WILLOWBROOK PERMANENT INJUNCTION

UNITED STATES DISTRICT COURT
EASTERN DISTRICT OF NEW YORK

NEW YORK STATE ASSOCIATION FOR RETARDED CHILDREN, BENEVOLENT SOCIETY FOR RETARDED CHILDREN, et al.,	:	
Plaintiffs,	:	PERMANENT INJUNCTION
-against-	:	72 Civ. 356, 357
MARIO CUOMO, et al.,	:	
Defendants.	:	

WHEREAS, plaintiffs and defendants entered into a Consent Judgment which was approved by the Court on May 5, 1975, 393 F. Supp. 715 (EDNY), requiring defendants to provide a range of individualized services to the plaintiff class of persons with mental retardation ("class member") and to place them in appropriate, less restrictive, normalizing residences in the community, and

WHEREAS, this Court has actively monitored and supervised, through regularly scheduled status conferences and hearings on various motions of the parties, the provision of services and community residential placements provided to class members pursuant to the Consent Judgment and subsequent orders of the Court, and

WHEREAS, on February 25, 1987, after several years of negotiations between the parties, this Court approved a settlement agreement which, inter alia, imposed the obligation on

defendants to place and maintain plaintiff class members in community residential facilities, placed specific limits on the size of such facilities, established timelines for the completion of all such placements, and provided for the entry of a permanent injunction upon satisfaction of defendants' service and placement obligations ("1987 Stipulation"), and

WHEREAS, defendants have achieved most of their quantitative placement obligations for class members, but will not be able to complete their remaining obligations within the December 31, 1992, timeline set by the 1987 Stipulation, and

WHEREAS, plaintiffs seek to protect the rights and ensure the quality of the residential placements and treatment services of those class members who will not be placed on or before December 31, 1992, and

WHEREAS, in order to prevent the recurrence of the tragic conditions which led to the filing of this litigation in 1972 and the entry of the Consent Judgment in 1975, both plaintiffs and defendants agree that the members of the plaintiff class must continue to receive high quality services in appropriate community residential settings for the rest of their lives, after the removal of this case from the active docket of the Court, and

WHEREAS, as a result thereof, and pursuant to the provisions of paragraph 11 of the 1987 Stipulation, the parties have agreed to the terms and provisions of a permanent injunction which assures that defendants will continue to provide appropriate community residential and habilitative services to the members of

the plaintiff class, replaces the Consent Judgment and subsequent orders of the Court, removes this case from the active docket and active supervision of the Court, and, if adhered to by Defendants, will hereafter assure that the class members continue to receive the high level of habilitation services and appropriate community residential options which have been the objectives of this litigation since its inception, and which have been the obligations required of Defendants by the orders of this Court, and

NOW, THEREFORE, for these findings and reasons, plaintiffs and defendants herein, through their respective counsel, stipulate and agree to the following provisions of this permanent injunction:

1. This permanent injunction supplants and replaces the Consent Judgment and all subsequent orders of this Court in this matter, except as specifically referenced herein. All such judgments and orders are hereby vacated and dissolved, subject however to the exceptions and reservations herein set forth. The Office of the Special Master shall terminate at the close of business on March 31, 1993. Any motions to enforce the rights of the plaintiff class shall be brought before this Court pursuant to the permanent injunction. The action shall otherwise be terminated, and the case shall be removed from the active docket.

Richmond Complex.

2. Defendants may, but are not required to, operate and maintain on the grounds of Willowbrook residential facilities which, in the aggregate, do not exceed a capacity for 150 persons. For purposes of this paragraph, "Willowbrook" shall be defined as set forth in paragraph 2(a) of the 1987 Stipulation, which definition is specifically retained and incorporated herein. (See Appendix A attached hereto)

3. Defendants shall render high quality and appropriate medical and habilitative services, shelter, food and clothing to the residents of the Richmond Complex. At a minimum these services shall conform to applicable state and federal requirements and all other requirements of this permanent injunction. For purposes of this paragraph, the "Richmond Complex" shall be defined as set forth in paragraph 3(a) of the 1987 Stipulation, as that definition incorporates paragraph 2(a) of the 1987 Stipulation, which definitions are specifically retained and incorporated herein. (See Appendix B attached hereto)

4. Defendants shall continue to prepare the residents of the Richmond Complex for placement in small community residential settings of 10 beds or less, to the extent warranted by interdisciplinary team recommendations. At the time the permanent injunction is entered, defendants shall provide plaintiffs a list of the names of every class member residing at the Richmond Complex on that date. A copy of that list shall be

attached to this permanent injunction. (See Appendix C attached hereto) No later than two years after the entry of this permanent injunction, defendants shall provide plaintiffs' counsel with the current address of each individual listed on Appendix C, the residential capacity of the facility where he or she resides, the name and address of the provider of residential services for each resident of the Richmond Complex who resided there on the entry of this permanent injunction, and placement plans for those residents who still remain at the Richmond Complex at that time. For those residents whose interdisciplinary team has recommended they should continue to remain at the Richmond Complex, defendants shall also provide plaintiffs' counsel with all data and reports in its possession which support, and which do not support, such recommendations.

5. Placements.

(a). With the exception of the class members listed on Attachment 1 to this permanent injunction, defendants have satisfied their quantitative placement obligations under the 1987 Stipulation, including Attachment A to the 1987 Stipulation. (A copy of Attachment A and a list of the other Willowbrook class members placed pursuant to the Willowbrook Consent Judgment is attached hereto as Attachment 2.)

(b). All class members who have not been placed in a community or qualifying facility by December 31, 1992 shall be placed on Attachment 1 to the permanent injunction. Before being included on Attachment 1, each class member must have a complete

placement plan which has been reviewed and approved by the Special Master and plaintiffs' attorneys.

(c). OMRDD shall place all class members listed on Attachment 1 into appropriate community residential facilities as defined in paragraph 4(d) of the 1987 Stipulation, see Appendix B, no later than August 31, 1993, however this deadline may be extended upon consent of plaintiffs and defendants, where appropriate to meet the needs of an individual class member. Appendix A to the Consent Judgment and subsequent orders of the Court shall continue to be applicable to these individuals until six months after each person on Attachment 1 has been placed in an appropriate community facility or, in the case of an individual who has been returned to a developmental center or otherwise placed in a non-qualifying facility as defined in paragraph 2(c) of the 1987 Stipulation, until the individual has lived continuously in an appropriate community facility for six months.

(d). Plaintiffs' counsel and defendants have agreed upon an independent evaluator who will closely monitor the individuals listed on Attachment 1 to ensure that they receive the services required in paragraph 1(c) above and verify the continued appropriateness of their placement plans. With regard to these individuals only, the independent evaluator shall have the same powers granted to the Special Master pursuant to paragraphs 5, 6, 8, 9, 10, 13, and 16 of the Order of Referral, dated July 13, 1982, including but not limited to monitoring,

providing technical assistance, and issuing formal recommendations. Defendants shall provide adequate funds to permit the independent evaluator to perform his or her duties under this permanent injunction. (See Appendix D attached hereto, setting forth the powers and duties of the independent evaluator).

(e). Defendants shall report regularly to both plaintiffs and the independent evaluator on the progress of their efforts to place individuals listed on Attachment 1. The independent evaluator shall certify to the court and the parties no later than September 30, 1993 whether defendants' placement obligations have been met under Attachment 1 and the individuals listed on Attachment 1 are receiving services consistent with Appendix A to the Consent Judgment and subsequent orders of the Court, as provided in paragraph 5 (c) above. Because these individuals are among the most difficult to place and maintain in the community, the independent evaluator shall continue to monitor their progress in the community for six months following their placement into a community facility.

6. Maintenance of Size of Community Residences.

Defendants shall maintain class members in the community residential facility in which they live at the time of the entry of this permanent injunction, or in such community residential facilities with equal or smaller residential capacities as are appropriate for the class member, except:

(a). in the event of an emergency as described in paragraph 8 (b) of the 1987 Stipulation (See Appendix E attached hereto);

(b). where the class members' medical needs require movement pursuant to the criteria for inclusion in Attachment A to the 1987 Stipulation which are described in paragraph five of said Stipulation and certain documents developed by the Special Master and which are specifically retained and incorporated herein (See Appendix F attached hereto);

(c). where the class member's interdisciplinary team recommends a residential movement for the purpose of providing treatment and services which are more appropriate to the class member's needs and which cannot be provided in the same or a smaller facility, subject to:

(i). the consent of the class member, if the class member has capacity; or, if the class member lacks capacity, the class member's correspondent or, in the case of noncorrespondents, the Consumer Advisory Board. However, consent shall not unreasonably be withheld if the class member is endangering other residents at the facility where the class member resides or is substantially interfering with the operation of the residential program; and

(ii). the considerations set forth in paragraph 6 of the 1987 Stipulation, which is specifically retained and incorporated herein. (See Appendix G attached hereto)

(d). where a class member with capacity requests a move to another facility;

(e). upon consent of plaintiffs' counsel.

7. Consumer Advisory Board.

Defendants shall comply with the Stipulation and Order of January 3, 1992, which shall remain in effect, and is specifically retained and incorporated herein. (See Appendix H attached hereto). For purposes of this permanent injunction and the Stipulation and Order of January 3, 1992, the parties agree that the term "noncorrespondent class member" shall mean any class member who does not receive active representation, as defined in Appendix H, attached hereto. Defendants shall refer for Consumer Advisory Board representation or co-representation those class members who lack active representation, as defined in Appendix H attached hereto. With the consent of a class member with capacity or his or her correspondent, the Consumer Advisory Board may also act as co-representative or advocate for those members of the plaintiff class who are not noncorrespondent class members. The Consumer Advisory Board shall continue to have 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.

8. Case Management.

Defendants shall continue to provide plaintiff class members with case management services, as defined in Appendix I, at a ratio of no less than one case manager to every 20 persons. No

later than the first day of January and the first day of July of each calendar year, so long as any plaintiff class member lives, defendants shall provide to plaintiffs' counsel, or their designated representative, and the Consumer Advisory Board a report detailing the current status of defendants' compliance with their case management obligations and listing the name and caseload of every case manager providing services for a member of the plaintiff class and the name and address of any class member who is not receiving case management services in accordance with this paragraph.

9. Access to Class Members and Records; Plaintiffs' Access to Commissioner of OMRDD.

(a). For so long as any class member lives, defendants shall provide plaintiffs' counsel, the Consumer Advisory Board and Mental Hygiene Legal Service ("MHLS"), to the extent it represents a class member, with the following rights of reasonable, unrestricted access to:

(1). all class members; and

(2). all records relating to class members maintained by or in the possession of defendants, or maintained by any provider of services to the class member upon reasonable advance request to the OMRDD Defendants, including but not limited to individual developmental plans and incident reports; and

(3). all facilities where class members reside or receive habilitation, treatment or other services; and

(4). copies of all residential or program surveys and audits for facilities where class members receive services upon reasonable advance request to the OMRDD Defendants. For purposes of this paragraph, surveys and audits shall include, but not be limited to, those completed by the New York State Commission on Quality of Care, and the OMRDD Quality Assurance Division, and/or any successor to either agency.

(b). For so long as a correspondent shall represent a class member, defendants shall provide each correspondent the right of reasonable, unrestricted access to each class member the correspondent represents and all records and facilities listed in paragraph 9 (a)(2), (3) and (4) above.

(c). Plaintiffs and plaintiffs' counsel shall continue to have reasonable access to the Commissioner of the Office of Mental Retardation and Developmental Disabilities ("OMRDD") to discuss matters of concern to members of the plaintiff class through telephone calls and informal meetings at mutually convenient times and places.

10. Programming.

(a). Defendants shall provide all class members with meaningful, full day habilitative programming and services appropriate to their individual needs each day during week days and meaningful, appropriate recreation and community integration each day during evenings and weekends for the remainder of their lives. Such habilitative programming and services, recreation and community integration shall include, but not be limited to,

compliance with applicable contemporary habilitation standards and contemporary federal and state regulatory standards. Class members with capacity have a right to refuse to partake in such programming.

(b). Defendants shall ensure that each class member's developmental plan is reviewed by the class member's interdisciplinary treatment team at least annually, and quarterly if the class member, correspondent, Consumer Advisory Board or MHLS, to the extent it represents a class member, so requests. The class member if he or she has capacity, the class member's correspondent or the Consumer Advisory Board, and MHLS, to the extent it represents a class member, shall be invited to attend such reviews and kept informed of the class member's educational, vocational and living skills, progress, medical condition and other matters relevant to his or her care, treatment and development. Defendants shall maintain current, appropriate professional assessments of each class member's needs, including where applicable, but not limited to, medical, psycho-social, habilitative, psychological, speech therapy, food and nutrition, physical therapy, and occupational therapy.

(c). In addition to the above, the notice to the class described in paragraph 18 below shall include the following notice of the following right of each class member under the permanent injunction:

> "Class members presently are entitled to receive active treatment and full day programs and it is the defendants' intention to continue these programs. If any aspect of the day program that the class member was entitled to under the

Consent Judgment is proposed to be changed, including but not limited to the nature or duration of the program, you will be given notice of the proposed change and will have an opportunity to discuss the proposal and object to it if you are not satisfied. You will be entitled to administrative and judicial review of the proposal if you object. Any future change in the program to which the class member was entitled under the Willowbrook Consent Judgment shall be permitted only on a showing that it provides a greater opportunity for the class member's growth and development and is based on an individualized assessment of the class member's current needs made by the individual's treatment team, including, where applicable, the individual's medical psycho-social, habilitative and psychological needs, in the exercise of its professional judgment. Appropriate changes in the individual developmental plan may be made where a class member is unable to participate fully in programming because of a medical condition or advanced age and such assessment is based upon a full individualized assessment of the class member's current needs in the manner described above. In the case of a class member incapacitated by a medical condition, prior programming shall be restored as soon as the individual is no longer incapacitated."

11. Safety and Physical Environment.

Defendants shall assure each class member protection from harm and a safe, clean and appropriate physical environment.

12. Staffing.

Defendants shall assure that there is sufficient staff present and on duty to protect each class member from harm; provide a safe, clean and appropriate physical environment; provide meaningful, full day habilitative programming and services appropriate to the individual's needs during week days and meaningful, appropriate recreation and community integration each day during evenings and weekends for the rest of their lives; and satisfy defendants' other obligations under this permanent injunction.

13. Behavior Modification, Research, and Hazardous or Experimental Treatment.

Paragraph P, subparagraphs (2), (3) and (4) of Appendix A to the Willowbrook Consent Judgment, attached hereto as Appendix J, is specifically retained in the permanent injunction, except that in subparagraph (2)(c) plaintiffs' attorneys shall designate the individual formerly designated by the Professional Advisory Board.

14. Names and Locations of Class Members.

Defendants shall provide plaintiffs' counsel and CAB with a list of the names and locations of all class members at the time the permanent injunction is entered and at six month intervals thereafter, so long as any class member lives.

15. Due Process Notices.

Except in emergencies as defined in Appendix K, defendants shall provide notice at least 30 days prior to the transfer of any class member from any residential facility or building in which he or she resides, to:

(a) the Consumer Advisory Board, so long as any class member remains alive;

(b) to plaintiffs' counsel for at least five years from the date of entry of this permanent injunction; and

(c) MHLS, to the extent it represents a class member.

In an emergency, as defined in Appendix K, one day's notice shall suffice unless circumstances are such that it is impossible to provide notice prior to the transfer, for example

in the event of a fire or other natural disaster. In such cases notice shall be provided as soon as practicable. Notice shall be provided through due process forms, a copy of which is attached hereto as Appendix L. Unless the parties expressly agree otherwise in writing, defendants' obligation to provide: 1) a hearing before an independent factfinder and the other rights presently afforded at such a hearing, as described in Appendix L; and 2) full, written notice of such rights 30 days prior to the proposed transfer, as described in Appendix L, shall remain in effect for so long as any class member is alive, regardless of any change in the form or content of defendants' due process notices.

16. Appropriate Services.

Defendants shall continue to provide each class member with residential, habilitative and programming services that are reasonably unrestrictive and appropriate to his or her individual needs.

17. Notice of Rights.

The OMRDD defendants shall place the following information describing the rights and entitlements under the permanent injunction in the permanent record of each class member, shall retain such information on record for so long as the class member is alive, and shall enter such information in the class member's file maintained by all providers of residential and habilitative services to class members:

(a). designation of membership in the Willowbrook class;

(b). notation that class membership results in rights and services guaranteed by this permanent injunction issued by the United States District Court, Eastern District, and a summary o those rights; and

(c). the name, address and telephone number of plaintiffs' counsel, MHLS and the Consumer Advisory Board.

18. Notice of entry of Permanent Injunction.

Defendants shall provide one time notice to all correspondents and class members of their rights and entitlemen under the permanent injunction. Within three (3) months of the entry of the permanent injunction, defendants shall mail the Notice to Correspondents, which is attached hereto as Appendix I to the Consumer Advisory Board, MHLS and all class members with capacity and each and every class member's correspondent at the last known address.

19. Commissioner's Task Force.

Defendants shall create a Commissioner's Task Force which shall meet quarterly and be comprised of parents, advocates, consumers, members and staff of the Consumer Advisory Board, OMRDD, other professionals in the field and plaintiffs' counsel. The Task Force shall, inter alia, review information from the monitoring provided in paragraph 21 below and advise the Commissioner on both the dissemination to other facilities of better practices at facilities found to be exemplary and on possible plans of corrective action where deficiencies are identified. The Task Force shall also identify and address

systemic problems, review the progress in implementing the systemic plans identified in paragraph 20 below, and advise the Commissioner regarding these and other matters concerning the plaintiff class. In addition to the monitoring reports described in paragraph 21 below, the Task Force shall receive quarterly reports of case management ratios and use other sources of information including but not limited to parents, consumers, the New York State Commission on Quality of Care, and the OMRDD Division of Quality Assurance. Plaintiffs and defendants have agreed upon the members of the Task Force. The Task Force shall operate until the 350 audits described in paragraph 21(d) below have been completed and reviewed by the Task Force. Thereafter, the Task Force, plaintiffs' counsel and the Commissioner shall evaluate the continuing need for the Task Force. The Task Force shall not be discontinued without the consent of plaintiffs' counsel and defendants.

20. Systemic Issues

(a). Defendants and plaintiffs agree that the continued delivery by defendants of high quality residential and habilitation services to class members is linked to the successful management of key professional interventions or services. The professional interventions and services which the parties have identified as critical to the successful implementation of this permanent injunction are: vocational and day programming, medical services, respite care, behavior management, case management, residential and integrative services, and incident review. The

items enumerated herein are not intended to be exclusive. Rather, defendants have agreed to continue to identify other professional interventions and services which are key to their obligation to successfully comply with the provisions of this permanent injunction.

(b). Defendants, while maintaining that the professional interventions and services set forth in paragraph 20 (a) above are currently being provided, have also agreed to take the steps necessary and required to improve these services. To that end, defendants and the Special Master will develop a master plan of action for each systemic issue in the areas set forth in paragraph 20(a), above. Plaintiffs and defendants have agreed upon and submitted to the Court the master plan and a plan for specific action during fiscal year 1993-94. Defendants will submit these plans to The Commissioner's Task Force, which will review the progress and problems related to these systemic issues and make recommendations to the Commissioner. Defendants will conduct individual audits of class members to determine how well their systemic solutions are improving the quality of services provided to class members, as provided in paragraph 21 below.

(c). For purposes of monitoring the development and implementation of the plans required by this paragraph, defendants agree to provide plaintiffs' counsel, if plaintiffs shall so request, information sessions to be attended by plaintiffs' counsel, any experts retained by plaintiffs' counsel and designees of the defendants, who are responsible for

designing and implementing the plans. The purpose of the meetings shall be to inform plaintiffs' counsel of their progress in developing and implementing the plans and to provide defendants with input and suggestions from plaintiffs' counsel, and to provide plaintiffs' counsel with status reports regarding the implementation of the plan.

21. Monitoring.

In order to ensure that class members are receiving the services required by this permanent injunction, defendants shall monitor class members' residential and day programs as described below. The parties agree that the audit instruments and methodology contained in Appendix N, attached hereto, measure compliance with the permanent injunction. Defendants agree to hire three staff members from the Office of the Special Master to monitor compliance with the permanent injunction and to perform the audits and related work described in paragraph 21(b), (c), (d), and (e), below.

(a). The Special Master shall complete approximately 700 validated full audits by March 31, 1993. Defendants shall take prompt action to correct any deficiencies cited in the audits.

(b). Within 24 months following entry of the permanent injunction, or longer on consent of the plaintiffs, defendants, together with staff from the Special Master's Office, shall complete surveys of each class member who was not fully audited by the Special Master as provided in paragraph 21(a) above, using

(f). Plaintiffs may select independent consultants to review and validate the survey findings and corrective actions described above and report quarterly their findings to OMRDD, plaintiffs and the Commissioner's Task Force. OMRDD will furnish the survey findings, and raw data if requested, to plaintiffs, the Consumer Advisory Board, and the Commissioner's Task Force.

(g). Three members of the professional staff of the Special Master's Office shall continue their work, but under the direct supervision of the OMRDD Internal Audit Unit, and shall serve as staff to the Commissioner's Task Force and shall conduct the audits of class members after March 31, 1993. Defendants shall continue to employ these individuals in such capacity until one month after the completion and validation of the audits and corrective actions described in paragraph 21(b), (d) and (e) above, or December 31, 1995, whichever occurs later. In the event any staff member of the Special Master's Office does not remain until the completion and validation of the audits and corrective actions described above, he or she shall be replaced by an individual agreed upon by plaintiffs' counsel and defendants.

22. The court retains jurisdiction to enforce the provisions of this permanent injunction and for purposes of requests for attorney's fees and costs related to the monitoring and enforcement of the permanent injunction, except that after December 31, 1995, or two months after the completion and validation of the audits and corrections described in paragraph

the short form audit instrument set forth in Appendix N attached hereto. Any class member whose compliance level is below 80% shall promptly be re-audited using the full audit instrument contained in Appendix N. Defendants shall promptly correct any deficiencies cited in the audits.

(c). Surveys, as required by state and federal law, will be conducted by the OMRDD defendants or the New York State Department of Health for every facility in which a class member resides and the results will be matched against the Willowbrook key indicators contained in Appendix N, attached hereto.

(d). In 1995, or at the completion of the process described in paragraph 21(b) above, whichever is later, defendants shall conduct a random sample audit of 350 class members at 350 different sites using the full audit instrument in Appendix N attached hereto, in order to determine whether class members are receiving the services required under the permanent injunction and whether the systemic problems identified in paragraph 20 have been corrected. Defendants shall devise a plan of correction for any deficiencies revealed by the audit.

(e). Defendants, together with the staff from the Special Master's Office described in paragraph 21(g) below, shall promptly devise and implement plans of correction for those individuals who are not receiving appropriate services as disclosed by the audits and surveys described above or other sources of information supplied to OMRDD.

21 above, whichever is later, plaintiffs may not seek attorney's fees for monitoring unrelated to a motion to enforce this permanent injunction.

23. Plaintiffs and defendants agree that the primary purpose of this permanent injunction is to guarantee members of the Willowbrook class certain basic, enumerated rights, high quality community residential and treatment services, high quality case management and advocacy services and the representation of noncorrespondent class members by the Consumer Advisory Board.

Dated: New York, New York
March 11, 1993

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SO ORDERED:

JOHN R. BARTELS
United States District Judge

WILLOWBROOK

"Willowbrook" shall refer to the grounds of the former Willowbrook Developmental Center and the Institute for Basic Research, including the Staten Island Developmental Center, the Karl D. Warner Center, the Richmond Complex, and any subsequent structures.

RICHMOND COMPLEX

Defendants may operate on the grounds of Willowbrook and the Institute for Basic Research a residential facility to be known as the Richmond Complex, which shall be an institution of 150 or fewer beds. The number of residential beds at Willowbrook shall be 150 or less and shall not exceed 150 at any time.

POWERS OF INDEPENDENT EVALUATOR

1. The independent evaluator shall be allowed full access to all information, records (including budget records), buildings and areas covered by the preliminary injunction and shall be permitted to interview any member of the class or any employee of defendants, at reasonable times and places, to the extent necessary to the discharge of his duties.

2. Any interference with the independent evaluator in connection with his or her performance of the duties described herein, by any person having notice of the contents of this Order, may be punishable as contempt of court and subject to other sanctions provided by law.

3. In addition to those powers described above, the independent evaluator shall have the authority to:

(a) Require the defendants or their agents or any person who provides services to class members to submit any reports necessary to assist the independent evaluator in performing his or her duties, including programs, records and evaluations of individuals, and to assist in accomplishment of the community placement provisions of the Permanent Injunction;

(b) Provide advice and assistance to the parties in implementing the Permanent Injunction;

(c) Issue such reports to the parties and the Court as he or she deems useful in performing his or her duties;

(d) Consult with all parties and interested persons and bodies concerning implementation of the Permanent Injunction;

(e) Identify specifically any terms of the Permanent Injunction with which defendants are not in compliance. He or she may recommend a resolution of any disagreements which arise concerning compliance with the terms of the Permanent Injunction. Such recommendations shall be communicated in writing to the following: defendants, counsel for defendants, counsel for plaintiffs, and such other persons as the independent evaluator deems appropriate.

4. All parties shall be bound by the recommendations of the independent evaluator issued pursuant hereto, unless within 15 business days following receipt of such recommendations they serve on all other parties and file with the independent evaluator written objection to such recommendations. The filing of such an objection by any party shall automatically stay the effect of any such recommendation until further order of the Court. Within ten

(10) days of receipt of written objections, the independent evaluator or any other party, may apply to the Court for a hearing to determine whether the recommendations to which objection has been made should be adopted. Such applications shall be upon prior written notice to all parties and to the independent evaluator.

5. In order to achieve the goal of compliance with and enforcement of the Permanent Injunction, information investigations by the independent evaluator may be conducted as informal working sessions. Informal private consultations without the presence of counsel are permitted but the fact that such meetings were held shall be made known to all counsel by the independent evaluator keeping a record of them and making the record available.

6. The independent evaluator shall have no authority to exercise any control or management over the operation of any facility operated or licensed by the State of New York, but shall have authority to monitor the location and acquisition of community placement facilities in order to meet the placement goals of the Permanent Injunction and to make a report to the parties with respect thereto.

7. Defendants and all of their agents, as well as public agencies of the State of New York, will cooperate fully with the independent evaluator in order to accomplish the purposes of this order.

EMERGENCY FOR INCREASED BED SIZE

For purposes of this paragraph, an emergency situation shall be limited to the revocation, suspension or precipitous surrender of the operating certificate of a community or qualifying facility in which class members reside.

ATTACHMENT A CRITERIA

Defendants may place in appropriate long-term care facilities those class members who require extended intensive medical care at a more service-intensive level than that which is provided in an Intermediate Care Facility for the Mentally Retarded ("ICF/MR"), as defined in the Social Security Act, §1905(c) and (d) and 42 C.F.R. §§442.400 et seq.

PARAGRAPH 6 OF THE 1987 STIPULATION

Defendants shall continue to provide class members placed in facilities pursuant to paragraphs 4 and 5, above, with the least restrictive and most normal living conditions possible, consistent with the provisions of Appendix A, §§(1) and (2) of the Consent Judgment. Any placement pursuant to this Stipulation shall be appropriate to the individual needs of the class member and consistent with the provisions of Appendix A to the Consent Judgment.

JANUARY 3, 1992 ORDER RE: CAB

Active Representation

Active representation is generally defined 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.

UNITED STATES DISTRICT COURT
EASTERN DISTRICT OF NEW YORK

NEW YORK STATE ASSOCIATION FOR RETARDED CHILDREN, et al., Plaintiffs, -against- MARIO CUOMO, et al., Defendants.	72 Civ. 356, 357 STIPULATION AND ORDER (J.R.B.)

WHEREAS, the Consumer Advisory Board was established pursuant to the provisions of §§ S and W of Appendix A to the Final Judgment entered on May 5, 1975 [393 F.Supp. 715 (EDNY)], and

WHEREAS, in paragraph 11a of the stipulation and order dated February 24, 1987, the defendants agreed to assure that necessary and appropriate representation and advocacy services were provided to noncorrespondent class members after the entry of a permanent injunction in this litigation,

NOW, IT IS HEREBY STIPULATED AND AGREED, by and between the parties, that the permanent injunction referred to in paragraph 11 of the stipulation and order dated February 24, 1987, shall contain the following paragraphs:

1. The seven member Consumer Advisory Board, as nominated and appointed pursuant to the provisions of § S (2) of Appendix A to the Final Judgment entered on May 5, 1975 [393 F.Supp. 715 (EDNY)] ("Consent Judgment") and paragraph 9 of the stipulation

and order dated February 24, 1987, shall continue to provide necessary and appropriate representation and advocacy services on an individual basis to all noncorrespondent former Willowbrook class members as long as any such class member shall live. The term "necessary and appropriate representation and advocacy services" shall include, but not be limited to, those representation and advocacy services which the Consumer Advisory Board has provided on an individual basis to noncorrespondent members of the Willowbrook class prior to the entry of this injunction.

2. The Consumer Advisory Board shall have direct access to all living areas and program areas used by noncorrespondent former Willowbrook class members and to all records relating to the care of any noncorrespondent former Willowbrook class member.

3. If necessary, or advisable, the Consumer Advisory Board may apply to an appropriate court for authority to exercise directly, or through its designees, the function of a guardian, for the purpose of providing necessary representation and advocacy services for a former Willowbrook class member. In general the defendants shall support such applications but reserve the right to oppose the particular person or persons nominated to serve as such guardian.

4. Defendants shall provide sufficient funds to ensure that the Consumer Advisory Board continues to be staffed with an executive director, two secretaries and program staff at a ratio of one (1) staff member for every 75 noncorrespondent clients

upstate and one (1) staff member for every 100 noncorrespondent clients in the New York City metropolitan area.

Dated: New York, New York
December 2, 1991

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SO ORDERED:

U.S.D.J.

January 3, 1992

Willowbrook Case Management

I. Definition of Case Management

A case manager is a qualified mental retardation professional (QMRP) who is either a state employee, or an employee of a voluntary agency that does not provide residential or day services to the class member. A class member or the class member's correspondent may choose a functionally independent case manager employed by the same agency that provides residential or day services if such a person is available. The case manager:

1. Promotes self-advocacy, self direction and choice;

2. Advocates and arranges for services that are accessible, community-based, comprehensive, and culturally appropriate;

3. Monitors the quality of services and programs provided to the consumer through measures of consumer satisfaction; and,

4. Monitors compliance of the services and programs with Willowbrook class requirements and entitlements and with state and federal laws and regulations.

II. Case Management Functions

The case manager shall perform the following functions on behalf of class members:

1. Advocacy

   a. The case manager shall protect and uphold the rights and entitlements of the class member in the residential program, in the day or work program, and in all spheres of the class member's life. These rights and entitlements are established by federal and state laws and regulations and by class membership under the permanent injunction. The case manager shall ensure that procedural and substantive due process requirements are met with regard to the class members and the class member's representatives.

b. The case manager shall ensure active representation, either by the class member or by a correspondent or Consumer Advisory Board ("CAB") representative.

c. The case manager shall display an appropriate long-term view for the class member that assures appropriately high, but realistic, expectations for growth, movement and independence.

2. Assessment

a. Through an interdisciplinary treatment team, appropriately constituted based on the needs of the individual, the case manager shall ascertain a class member's developmental level and specific needs for services.

b. The case manager shall ensure that all assessments for the class member including, where applicable but not limited to, medical, psycho-social, habilitative, psychological, speech therapy, food and nutrition, physical therapy, and occupational therapy, have been either completed or scheduled and the case manager shall request appropriate documentation of such.

3. Program Plan Development

a. The case manager shall make every effort to ensure that all appropriate parties, including the class member, the correspondent, the Mental Hygiene Legal Services ("MHLS") and the CAB representatives to the extent it represents a class member, are invited and in attendance at interdisciplinary treatment team meetings.

b. The case manager shall ensure development of a plan of needs and services for the class member.

c. The case manager shall ensure that each class member's developmental plan is reviewed by the class member's interdisciplinary treatment team at least annually or more frequently when required by the class member's individual needs. A class member's development plan shall be reviewed by the

interdisciplinary treatment team on a semi annual or quarterly basis if the class member, the correspondent, Consumer Advisory Board, or MHLS, to the extent it represents a class member, so requests.

4. Recordkeeping

a. The case manager shall ensure that the individual's record is maintained including the individual's plan for needs and services, persons responsible, and plans for data maintenance and monitoring.

b. The case manager shall prepare monthly case notes reflecting visits and progress.

c. The case manager shall ensure written notifications to the class member and correspondent as required by OMRDD's Client Placement Procedures.

5. Coordination

a. The case manager shall serve as a focal point for services.

b. The case manager shall coordinate among the diverse providers of service required by the class member, including their day and residential programs.

6. Linking

a. The case manager shall ensure that the class member is linked to new services, as needed. In doing so, the case manager shall, as needed, make referrals for the new services, arrange services at generic agencies, accompany the class member to agencies providing services or arrange for a person familiar with the class member and his or her needs to do so, assist in completing forms and applications, and perform other related duties.

7. Support

a. The case manager shall assist the class member and/or their family with unanticipated crisis intervention.

8. Monitoring/Follow-Up

a. The case manager shall assure that the class member is receiving appropriate services in accordance with their plans of needs and goals, and periodic reassessment of the class member's progress.

b. The case manager shall ensure that the class member's correspondent or CAB and MHLS representatives are kept informed of the class member's educational, vocational and living skills, progress, medical condition and other matters relevant to his or her care, treatment and development.

c. The case manager shall ensure reporting, investigation, implementation of preventive actions, and other needed follow-up on incidents which pose a risk to the health and safety of the class member or to others in the class member's immediate environment.

9. Discharge

a. The case manager shall coordinate the termination of services which are no longer needed by the class member or for which the class member is no longer eligible.

10. Case Manager Reporting

a. Case managers shall keep a list of dates of monthly contact with the class members and dates of attendance at team meetings, which shall be available to the plaintiffs and CAB upon request.

b. The DDSO shall monitor and evaluate case management services provided by voluntary agencies in order to ensure that all class members receive services in accordance with Appendix I.

PARAGRAPH P(2),(3), and (4) FROM THE CONSENT DECREE

P. Behavior Modification, Research, and Hazardous or Experimental Treatment

2. The use of aversive conditioning shall be permitted only after positive reinforcement procedures and other less drastic alternatives have been explored and approval has been obtained:

A. from the resident, if he or she is capable of giving informed consent, or

B. from the parent, relative or guardian if the resident can not give informed consent and the parent, relative or guardian can give informed consent, and

C. from a three person special committee on aversive conditioning, designated by the Director, which shall include at least one designee each from the Consumer Advisory Board and Professional Advisory Board.

The Deputy Commissioner for Mental Retardation, and the New York City Regional Director of the Department, shall be advised when a decision has been reached and approved to utilize such aversive conditioning. Aversive conditioning techniques shall be employed only under the supervision of and in the presence of a psychiatrist or psychologist licensed to practice in the State of New York who has had proper training in the use of such techniques, and who is specifically authorized by the Director to conduct such aversive conditioning.

3. Behavioral research or experimentation shall be conducted only after approval has been obtained as set forth in paragraph 2(A)-(C) above.

4. Because of the necessity to concentrate on the basic programmatic needs of Willowbrook residents and the history of experimentation at Willowbrook, no physically intrusive, chemical, or bio-medical research or experimentation shall be performed at Willowbrook or upon members of the plaintiff class. This standard, however, recognizes the possibility that such research or experimentation, under proper safeguards, may be appropriate for persons who are not members of the class, in other facilities or programs.

EMERGENCY MOVE

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 circumstance necessitating the immediate change of residence of a person.

SAMPLE - PLACEMENT NOTIFICATION LETTER TO CORRESPONDENT
This letter is to be adapted to suit the recipient and situation,
but must contain all the information herein

Date _____

Dear _____(correspondent)_____:

We are planning to move _____ from _____ (with a certified capacity of ___) to a __(specify ICF/DD, CR, Family Care Home, DC, or any other placement__ operated by _____ and _____ located at _____ (with a certified bed capacity of ___) on or about _____.

This move has been planned because it has been determined that the proposed placement would offer him/her better services, a greater opportunity for personal development, and a more suitable living environment.

The staff of this facility/agency have considered whether the proposed placement complies with statutory, regulatory and other legal requirements and whether it is the least restrictive and most normal setting available and appropriate to _____'s needs. Since we believe this proposed move meets these conditions and is in _____'s best interest, we are requesting your agreement. Although we are including a copy of the Community Service Plan, you are invited to inspect the complete record on which the proposed placement is based.

You are also invited to visit both the residential placement site and proposed day program site. If you wish to do so, please contact me so I can make the arrangements, or you may contact the following parties directly:

Contact	(Name of Residential Placement Site Contact Address Telephone Number)	(Name of Day Program Address Telephone Number)

Please indicate on the enclosed form as to whether you agree or disagree with the proposed placement. If you do not agree, you have the right to request a hearing at which you may present your objections (see attached " Summary of Procedures for Responding to Placement Proposals").

If you, as correspondent, do not complete and return the enclosed "Proposed Placement Response" form within 30 days of receipt of this notice, the Consumer Advisory Board for the Willowbrook Class will be designated to advocate for the Class member, to review the proposed placement, and to make recommendations.

If you have any questions, including how to complete the attached "Proposed Placement Response" form, please contact me at __(Phone number)__.

Sincerely yours,

Attachments: Proposed Placement Agreement Response Form
Summary of Procedures for Objecting to Placement Proposals
Community Services Plan (IPP-70)(or equivalent)

cc: Person for whom Placement is Proposed
Mental Hygiene Legal Service (MHLS)
Consumer Advisory Board
Plaintiffs' Attorney
Receiving Facility (send to staff member named as contact)
Day Program (send to staff member named as contact)
B/DDSO

STATE OF NEW YORK
OFFICE OF MENTAL RETARDATION AND DEVELOPMENTAL DISABILITIES

44 HOLLAND AVENUE • ALBANY • NEW YORK • 12229-0001

ELIN M. HOWE
Commissioner

THOMAS A. MAUL
Executive Deputy Commissioner

_M_E_M_O_R_A_N_D_U_M_

March 12, 1993

To: All Willowbrook class members
All Willowbrook correspondents
Consumer Advisory Board
Mental Hygiene Legal Service

From: Alan M. Adler
Deputy Counsel

Subject: Notice of entry of Permanent Injunction

On March 11, 1993, Judge Bartels approved the entry of the Willowbrook permanent injunction which replaces the Willowbrook Consent Decree and all other orders in the Willowbrook litigation. Pursuant to the terms of the permanent injunction, you are to receive notice of class member rights and entitlements under the permanent injunction. The attached notice of rights will be placed in every class members' permanent record and will also serve as your notice.

In addition to the notice placed in the class members' permanent record, we are also notifying you that class members presently are entitled to receive active treatment and full day programs and it is the defendants' intention to continue these programs. If any aspect of the day program that the class member was entitled to under the Consent Judgment is proposed to be changed, including but not limited to the nature or duration of the program, you will be given notice of the proposed change and will have an opportunity to discuss the proposal and object to it if you are not satisfied. You will be entitled to

Right at home. Right in the neighborhood.

administrative and judicial review of the proposal if you object. Any future change in the program to which the class member was entitled under the Willowbrook Consent Judgment shall be permitted only on a showing that it provides a greater opportunity for the class member's growth and development and is based on an individualized assessment of the class member's current needs made by the individual's treatment team, including, where applicable, the individual's medical psycho-social, habilitative and psychological needs, in the exercise of its professional judgment. Appropriate changes in the individual developmental plan may be made where a class member is unable to participate fully in programming because of a medical condition or advanced age and such assessment is based upon a full individualized assessment of the class member's current needs in the manner described above. In the case of a class member incapacitated by a medical condition, prior programming shall be restored as soon as the individual is no longer incapacitated.

NOTICE OF RIGHTS

_____ was a member of the Willowbrook class and as such is entitled to certain rights and services which are guaranteed by a permanent injunction. This injunction was issued by the United States District Court for the Eastern District of New York on March 11, 1993 in the case of New York State Association for Retarded Children, et al., v. Cuomo, et al., 72 Civ. 356, 357.

This notice of rights must be placed in the consumer's files maintained by all providers of residential and habilitative services.

The consumer is represented by Rob Levy, an attorney with the New York Civil Liberties Union located at 132 West 43rd Street, New York, New York 11036. The telephone number of the NYCLU is 212 382-0557. The consumer may also be entitled to be represented by the Consumer Advisory Board, an advocacy group, located at 1150 Forest Hill Rd., Staten Island, New York 10314. The CAB's phone number is 718 983-5205. In addition to this special representation by the NYCLU and the CAB, the consumer may also be entitled to representation, like all other consumers, by the local office of the Mental Hygiene Legal Service (MHLS). If any problems arise concerning the consumer's rights under the permanent injunction, the NYCLU, CAB, and MHLS should be notified.

The following is a summary of the consumer's rights under the permanent injunction:

1. If the consumer is a resident of the Richmond Complex on Staten Island, the consumer has the right to high quality and appropriate medical and habilitative services, shelter, food and clothing which at a minimum conforms to state and federal regulations. Consumers at the Richmond Complex also have the right to be prepared for placement in a small community residence of 10 beds or less. The NYCLU will be notified of placement plans for consumers residing at the Richmond Complex by February 26, 1995.

2. If the consumer is not a resident of the Richmond Complex and is awaiting placement on February 26, 1993, the consumer is entitled to be placed pursuant to the approved placement plan by August 31, 1993. The placement will be monitored by Ms. Ronnie Cohn, an independent evaluator, pursuant to the permanent injunction.

3. Consumers who reside in community residential facilities on February 26, 1993 have the right to be maintained in that facility or another facility of equal or smaller residential capacity. The consumer can only be moved to a larger facility if a) medical or treatment needs require it, or b) if the consumer requests such a move, or c) the consumer is endangering other residents at the facility or is substantially interfering with the

operation of the facility, or d) in the event of an emergency as defined in the permanent injunction.

4. If the consumer does not have an active family member or friend to act as a correspondent, the consumer is entitled to be represented by the Consumer Advisory Board.

5. The consumer is entitled to case management services from a case manager who has a case load of no more than 20 consumers.

6. The NYCLU, CAB, and MHLS to the extent they represent the consumer, have access to the consumer, his or her records, and all facilities where the consumer receives residential or habilitative services.

7. The consumer has the right to a meaningful, full day habilitative program and services appropriate to his or her individual needs week days and meaningful, appropriate recreation and community integration weekday evenings and weekends. These habilitative services and recreation shall meet applicable regulatory standards. Consumers with capacity have the right to refuse such services and recreation.

8. The consumer's developmental plan shall be reviewed at least annually by the consumer's program planning team. More frequent reviews may be requested where appropriate. The consumer, if he or she has capacity, the consumer's correspondent or CAB representative, and the MHLS to the extent it represents the consumer, shall be invited to attend such reviews. Current professional assessments of the consumer's needs shall be maintained in the consumer's files.

9. The consumer is entitled to be protected from harm and is also entitled to a safe, clean, and appropriate physical environment.

10. The consumer is entitled to have sufficient staff members present to provide protection from harm and the habilitative and recreational services required by the permanent injunction.

11. Aversive conditioning, behavioral research, or experimentation may only be conducted after approval by a three person special committee.

12. Except in emergencies, the consumer, the CAB, the NYCLU until February 26, 1998, and the MHLS to the extent it represents the consumer, shall be given 30 days notice of any proposed transfer from the consumer's present residence. In addition, the consumer has the right to a hearing before an independent factfinder. These rights are the same as are afforded to all consumers on February 26, 1993. However, these rights must be afforded to this consumer for life regardless of changes that may be made that affect other consumers not subject to the permanent

injunction.

13. The consumer is entitled to continued residential, habilitative, and programming services that are reasonably unrestrictive and appropriate to his or her individual needs.

If anyone has any questions concerning this notice or the permanent injunction, please contact the attorneys for the plaintiffs or defendants:

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THOMAS A. MAUL
Executive Deputy Commissioner

March 11, 1993

Robert Levy, Esq.
New York Civil Liberties Union
132 West 43rd St.
New York, New York 10036

Re: Willowbrook Permanent Injunction

Dear Rob,

This "side letter" will serve to confirm some of our understandings concerning the permanent injunction.

With regard to paragraph 5(a)'s Attachment 2, we have accounted for the 5,343 class members as best as humanly possible. If a class member whose present address is unknown should turn up at a later date, we will provide services and a placement. Likewise, if what appears to be a valid community placement turns out to be a nonqualifying facility, we will also be responsible for finding a placement in a qualifying facility. If there are any disputes as to whether an individual is entitled to a placement, the independent evaluator will resolve the dispute. If a class member is entitled to a placement, they will also be entitled to consent judgment services while awaiting placement.

With regard to paragraph 5(d), we have agreed that Ronnie Cohn will serve as the independent evaluator. While we do not expect that Ronnie will need the services of consultants, in the extraordinary circumstance that she does, she can request them from the defendants. Defendants will make sure that Ronnie has access to whatever technical assistance is necessary for her to carry out her duties.

With regard to paragraph 8, existing case management assignments will be continued and are in compliance with the permanent injunction. New case management assignments will meet the new definition contained in Appendix I.

With regard to paragraph 15(a), the notice to the CAB is informational only and does not give them any independent right to object to the placement. CAB may object where they represent a noncorrespondent class member.

With regard to paragraph 21(f), defendants will pay for up to 60 person days of independent consultants for the plaintiffs.

The defendants will spend up to $10,000 to contract with Peg Fletcher for audit start up if Ronnie Cohn is unavailable due to her independent evaluator responsibilities.

Please sign a copy of this letter to indicate your agreement with the above.

Sincerely,

Alan M. Adler
Deputy Counsel

AMA:ms

Robert Levy
Robert Levy