identified when applicable

Services should not be removed from the plan of services without discussion at a team meeting



Considerations for Class Member Plan of Services continued

Whether an ISP or CFA, the plan of services should identify supports and coverage needed in the event the person is hospitalized (hospital coverage), and list any circumstances that impact the individual's frequency of inclusion activities, i.e., clinical/health concerns, weather restrictions, preferences, etc.

- ✓ In the ISP, hospital coverage should be in the Safeguard section OR in the Individual Protective Oversight Plan (IPOP) for people who live in IRAs

Considerations for Class Member Plan of Services continued

Whether an ISP or CFA, the annual plan should include individual strategies that promote community life (community inclusion strategy) for the class member

- ✓ based on capabilities, needs and preferences;
- ✓ variety that reflects a rhythm of life appropriate for the person;
- ✓ frequency as often as possible given the individual's needs, interests and capabilities;
- ✓ group size as appropriate for the person and the community experience; and
- ✓ documentation to confirm implementation



Considerations for Class Member Plan of Services continued

If the annual plan is an ISP, attachments include:

- ✓ Individual Protective Oversight Plan (IPOP), if the person lives in an IRA]
- ✓ Medicaid Service Coordination Activity Plan
- ✓ Any Waiver Habilitation Service Plan including residential habilitation, day habilitation, prevocational services, supported employment plan, community habilitation, consolidated supports and services [select all that apply]
- ✓ Clinic treatment plan recommendations for long-term therapies provided by Article 16 clinics

Also include related documents

- ✓ i.e., personal expenditure information and current assessments as appropriate



Considerations for Class Member Plan of Services continued

Options for ISP Update [6 month review]

- ✓ Rewrite if there are significant changes to outcomes, priorities, profile OR
- ✓ If the ISP is not re-written and dated, changes may be made by attaching an addendum

The monthly summary may also be used to document outcomes of an ISP review meeting.



Considerations for Class Member Plan of Services continued

The following documents would be submitted per team discussion at an ISP Review [6 month review]:

- ✓ ISP or ISP Addendum [*specify date*] or case note summary
- ✓ Individual Protective Oversight Plan (*if the person lives in an IRA*)
- ✓ MSC Activity Plan
- ✓ Any Waiver Habilitation Service Plan including residential habilitation, day habilitation, prevocational services, supported employment plan, community habilitation, consolidated supports and services
- ✓ Clinic treatment plan recommendations for long-term therapies provided by Article 16 clinics

Also submit personal expenditure information and current assessments as appropriate



Team reviews

For class members, team reviews should

- ✓ occur every six months
- ✓ convene as face-to-face meetings
- ✓ involve the individual, his/her active representative, CM/SC, service providers and persons relevant to the plan of services

The CM/SC should make every effort to ensure that the appropriate parties are invited and in attendance at team reviews

Willowbrook advocates (or parent) may request quarterly meetings on behalf of an individual class member

**** Please note that quarterly reviews are required for class members on Attachment 1 and they are to be submitted to the Independent Evaluator within 30 days of review.***



Expectations MSC, WSC & WCS:

Team Reviews

MSC/WSC/WCS role differs based on class member's residential setting

- ✓ class in ICFs: QIDP schedules/invites the participants/facilitates the meeting ; WCS attends
- ✓ class in nursing homes: facility schedules/ invites the participants/facilitates the meeting; WSC attends
- ✓ class receiving MSC and WSC [other than nursing homes]: MSC/WSC schedules/ invites the participants/facilitates the meeting

MSC/WSC/WCS responsible for informing MHLS of team reviews for class members



Team meeting preparation

- ✓ Confirm active representation, including relationship, frequency of contact and notification information
- ✓ Prepare a review of the progress since the last meeting related to his/her valued outcomes
- ✓ Confirm that current assessments appropriate to the class member are reviewed and deemed current as written, completed or scheduled and appropriate documentation requested
- ✓ Personal expenditure planning/spending information should be available to reflect spending of personal allowance monies for the period

Team meeting discussion

Consider safeguards:

- ✓ bed safety
- ✓ hospital coverage
- ✓ environmental adaptations
- ✓ emergency evacuations
- ✓ special diet
- ✓ special medical considerations
- ✓ aides, i.e., dentures, glasses, hearing aides, braces, positioning devices, adaptive appliances, ramps, etc.



Team meeting discussion

- ✓ Address educational/vocational/living skills; progress for the review period, medical condition and other matters relevant to his/her care, treatment and development
- ✓ Use a long-term view of the class member to assure appropriately high but realistic expectations for growth, movement and independence AND to accommodate changing needs due to aging



Team meeting documentation

Documentation should reflect...

- ✓ team meeting participants
- ✓ what has occurred in his/her life during the review period
- ✓ new recommendations
- ✓ who will be responsible for what follow up actions



Are triennial IQ tests and psychological testing required for class members?

While there is no requirement for triennial IQ tests, it is required that there be current professional

- ✓ As appropriate, the psychological should address adaptive behavior, communication and social skills

A new IQ test should be administered if it appears that there has been a significant change in functioning

- ✓ i.e., if a class member is showing signs of regression due to dementia or stroke



What is the difference between current and annual assessments?

The team must use current and appropriate information when developing the annual plan of services; therefore, assessments must be reviewed annually to confirm that the information is current

Current means up-to-date information on a person's circumstances, needs, regulatory requirements and other generally professional practice

- ✓ If an assessment continues to be current, a notation and initials may be used in lieu of an annual assessment

Appropriate will vary from one person to another based on individual need

- ✓ What is appropriate for one person may not be appropriate for another
- ✓ Assessments required by OPWDD regulation, i.e., medical, must be completed



Willowbrook Residential/Hospitalization Notification

Willowbrook Residential/Hospitalization Notification

Utilize the Guidelines for Willowbrook Residential Notification (dated 7/9/2015)

✓ Aka **Green** “Cheat Sheet”

Guidelines presented as an abbreviated grid as follows: By situation; Reference; Notify whom; How AND When?

Guidelines reflects the notification requirements for:

✓ Hospitalizations, Planned moves, emergency moves, conversion of residential and other services and expansion of certified capacity of homes serving class members

Send individual notices consistent with active representation status



Notifications to Service Coordinators of Hospital Admissions and Discharges

- ✓ May 5, 2015 Memorandum sent as a reminder that effective communication among all parties is essential to ensure the person's Service Coordinator can support the person during the hospital admission and discharge process.
- ✓ Upon being notified, residential staff/family care providers must immediately ensure that an individual's Service Coordinator is informed of hospital admissions and discharges, so that he or she can assist with follow-up activities that may be needed.
- ✓ Service Coordinators play an integral role in promoting and supporting informed choice and advocating for individuals with ID/DD who reside in state and voluntary-operated residential settings. Timely sharing of information helps the Service Coordinator to advocate on the person's behalf while hospitalized.
- ✓ Service Coordinator may need to participate in discussions regarding whether the person can and would like to return home, or if he/she needs assistance in exploring alternate residential options or a nursing home stay.



PASRR/Willowbrook Communication Flow for Nursing Facility Individuals

- ✓ Reference May 14, 2014 memorandum for when a Nursing Facility (NF) admission or request for a continued stay occurs for a WB class member.
Link to memorandum:
<https://spi.opwdd.ny.gov/teamsites/pasrr/Shared%20Documents/Willowbrook/PASRR%20WB%20Comm%20Flow%20Chart.pdf>
- ✓ Provides guidance on communications and to ensure proactive collaboration and advocacy for Willowbrook Class members.
- ✓ Defines Willowbrook Service Coordinator responsibility for the submission of placement packages to the local vacancy management team for those individuals determined to be appropriate for a residential options (whose medical condition does not necessitate a long-term stay in a nursing facility).
- ✓ Specifics on the role of the Willowbrook Liaisons and PASRR Coordinators.
- ✓ The intent is to ensure consistent agency-wide interactions on behalf of these individuals.

Due Process (30 day) Notice

Permanent Injunction requires 30 day written notification via due process forms for planned moves

Use correct letter format, i.e., IRA or non-IRA

- ✓ See *Beyond Willowbrook* for Sample Letter Formats at http://www.opwdd.ny.gov/willowbrook/hp_willowbrook_plannedmove.jsp
- ✓ Match letter to placement proposal, NOT current residence
- ✓ NO “hybrid” letters

Remember necessary cc's and enclosures



Due Process continued...

Residential agencies should not issue notification for planned or emergency moves for class members.

OPWDD looks to the Willowbrook Service Coordinator (MSC/WCS/WSC) to issue due process notifications for class members.



Emergency Notification

“Emergency” is defined in Appendix L of Willowbrook Permanent Injunction

- ✓ “The immediate and unplanned change of residence of a person due to a sudden and acute medical or psychotic episode, behavior constituting an imminent danger of serious harm to the resident or others, or any other change necessitating the immediate change of residence of the person”

The “Green Book” CP9 identifies the following types of emergency moves:

- ✓ Time limited services elsewhere [which requires bed hold]
- ✓ Emergency transitional or emergency permanent moves

Use correct letter format for emergency moves: see Sample Letter Formats in *Beyond Willowbrook* website at

http://www.omr.state.ny.us/willowbrook/hp_willowbrook_dueprocess.jsp

Remember necessary cc’s



Waiving the 30 day review period for planned moves

- ✓ Purpose of 30 day notice: obtain consent from active representative AND give Willowbrook interested parties an opportunity to object
- ✓ Due process should be issued using appropriate sample letter format on *Beyond Willowbrook* website
- ✓ DDSO Willowbrook Liaison sends copy of notification letter and request for waiver of 30 day review period with reason for request to Lori Lehmkuhl, OPWDD Willowbrook Liaison
- ✓ Ms. Lehmkuhl seeks waiver for 30 day review period from Roberta Mueller, lead Willowbrook attorney for due process, upon receipt of consent from active representative and MHLS written agreement to waive the 30 day review period

Facility Expansion

For increases in certified capacity of an OPWDD certified residence serving class members, or to change temporary use bed (TUBS) to a regularly certified bed, an agency must:

- ✓ Follow all OPWDD applicable requirements related to an increase in residential capacity
- ✓ Follow the procedures set forth in DQI memoranda, *Willowbrook Residential Expansion dated 1/13/2003* and *Provision of Emergency Services dated 6/4/2003*; both accessed at http://www.opwdd.ny.gov/willowbrook/hp_willowbrook_dueprocess.jsp
- ✓ With agreement from the DDRO, submit the *Request for Expansion of Community and Qualifying Facilities* to Lori Lehmkuhl, OPWDD Willowbrook Liaison, who facilitates the OPWDD review prior to submission to the Willowbrook attorneys



When the move is across DDSOs...

- ✓ The receiving DDRO Willowbrook liaison must be officially notified that a class member has/will move into district
- ✓ Both the sending and receiving DDRO Willowbrook liaison is copied in due process notification
- ✓ There can be NO disruption of CM/SC
- ✓ Ensure complete exchange of information across districts



Auspice Change

- ✓ The DDSO Willowbrook Liaison coordinates with the OPWDD Willowbrook Liaison for guidance on due process and protocol on behalf of class members



When moving out of NYS

- ✓ Notify the DDSO Willowbrook liaison and the OPWDD Willowbrook Liaison of the proposed move
- ✓ Follow CP2 of the **“Green Book”**
- ✓ It is important that the class member and advocate are aware that Willowbrook entitlements are only in place in NYS during planning and due process timeframes
- ✓ Due process must enclose a copy of the Willowbrook Permanent Injunction along with other enclosures
- ✓ The class member would again be eligible for Willowbrook entitlements upon return to NYS



Willowbrook Incident Reporting

Willowbrook Incident Notification

Utilize the Guidelines for Willowbrook Incident Reporting

- ✓ Aka **GREY** “Cheat Sheet”
- ✓ Includes changes to the Part 624 in accordance with the Protection of People with Special Needs Act (Justice Center).
- ✓ New definitions for reportable incidents, notable occurrences (including deaths) and new procedures for reporting incidents.
- ✓ Reporting guidance for incidents involving law enforcement
- ✓ Provides updated contact information for the Willowbrook parties for submission of required information

Guidelines are presented as an abbreviated grid as follows: By situation; Notify whom; How AND When?



Guidelines for Willowbrook Incident Reporting continued

Situations include

- ✓ Deaths (all)
- ✓ Reportable Incidents
 - Physical, psychological, sexual abuse and neglect, use of aversive conditioning, obstruction of reports of reportable incidents, deliberate inappropriate use of restraints, unlawful use or administration of a controlled substance, and
 - Significant incidents which include: certain contact between persons receiving services and certain types of mistreatment by staff such as unauthorized use of time out, medication errors with adverse effects, missing person (risk of injury) choking with known risk, self abusive behavior with injury.
- ✓ Notable Occurrences
 - Serious Notable Occurrences including: death, injuries that require hospital admission, choking with no known risk, unauthorized absence, theft and financial exploitation involving values of over \$100, and ICF violations (circumstances described in federal ICF regulations 42CFR Part 483 that do not meet the definitions of reportable incidents).
 - Minor Notable Occurrences including: injuries that require treatment beyond first aid but not hospitalization and thefts of \$15 - \$100.

Jonathan's Law ~ Willowbrook Impact

The requirement within the Willowbrook Permanent Injunction and OPWDD directives related to access of incident reports for the Willowbrook parties have not changed.

However changes in the regulations expand access to incident related information because all categories of incidents are now subject to Jonathan's Law notification requirements.



When applying reporting requirements for Jonathan's Law on behalf of class members...

CAB receives OPWDD 147s of all reportable incidents and notable occurrences for all class members, not only those it represents AND Incident Review Committee Minutes.

If the CAB is the correspondent:

- ✓ CAB must receive the notification, with offers and Report on Actions Taken (OPWDD 148 or equivalent)

If the CAB is co-representative:

- ✓ CAB and the other correspondent must both receive the notification, with offers and OPWDD 148 or equivalent

CAB does not need to make a request for the OPWDD 147; it is to be sent automatically



Ongoing Willowbrook incident reporting

NYCLU receives the OPWDD 147 for reportable incidents and notable occurrences.

NYLPI receives notice of death of class members, including Report of Death.

Independent Evaluator receives notice of reportable incidents and notable occurrences for class members on Attachment 1 monitoring status.

Please note: the initial IRMA entry creates the 147 form in IRMA.



Reporting Considerations ~ CAB

When calling Central CAB regarding an incident and to offer a meeting per Jonathan's Law, the response will come from the local CAB, not the person taking the call.

- ✓ Calls may be answered by the Executive Director, Assistant Director or secretarial staff.
- ✓ Be prepared to provide the details, i.e., class member name and details of the incident, protections taken, etc.

Reporting Considerations ~ CAB continued

When leaving information on the CAB Staten Island Office answering machine, include details, i.e., class member name and details of the incident, protections taken, etc.

- ✓ This is a HIPAA secure line so you should leave as much detailed information as possible related to the incident. It is not necessary to leave a phone number and require a call for CAB to obtain the details
- ✓ Remember to leave a call back number for response to offer of a meeting per Jonathan's Law



Reporting Considerations ~ CAB continued

CAB will receive the Incident Review Committee Meeting Minutes, 147/148 Reports and 30 day updates on investigations electronically at:
OPWDD.CABINCIDENTS@opwdd.ny.gov



Reporting Considerations ~ Independent Evaluator

Provide notice of reportable incidents and notable occurrences for class members on Attachment 1 monitoring status via email or voice mail [email preferred]

- ✓ Follow up with the OPWDD 147 report sent via secure email or fax
- ✓ She may request other reports, including the OPWDD 148, to assist with monitoring

The Independent Evaluator may monitor additional class members at the request of the Willowbrook attorneys



Reporting Considerations ~ Deaths

For deaths of class members

- ✓ Notify the correspondent, CM/SC, DDRO Willowbrook Liaison, OPWDD Willowbrook Liaison
- ✓ IF class member is on Attachment 1 monitoring status, immediately notify Independent Evaluator
- ✓ Send 147 to CAB Staten Island Office via the email address at: OPWDD.CABINCIDENTS@opwdd.ny.gov
- ✓ Send written notice within 24 hours of initial IRMA entry, Report of Death within 5 business days to NYLPI secure email including Report of Death
- ✓ Also send copies to the OPWDD Willowbrook Liaison (Albany) and Ms. Ferguson at the CAB Staten Island via email at: OPWDD.CABINCIDENTS@OPWDD.NY.GOV. **Only** send via fax or paper mail **IF** you do NOT have secure email.



Willowbrook “OTHER” Notifications

Utilize the Guidelines for Willowbrook “Other” Reporting

- ✓ Aka YELLOW “Cheat Sheet”
- ✓ Medical Treatment Court Ordered, Treatment Over Objection
- ✓ CAB Informed Consent, or Surrogate Decision Making Committee
- ✓ Receipt of Any Court Order
- ✓ Guardianship

Please note: When emailing “other notifications” to the CAB, you should be using the OPWDD.CAB.@opwdd.ny.gov email address.



Informed Consent for “Professional Medical Treatment”



When is Informed Consent Necessary?

Reference:

14 NYCRR § 633.11 contains procedures for obtaining informed consent for professional medical treatment



“Professional medical treatment” defined in 633.99 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.

Informed consent is not required...

for medical treatment that

- ✓ does not meet the 633.99 definition - generally routine, or
- ✓ emergency treatment

However....

A physician/hospital may request informed consent for any procedure at their discretion regardless of whether required per 633.11



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 and for whom CAB provides full representation.



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;
- ✓ the CAB for class members for whom it fully represents;
- ✓ 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 have other actively involved family member to act as surrogate decision maker
- ✓ when the above entity has objected to the proposed treatment
- ✓ CAB provides co-representation

When CAB is the identified surrogate for a class member

Provider submits to CAB the Dental Consent Overview OR Medical Consent Overview, depending on procedure, 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 sent **electronically** to Antonia Ferguson to the CAB mailbox.



Requesting agencies are expected to...

1. 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
2. Maintain a detailed chronology of contacts following submission of its request for informed consent, with local CAB reps and CAB Staten Island Office
 - ✓ include all dates of verbal or phone contact, questions from CAB and follow up actions taken by the agency



Requesting agencies are expected to...

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



Requesting agencies are expected to...

4. Ensure that the primary health services contact 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
5. Keep the DDRO 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*
6. If the request is still outstanding, the DDRO Director or designee will contact Ms. Ferguson to ascertain the status of the submission



WHO serves as primary and secondary contacts?

The primary health services contact is typically the RN or MD.

The secondary contact may be the service coordinator/case manager, residential director or other agency designee

- ✓ The secondary contact should be aware and knowledgeable of the submission
- ✓ The local CAB rep is NEVER the secondary contact

Include all communication by the primary health services contact in the chronology maintained by the requesting agency

WHEN will requesting agencies hear from CAB?

Regular reviews

When all required documentation is submitted, CAB will complete a regular review within 21 business days.

Expedited reviews

When all required documentation is submitted, expedited decisions will be made within 8 business days of submission.



For expedited decisions

- ✓ Inform the local CAB representative
- ✓ Reflect on both the *CAB Informed Consent Submission Checklist* and cover letter
- ✓ Provide the medical recommendation/justification within the packet to support the expedited review



HOW will requesting agencies hear from CAB?

Once all questions are fully addressed and information received, the signed or declined consent will be forwarded **electronically** directly to the originating requestor as reflected on the **CAB Informed Consent Submission Checklist** along with the local CAB representative



What if an alternate surrogate exists?

Per 633.11, the requesting agency is able 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.”

- ✓ In such instances, 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?

Per Section 633.11

“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

“Emergency” is defined 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 Staten Island Office, 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



Remember

- ✓ Do not use Surrogate Decision Making Committee (SDMC) forms ~ they will be returned to the originating requestor.
- ✓ Incomplete submissions will result in the return of the information packet to the originating requestor for resubmission.
- ✓ Piecemeal submission also delay the review process.
- ✓ Always request status updates from the local CAB representative



Is informed consent required for IV sedation for dental services?

- ✓ Dental procedures performed under general anesthesia must go before the CAB for informed consent.
- ✓ When dental procedures require informed consent and IV sedation is required, the informed consent from 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.

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

Informed consent for pre-sedation is included in CAB's informed consent for the underlying professional medical treatment.

Once the procedure/treatment is completed, 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



For more about Willowbrook informed consent...

Reference the document, Informed Consent for “Professional Medical Treatment” for Class Members Fully Represented by the Consumer Advisory Board (CAB), reissued September 30, 2011

Accessed on OPWDD’s website at

http://www.opwdd.ny.gov/wt/images/wt_publication_willowbrookinformedconsent.pdf



Another important resource for health concerns...

Reference HEALTH CARE CHOICES: WHO CAN DECIDE?, issued March 2011, and is located at:
http://www.opwdd.ny.gov/willowbrook/hp_willowbrook_healthcarechoices.jsp

This document includes information on...

- ✓ informed consent for medical treatment
- ✓ health care proxies
- ✓ DNR Orders
- ✓ Health Care Decisions Act for Persons with Mental Retardation
- ✓ Living Wills



For more information on Informed Consent

GO TO OPWDD'S BEYOND WILLOWBROOK WEBSITE
ON [CASE MANAGEMENT/SERVICE COORDINATION](#)

POWERPOINT:
[WILLOWBROOK SERVICE COORDINATION/CASE MANAGEMENT
TRANSITION](#)

ACCESSED AT
[HTTP://WWW.OPWDD.NY.GOV/WILLOWBROOK/HP_WILLOWBROOK_CM_TRANSITION.PDF](http://www.opwdd.ny.gov/willowbrook/hp_willowbrook_cm_transition.pdf)



**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



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

Order of priority for decisions to withhold or withdraw LST

- ✓ 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
- ✓ For more detailed information please refer to the Health Care Choices Booklet (pages 18 and 19)



When is CAB the 1750-b surrogate?

When CAB is the court appointed legal 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, treatment team 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 an (email) letter issued by Antonia Ferguson, Executive Director

- ✓ In lieu of an (email) 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 confirms that the appropriate statutory standards have been met per the Health Care Decisions Act (HCDA)

The MOLST LEGAL REQUIREMENTS CHECKLIST **may** be used as a tool when a decision is being made regarding LST.

✓ MOLST = Medical Orders for Life Sustaining Treatment

A Nonhospital DNR order may be documented on either the DOH Nonhospital DNR form or on the MOLST

When should the MOLST be used?

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?

A DNR issued on a MOLST form is transferable between settings

- ✓ It is effective in hospitals, nursing homes, community settings



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 (see link below):

http://www.opwdd.ny.gov/opwdd_resources/information_for_clinicians/MOLST

After the MOLST Legal Requirements Checklist has been completed, the 1750-b Surrogate will determine whether or not they want the MOLST completed. If MOLST is completed, the checklist must be attached.



Other Willowbrook Expectations

Personal Expenditure Plan (PEP) Money Management Assessment

Personal Expenditure Plan (PEP)

- ✓ *If required by residential setting, MSC/WSC/WCS ensures that the PEP is developed as part of team review process and ensure receipt of a copy for inclusion in case record*
 - ✓ Non-agency payee doesn't have to do PEP

Money Management Assessment

- ✓ *If required by residential setting, MSC/WSC/WCS ensures that this assessment is completed as part of the PEP process to reflect how much cash the class member can safely handle at any time and the frequency funds are provided*
 - ✓ A copy of the assessment is included in the case record

Notice of Rights for Willowbrook Class Members

NOTICE OF RIGHTS [Revised 1/2012], printed on sturdy purple paper stock, must be placed prominently in each class member's record to comply with Paragraph 17 of the Willowbrook Permanent Injunction

- ✓ Required to be included in residential, day and service coordinator records



Guardianship

Plaintiffs' counsel are to receive all guardianship petitions for class members

Copies of guardianship petitions are to be forwarded to the DDRO Director and to Ms. Haroules, NYCLU

- ✓ Refer to the **Yellow** "Cheat Sheet" which details notification requirements

If guardianship is being considered for a class member who does not self advocate and does not have actively involved family willing to serve as guardian, CAB should be considered



For a class member with a guardian and standby guardian...

The standby guardian does not automatically become legal guardian

Include a reference in the plan of services

If a legal guardian dies, becomes incapacitated or renounces their role, the standby guardian must go back to court to confirm appointment as a guardian **within 60 days** after the legal guardian's death/incapacity/renunciation

- ✓ If a request for confirmation is not made within 60 days, any person can petition the court for guardianship (including the standby guardian who did not obtain timely confirmation)

Plaintiffs' counsel has asked that the CFA/ISP include current guardian/standby guardian contact information and a reminder of the 60 day timeframe available for the standby guardian to petition the court for guardianship



In the event that guardianship action will be needed for a class member, ensure that

A birth certificate is available and a comprehensive family history is completed

FAMILY HISTORY INCLUDES...

1. documentation reflecting parent(s), sibling(s), half-sibling(s) or other family members, with date of birth AND date/location of death, if applicable/known
2. participation of family member(s) on behalf of the class member and
3. efforts to involve them OR contact them if they are no longer involved

DOCUMENTATION MAY INCLUDE...

1. historical psycho-social summaries/updates; therapeutic progress notes; and correspondence to/from family reflecting their interest, participation or lack thereof



Infrequent but problematic issue with birth certificates

Several class members have birth certificates that lack a first name, i.e., “male” or “boy” as first name

Not having a birth certificate with a first name prohibits anyone from obtaining additional ID such as a non-driver's license, which may prohibit someone from being hired for a job.

To amend a birth certificate the DDRO will need proof of the full name being used in official transactions that are more than 10 years old, while official government records are preferred you may need to use library cards, association membership, etc.



Questions?

Contact

Your Local DDSO Willowbrook Liaison

OR

Lori Lehmkuhl, Statewide OPWDD Willowbrook
Liaison

