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September 20, 2021

Hon. Raymond J. Dearie
U.S. District Court Judge
United States District Court
for the Eastern District of New York
225 Cadman Plaza
Brooklyn, New York 11201

re *New York State Association for Retarded Children, et al. v. Hochul, et al. ("Willowbrook"), 72 Civ. 356, 357 (RJD)*

Request for Pre-Motion Conference relating to Defendants' Failure to Comply with the Willowbrook Permanent Injunction's Mandate to Protect Willowbrook Class Member Peter S. from Harm

Dear Judge Dearie:

We write as Willowbrook plaintiffs' counsel, in accord with the Court's Individual Motion Practices IIIA, to request that the Court convene a pre-motion conference between defendants' and plaintiffs' counsel on a motion to compel the New York State defendants to provide Willowbrook class member Peter S. immediately with an appropriate residential placement; to ensure that Mr. S has familiar staff with him at Samaritan Hospital pending his discharge from Samaritan Hospital,; and to ensure appropriate oversight over, and protection from harm for, the other Willowbrook class members receiving services from Mr. S's current residential provider, the Center for Disability Services ("CFDS").

Willowbrook class member Peter S. has been hospitalized at Samaritan Hospital in Albany, New York since August 2, 2021. Prior to causing Mr. S. to be hospitalized this most recent time, CFDS, Mr. S.'s residential service provider, caused Mr. S. to be hospitalized on at least nine other occasions since February 2021 alone. CFDS's persistent failures to provide appropriate services to Mr. S. in the community violate its obligations under the Willowbrook Permanent Injunction and have resulted in these repeated hospitalizations.

On or about August 4, 2021, the Consumer Advisory Board, Willowbrook Class (the "CAB"), as well as Willowbrook Plaintiffs' Counsel, objected to Mr. S.'s discharge back to CFDS and have requested that the New York State Office for People with Developmental Disabilities ("OPWDD") locate an alternative residential placement for Mr. S., as the discharge back to CFDS is an unsafe discharge. OPWDD has refused to comply with our request.

As set out more fully below, OPWDD's failures to comply with the Permanent Injunction manifest in three separate categories:

- First, Mr. S. requires an alternative residential placement as CFDS, his current provider agency, has failed to provide Mr. S. with a safe living environment and has failed to abide by its obligations under the Permanent Injunction. OPWDD has failed to ensure that Mr. S. is provided with an alternative safe and appropriate residential placement as is mandated by the Permanent Injunction.

- Second, Mr. S. has no familiar staff providing support and assistance to him at Samaritan Hospital in Albany, New York where he has been hospitalized since August 2, 2021. CFDS has objected to providing familiar staff coverage, on the basis that an incident report had been filed against the agency for the care and treatment of Mr. S. OPWDD has failed to ensure compliance with Mr. S.'s right to familiar staff at this medical facility.

- Third, OPWDD has completely abdicated responsibility for assuring its certified providers' compliance with the Permanent Injunction. Rather than appropriately supervising its residential provider, CFDS, OPWW has relied on the Care Coordination Organization ("CCO") that serves Mr. S to locate an alternative residential placement for Mr. S and to advocate for Mr. S to have familiar staff coverage from CFDS. Yet individual CCOs and their employees -- the CCO care managers[1] -- are completely powerless to resolve refusals by resistant state-operated or voluntary providers. Moreover, the CCO and the CCO care managers, although they act as agents of OPWDD, have no mandate or ability to enforce compliance with the Permanent Injunction by defendant OPWDD's other agents, such as CFDS or the various other residential providers who have simply refused to even consider providing residential services to Mr. S.[2]

Over the last two years, there have been an increasing number of refusals by provider agencies, including state residential settings, to provide a variety of services, including

[1] Under Paragraph 8 and Appendix I of the Permanent Injunction, care managers are obligated to advocate and arrange for services for Willowbrook class members that are accessible, community-based, comprehensive, and culturally appropriate.

[2] To the extent that issues of Medicaid funding are viewed by OPWDD or their provider agencies as a stumbling block, we note that the Willowbrook state defendants, including the New York State Department of Health and OPWDD, are obligated to provide Willowbrook class members with high quality services, regardless of source of funding. *See e.g.* ECF Docket 66. Moreover, OPWDD, beyond its obligations under the Permanent Injunction, as a state provider of services, is the *de facto* provider of last resort. *See, e.g.,* N.Y. Constitution Article XVII.

appropriate residential placements, hospital coverage, and/or staff support, to Willowbrook class members who are hospitalized or in nursing home settings.[3] Contrary to their past efforts to ensure their agents' compliance with the provisions of the Permanent Injunction, OPWDD has now simply acquiesced to their agents' refusal to comply – all in derogation of their obligations to ensure Mr. S's rights and entitlements as a Willowbrook class member.

Plaintiffs raise this pressing issue by way of a motion to ensure defendants' compliance with the oversight provisions of the Permanent Injunction and to ensure that Willowbrook class members are protected from harm in accord with Paragraph 11 of the Permanent Injunction.[4]

OPWDD's Failure to Appropriately Serve Willowbrook Class Member Peter S.

Since 1990, Peter S. has resided at a residential group home operated by CFDS, a not-for profit entity, in Watervliet, New York. CFDS operates residential programs for people with intellectual and developmental disabilities under the licensing auspices of OPWDD.

Mr. S. is similar to many people served by OPWDD and its not-for-profit service delivery providers. He has some challenging behaviors that are the result of the stunted developmental growth he experienced at the Willowbrook institution. For example, he needs supervision to pace his food intake at meals as he rushes through his meals because he was deprived of food at Willowbrook. He requires supervision in the bathroom as he was trained at Willowbrook to drink water from the toilet if he does not receive adequate hydration and is thirsty (which he often is as he has poorly controlled diabetes). He also requires supervision at most other times, as he will try to leave his group home when he does not have appropriate activities to occupy his attention.

Due to multiple CFDS failures to provide appropriate services to Mr. S., including failure to adhere to Mr. S.'s behavioral support plan, his Individual Plan of Protective Oversight, and his medication regimen, Mr. S. has had ten hospitalizations since February 2021.[5] The agency has

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[3] As the Court is aware, the ongoing uncertain rollout of Medicaid managed care and the "rate rationalization" system that the New York State Department of Health and OPWDD negotiated with the federal Centers for Medicaid Services have resulted in increasing uncertainty in the OPWDD service system and significant diminutions of the quality and range of services afforded class members.

[4] Paragraph 11 of the Permanent Injunction states that "Defendants shall assure each class member protection from harm and a safe, clean and appropriate physical environment." Moreover, Paragraph 12 of the Permanent Injunction states that "Defendants shall assure that there is sufficient staff present and on duty to protect each class member from harm." Beyond the agency's refusal to provide familiar staff to assist Mr. S at Samaritan, the agency appears to have also failed to staff the group home with sufficient numbers of staff to ensure Mr. S.'s safety.

[5] The failures of CFDS to provide services to Mr. S. are legion. In addition to the frequent abandonments of Mr. S. at Albany Medical Center and Samaritan Hospital –which often occurred on weekends -- CFDS permitted Mr. S. to develop facial abscesses and infections from self-inflicted facial wounds, self-inflicted corneal abrasions, medically dangerous urine retention and constipation, toothaches, and tooth infections. Mr. S. has also been diagnosed with failure to thrive due to poor food intake; he went from weighing 145 pounds in November 2020 to weighing 115 pounds in June 2021. These circumstances, were apparently caused by a complete disregard of Mr. S. by CFDS when he was in their residence.

failed to notify his Care Coordinator, the CAB, and, we understand, even OPWDD with respect to these various hospitalizations.

Mr. S. was brought into the Samaritan Hospital Emergency Department most recently on July 31, 2021 where he was treated for a toothache and promptly discharged back to CFDS. CFDS brought Mr. S. back to the Samaritan Hospital Emergency Department almost immediately on August 2, 2021 and, effectively, abandoned him there. CFDS has refused to provide familiar staff to Mr. S. while he has been at Samaritan Hospital. CFDS has not provided Mr. S. with clothing while he has been at Samaritan Hospital. CFDS has not even communicated with Samaritan personnel about Mr. S.'s needs while he has been at Samaritan Hospital. Mr. S. remains at Samaritan Hospital on a medical unit, notwithstanding the fact that he is medically cleared for discharge.

As noted above, CFDS' persistent failures to provide basic care and services to Mr. S., much less comply with their obligations under the Willowbrook Permanent Injunction, have resulted in the Willowbrook parties' objection to Mr. S.'s discharge back to CFDS and our request for an immediate alternative residential placement for him because his discharge back to CFDS is an unsafe discharge.

OPWDD's Failure to Ensure that Willowbrook Class Member Peter S. Is Provided with an Alternative Residential Placement

OPWDD has failed to comply with its obligations under the Permanent Injunction to protect Mr. S. from harm. An alternative residential placement, away from CFDS and out of the hospital, is required to protect Mr. S. from harm. Mr. S. has long been ready for discharge from the hospital setting and is potentially at further risk of harm from this extended stay there.

Plaintiffs' counsel requested expedited intervention by OPWDD to assure an appropriate alternative residential placement. Rather than initiate the process to facilitate an alternative placement for Mr. S., OPWDD instead delegated its responsibilities to Mr. S.'s care manager at

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In addition to mishandling Mr. S.'s routine care, CFDS also mismanaged all of Mr. S.'s behavioral support services. On or about May 5, 2021, the CAB obtained a tele-medicine consult for Mr. S. by professionals from OPWDD's George A. Jervis Clinic. The Jervis Clinic specializes in psychiatric and behavioral evaluations, including recommendations for psychotropic medications for people displaying self-injurious, aggressive, and other challenging behaviors, or signs of dementia. *See* https://opwdd.ny.gov/ibr/george-jervis-clinic. It has been our experience that both OPWDD's state-operated residential staff and OPWDD's not-for-profit providers welcome the clinical and technical expertise provided them by the Jervis Clinic. The Jervis Clinic developed a series of medication regimen changes for Mr. S. and provided suggested modifications to Mr. S.'s behavioral support plan, including close tracking, and reporting, of behavioral data. CFDS failed, or refused, to follow the Jervis Clinic's input. CFDS failed to maintain the required behavioral tracking data and could not report any information – behavioral or physical -- to Mr. S.'s advocates or the Jervis Clinic consultants. Moreover, not only did CFDS fail to make the medication changes that had been agreed upon at the May 5, 2021 special team meeting, CFDS's psychiatric clinician, Dr. Zvi Klopott, discontinued the orders for the medications the Jervis Clinic had indicated were warranted. In addition, when CFDS ran out of one of Mr. S.'s psychotropic medications, Risperdal, Dr. Klopott unilaterally determined to discontinue that medication rather than issue a new prescription to refill that medicine.

Tri-County Care, the CCO serving Mr. S., to identify and obtain an alternative residential placement for Mr. S. As noted above, the care manager has little to no power, or access to resources, as OPWDD does, to accomplish a successful alternative placement for Mr. S. While the CCO has prepared a referral package for Mr. S., and has requested, in accord with the CAB's request, that Mr. S. be screened by agencies statewide, no provider has indicated that it was willing or able to accept Mr. S.[6] It is unclear whether Mr. S., to date, has even been screened for placement at any state-operated residential site.

Plaintiffs' counsel also requested that OPWDD intervene with its state and voluntary providers to mandate that the providers comply with the Permanent Injunction and to abide by the Guidelines. OPWDD refused to do so.

OPWDD's Failure to Ensure that Willowbrook Class Member Peter S. Receives Hospitalization Coverage

For almost 25 years, OPWDD has mandated that all OPWDD-certified providers, both state and voluntary provider agencies, abide by Hospital Coverage Guidelines (the "Guidelines"). However, providers of both state-operated residential settings and private provider residential settings are now either outright refusing, or are fiscally completely unable, to provide Willowbrook class members with familiar staff coverage when the person is hospitalized.[7]

The Guidelines were developed and adopted as an "Administrative Memorandum" in response to a recommendation made to the Commissioner by the Willowbrook Task Force on Health Care Services. The Guidelines apply to all people receiving services from OPWDD-certified residential settings, not just to the Willowbrook class members. A copy of the Administrative Memorandum (February 24, 1997), as well an updated Administrative Memorandum (May 24, 2006) are attached as Exhibits A and B, respectively. The Guidelines rest on three self-evident and incontrovertible principles:

- Hospitalization for members of the general population increases anxiety and can result in a loss of functioning in daily living skills. Chances of such results may be intensified for people with developmental disabilities.
- Current staffing levels in some hospitals may, at times, make it difficult for these hospitals to provide hospital staff to feed, bathe, or supervise patients who need individual assistance.

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[6] Most recently, and most astonishingly, OPWDD directed the care manager, and her supervisor, to cease and desist from all communications, including advocacy for Mr. S, to OPWDD and any potential residential service provider relating to Mr. P. OPWDD also directed the CCO to prohibit their care manager employees from making such communications, indicating that OPWDD will speak only with the CCO Vice President of Care Management and the CCO Regional Director. It is entirely unclear why OPWDD would structure its communications in this fashion, cutting out the CCO employees who actually know what Mr. S's needs are.

[7] For the past 25 years, the Guidelines were also followed when a Willowbrook class member was discharged from a hospital into a short-term rehabilitative stay in a nursing home or skilled nursing facility.

- The presence of staff (DDSO, voluntary agency, home health agency, or hospital staff) who cared for the individual with developmental disabilities and who are knowledgeable about the individual's special needs, likes, and dislikes, helps ensure that the individual receives appropriate daily care, and also facilitates communication with hospital staff related to the patient's needs. The presence and support of knowledgeable staff will help patients with developmental disabilities feel better and recover more quickly.

The Guidelines do not establish a per se rule that any person with I/DD who is hospitalized requires familiar staff coverage on a 24/7 basis. Rather the guidelines set forth the process by which an individual's "interdisciplinary treatment team," or other specified personnel, engage in a person-centered planning process focused on determining a person's need for hospitalization coverage "prior to any planned admission and/or upon any emergency admission." The determination must also document the "person's NEEDS related to hospitalization coverage; the TYPE of coverage needed by the person; and the AMOUNT of coverage needed (emphasis in original)."[8]

As was and is the case with Mr. S., the consequences of being left without familiar staff coverage in a hospital can be dire. Mr. S. is confined to a room on the medical ward of Samaritan Hospital. Mr. S., who is non-verbal, has struck out in frustration at Samaritan staff and, according to counsel for Samaritan, has injured hospital staff. Mr. S. has managed to enter into other patients' rooms. He has stolen other patients' food. Hospital staff, who are medically trained, are not familiar with the details of Mr. S.'s behavior support plan, and have not been provided any information or support from CFDS or OPWDD to allow them to understand or manage his behavior, even if they have the time.

Samaritan personnel, including their Counsel's office, have made many requests for assistance from CFDS and from OPWDD – their requests have gone unanswered. CFDS has told the CCO that they will not provide any assistance – by way of staffing or even discussion – with Samaritan personnel. The CCO is powerless to force CFDS's compliance with these requests for aid from Samaritan. OPWDD has also refused to step in to provide any assistance to Samaritan and has also ignored the CCO's requests for assistance – in particular to force their certified provider agency to abide by their obligations. This is an entirely untenable situation and violates Mr. S.'s rights under the Permanent Injunction.[9]

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[8] The type of needs that would justify hospitalization coverage by familiar staff runs the gamut from a person's communication needs and need for advocacy, functional skills, level of self-care skills, behavioral profile, including any emotional or behavioral support needs, to the purpose of the hospitalization, the attitude of a particular hospital as to whether the person needs assistance and whether the facility is able to meet the person's needs. Similarly, the type and amount of coverage to be assessed by the ITT runs the gamut from daily social visits, daily visits to provide support and to ensure appropriate care and treatment, visits to assist with meals or to feed the individual to "waking hour" coverage, 24-hour continuous coverage, or staff who know the person serving as an on-site resource to hospital staff.

[9] An individual's "Life Plan" is supposed to contain an Individual's Plan of Protective Oversight ("IPOP"). Generally speaking, the IPOP is supposed to set forth a person's need for staffing coverage while hospitalized, as well as how that need will be met by the person's residential services provider. Mr. S.'s Life Plan from 2020 and his draft 2021 Life Plan in fact contain a hospitalization coverage statement. This is not a new need for Mr. S. His need for hospitalization coverage is a long standing identified protective support need. CFDS has, however, for at least

The CAB has long objected to these refusals by OPWDD's provider agencies to provide hospitalization coverage. The CAB and plaintiffs' counsel have long raised these concerns to OPWDD's Central Office for resolution. OPWDD has refused to ensure their certified providers' compliance with the Permanent Injunction.

OPWDD's complete abdication of its responsibilities to ensure that Willowbrook class member Peter S. is protected from harm is a grievous violation of the Permanent Injunction. Accordingly, we request that the Court convene a pre-motion conference to discuss this matter and to establish an expedited briefing schedule on a motion to compel compliance if there is no resolution. Plaintiffs' counsel is available at the Court's convenience for the conference.

Thank you for your consideration of our request.

Respectfully submitted,

s/*Roberta Mueller*
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s/ *Beth Haroules*
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ECF Service List

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the past year, simply not abided by the Guidelines or Mr. S.'s Life Plan, and failed to provide hospital coverage to a Willowbrook class member who requires hospitalization coverage to be protected from harm.