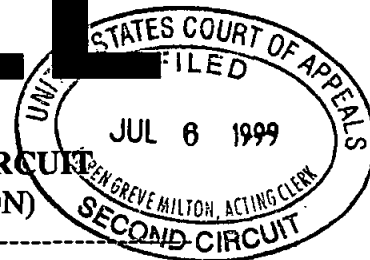


99-7572L

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UNITED STATES COURT OF APPEALS FOR THE SECOND CIRCUIT

99-7586 (CON), 99-7588 (CON), 99-7604 (CON), 99-7618 (CON)

JUANA RODRIGUEZ, by her son and next friend, Wilfredo Rodriguez, AMELIA RUSSO, MARY WEINBLAD by her daughter and next friend, Susan Downes, CHRISTOS GOUVATSOS, SIDONIE BENNETT, individually and on the behalf of all others similarly situated,

Plaintiffs-Appellees,

MOLLIE PECKMAN, by her son and next of friend, Alex Peckman,

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Intervenor-Plaintiff-Appellee,

v.

CITY OF NEW YORK, IRENE LAPIDEZ, Commissioner Nassau County Department, of Social Services, COMMISSIONER OF THE WESTCHESTER COUNTY DEPARTMENT OF SOCIAL SERVICES, NEW YORK CITY DEPARTMENT OF SOCIAL SERVICES, COMMISSIONER, SUFFOLK COUNTY DEPARTMENT OF SOCIAL SERVICES, THE NEW YORK CITY DEPARTMENT OF SOCIAL SERVICES,

Intervenors-Defendants-Appellants,

DENNIS WHALEN, Commissioner of the New York State Department of Health, BRIAN WING, Commissioner of the New York State Office of Temporary Disability Assistance,

Defendants-Appellants.

On Appeal from the United States District Court for the Southern District of New York

BRIEF FOR PLAINTIFFS-APPELLEES RODRIGUEZ, et al.

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PRELIMINARY STATEMENT

Defendants appeal from an order of the United States District Court for the Southern District of New York (Shira A. Scheindlin, U.S.D.J.), dated April 19, 1999, that granted plaintiffs' motion for a permanent injunction directing defendants to assess the need of mentally impaired Medicaid recipients for personal care services to monitor their safety and to include this crucial service as part of the patient's plan of care. After a two-week hearing, subsequent opportunity to submit additional evidence, and briefing on the issues at both the preliminary and permanent injunction stages, the district court determined, *inter alia*, that safety monitoring for cognitively impaired individuals (a) is comparable to other personal care tasks routinely provided under the program, (b) was a personal care service that the defendants had provided in the past, and (c) was essential to the health and safety of the elderly and disabled individuals needing Medicaid personal care services.

The district court properly rejected defendants' defense of their policy on grounds of fiscal or administrative burden. Contrary to defendants' assertions, the court found that defendants had provided safety monitoring in the past. As defendants had provided these services in the past, defendants had the administrative ability to do so in the future. Further, the district court found that defendants' cost argument is inherently flawed. Defendants provide personal care services in equivalent or greater amounts to persons without mental impairments and a separate fiscal assessment law governs those relatively rare cases where home care costs are greater than the cost of nursing home care.

The court correctly determined that defendants' practices violate the "comparability" provision of the federal Medicaid law, which requires that a State provide each categorically

eligible recipient with services equal in amount, scope, and duration to services provided to any other recipient. The court also correctly found that defendants' policy violates federal anti-discrimination laws because individuals with mental impairments are being denied personal care services that are comparable to those provided to persons with physical impairments and the involuntary institutionalization of mentally impaired individuals who could benefit from care in the community violates the integration mandate of the Americans With Disabilities Act.

The court also rejected defendants' contention that the exclusion of medically necessary and appropriate safety monitoring was justified as an exercise of agency discretion. The policy could not be characterized as the implementation of a federal interpretation, since the Health Care Financing Administration ("HCFA"), the federal agency responsible for administering the Medicaid Act, determined, in a response to State defendant's inquiry on the issue, that the safety monitoring services at issue in this case would be expected to be provided to a non-self-directing individual receiving other assistance under the personal care services program.

The court properly determined that plaintiffs established that they suffer irreparable harm as a result of defendants' policy. The overwhelming evidence supported the fact that many cognitively impaired individuals, including named plaintiffs and plaintiff-intervenors, can be maintained safely in their homes with a home attendant -- a fact supported by defendants' past and current policies and regulations. The very people who have been safely maintained in their homes with safety monitoring by a personal care attendant under defendants' pre-TBA policy are now having their services reduced or terminated as a result of the new policy. Individuals applying for services are being denied services entirely or are receiving inadequate personal care authorizations. As a result, recipients either forego necessary medical services or suffer

involuntary relocation to nursing homes away from familiar home and family. The court properly issued the permanent injunction.

Statement of the Issue on Appeal

Whether the district court abused its discretion or committed legal error in granting a permanent injunction to allow mentally impaired plaintiffs the opportunity to participate in the Medicaid personal care program to the same extent as persons with physical impairments?

Statement of the Case

Nature of the Case

The local "task-based assessment" or "TBA" programs, authorized by State defendant, all work in essentially the same way: a recipient's home care authorization is determined by adding the sums of the pre-determined maximum allowable times for each task identified as needed by the recipient. TBA dramatically changes the manner of determining the number of home care hours provided to Medicaid recipients. Prior to "task based" authorizations, personal care services were authorized based on the span of time over which an individual's need for assistance arose.

Under TBA the focus is on "tasks," but only those tasks defendants now recognize. Although safety monitoring had previously been provided under the program and was included on assessment forms, it no longer appears on defendants' task list and plaintiffs receive no personal care time to meet this crucial need. Because the program was changing its focus to physical needs, members of the plaintiff class were not even receiving task time needed for verbal direction, or cuing, needed to complete "covered tasks" such as eating and toileting. Without any relevant change in law or regulations, home care recipients are denied essential home care services previously provided under the Medicaid program.

Earlier Proceedings

Plaintiffs, elderly and disabled Medicaid recipients, filed a class action complaint against New York State challenging task based authorizations of Medicaid personal care services. Four local social services districts intervened as defendants. Plaintiffs moved for certification of a statewide class of Medicaid personal care applicants and recipients; entry of a preliminary injunction prohibiting, inter alia, the continued use of TBA to the extent that it failed to provide for safety monitoring, as well as continuing, recurring and unscheduled needs; and intervention of 12 additional named plaintiffs. After limited expedited discovery that did not include production of client's files (other than those of named plaintiffs) from any district except New York City, the district court held two weeks of hearing.

The court entered a preliminary injunction directing the defendants to include safety monitoring as a task for which home care services time is allocated. The court certified a statewide class on the safety monitoring claim and issued an injunction requiring defendants to separately assess and provide personal care services for safety monitoring. A4044-4065.¹ The district court stayed the order pending defendants' appeal to this Court. This Court vacated the preliminary injunction without reaching the merits of the appeal, finding that the district court must have misapprehended the requirement of "imminent" irreparable harm in light of the court's stay pending appeal. A4290.

On remand and without objection from any party, the safety monitoring claim was

¹ The court certified a subclass of personal care applicants and recipients from New York City and Nassau County on plaintiffs' claim that TBA results in systemic denials of care to individuals with unscheduled or recurring needs, but did not find that plaintiffs had met their burden to obtain preliminary relief on this claim.

bifurcated from the span of time claim and the parties moved for final resolution of the safety monitoring issue under Fed. R. Civ. P. 54(b). The district court, after giving all parties an opportunity to present additional evidence, issued a permanent injunction requiring defendants to provide safety monitoring.

The District Court Decision

In a carefully considered opinion, the district court determined that the failure to provide time for safety monitoring to cognitively impaired individuals at moments when they are not also receiving assistance with a task on the TBA task list, along with the failure to provide task time for non-verbal assistance with recognized tasks, violates the Americans With Disabilities Act and the Rehabilitation Act, as well as the comparability provisions of the Medicaid Act and Medicaid regulations.² The court rejected defendants' contention that defendants did not historically provide safety monitoring as a separate task to non-self-directing individuals. The court cited, as evidence of defendants' past practice, the state regulation that authorized the provision of additional personal care services to monitor the safety of a non-self-directing patient, 18 N.Y.C.R.R. §505.14(a)(6)(ii)(b)(v), the state defendants' designation of "safety monitoring" as a separate item in a list of "services provided" in the State's own evaluative study of NYC's personal care services program, and the admission of the State's witness that the State "did at one point consider safety monitoring as a separate task." A3999-4000 (cited at A4532).

The court rejected defendants' contention that safety monitoring/supervision of a non-self-directing individual cannot be provided by the home attendant under the regulations.

² The permanent injunction incorporates many of the findings made in the preliminary injunction. A4515.

A3997-3999. The court concluded that safety monitoring/supervision of a non-self-directing client is distinct from the supervision and direction of the home care aide that is provided by another person or agency on behalf of a non-self-directing person under state regulations. The district court found that the evidence demonstrated that many persons with mental impairments could be safely maintained at home with the assistance of a home attendant. A4000-1; 949-950; 1015; 1108; 1114-1115.

The court specifically found it was the failure to provide home care services, rather than the patient's condition, that rendered the situation unsafe for class members with cognitive impairments. Additionally, the court found that services provided to persons with physical impairments, such as turning and positioning, were comparable to the safety monitoring in this case. A4515, 4001. The court found that verbally directing a cognitively impaired individual was comparable to helping an individual walk to the bathroom or changing a diaper. Further, the court found that safety monitoring as a separate task was not opposed by HCFA, the government agency to whose judgment the court might normally defer. A4002. The court concluded that defendants' decision to exclude safety monitoring from the program resulted more likely from fiscal concerns than a belief that HCFA prohibited such services. A4002-4.

The district court correctly found that plaintiffs were entitled to relief on their claims under Title II of the Americans With Disabilities Act and §504 of the Rehabilitation Act and that plaintiffs had shown that they: (1) have a disability (A4524, n.21); (2) are "otherwise qualified" for home care (A4529); and (3) were excluded from home care because of discrimination based solely on disability (A4543). Because mentally impaired individuals were seeking services needed due to their disability, the Court also considered whether plaintiffs could be reasonably

accommodated in the program. The district court carefully considered and then correctly rejected defendants' contentions that they could not accommodate mentally impaired plaintiffs in the personal care program. A4536.

The court found defendants' arguments about cost to be speculative. A4544. Moreover, the court found that these estimates did not account for the cost of alternative care and the potential savings to be derived from caring for plaintiffs at home (instead of in costly institutions). A4545-4539. The court concluded that defendants could address the cost of treating mentally impaired individuals in the same way as they did for the physically impaired individuals: through the state's fiscal assessment law, N.Y. Soc. Serv. L. §367-k. Cost could not justify the elimination of safety monitoring. A4536-9, 4003-4. The Court found that plaintiffs were vulnerable and would suffer significant harm from the denial of safety monitoring and that equitable considerations favored plaintiffs. A4542-5, 4018-9.

Statement of Facts

Named Plaintiffs and Intervenors Needing Safety Monitoring

Mariamamma David, age 85, resided with her adult son and daughter-in-law and required 10 hours of personal care services while the adult children were at work. A3337. Her physician completed a medical request so that she could receive home attendant services. A3336. Nassau County's assessing nurse found that her medical condition was stable, A3331 (Item 3), and that she needed personal care assistance with bathing, dressing, grooming, meal preparation, some household chores, and errands. Her mental impairment, cognitive meulet syndrome, caused her to stop and stand still, waiting for direction. A3333. Despite Nassau County's recognition of this problem, the County did not allocate any service time for assistance to cue her to ambulate or

toilet. A3333, 3337. Under her task based assessment, she was found to need personal care services in the amount of 23 hours per week. A3333. Because of her need for 24 hour supervision, however, Nassau County issued a notice denying her request for services in its entirety. A3336. After a hearing, the State upheld the county's denial of services because of Ms. David's "mental confusion" and because "she is not capable of self-direction and requires supervision." A3338. Ms. David did not receive the home care services she needed until her intervention in this action.

Ann Reece, at age 86, suffered from heart disease, arthritis, impaired memory and disorientation. A3328. Prior to TBA, she had been authorized by Nassau County to receive sleep-in home attendant services. A3321. To obtain a reauthorization of these services her physician submitted a formal medical request. A3321. The County's assessing nurse determined that her condition was stable, that she wandered "sometimes," A3329, and that she needed personal care assistance with bathing, grooming, dressing, feeding, meal preparation, housekeeping, and errands. A3326. The Plan of Care would allow for 7-8 hours of daily "task" care. Nevertheless, she was found to be inappropriate for personal care because of her need for safety monitoring and the County issued a decision discontinuing her personal care services which was upheld by the State. A3324-5. After her intervention in this action, she received services at home until her death.

Amelia Russo was a 103 pound, 82 year old woman who suffered from hypertension and Alzheimer's disease. A2052. In January 1995, just as TBA was being implemented, Ms. Russo was authorized to receive sleep-in services to protect her safety due to wandering and some other dementia-related behaviors. A2042-43. In May, 1995, Ms. Russo's doctor submitted a medical

request to continue her home care. A2052. As in January, the assessing nurse determined that she needed assistance with bathing, grooming, dressing, transferring, meal preparation and household chores, entitling her to 4 hours of daily “task” care. A2055. This time, however, despite her need for safety monitoring, the county discontinued her personal care because her health and safety could not be maintained without “24 hour supervision.” A2057-8. The state upheld that determination because of Ms. Russo’s need for “supervision and companionship.” A111-112.³ At the hearing the County representative explained that since the implementation of TBA its safety monitoring policy had been “refined,” A65-6, and offered to provide a home attendant for four hours if the family paid for the balance of needed hours. A2159. As a result of prior litigation, Ms. Russo was able to continue residing in her home with home care services until her death in 1997.

Mary Weinblad is an 87 year old woman with a stable medical condition, suffering from hypertension, transient ischemic attacks, history of strokes, confusion and short-term memory deficits. A2276, 2282. Her doctor requested 24 hour personal care services for “assistance and supervision of personal care, activities of daily living, safety supervision and orientation of the patient,” and noted her history of repeated falls and errors in medication administration due to forgetfulness leading to both under- and over-administration of medications. A2274, 2288. Instead of providing the needed level of personal care services, Nassau County, pursuant to a task-based assessment, provided only four hours of daily services to assist with bathing,

³ The nurse who testified at the hearing did not rely on the alleged single incident with a broom, which defendants repeatedly cite as the basis for termination of her home care. A2149, A2157 (“my specific problem is not the attacking”). The fair hearing decision mentioned, but did not rely on the alleged incident. A111-12.

grooming, dressing, meal preparation and household chores. A2275. The assessing nurse noted that Ms. Weinblad had been paying privately for sleep-in care but had run out of funds. A2275.

State defendant upheld the local agency's determination at an administrative hearing, finding that:

While the Agency nurses conceded that Appellant needs twenty-four hour supervision, the Agency properly determined that Appellant needs only four hours of personal care services tasks per day. The remainder of the time Appellant needs services in the nature of supervision and companionship and one-to-one cuing. These are not appropriate tasks for personal care services aides.

A2269.

New York's Medicaid Personal Care Program

The Medicaid program is a joint federal-state program that provides general medical assistance to low income elderly, and disabled adults and to certain low-income households. New York State's Medicaid plan provides for medical and remedial services that are necessary to "prevent . . . conditions in the person that cause acute suffering, endanger life, result in illness or infirmity, interfere with such person's capacity for normal activity, or threaten some significant handicap," N.Y. Soc. Serv. L. §§365-a, and that assist eligible individuals attain or retain capability for independence or self-care. 42 U.S.C. §1396.

The state legislature, in an effort to avoid unnecessary use of institutional care with its "concomitant high costs and associated adverse social and medical implications," favors the expansion of home care services. N.Y. Pub. Health Law §3600. Consistent with this priority, New York State has opted to include personal care services in its state Medicaid plan. See 42 U.S.C. §1396d(a)(24); N.Y. Soc. Serv. L. §365-a(2)(e); 18 N.Y.C.R.R. §505.14(a)(1)(personal care services are medically necessary services that enable individuals to carry out their activities of daily living and that are "essential to the maintenance of the patient's health and safety in his or

her own home".)

A State "fiscal assessment" law was enacted that requires local districts to develop the most cost efficient community service that is appropriate and available for a personal care applicant or recipient. After doing so, if the cost of medically necessary personal care services for the individual exceeds 90% of the cost of a nursing home, personal care services may be denied if the individual does not meet one of the specified exceptions designed to avoid unnecessary harm to recipients. N.Y. Soc. Serv. L. §367-k. 18 N.Y.C.R.R. §504.14(b)(3). Although aspects of the fiscal assessment law have been and are being challenged in other litigation, the law is currently in effect and a recent challenge was unsuccessful in a state appellate court.

Home Care Authorization Process

The patient's treating physician must formally request personal care services on the patient's behalf. The local district assesses social factors, such as, the availability of informal caregivers to assist in the plan of care or to provide direction of the home attendant if the case involves a non-self-directing individual. A nurse conducts an assessment of the individual's mental and physical limitations and develops a plan of care. 18 N.Y.C.R.R. §504.14(b)(3). New York City's current assessment forms show that assessing nurses and physicians are already obligated to assess the spectrum of mental impairments. A3794-3801, 2802, 2804.⁴

Eligibility for personal care services

In determining whether an individual can be safely maintained in the community with the receipt of personal care services, the regulations require an assessment of medical stability and

⁴ Current assessment forms ask the assessor to determine if the person has impaired judgment or memory, needs reminding to take medications, wanders and whether or not they can be safely left alone. Old assessment forms included safety monitoring. A1224, 3089.

capability for "self-direction." See 18 N.Y.C.R.R. §505.14(a)(4). A condition is medically stable if it is not expected to exhibit sudden changes or does not require frequent medical or skilled professional care or assessment. 18 N.Y.C.R.R. §505.14(a)(4)(i).

The regulations also provide that an individual must be "self-directing," i.e., able to make choices about life activities, such as when to go outside and when or what to eat, to understand the impact of those choices and assume responsibility for such choices. The state wished to permit cognitively impaired individuals to remain in their homes and avert unnecessary institutionalization, so the personal care regulations explicitly provide that "non-self-directing" individuals with stable medical conditions can receive personal care services if a family member, friend, or agency assumes responsibility for directing the activities of daily living "on an interim or part-time basis." 18 N.Y.C.R.R. §(a)(4)(ii)(a)-(c); A1274; 1277; 945-946 (Dr. Meier); A3680-3681 (describing some of the obligations of a person who assumes "direction" for the non-self-directing individual).

Accordingly, many cognitively impaired individuals are currently served under the Medicaid personal care program. A State review of New York City personal care services cases from 1992 and 1993 found a significant population of recipients with mental impairments. A3149. This State DSS study found that 40% of all personal care clients in New York City had impairment of short term memory. See, also, A4100-4104 (data collected by the United Hospital Fund indicating that 29% of New York City Medicaid personal care recipients have moderate to severe cognitive impairments; 40% of the 85 year and older population has moderate to severe cognitive impairment and about 50% of the personal care population has some degree of cognitive impairment). Not surprisingly, a State directive to its local districts includes among the

population of eligible personal care recipients people who may be delusional, disoriented, subject to wandering, or have periods of agitation. A3680.

Safety Monitoring as a Separate Task under Task-based Assessment Programs

Since at least 1985 when the State explicitly permitted the provision of personal care services to non-self-directing individuals, local districts have had authority to "authorize [separate] additional hours called safety monitoring." A1287, 1350-1. Hence, the state regulations explicitly permitted the provision of additional hours of home care services when "monitoring of the patient's safety is required as part of a plan of care for a non-self-directing patient . . ." (emphasis added). 18 N.Y.C.R.R. §505.14(a)(6)(ii)(b).⁵

An administrative directive issued by the State as recently as 1995 underscores the State's recognition that cognitively impaired individuals will be served under the personal care program. A3104; 3108 (acknowledging that "supervision of non-self-directing clients ... having a need for continuous supervision and/or monitoring of their health and safety must have that need met by an appropriate means such as the utilization of traditional one-on-one aide service.") A3108.⁶

Notably, the State's own study lists "safety monitoring" as a "service required" by 77% of New York City personal care recipients. A3138-3140; 3129 ("safety monitoring" was eighth of

⁵ This provision was included as an exception to an invalidated cap on service hours for personal care applicants. See DeLuca v. Hammons, 927 F. Supp. 132 (S.D.N.Y. 1996).

⁶ Cluster care/shared aide is the task oriented service delivery model upon which task based assessment is based. A3104, 3170. Although the Court refused to admit this document at the hearing the full document was submitted with plaintiffs' reply in support of the preliminary injunction motion and is a part of the record on appeal.

the 15 most frequently utilized services).⁷

HCFA Correspondence

The State now contends that because of a letter received from HCFA, the agency that administers the Medicaid program, safety monitoring can be provided only at the same time that a person is receiving assistance with another personal care services task. A1291-7. For example, safety monitoring may be provided by the program to ensure that a person does not fall off the toilet, does not trip over a rug, or does not spill a hot beverage on themselves, because that assistance would be provided while the home attendant is respectively assisting with toileting, ambulating, and feeding.⁸

In August 1996 State defendant wrote to HCFA asking whether under its personal care program, the State should provide to a dementia patient who had a need for "hands-on" assistance, "supervising/monitoring during those periods of the day when no 'hands-on' care is required in order to assure that a patient with impaired judgment does not pose a risk to

⁷ See, also, state fair hearing decisions recognizing that safety monitoring has been a service provided by personal care services programs, A3394 (reversing New York City's task-based assessment service plan where the identified need for safety monitoring was ignored); A3494 (service claimed by district to be "supervision", found to be essential to patient safety and covered under program); A3410 (reversing City TBA plan providing less than 24 hour care despite assessing nurse's finding that patient could not be left alone).

⁸ Despite some contradictions in their own papers, at the hearing the state defined its policy on the provision of safety monitoring under the personal care services program: social services districts have been permitted to authorize, and may currently continue to authorize, hours of safety monitoring for recipients; provided, however, that the recipients otherwise need assistance with one or more personal care services tasks; and the recipients' medical conditions, which embraces their mental status, have not deteriorated so that personal care services cannot maintain their health and safety in their homes.

themselves or others?" A3737. In response, HCFA stated that safety monitoring of cognitively impaired individuals who are at risk to themselves is "an integral part of the personal care services provided." A3740-1.⁹

In April 1997, after briefing was completed and the preliminary injunction hearing was about to begin, the State sought a modified letter from HCFA and, apparently dissatisfied with that letter, sought yet another modified letter two weeks later. A3745. In response, plaintiffs sought to introduce a letter from HCFA stating that its policy on "safety monitoring" was contained in its November 15, 1996 letter and that it did not have a policy requiring "simultaneous safety monitoring." The court refused to admit the exhibit, but stated she would only rely on the earlier November 1996 policy letter. A1845, 1877. The State never was denied federal financial participation due to the provision of safety monitoring at times when other "hands-on" tasks were not being performed. A1357.

At the preliminary injunction hearing, plaintiffs presented evidence from two expert witnesses¹⁰ who testified to the prevalence of cognitive impairments in elderly individuals due to various conditions such as strokes or Alzheimer's disease. A913.¹¹ These cognitive impairments

⁹ HCFA also stated in its letter that the personal care services program would not encompass the provision of supervising/ monitoring without the provision of any recognized "hands-on" personal care services. A305. The record is replete with evidence that any non-self-directing individual who needed monitoring to ensure their safety would also need some assistance with hands-on personal care services. See, e.g. A914, 421-22 (eating; taking medication), 1109-10 (bathing, dressing, toileting), 1549-1550 (City witness).

¹⁰ See A913, 3062 (Dr. Diane Meier, expert in geriatric medicine and medical assessment of ADL needs); A1109, 3082 (Adeena Horowitz, expert geriatric social worker with focus on persons with dementia).

¹¹ See A1104-7 for discussion of the stages of the disease. Rapid decline in the ability to care for oneself is unusual in Alzheimer's disease. A994.

cause disorientation and memory loss. A914, 1106. As a result, though they may be physically capable of performing various activities of daily living, individuals with cognitive impairments require physical or verbal cuing to enable them to carry out ordinary activities of daily living because they cannot remember the location of the bathroom or when they should eat or take medications.¹² A914, 902, 1106. If they do not continue to perform these functions, they will lose the ability to perform them on their own because their muscles become deconditioned.

A1114, 1115. If, for example, an individual does not have needed assistance with toileting when still continent or partially continent, the person will become incontinent, creating the risk of skin irritation and ultimately the development of pressure sores, which are particularly dangerous for the elderly because of their diminished ability to fight infection. A898, 899, 910.¹³

People with Alzheimer's are often cared for at home. A958-9, 1108, 1124. Some individuals with milder cognitive impairments can be safely maintained in their homes without constant assistance. A949, 950. In the majority of cases, a home attendant is capable of providing the safety monitoring and supervision needed to reduce/eliminate the possibility of risk to the Alzheimer's patient from unsafe wandering or hazardous home experiences. See, e.g., A1015, 958-9, 1108, 1124, 913-4, 1114.¹⁴ Further, cases like those of plaintiffs Amelia Russo

¹² Cuing or prompting involves guiding the person through a task (such as eating or going to the toilet and reminding of its location) while encouraging them to do it for themselves. A1109, 1110, 1115. Cuing also encompasses putting food on a fork and placing it in the individual's hand and then encouraging them to bring the food to the mouth. A903.

¹³ Older individuals are more vulnerable to the breakdown in the integrity of the skin and the development of pressure sores. A900.

¹⁴ It is exceedingly rare for Alzheimer's victims to be dangerous to people around them, A932-3. While some forms of agitation can be found in Alzheimer's patients, these symptoms are rarely found without precipitating factors, and can usually be treated with the individual

and Ann Reece demonstrate that, prior to the full implementation of task based assessment, districts provided independent safety monitoring to cognitively impaired individuals under the personal care program.

TBA as Implemented by Local Districts

New York City: New York City obtained state approval of its plan in March, 1996. In its initial proposal to implement task based assessment, New York City listed as a "key assumption of the plan" the restriction of live-in service to certain persons including those who "require night-time monitoring due to mental status." A3170 (emphasis added). The City began its task-based assessment program in July 1996 for new applicants and in October 1996 for current recipients. A1045-6.

The City's policy eliminating safety monitoring is reflected in its Nurse's Assessment Forms (form M-27R). The pre-TBA form listed safety monitoring as a separate task to be evaluated in determining the clients' service needs. A3089. In contrast, the 1996 form contains each of the tasks from the list of required services/plan of care on the old form except safety monitoring. A3056-3058, 1226, 1227.¹⁵

Other Local Social Services Districts:

Task-based assessment was first used by Westchester County in 1990.

Nassau County began utilizing task based plans of care in December 1994 or January 1995. Like New York City, prior to task based assessment, Nassau County did provide sleep-in

continuing to remain safely at home. A1112, 1113, 953.

¹⁵ While the new form contains a question about whether the client can be safely left alone, it does not incorporate any mechanism for including the patient's time-related needs for safety monitoring in the plan of care. A974-5, 976, 1014, 1015.

care for supervision/safety monitoring. A1707-8. Since the implementation of TBA, Nassau County will no longer authorize sleep-in care for supervision/safety monitoring where there are no other nighttime tasks. A1705, 1710.

Suffolk County implemented a similar program in 1991. A1824. Suffolk County does not provide safety monitoring as a separate task as part of its Personal Care Aide Program. A1962, 1968.

Defendants' claims regarding the availability of alternative services, instead of home care, are not supported by the record. A1840, 1868-74. Most of the programs cited by defendants' witnesses are either inappropriate for most people who need safety monitoring or unavailable to the vast majority of people who have safety monitoring needs. A1863-8. There are a minute number of enriched housing beds and the program does not provide continuous safety monitoring or supervision. 18 N.Y.C.R.R. §488.4(b). Adult homes are state licensed residential facilities that have a staff-resident ratio of one to forty residents and provide only 3.75 hours of weekly staff time per resident, making it an inappropriate setting for persons with any significant dementia. 18 N.Y.C.R.R. §487.9(f)(6), 487.9(g)(2). Assisted living programs are fairly new, have few beds, and cannot provide services to people with mid- and late-stage dementia due to requirements relating to cognitive functioning. Soc. Serv. L. §461-1, 18 N.Y.C.R.R. §494.4(c). See A1422 (no assisted living programs in Suffolk County). Long term home health care generally provides a limited amount of daily service hours due to the program focus on comprehensive services and its moderate fiscal cap. 10 N.Y.C.R.R. §§86-5.9. Adult foster care programs and the foster family care demonstration program are very limited options that do not accept individuals with significant dementia. 18 N.Y.C.R.R. §§489.7; 505.29(d)(2).

ARGUMENT

DEFENDANTS' REFUSAL TO PROVIDE SAFETY MONITORING AND VERBAL CUEING NEEDED BY NON-SELF-DIRECTING INDIVIDUALS DISCRIMINATES AGAINST COGNITIVELY IMPAIRED MEDICAID RECIPIENTS IN VIOLATION OF THE MEDICAID ACT AND ITS REGULATIONS, THE AMERICANS WITH DISABILITIES ACT, AND §504 OF THE REHABILITATION ACT.

POINT I

Plaintiffs are Entitled to Relief under the Disability Discrimination Laws.

The district court correctly found that plaintiffs were entitled to relief on their claims under Title II of the Americans With Disabilities Act ("ADA") and §504 of the Rehabilitation Act (§504). See, 29 U.S.C. §794; 42 U.S.C. §12132.¹⁶ In Olmstead v. L.C. By Zimring, 1999 U.S.LEXIS 4388, *32-35, the Supreme Court clarified that the proscriptions of the ADA, including the prohibition against unnecessary segregation, apply to discrimination among disabled individuals in programs that provide services only to persons with disabilities, laying to rest any question that the ADA reaches the type of discrimination at issue in this case. Further, the district court carefully considered and then correctly rejected defendants' contentions that they could not accommodate mentally impaired plaintiffs in the personal care program in light of their obligation to provide long term care to the Medicaid population as a whole.

A. Plaintiffs are "qualified individuals with disabilities" with respect to the Medicaid personal care program.

Mentally impaired plaintiffs are "qualified individuals with a disability" with regard to the

¹⁶ The ADA was enacted because of the inadequacy of existing laws "to combat the pervasive problems" of disability discrimination. Helen L. v. DiDario, 46 F.3d 325, 331(3d Cir. 1995) (citing S.Rep.No. 116, 101st Cong., 1)(1989)). The ADA adopts the remedies, procedures, and rights available for a violation of Section 504. 42 U.S.C. §12133.

personal care program because they meet the program's essential eligibility requirements even without accommodation. See 42 U.S.C. §12131(2). Under the State's Medicaid program an individual is eligible for personal care services if he or she has a stable medical condition and is self-directing or has another individual or organization willing to direct the home attendant on an interim or part-time basis. A4501, 4529; A3997. See, 18 N.Y.C.R.R. §505.14(a)(1) and (4).¹⁷ The district court explicitly found that, although defendants attempted "to show that many persons with mental impairments are inappropriate for home care, the evidence showed that the opposite is often true." A4000 (citing Plaintiffs' expert evidence); A4541; A353 (§197).

The record contains overwhelming evidence that mentally impaired plaintiffs are eligible for the Medicaid personal care services program and that they can be safely maintained at home if they are given adequate personal care services. The fact that in the past defendants provided personal care services to mentally impaired individuals that included independent safety monitoring and have been permitted by the State and Federal Government to do so, proves that plaintiffs meet the essential program qualifications. See A1287, 1350-1, 1356-7, 3983, n. 9; 18 N.Y.C.R.R. §505.14(a)(6)(ii)(b)(V). See also, A1708 (Nassau County admission that it provided independent "safety monitoring" prior to TBA), A1553-4 (NYC's provision of sleep-in services to mentally impaired individuals needing nighttime safety monitoring) Even after the implementation of TBA, on an ad hoc basis, the record establishes that Nassau County offered to provide some hours of Medicaid personal care services to plaintiffs such as Russo and Weinblad if their families

¹⁷ In its argument the State continues to confuse the safety monitoring/supervision of the patient with the "supervision/direction" of the home attendant by another on behalf of a non-self-directing individual. The district court correctly addressed this obfuscation in its preliminary injunction decision. A3995, n. 15.

would pay for the balance of the medically necessary care. A3975-7; A3330.¹⁸

Finally, the district court's injunction by its terms only applies to individuals who meet the eligibility criteria of medical stability and being either self-directing or having a surrogate to direct the attendant. A4524; A3997. Consequently, the injunction will provide relief only to persons who are "otherwise eligible" for personal care services even without accommodation.

B. Defendants are Discriminating Against Mentally Impaired Plaintiffs Based on Their Disability.

The district court determined that defendants discriminate against mentally impaired plaintiffs in two ways. A4530-31. First, defendants deny cognitively impaired plaintiffs assistance in the form of verbal direction needed to perform those personal care tasks "recognized" by the State.¹⁹ A3999 (citing toileting example). Second, defendants deny "independent safety monitoring" to plaintiffs with cognitive impairments and either provide an inadequate amount of home care services (e.g. Weinblad), or completely deny services because the individual cannot be safely maintained at home without the "safety monitoring" defendants refuse to provide (e.g. David). As a result, mentally impaired plaintiffs are denied, in whole or in part, services that are provided to physically impaired individuals in violation of the ADA and §504. See, 42 U.S.C. §12132; 45 C.F.R. §§84.4(b), 84.52.

¹⁸ At the Russo fair hearing, the Nassau County representative said: "And you understand that the Agency's position is that she can remain at home with four hours if supervision is provided?" A2185.

¹⁹ Defendants' argument that the program only provides assistance with recognized "hands-on" or "physical" personal care "tasks" that appeared in the regulatory list of services does not withstand scrutiny. Defendants acknowledge that the program provides assistance with "non-hands-on" tasks such as reminding to eat or take medication and covers tasks not included on the task list, such as, turning and positioning. A3816, 18 N.Y.C.R.R. §505.14(a)(6)(a), A3998.

The District Court correctly rejected defendants' defense that their policy is disability neutral. Defendants contend that they do not provide safety monitoring to anyone — whether physically or mentally disabled -- unless it is in conjunction with the provision of assistance with a recognized physical task.²⁰ A3997-8, 1197, 1289, 1301. First, the record demonstrates that appellants regularly fail to provide mentally impaired individuals with verbal assistance needed to complete “recognized tasks” such as toileting. Second, defendants cannot circumvent the mandates of the disability discrimination laws by simply “collapsing” their discriminatory policy into a new definition of the personal care benefit as one that provides assistance and safety monitoring only in conjunction with tasks that cannot be performed because of physical impairments. See, Alexander v. Choate, 469 U.S. at 301, 301, n.21, 302; 45 C.F.R. §84.4(b)(4); 28 C.F.R. §35.130(b)(3)(prohibiting use of exclusionary criteria).

New York State’s personal care program is part of the federally approved general Medicaid program. The program was designed to provide personal care services to enable disabled individuals to reside safely in their homes, even when a person’s mental disability necessitates the use of a surrogate to direct the personal care attendant. See, 18 N.Y.C.R.R. §§505.14(a)(4)(ii). As a result of their respective medical conditions, plaintiffs require assistance with personal care and the services of a home attendant are essential to maintenance of their health and safety at home. The record demonstrates that mentally impaired individuals are denied personal care services offered to physically impaired individuals, solely because their need for

²⁰ Denying “independent safety monitoring” to the mentally and physically impaired alike is no more equal than denying ambulation assistance equally to those who can and cannot walk or denying heart surgery to those with and without cardiac conditions.

services stems from a mental, rather than a physical impairment. A3330.²¹ "States must adhere to the ADA's nondiscrimination requirement with regard to those services it does provide," Olmstead at *39, n. 14, and the state cannot deny mentally impaired individuals the home attendant services necessary for safe maintenance in the home.

Defendants suggest that plaintiffs, like the plaintiffs in Alexander v. Choate, are seeking services beyond those that the state has determined to provide. In Alexander, however, plaintiffs were challenging a general, 14-day limit on inpatient hospital days which applied equally to all recipients. 469 U.S. 287, 301 (1985). Here, cognitively impaired plaintiffs are denied precisely those Medicaid personal care services generally available to persons who do not have mental impairments—i.e., the medically necessary amount of care, up to 24 hours per day, subject to the fiscal assessment law, including its protections, when applicable.

Defendants seek to rely on cases from this Circuit finding that §504 and the ADA do not require that they provide plaintiffs with "special services." But unlike the cases cited by defendants where plaintiffs were not alleging the denial of services provided to other similarly situated individuals, A4521-23 (distinguishing cases), in this case plaintiffs with mental impairments seek only services comparable to those provided to persons with physical impairments.²²

²¹ The David fair hearing decision presents a stark example of the disability-based nature of service denials. A3338. Similarly, the State's brief demonstrates that Ms. David was denied services because "[a]s a result of a cognitive syndrome, she had forgotten where the bathroom was located, was incapable of remembering to take her medication and could not recall what day it was." State's Brief at 15-16.

²² In Traynor v. Turnage, 485 U.S. 535, 549-550 (1988), veterans whose disabilities were attributable to their own 'willful misconduct' sought application of a special extension of 10 year delimiting period for benefits that was available only to disabled veterans whose disabilities were

The crucial inquiry is, then, what is the benefit being sought by plaintiffs? Plaintiffs seek personal care services provided by a home attendant to maintain their health and safety and help them carry out their daily living activities such as eating, toileting, dressing, taking medications, so that they can continue to reside in their homes. In each case in the record involving the denial of personal care benefits in whole or in part, the patient's treating physician had requested personal care services for his or her patient on the medical request form required for the application for these services. In each case, the plaintiff was found by the assessing nurse to have a stable medical condition, see, e.g., A3331, 3329, and each individual had a family member who accepted responsibility for the supervision and direction of the home attendant. By denying medically necessary amounts of personal care services because mentally impaired plaintiffs' need for these services has a mental rather than a physical genesis, defendants discriminate based on disability in violation of federal law.

Further, the district court also correctly determined that defendants violate the ADA's integration requirement by routinely utilizing institutionalization in a nursing home as "the alternative to home" for the majority of plaintiffs who are elderly Alzheimer's patients. City Brief at 39-40 (emphasis added). See A4537-39.²³ According to the decision in Olmstead, the wholesale institutionalization of "elderly, Alzheimer's patients" who need assistance results in the unlawful segregation of the mentally disabled outlawed by the ADA. Olmstead, 1999 U.S.LEXIS 4388, at *35. See Helen L., 46 F.3d at 335; 42 U.S.C. §12101(a)(2),(3), and (5). Further,

unrelated to "willful misconduct."

²³ Olmstead specifically applies the ADA's "integration" mandate to discrimination in access to programs that are only available to disabled individuals, thereby negating the arguments presented in the City's Brief at 42-43. Olmstead, 1999 U.S.LEXIS 4388, at *30-40.

defendants' blanket determination that all persons suffering from cognitive impairments must receive their assistance in an institution rests on the very irrational stereotypes sought to be outlawed by the disability discrimination laws. See 42 U.S.C. §12101(a)(7)(finding discrimination resulting from "stereotypic assumptions not truly indicative of the individual ability of such individuals to participate in, and contribute to society").

City defendant now argues that there is no evidence that institutional placement or other "alternative programs" are more segregating than care provided in one's home and community. With regard to the alleged "alternative programs" there was no evidence that any plaintiff had been denied personal care because they refused to accept an available, appropriate community alternative.

With regard to the involuntary institutionalization of mentally impaired plaintiffs, the ADA's implementing regulations provide for integration in "a setting that enables individuals with disabilities to interact with non-disabled individuals to the fullest extent possible," 28 C.F.R. pt. 35, App. A, p. 450 (1998), an objective more likely to be achieved in the community, rather than a nursing home setting. In fact, the State legislature itself has formally recognized the adverse social and health consequences of institutionalization and has set a public policy in favor of providing care in the home. N.Y. Pub. Health L. §3600.²⁴

The Olmstead Court found that unjustified isolation of individuals in institutions is discriminatory on at least two grounds.

First, institutionalization of persons who can handle and benefit from community settings perpetuates unwarranted assumptions that persons so isolated are incapable or

²⁴ See Olmstead *36-37(rejecting notion that Medicaid statute currently prefers institutional to community care.)

unworthy of participating in community life. Second, confinement in an institution severely diminishes the everyday life activities of individuals, including family relations, social contacts....Dissimilar treatment correspondingly exists in this key respect: In order to receive needed medical services, persons with mental disabilities must, because of these disabilities, relinquish participation in community life they could enjoy given reasonable accommodations, while persons without mental disabilities can receive the medical services they need without similar sacrifice.

1999 U.S.LEXIS 4388, at *35-36. Defendants' safety monitoring policy discriminates against mentally impaired individuals based on disability because they are denied or receive less effective personal care services than are provided to physically impaired individuals and because the policy, at best, results in unjustified segregation of cognitively impaired individuals.

C. Defendants' defenses to the discrimination are without merit.

Although the district court could have rested on its conclusion that plaintiffs were "otherwise eligible" for the personal care program without accommodation, the district court correctly determined that even if the provision of safety monitoring or verbal cuing were deemed a necessary accommodation, the defendants could provide the accommodation without undue burden or a fundamental alteration of the program. A4532, 4539, 4540-42; 28 C.F.R. §35.130(b)(7). See, Olmstead, 1999 U.S.LEXIS 4388, *13, 30, 41 (requiring showing that accommodation cannot be made based on state's obligation to serve all persons within relevant care system appropriately and with an even hand).

Olmstead involved the placement of only two individual litigants. On remand, the Eleventh Circuit directed the lower court to consider only the burden of providing services to the two individual plaintiffs to determine whether the provision of services to them would constitute an undue burden in light of the State's mental health budget. See 1999 U.S.LEXIS 4388, * 29, 40-41. The Supreme Court found that the district court should consider the overall program

costs of providing community placements to L.C. and E.W., in a sense requiring a more classwide analysis of the burden of community placement. Olmstead, at *41. Because this is a class action, the defendants already attempted and failed in their effort to demonstrate that the class of mentally impaired individuals could not be "reasonably accommodated" within the personal care program. The district court properly found that defendants had failed to meet that burden.

1. Fundamental alteration of the program.

The evidence demonstrates that the provision of independent safety monitoring would not cause any meaningful alteration of the personal care services program as defined in the state regulations and numerous policy statements since at least 1985, and that those services have been provided by defendants in the past. A3999, n.19; A1287, 1351. See also, Borkowski v. Valley Central School District, 63 F.3d 131, 140 (2d Cir. 1995)(identification of essential job functions requires fact-specific inquiry into both employer's job description and how job is actually performed [emphasis added]).

Having thoroughly considered the evidence, the district court could find no legitimate reasons why a home attendant could be available to take an individual to the toilet at unpredictable times throughout the day and night or assist with a special diet or change dressings but could not be available to re-direct or prompt an Alzheimer's patient so he or she does not wander out the front door or forget to take medications or eat meals or go to the toilet. A4001. See, A948-50, 1015, 1108, 1114-5. See, Helen L. v. DiDario, 46 F.3d at 337 (no fundamental alteration of either home attendant or nursing home programs from providing home attendant services to nursing home resident).

Defendants now argue on this second appeal that the provision of care to mentally

impaired individuals would fundamentally alter the nature of the program because it was designed exclusively for the "physically homebound". City Brief at 39. No evidence supports this asserted historical purpose of the program, and, for the reasons described above, the definition itself violates the anti-discrimination laws.²⁵

Defendants' revised program purpose is not justified by the record. First, defendants do not, and in fact cannot, cite to any authority for a requirement in the relevant laws or regulations that an individual must be homebound in order to be eligible for services. In fact, recent federal and state statutory amendments making Medicaid personal care services available to recipients in their "home or other location," are wholly inconsistent with a service available exclusively to persons who cannot leave their homes. See 42 U.S.C. §1396d(a)(24)(C); N.Y. Soc. Serv. L. §365-a(2)(e) (emphasis added). Further, in analogous cases this Court has recognized the importance of community integration and has rejected Medicaid policies limiting provision of services to the person's residence. See Detsel v. Sullivan, 895 F.2d 58 (2d Cir. 1990)(Medicaid private duty nursing); Skubel v. Fuoroli, 113 F.3d 330 (2d Cir. 1997)(Medicaid home health benefit).

²⁵ Defendants' suggestion that they are denying services to persons with mental disabilities because their care involves wasteful "down-time" not present in cases involving persons with physical impairments is without basis in fact. First, non-self-directing individuals who need independent safety monitoring will also need assistance with recognized personal care tasks, thereby diminishing so-called "down-time". See A914 (Dr. Meier); A1109 (Horowitz), A1549-50 (Louth). Second, a home attendant who stays with a non-self-directing individual to ensure that he or she doesn't wander from the home or repeat medications, although not engaged in physical activity, is fulfilling a crucial safety function that is no different from being available to assist an individual in ambulating to the bathroom when the need for a visit arises. Finally, every personal care case involves time when the attendant is not engaged in physical activity. This is true in split shift cases providing assistance with toileting, or turning and re-positioning every two hours, as well as, necessarily, in "sleep-in" cases. The argument is a red herring properly rejected by the district court. A4538-39.

By innuendo and explicit statement, defendants suggest that as a result of the injunction the state will be required to provide personal care services to psychiatrically “unstable” individuals or those whose mental conditions are so complex that their care is beyond the abilities of a home care attendant.²⁶ The suggestion is without basis in fact. See Wagner by Wagner v. Fair Acres Geriatric Center, 49 F.3d 1002, 1009, 1016 (3rd Cir. 1995)(requiring factual basis beyond general allegations that nursing home could not adequately accommodate admission of aggressive Alzheimer’s patient.). In the most simplistic of ways, defendants seek to equate the existence of any mental impairment with a psychiatrically unstable individual who would not qualify for this level of services.²⁷

In every instance personal care services must be requested by the individual's treating physician who has determined that the individual is appropriate for care with the services of a home attendant. Amelia Russo, Ann Reece, Mariamma David, and Mary Weinblad lived successfully in their homes with the services of an ordinary home attendant for significant periods of time. Significantly, the defendants’ own assessors did not find any of the cognitively impaired plaintiffs who would be aided by the challenged injunction to have an unstable medical condition.

²⁶ Defendants may be trying, indirectly, to re-assert a “direct threat” defense properly rejected by the district court. A4540-42. Cognitively impaired individuals as a group present no greater risk to themselves than individuals who are at risk of falls and fractures without ambulation assistance from a home attendant. A4000-1. Plaintiffs' experts testified that it is exceedingly rare for Alzheimer's victims to be dangerous to people around them, A932-3, 952, and that they become dangerous to themselves only in some cases. A958.

²⁷ In Olmstead, the Supreme Court went beyond unfounded stereotypes about the needs of mentally impaired persons to endorse the community placement recommended by treating physicians of L.C. and E.W., two retarded women diagnosed respectively with schizophrenia and a personality disorder. This was true despite the Supreme Court’s recognition that both women had conditions that varied over time and had necessitated multiple institutional placements. Olmstead, at *22-23, 24, n.6.

See, e.g., A3331 (David, item 3); A2276, 2282 (Weinblad). The program would simply not be open to an individual with an unstable psychiatric condition just as it is not open to a person with an unstable physical condition.

No doubt defendants will argue that Olmstead requires the court to defer to the “reasonable” opinion of state health professionals that mentally impaired individuals be treated in institutions rather than the community, citing language at 1999 U.S. Dist. LEXIS 4368 at *38. L.C. and E.W. resided in a State mental health facility and were treated by physicians employed by the state. When the Supreme Court stated that deference was owed to the opinions of state health professionals about the propriety of community placement, the Court was referring to the patients' treating professionals. See, e.g., Olmstead, at *22-23 (“treatment team determined”); *23 (“treating psychiatrist concluded”); *26 (same); *46 (“state’s treatment professionals”); *50-51 (“opinion of a responsible treating physician”[Kennedy, J., concurring]). Most importantly, however, it is simply not reasonable to conclude that all cognitively impaired individuals needing a home attendant to monitor their safety (along with providing assistance with other tasks) must be cared for in an institution. As the district court correctly observed, it is defendants’ refusal to provide safety monitoring, not the condition of the individual needing safety monitoring that causes maintenance at home to be unsafe. A4000-1.

Defendants also argue that the permanent injunction would require them to provide personal care services to persons who have mental impairments, but who lack any personal care needs beyond the need for independent monitoring. This assertion is in direct conflict with the record. Plaintiffs’ experts testified that any individual who had a mental impairment so severe as to require the need for a home attendant to ensure that they did not inappropriately wander from

their home, would also need assistance with activities of daily living; the individual's mental condition would make it unlikely that they could make their meals and eat at necessary and appropriate intervals, take medications at appropriate times and in appropriate amounts, or get to the toilet in a timely fashion. A914, 1109. The examples of the plaintiffs also demonstrated that the need for safety monitoring went hand-in-hand with the need for assistance with activities of daily living. See Russo, David, Weinblad (four daily hours for "tasks"), Reece (8 daily hours for "tasks"). Even the City's witness conceded that she had never encountered someone who only required "safety monitoring" without the need for assistance with any personal care "tasks". A1549-50.

Defendants also argue that the injunction will interfere with their ability to utilize alternative programs such as assisted living or enriched housing. These alternative programs, however, are not a realistic option for most mentally impaired plaintiffs needing "safety monitoring." These programs are either not available because of limited spaces or are not appropriate because they are structured for persons with higher degrees of cognitive functioning. A1863-8. Furthermore, under current law, prior to authorizing personal care services, respondents are currently required to determine whether other community-based alternative programs such as long-term home health care, assisted living, and enriched housing services, could serve the individual appropriately and cost-effectively. N.Y. Soc. Serv. L. §367-k(2)(a)(v) and (b). The injunction would not change that legal requirement.

Finally, appellants also argue that the permanent injunction would fundamentally alter the program because they are unable, without new staff or additional training, to determine how much home attendant time would be needed for "independent safety monitoring." A review of New

York City's current assessment forms show that assessing nurses and physicians are already obligated to assess the spectrum of mental impairments. A3794-3801, 2802, 2804.²⁸ The fact that the State had given unlimited discretion to districts to provide independent safety monitoring (and several provided the service prior to TBA and may continue to do so when they wish) indicates that districts are capable of determining the amount of "safety monitoring" needed to ensure the safety of mentally impaired plaintiffs. In the case of Mariamma David, Nassau County denied her request for 10 hours of daily home care because it concluded that she had between 4-5 daily hours of home care but needed safety monitoring for the other 5. A3979. In the case of Ann Reece, Nassau County denied her services where her "task needs" came to "at most 8 hours daily," but she needed a 10 hour "sleep-in" authorization to be safely maintained at home. A3324. Obviously, the assessors are currently able to determine the amount of time needed for safety monitoring. Defendants' arguments to the contrary are without merit.

2. Cost of Accommodation

There are two fatal aspects to defendants' arguments that the provision of safety monitoring services cannot be provided as an accommodation for reasons of cost. First, defendants cannot be permitted to deny services to mentally impaired individuals due to the cost, when they are willing to provide personal care services that are equal to or greater in cost to physically impaired individuals. A4537, 4002-4 (finding defendants unable to justify this inequity). The State simply cannot address the cost of Medicaid covered personal care services

²⁸ For example, current assessment forms ask the assessor to determine whether the person has impaired judgment, impaired memory, needs reminding to take medications, whether they wander or whether they can be safely left alone. See also 18 N.Y.C.R.R. §505.14(b)(3)(iii)(requiring assessment of patient's physical and mental condition).

by denying services to a class of disabled individuals, just as State officials could not attempt to save education expenditures by refusing to educate a particular racial or ethnic group of schoolchildren.

Second, defendants' cost estimates are inherently flawed because they never account for the countervailing cost of providing alternative services to those mentally impaired individuals denied personal care. Of course, one could posit that defendants give no estimate of countervailing costs because there are virtually none; persons with mental impairments are simply abandoned or left without services. A3338 (David)(fair hearing decision denying all services); 3324-5 (Reece)(decision upholding the termination of all personal care services notes that assessing nurse advised family to "investigate" use of adult day care which at best would only provide some daytime assistance.)

Assuming however, that defendants did institutionalize a significant segment of the plaintiff class, the cost of nursing home care will almost always exceed the cost of caring for the individual at home. As the district court correctly observed, in those limited number of cases where the cost of maintaining a cognitively impaired person at home exceeds the expense of nursing home care, "defendants can look to the fiscal assessment law, just as they do in high cost cases involving persons with physical impairments." A4537.²⁹

²⁹ Claims that fiscal assessment may not be available in the future because it is being "threatened" by a separate lawsuit, Best v. Whalen, Index No. 404648/98(N.Y.Co.)(Moskowitz, J.), are speculative and not a consequence of the order in this case. Thus far, the fiscal assessment law remains the currently effective mechanism available to ensure that home care costs do not exceed the cost of institutional care. Any claims by defendants that, notwithstanding the fiscal assessment law, they will be injured because they must comply with the law's procedural protections, are beside the point as they presumably comply with those protections in the case of physically disabled individuals.

Defendants have not met their burden of persuasion on undue financial burden. Relying on this Court's decision in Borkowski v. Valley Central School District, 63 F.3d 131, 138-39 (2d Cir. 1995), the district court correctly determined that: "[d]efendants have not shown that the financial burden of a permanent injunction will be 'clearly disproportionate' to the benefits it will produce in preventing unnecessary segregation of mentally impaired individuals." A4539.

Without considering any costs of alternative care, defendants produced only a conclusory affidavit contending that the cost of the injunction, on all levels of government, would be approximately \$40.8 million annually for new cases in New York City, where most home care cases are concentrated.³⁰ The district court concluded that even accepting the speculative figures put forth by defendants that any costs of complying with the injunction would "be a mere fraction of the \$2.7 billion total cost of New York State's home care program."³¹ A4544.

³⁰ Defendants have not responded to discovery demands seeking the data underlying these cost estimates. At a minimum defendants' figures appear to be distorted by the use of case costs based on an authorization of 24 hour care for all cognitively impaired individuals. People with mental disabilities have a spectrum of needs, just like people with physical disabilities. A1956, 949, 950. Defendants themselves conceded that persons with mental disabilities do not all require continuous care. A353 (¶¶196-97). For a further discussion of the flaws in defendants' cost estimates, including Nassau County's post-judgment estimates of \$70 million increase (way beyond that of New York City's which has a home care program approximately 20 times the size of that in Nassau County), see Dougherty Declaration in Opposition to Defendants' Motion for Stay Pending Appeal to this Court, ¶15.

³¹ The total monthly cost of New York's Medicaid program was almost \$1.7 billion in February, 1999 and was almost \$ 2.3 billion in March, 1999, making overall annual expenditures for the program in excess of \$20 billion. See New York State Health Dept., Information for Researchers, located at <http://www.health.state.ny.us/nysdoh/research/medicaid.htm>.

Defendants first argue before this Court that they will have to pay home attendants additional monies to care for mentally impaired plaintiffs (an additional \$.10 per hour at the cost of \$9,780,000 per year.) There is no indication that any defendant has ever paid any home attendant a greater hourly wage to care for any of the named plaintiffs when they received personal care services for safety monitoring or verbal cuing. In any event, these additional costs, in addition to being speculative, are nevertheless small in comparison with the \$ 2.7 billion cost of personal care

Significantly however, the district court found:

“In addition, defendants’ costs will be offset to the extent defendants intended to substitute institutionalization in nursing homes in place of home care which would be less expensive in some circumstances. While defendants have provided no estimate for the competing costs of nursing home care, it is likely that their estimated costs of implementing this Order will be reduced to the extent that some mentally impaired individuals may be cared for at home at a lesser expense.”³²

A4544-45.³³

The district court’s decision regarding defendants’ asserted cost defense is wholly consistent with the Supreme Court’s decision in L.C. v. Olmstead where the Court elucidated the standard for determining whether a programmatic accommodation is too costly to be required of a state(Part IIIB). In L.C. v. Olmstead the Eleventh Circuit had remanded the case for a determination of “whether the additional expenditures necessary to treat L.C. and E.W. in community based care would be unreasonable given the demands of the State’s mental health budget.” 138 F.3d 893, 905 (11th Cir. 1998). The Supreme Court determined that the State could have more leeway in proving undue burden beyond a simple analysis of the cost of the

services or the \$20.4 billion cost for the Medicaid program.

Defendants also contend that they will be forced to pay penalties for failing to meet cost containment targets, “up to \$42 million.” This cost is extremely speculative and may not be appropriately tied to the relief awarded in this case. The cost containment targets, which we do not know will be part of the new state budget, set targets for savings through a variety of efficiencies. Further, the speculation that cost savings targets will be exceeded does not seem to account for projected savings from task-based assessment generally, which the City had estimated in an amount of \$10 million monthly. See Dougherty Declaration in Opposition to Defendants’ Motion for Stay Pending Appeal to this Court, Exhibit 5.

³² Individuals like Mariamma David reside with their families and only require home care when family members are at work and some require lower amounts of care.

³³ See, Helen L. at 338-339(recommending that state might have to transfer funds from a nursing home budget to a home care budget to avoid such segregation.)

accommodation for two individuals in relationship to overall programmatic expense. The Court indicated that a State could show that an accommodation could not be made, despite the fact that the cost was not excessive in light of overall program expenses, where the refusal to accommodate was done to further the State's obligation to "maintain a range of facilities and to administer services with an even hand." Olmstead. *44-45.

If for example, the State were to demonstrate that it had a comprehensive, effectively working plan for placing qualified persons with mental disabilities in less restrictive settings, and a waiting list that moved at a reasonable pace not controlled by the State's endeavors to keep its institutions fully populated, the reasonable-modifications standard would be met... by asking [a] person to wait a short time until a community bed is available, [the state does not unlawfully discriminate against persons with disabilities]... a court would have no warrant effectively to order displacement of persons at the top of the community-based treatment waiting list by individuals lower down who commenced civil actions(emphasis added)."

Id.

Defendants cannot supplement their unpersuasive cost argument with an Olmstead reasonable modification defense. Defendants have not and cannot meet the Olmstead standard. The denial of safety monitoring does not further any legitimate aspect of the State's obligation to provide long term care services to needy individuals. This policy is not part of a comprehensive and effective plan that the State is implementing to achieve the goal of providing appropriate community based care to individuals who are eligible for such care and who desire treatment in a community setting. Defendants have no such plan. The only purpose served by the safety monitoring policy is to reduce the single budget item for personal care services. This objective is being achieved by moving mentally impaired plaintiffs from the community to institutions, in many cases at greater expense to defendants; such a plan cannot be justified. Warehousing of the mentally impaired will not be tolerated by the Supreme Court. Defendants remain unable to

justify why their plan for long-term care services pays for physically impaired individuals to remain at home, but sends mentally impaired individuals with comparable medical needs only to institutions.

For these reasons, the denial of essential personal care services to cognitively impaired individuals in the form of "safety monitoring" violates the ADA and Section 504.

POINT II

THE DISTRICT COURT CORRECTLY FOUND THAT DEFENDANTS' SAFETY MONITORING POLICY VIOLATES MEDICAID LAW AND REGULATIONS.

A. Comparability

Under defendants' current safety monitoring policy, medically stable individuals with cognitive impairments needing Medicaid home care services are provided services that are "less in amount, duration and scope" than those provided to similarly situated individuals with physical impairments in violation of federal law, 42 U.S.C. §1396a(a)(10)(B) and 42 C.F.R. §440.240(b). A3997, 4001. The comparability provision is an equality provision. The language of the comparability provision is clear and straightforward: any categorically needy individual must be eligible for medical assistance in the same amount, scope, and duration as any other categorically needy individual or any medically needy individual. 42 U.S.C. §1396a(a)(10)(B)(i) and (ii). The courts have consistently found that Medicaid's comparability provision, §1396a(a)(10)(B), is enforceable. See also, Blanchard v. Forrest, 71 F.3d 1163, 1167-8 (5th Cir. 1996), cert. denied, 518 U.S. 1013 (1996); Greenstein v. Bane, 833 F. Supp. 1054 (S.D.N.Y. 1993); Sobkey v. Smoley, 855 F. Supp. 1123 (E.D.Cal. 1994).

The district court's literal interpretation of the comparability provision is supported by

numerous cases finding violations of the comparability provision. In addition to Blanchard and Clark, supra, a number of other courts have found violations of the comparability requirement where Medicaid programs have failed to provide equal access or equal services to all who are eligible. See, e.g., Parry v. Crawford, 990 F.Supp. 1250, 1257 (D. Nevada 1998)(violation of comparability found where state defined service to exclude an entire class of categorically needy individuals, providing services to those diagnosed as mentally retarded but denying the same service to those diagnosed with conditions “related to mental retardation”); Greenstein v. Bane, supra (reimbursement methodology invalidated based on finding that comparability provision violated where some Medicaid recipients forced to pay for services or treatment furnished to other recipients without charge); Sobky v. Smoley, supra (comparability requirement violated where methadone maintenance treatment provided to some but not all categorically needy individuals due to lack of availability of funded treatment slots); Mayer v. Wing, 922 F. Supp. 902, 912, n. 11 (S.D.N.Y. 1996)(Scheidlin, J.)(arbitrary reductions of home care services potentially affecting any recipient of services violate comparability provision's mandate of equality of services). Relief similar to that ordered by the district court has been ordered by other courts that have found violations of 42 U.S.C. §1396a(a)(10)(B); it is the relief necessary to ensure provision of comparable services.

Defendants continue to confuse Medicaid comparability provisions. Plaintiffs’ claim, based on 42 U.S.C. §1396a(a)(10)(B), is easily distinguished from claims based on other comparability provisions of the Medicaid Act upon which defendants rely, for example, 42 U.S.C. §1396a(a)(10)(C) governing eligibility requirements. See, e.g., cases cited by defendants decided under 42 U.S.C. §1396a(a)(10)(C)(i)(III), Camacho v. Perales, 786 F.2d 32, 34 (2d Cir. 1986)

and DeJesus v. Perales, 770 F.2d 316. Compare, Martinez v. Ibarra, 759 F.Supp. 664, 669 (D.Colo. 1991)(finding comparability claim “promising” in challenge to use of screening procedure that permits people “who need the same level of care [to be] distinguished from each other” but for specific federal waiver of comparability requirement granted to state agency).

Defendants complain that other circuits have “broadened the comparability principle” when other circuits have merely considered the Medicaid provision at issue in this litigation, 1396a(a)(10)(B), rather than the income and budgeting provisions relied upon by defendants in their argument. See, e.g. Blanchard v. Forrest, *supra* (state ordered to establish mechanism to ensure that reimbursement policy does not result in different coverage of medical treatment based solely on whether or not applicants paid privately for services prior to application), Clark v. Kizer, 758 F.Supp. 572, 580 (E.D.Cal. 1990)(denial of dental services to some Medicaid recipients due to unavailability of services in certain locations violates section 1396a(a)(10)(B)).

The district court properly rejected the state’s claim that defendants have not violated the comparability provision because the provision does not require provision of the same treatment to individuals with different medical conditions. In a thorough analysis of the services provided to physically and mentally disabled people in its preliminary injunction order, the district court found that comparable treatment was being denied to mentally disabled people. A3994-4004 (incorporated by reference in the permanent injunction currently on appeal). The district court properly found that the safety monitoring/verbal direction provided to mentally impaired individuals to enable them to complete “recognized” tasks or to enable them to be safely maintained in their homes is comparable to the “safety monitoring” provided to an individual with a physical impairment while the individual is receiving assistance with a “recognized” personal

care task. A3998-3999. The district court found that defendants imposed an arbitrary exclusion of mentally impaired individuals regardless of their medical need for personal care services.

A4515. The record indicated that defendants' distinctions were not based on medical need, but rather on impermissible categories of exclusion so that no person with mental impairments could qualify for personal care services even when the services were medically necessary and appropriate.

Contrary to the state's claim, the district court did not require the state to add services to its Medicaid program or to provide a service not previously provided. Instead, after extensive testimony, the district court found that safety monitoring had previously been provided to people with mental (as well as physical) disabilities. The district court found that "despite defendants' assertions to the contrary, the evidence at the hearing revealed that they have historically provided and continue to provide safety monitoring to guard against such dangers as wandering out of the house and turning on the stove -- both of which present dangers to cognitively impaired individuals." A4532. See also A3999, n. 19; 1287, 3140 (listing safety monitoring as a "required task"); 18 N.Y.C.R.R. §505.14(a)(6)(ii)(b)(v). Based on this evidence, the district court made correct factual findings that defendants had provided independent safety monitoring in the past. Notwithstanding defendants' protestations to the contrary, the district court did not order defendants to add a new service for mentally disabled people.

B. The District Court Correctly Found That Defendants' Policy Violates 42 C.F.R. §§440.240(b) and (c).

Defendants cite no persuasive authority to undermine the district court's well-reasoned decision that plaintiffs have an enforceable right under 440.230(b)(a service must be sufficient to

reasonably achieve its purpose) and (c)(prohibiting discrimination based on diagnosis).³⁸ A regulation along with its underlying statutory provisions can create a federally enforceable right.³⁹ See Wright v. City of Roanoke Redevelopment & Hous. Auth. 479 U.S.418, 420 (1987); Doe v. Chiles 136 F.3d 709, 714 (11th Cir. 1998)(finding enforceable under §1983 the provisions of 42 U.S.C. §1396a(a)(8) and implementing regulations 42 C.F.R. §§435.930(a)-(b) and 435.911 requiring the furnishing of Medicaid with reasonable promptness).

The district court found that both regulations define the contours of class members' right to "reasonable standards" and "comparable assistance" for determining eligibility for and extent of medical assistance under 42 U.S.C. §§1396a(a)(17) and 1396a(a)(10)(B). See e.g. Smith v. Palmer, 24 F. Supp.2d 955 (N.D. Iowa 1998)(finding that §1396a(a)(17) and 440.230(b) meet §1983 requirements). State defendant has the discretion to provide medically necessary services in many ways, but it cannot adopt a policy antithetical to the very purpose of the service -- maintaining the health and safety in the home of otherwise eligible individuals without violating 440.230(b).⁴⁰ Also, a policy denying personal care services to cognitively impaired individuals is

³⁸ As the district court noted, a private right of action deriving from Medicaid regulations has been recognized in several circuits and courts have enforced 440.230(b) without a discussion of private rights under 1983. A4511, n15.(citing cases from the 11th, 8th, and 5th circuits).

³⁹ A regulation standing alone can create a federal right if it meets the test set forth in Wilder and restated in Blessing. See Boatman v. Hammons, 164 F.3d 286, 289 (6th Cir. 1998) (rejecting the Eleventh Circuit's position stated in Harris v. James and finding federal regulations enforceable under §1983). See, also, Loschiavo v. City of Dearborne, 33 F. 3d 548, 551 (6th Cir. 1994), cert. den., 513 U.S. 510 (1995); Reynolds v. Giuliani, 1999 WL 66119, *10 (S.D.N.Y. 1999). But see, Graus v. Kaladjian, 2 F.Supp.2d 540, 544 (S.D.N.Y. 1998)(decided just after the Eleventh Circuit's decision in Harris, but before Boatman (6th Cir.)and Doe v. Chiles (11th Cir.)). However, this specific question remains open in this and other circuits.

⁴⁰ See 3997 (district court finding that plaintiffs meet the eligibility criteria for the personal care services program.)

not a “reasonable standard” as it arbitrarily denies or reduces the amount, duration or scope of required services based solely on diagnosis, type of illness or condition in violation of 440.230(c).

Moreover, the court found that these regulations set the floor under §1396a(a)(10)(B) for what equivalent services to Medicaid recipients must be, sufficient to reasonably achieve the purpose of the service:

Once New York sets its goal for the home care program to maintain the health and safety of eligible individuals in their homes, the State may not allow its services to fall below this ‘floor’ set by § 42 C.F.R. §440.230(b). Therefore home care services must be ‘sufficient in amount, duration, and scope’ to meet the goal of maintaining eligible individuals in their homes and communities and avoiding institutionalization.

A4514.

The district court found that the provisions were neither so “vague and amorphous as to be beyond the competence of the judiciary to enforce.” Congress intended to require states to: (1) adopt reasonable standards for determining eligibility for and the extent of medical assistance under the plan to meet the primary objective of Medicaid of providing necessary medical care, 42 U.S.C. §1396a(a)(17); and (2) provide comparable assistance between recipients. 42 U.S.C. §1396a(a)(10)(B). The regulations further define these mandates. The States have discretion in developing the services, but Congress retained the underlying requirements of “reasonable standards” and “comparable assistance.” A court is competent to measure whether or not the defendants have violated these standards when they deny otherwise eligible mentally disabled individuals needed services based solely on their need for safety monitoring.

This Court should reject defendants’ contention that the mandate of “reasonable standards” is akin to “substantial compliance” in Blessing and “reasonable efforts” in Suter and

that the word “reasonable” creates ambiguity when dealing with program benefits. Whether a State has made “reasonable efforts” to keep families together necessarily depends on the circumstances of each case, “reasonable efforts” for one family may be insufficient for another. Standards, such as those relevant for this case, are quantifiable. Like reasonable promptness, “reasonable standards” and “comparable assistance” are identifiable benchmarks against which to measure a State’s activity. See Wilder at 519 (“While there may be a range of reasonable rates, there certainly are some rates outside that range that no State could ever find to be reasonable and adequate under the Act.”); Doe 1-13 v. Chiles, 136 F.3d 709, 717 (11th Cir. 1998).

This case is also very different from the federal auditing mechanism in Blessing enacted to ensure a state’s substantial compliance with Title IV-D of the Social Security Act. Even so, the Supreme Court acknowledged that some provisions of Title IV-D may create enforceable rights and remanded the matter back to the district court. Blessing at 1362-1363.

Contrary to defendants’ assertions, the fact that the State has discretion in adopting standards for determining the scope of the services does not render these provisions unenforceable. In Wilder, the Supreme Court enforced Medicaid provisions under the Boren Amendment that gave states at least as much discretion as the provisions here.⁴¹

The Supreme Court’s recent vacatur and remand of DeSario v. Thomas provides further support for the district court’s finding that 440.230(c) is enforceable in this case. The Supreme Court vacated and remanded for this Court’s consideration of the “interpretive guidance issued by the Health Care Financing Administration on September 4, 1998.” DeSario v. Thomas, 139 F.3d

⁴¹ The Boren Amendment required provider reimbursement rates which the “State finds, and makes assurances satisfactory to the Secretary,” are “reasonable and adequate” to meet the costs of “efficiently and economically operated facilities.” 42 U.S.C. §1396a(a)(13)(A).

80 (2d Cir. 1998), order vacated sub. nom., Slekis v. Thomas, ___ U.S. ___, 119 S.Ct. 864 (Jan. 19, 1999). The HCFA interpretive guideline informed the States that in determining the extent of covered home health services, a State must comply with the requirements of 42 C.F.R. §§440.230(c).

Despite the State's assertions that it can ignore §440.230(c) for any service which it has opted to provide under its Medicaid plan, this provision is enforceable as to all services a state chooses to include in its state plan . It is well-settled that once a state undertakes to provide an optional Medicaid service, that service becomes part of the State's Medicaid plan and must be provided in accordance with federal law. "A state's participation is voluntary, but once a state chooses to participate in the program, it must comply with federal statutory and regulatory requirements." DeLuca v. Hammons, 927 F. Supp. 132, 133 (S.D.N.Y. 1996)(citing to Alexander v. Choate, 469 U.S. 287, 289 n. 1 (1985) and 42 U.S.C. §1396a); See also, Doe 1-13 at 714. In light of this principle, "required service" in the regulation refers to those services required under the State's Medicaid plan. 42 U.S.C. §1396a. See White v. Beal, 555 F.2d 1146 (3d Cir. 1977).

C. Defendants' Denial of Safety Monitoring for Cognitively Impaired Individuals Violates Federal Law

The district court correctly held that the state's revised policy denying home care services to prompt, observe, and monitor the safety of a mentally impaired person denies them services which are necessary to maintain their health and safety at home based on their mental impairment and therefore violates 42 C.F.R. §440.230(b) and (c). Defendants' safety monitoring policy denies cognitively impaired individuals sufficient personal care services to enable them to safely

reside in their homes – the stated objective of the services. Consequently, the safety monitoring policy violates the federal Medicaid mandate that state Medicaid plans provide services that are “sufficient in amount, duration, and scope to achieve [the plan’s] purpose.” 42 C.F.R.

§440.230(b). See e.g., Mitchell v. Johnston, 701 F.2d 337 (5th Cir. 1983); Hunter v. Chiles, 944 F. Supp. 914, 920 (S.D. Fla. 1996).

This Court should reject defendants’ dangerous contention that the State can exclude eligible individuals from a Medicaid service and not run afoul of 440.230(b) as long as that service meets the needs of “most” Medicaid recipients. Here the evidence showed that the defendants cut a service which was previously part of the basic package of services provided under the personal care program. Unlike the exceedingly uncommon medical equipment at issue in DeSario, safety monitoring is needed by thousands of Medicaid recipients. A3124. The State’s own study of the City’s home attendant caseload (A3124) and the United Hospital Fund Study (A4100-4104) both showed large numbers of home care recipients needing safety monitoring. See also A912-913 (plaintiffs’ experts’ testimony about the prevalence of cognitive impairment in the elderly).

Defendants’ claim that they can provide “separate but equal” services for the mentally disabled is as false as it is offensive. Not only does the record demonstrate that the state upheld the denial of crucial home care services without requiring the districts to provide any alternative services, it also showed that the alleged alternative options are illusory. See, e.g., A3979, 3320 (Reece), A3330 (David).

The policy also violates the prohibition against discrimination based on diagnosis. 42

C.F.R. §440.230(c).⁴² In White v. Beal, 555 F.2d 1146 (3rd Cir. 1977), a refusal to provide for eyeglasses to Medicaid eligible individuals with a simple visual impairment such as refractive error was found to be illegal where the state did provide glasses for Medicaid recipients whose vision was impaired due to eye disease or pathology. The court found that, based on 42 C.F.R. 440.230(c) as implementing 42 U.S.C. 1396d(a) and (a)(12), the state did not have discretion to create a limitation on Medicaid payments for eyeglasses to people who needed them because of pathology as opposed to eye defects. See also, Weaver v. Reagan, 886 F.2d 194, 197-98 (8th Cir. 1989). According to the State, it has “limited the personal care services program to those individuals whose medical conditions enable them to benefit from the service safely, and without excessive cost.” State brief at 24. Plaintiffs meet this definition. The defendants violate 440.230(c) by providing split-shift services to persons with physical disabilities, while at the same time denying adequate personal care services if the individual has a cognitive impairment.⁴³

Defendants’ contention that the denial of safety monitoring is a permissible limitation on service based on medical necessity and utilization control procedures under 42 C.F.R. §440.230(d) is without merit. A state may not deny an otherwise covered medically necessary service to an individual based on diagnosis, such as mental impairment. A4514. The district court’s order does not impose an inflexible duty to meet the needs of all recipients regardless of

⁴² A number of courts have relied on this regulation to strike down restrictions on Medicaid-funded abortions found to discriminate based on medical condition. See, e.g. Hern v. Beye, 57 F.3d 906, 910 (10th Cir. 1995), cert. den., 516 U.S. 1011; Planned Parenthood Affiliates of Michigan v. Engler, 73 F.3d 634, 49 (6th Cir. 1996).

⁴³ Ironically, if the failure to provide assistance with toileting leads a mentally impaired individual to become incontinent, under defendants' policy they will be much more likely to receive home care services to assist with the "hands-on" task of diaper changing.

cost. Defendants must treat high cost cases involving the cognitively impaired just as they treat high cost cases involving the physical impaired. A4537.

POINT III

DEFENDANTS DO NOT HAVE DISCRETION TO ESTABLISH A DISCRIMINATORY SAFETY MONITORING POLICY.

Although defendants are permitted, within limits, to determine the scope of services offered by their program, they must establish reasonable standards which are consistent with the governing laws. Beal v. Doe, 432 U.S. 438, 444 (1977). For the reasons stated above, defendants' safety monitoring policy violates federal disability discrimination and medicaid laws. In addition, the policy lacks a rational basis. See, Skubel v. Fuoroli, 113 F.3d 330, 336, 337 (2d Cir. 1997)(finding assumptions behind restricting home health services to recipient's place of residence to be obsolete and at odds with "the consensus among health care professionals that community access is not only possible, but desirable for disabled individuals.") The state's safety monitoring policy is also not entitled to deference because it is an "informal" policy never subjected to public comment which has changed over time (A1287; 1351-1352; 1708 evidence of prior safety monitoring policy.). See Detsel v. Sullivan, 895 F. 2d 58, 65 (2d Cir. 1990). Courts owe less deference to an agency interpretation of a regulation that is inconsistent with earlier pronouncements it has made, because the "agency's expertise to which we normally defer becomes dubious when the expert cannot make up its own mind." New York City Health and Hosp. Corp. v. Perales, 954 F.2d 854 at 861-862 (2d Cir. 1992).

Moreover, the Health Care Financing Administration ("HCFA"), the government agency to whose judgment the appellate court might normally defer, does not support the State's policy.

In August 1996 State defendant wrote to HCFA requesting an answer to the following question:

if an individual with a dementia diagnosis needs assistance with 'hands-on care' such as bathing and dressing, should personal care services also include supervising/monitoring the patient during those periods of the day when no 'hands-on' care is required in order to assure that a patient with impaired judgment does not pose a risk to themselves or others?

A3737. HCFA responded to the State's inquiry affirmatively:

Monitoring an individual's activities should be an inherent part of personal care services, that is, a provider that is assisting an individual who is not self-directing and is at risk to themselves or others (for example, an individual with dementia) in meal preparation, bathing, grooming, dressing, etc., should also be expected to monitor the individual's activities as an integral part of the personal care services provided.

A3740. A plain reading of the HCFA's correspondence leads to the conclusion that safety monitoring, in and of itself, should be an integral part of the personal care services authorized for a non-self-directing recipient who is at risk if unattended. In a subsequent, unadmitted letter,⁴⁴ the agency wrote that it had no policy "requiring that safety monitoring be delivered simultaneously with the provision of Medicaid Personal Care Services tasks." A3347.⁴⁵ To the extent that this Court should defer to HCFA's opinion, the district court's decision is consistent with that opinion.⁴⁶

⁴⁴ It was error for the district court to refuse to admit this letter while admitting two letters obtained by the state from HCFA in the midst of this litigation (State Exhs. 6 and 7). A1330-1335.

⁴⁵ Unlike the cases cited by defendants, there is no explicit federal agreement with the state interpretation of federal law. Parry v. Dowling, 95 F.3d 231,236-37 (2d Cir. 1996); Liegl v. Webb, 802 F.2d 623 (2nd Cir. 1986); Skandalis v. Rowe, 14 F.3d 173 (2d Cir. 1994).

⁴⁶ The State now claims that its interpretation that no safety monitoring is required outside recognized tasks is bolstered by a HCFA Transmittal, State Medicaid Manual, Part 4, HCFA Pub. 45-4 Transmittal No. 72, Jan. 1, 1999(Med-Guide-TB para. 150,239). The cited transmittal does not directly address this point. The transmittal makes absolutely clear, however, that personal care services should be provided to persons with "cognitive impairments,"

POINT IV

THE DISTRICT COURT CORRECTLY HELD THAT PLAINTIFFS ARE BEING IRREPARABLY HARMED BY DEFENDANTS' UNLAWFUL POLICY.

As a result of defendants' safety monitoring policy, plaintiffs are either denied medically necessary services, in whole or in part, or are institutionalized involuntarily when they could continue living in their homes with personal care services, just as persons with physical disabilities are able to do. Mentally impaired individuals are denied assistance with "recognized tasks" and are denied the amount of personal care required to safely maintain them at home.⁴⁷ The credited expert testimony confirmed the irreparable harm that results from the failure to direct to the toilet, to remind to take medications or to prevent wandering. See A908-910 (skin irritation, infections and ultimate incontinence from failure to provide toileting assistance); A914-917 (improper

explaining: "An individual may be physically capable of performing ADLs and IADLs but may have limitations in performing these activities because of a cognitive impairment. Personal care services may be required because a cognitive impairment prevents an individual from knowing when or how to carry out the task....personal assistance may include cuing along with supervision to ensure that the individual performs the task properly." Reading HCFA's 1996 letter in conjunction with this clarification of coverage of cognitively impaired individuals under the personal care program, leads to a result entirely consistent with the district court's order.

⁴⁷ The record is replete with examples of individuals who have been harmed by defendants' policies. For example, Mary Weinblad was authorized to receive only four hours of care per day, despite her need for twenty-four hour "safety monitoring," "supervision," and "one to one cuing." A3976. Mariamma David was given no time for assistance with toileting or ambulating even though she stood in place without direction because of her dementia. She was ultimately denied any personal care services because of her mental confusion. A3979. Ann Reece, who would wander unless supervised due to her mental impairment, received no time for toileting assistance, though she forgot where her bathroom was. Her sleep-in services were discontinued because of her need for constant supervision. A3979. As would be expected, a sampling of more recent cases from various counties and fair hearing decisions echoes the same types of harm (inadequate home care authorizations and forced institutionalizations) that were experienced by plaintiffs and plaintiff-intervenors. See Dougherty Declaration In Opposition to Defendants' Motion to this Court Seeking a Stay Pending Appeal.

administration of medications); A913-914 (failure to monitor wandering). The denial of these types of services has “a devastating effect on [plaintiffs’] health and safety.” A4017.

The evidence also proves that the local defendants offer no alternative services to plaintiffs and that the state upholds the denial of crucial home care services without requiring the districts to provide any other services. See, e.g., A3325, 3338. The alleged alternative options cited by defendants are virtually nonexistent. A1863-8 (Suffolk County testimony about significantly limited options). Most of those programs that do exist are not available to non-self-directing individuals. Involuntary nursing home placement is not a comparable alternative service. Being torn from one’s home, family, and friends and placed in a nursing home, usually for the balance of one’s life, is a harm that cannot be repaired by money damages. A4543, N.Y. Public Health L. §3600.

None of the defendants’ claims demonstrate injury to the State or local districts which outweighs the irreparable harm to plaintiffs. Defendants’ speculative arguments about cost, which do not include the cost of alternative care are unavailing, particularly in light of the overall budgets for personal care services, Medicaid long-term care services, and the Medicaid program as a whole. A4544-45.

In any event, mentally impaired individuals do not ask the Medicaid program to spend any more for their home care than it would for a physically disabled individual -- up to 24 hour continuous care subject to the provisions of the fiscal assessment law.

The district court appropriately balanced the competing public interest concerns and correctly found that the balance tipped in favor of maintaining the health, safety, and personal integrity of the elderly and disabled. As the district court stated, “[t]he public has an interest in

protecting its most vulnerable members from practices that do not comply with federal law.”

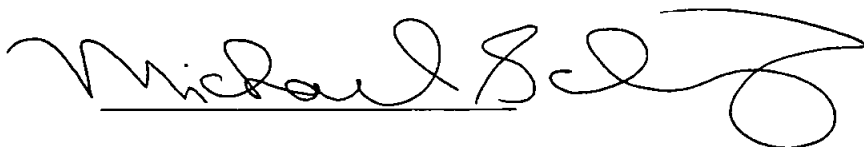
A4545.

CONCLUSION

The Order and Decision and the Judgement appealed from should be affirmed in its entirety, with costs.

Dated: New York, New York
July 6, 1999

Respectfully submitted,

A handwritten signature in black ink, appearing to read "Michael Scherz", with a long horizontal line extending from the end of the signature.

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CERTIFICATE REGARDING COMPLIANCE

(motion for permission to file brief exceeding the page limit is being filed)

In accord with Fed. R. App. P. 32(a)(7)(c), I certify that, excluding the cover, table of contents, table of authorities, and this certification, this brief contains approximately 15690 words as recorded by the word count of the WordPerfect program used to prepare this brief. Contemporaneous with the filing of this brief, plaintiffs are seeking leave to submit a brief exceeding the limits in Fed. R. App. R. 32.

By: 