Mental Health and Safety Monitoring: Personal Care Services for Elders with Dementia

By Brian M. Salazar and Nicole Pecorella

I. Introduction

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Following a Second Circuit Court of Appeals ("Court of Appeals") ruling,[1] social services districts[2] were no long required to provide personal care services (PCS) to individuals who required only "standalone safety monitoring."[3] Safety monitoring is defined as instances where there was no valid personal care task, such as toileting, walking, or transferring, was occurring.[4] In practice, this applied largely to individuals who suffer from mental disabilities, such as dementia or Alzheimer's Disease. These individuals may therefore be prone to forgetfulness, wandering, and bouts of confusion, among other symptoms. Although the New York State Department of Health (DOH) issued guidance following the decision, it remained difficult to fully differentiate between instances of safety monitoring and valid personal care tasks. For example, what becomes of the person who needs assistance walking but is also prone to wander? Is someone prone to falling when left alone an appropriate recipient for PCS? Further, an explicit bar against standalone safety monitoring fostered the opportunity for bias against individuals with mental health disabilities. Their needs could more readily be labeled under standalone safety monitoring, leaving their needs unmet and their well-being in jeopardy. This article discusses (1) the restrictions on obtaining PCS due to standalone safety monitoring, (2) common obstacles individuals with mental health disabilities and their advocates may face, and (3) ways in which individuals with mental health disabilities can still obtain the care needed.

II. The Advent of Standalone Safety Monitoring

In *Rodriguez v. City of New York,* advocates argued that PCS provided without safety monitoring as an independent task were inadequate to allow the appellees, a class of individuals with mental health disabilities, to remain safely in the community.[5] They contended that this constituted discrimination against the mentally disabled under the Medicaid Act, its regulations, the Rehabilitation Act, and American with Disabilities Act (ADA), who would be otherwise eligible for PCS if not for their mental conditions.[6] Specifically, the appellees' argument rested on provisions in the Medicaid Act stating that medical assistance provided to an individual "shall not be less in amount, duration, or scope than the medical assistance made available to any other such individual"[7] and the ADA promulgating that no disabled individual could be denied the benefits of a public entity due to that disability.[8] They further argued that there was precedent in previous Second Circuit decisions, such as *Camacho v. Perales,* which found that the state could not provide more assistance to medically needy individuals as opposed to categorically needy individuals as doing so was a violation of the Medicaid Act.[9]

Chief Judge Ralph K. Winter found the argument unpersuasive. Writing for the majority, he found that the Medicaid program is not required to provide a benefit that it does already provide at all.[10] The relevant sections in the ADA and Medicaid Act, as well as prior Second Circuit decisions, found discrimination only when one group was receiving a public benefit while another group in need of those benefits was not.[11] In other words, refusal to provide standalone safety monitoring was not in violation of the Medicaid program or the ADA because it was not being provided to any recipient of personal care services. The decision found that the appellees were seek-

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ing an entirely new benefit and not the provision of an already covered one.[12] Winter leaned on a footnote in the at-the-time recent decision in *Olmstead v. L.C.*, where the United States Supreme Court found that the ADA did not impose a requirement on states to provide new services to disabled individuals, and thus only applied to services already provided.[13]

III. Implications of *Rodriguez*: Unconscious Bias and Mental Illness

In *Rodriguez's* aftermath, it became increasingly difficult for individuals diagnosed with mental health disabilities to obtain proper home care. DOH issued a General Information System (GIS) clarifying the distinction between appropriate safety monitoring and standalone, explaining that:

> a clear and legitimate distinction exists between 'safety monitoring' as a non-required independent stand alone function while no Level II personal care services task is being provided, and the appropriate monitoring of the patient while providing assistance with the performance of a Level II personal care services task, such as transferring, toileting, or walking, to assure the task is being safely completed.[14]

Many were denied in part, or all together, under the guise that their requests constituted standalone safety monitoring. In the years following the *Rodriguez* decision, many barriers continue to exist for legal advocates in trying to obtain home care services for those diagnosed with mental illness or disability. Yet procedural and regulatory barriers are only further compounded by the numerous unconscious biases that exist surrounding both mental illness and those deemed worthy of obtaining home health care.

Unconscious biases are stereotypes about certain groups of people that individuals form outside their own conscious awareness.[15] Everyone holds unconscious beliefs about various social and identity groups, and these biases stem from one's tendency to organize social worlds by categorizing.[16] These biases operate undetected and can influence a person's decision making whether aware of their presence or not.

In New York City, in determining whether one is appropriate for home care, a Medical Request for Homecare Form (M11Q) is required, in which a person's physician attests to the presence of a chronic condition and its adverse effects on one's ability to perform the activities of daily living.[17] Alcohol dependence, dementia, Alzheimer's Disease, major depression, and anxiety are all disease diagnosis listed by the International Classification of Diseases (ICD), a disease classification tool published by the World Health Organization and utilized by the Uniform Assessment System.[18] Yet it is not the presence of these illnesses that deem eligibility for home care, but their effects on one's physical ability to care for themselves and perform their activities of daily living that determine whether personal care services are authorized or not.

Trying to prove the chronic nature of mental illness and its effects on a person's physical functioning is further complicated by the stigma of mental illness that exists. This bias functions as a pervasive barrier for persons with mental illness trying to access health care services. According to a study published in the *Journal of Social and Clinical Psychology*, persons with mental illness were often negatively perceived and associated with traits such as blameworthiness and helplessness.[19] For instance, a person may unconsciously associate alcohol dependency with a personal choice a person is making about their behavior, rather than a disease, as classified by the ICD. These feelings of blame may operate on an unconscious level, with the person holding them not even aware of their existence. Nonetheless, a person may still be swayed into thinking home care services are not necessary whether or not they are conscious from where this belief is resonating

IV. Best Practices Moving Forward

It is not uncommon for individuals with mental health disabilities to receive denial notices stating that their PCS request was denied due to standalone safety monitoring concerns. Although advocacy for such an individual may prove more difficult, it is not impossible for someone to overcome this. First and foremost, all PCS requests should be tied to physical needs, even if execution and completion of those needs require safety monitoring.[20] It is possible that an individual's physical needs can encompass or overlap their safety monitoring needs. For example, an individual may be prone to wandering throughout the nighttime, but their toileting needs may be severe enough to warrant a PCS aide there throughout the entire day. Similarly, an individual may have a history of falling but only while attempting to cook or bathe. In those instances, PCS would be included to allow the safe completion of each activity.[21]

Second, it is important to note that prompting and cuing are valid personal care tasks that should be covered by an appropriate PCS authorization. For example, an individual is still eligible for PCS even if they are able to physically walk to and use the bathroom on their own but require someone to direct them to the bathroom and remind them to complete safely complete all of the appropriate stages. This means that an individual may be eligible for 24-hour care with only prompting and cueing, if they need such care to complete their activities of daily living each day.

V. Conclusion

In the aftermath of the *Rodriguez* decision, obtaining PCS for people with mental health disabilities became more difficult. The hardline rule against providing PCS for standalone safety monitoring allowed social services districts to more easily deny requests even when valid PCS tasks were involved. However, there are several avenues PCS recipients and their advocates can take to obtain the proper level of care.

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Endnotes

1. *Rodriguez v. City of New York*, 197 F.3d 611 (1999).
2. In New York State, this refers to each county's Department of Social Services, except for New York City, where this refers to the Human Resource Administration.
3. GIS 03 MA/003.
4. *Id.*
5. *Supra* note 1.
6. *Id.*
7. 42 U.S.C. § 1396ª(a)(10)(B)(j).
8. 42 U.S.C. § 12132.
9. *Camacho v. Perales*, 786 F.2d 32, 38 (2d Cir. 1986).
10. *Supra* note 1.
11. *Id.*
12. *Id.*
13. *Olmstead v. L.C.*, 119 S.Ct. 2176, 144 L.Ed.2d 540 (1999).
14. *Supra* note 2.
15. https://diversity.ucsf.edu/resources/unconscious-bias.
16. *Id.*
17. *See* https://www1.nyc.gov/assets/hra/downloads/pdf/services/micsa/m_11q.pdf.
18. *See* https://icd.who.int/browse11/l-m/en for further reading.
19. Bethany A. Teachman, Joel G. Wilson, Irina Komarovskaya (2006). *Implicit and Explicit Stigma of Mental Illness in Diagnosed and Healthy Samples*, Journal of Social and Clinical Psychology, Vol. 25, No. 1, pp. 75-95.
20. *Id.*
21. *Id.*

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