Expanded Home and Community-Based Services Under the PPACA and LGBT Elders: Problem Solved?

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There are an estimated three million people over the age of sixty-five that currently identify as Lesbian, Gay, Bisexual and Transgender (LGBT)—a number which could grow as large as four million by 2030.¹ As the Patient Protection and Affordable Care Act (PPACA) has greatly incentivized states to increase home and community-based services (HCBS)² and move away from traditional institution-based long term care, growth in the elderly LGBT population portends increased resident abuse, discrimination and substandard care in the HCBS setting. While the prospect of aging “in place” is appealing to all Americans,³ there are significant dangers posed to the health of LGBT elders that call into question the benefits of HCBS.

This article will first describe HCBS and the present Medicaid waiver system; second, the unique health issues LGBT elders face; third, the possible benefits of HCBS for LGBT Elders; fourth, the dangers posed to LGBT elders by HCBS; and fifth, the current means to mitigate these dangers through cultural competency training, the possibility of a private right of action under the Nursing Home Reform Act (NHRA) and the

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1. See Michael J. Ritter, Quality Care for Queer Nursing Home Residents: The Prospect of Reforming the Nursing Home Reform Act, 89 Tex. L. Rev. 999, 999 (2011).


reporting and oversight of HCBS waivers and programs.

I. INTRODUCTION TO HCBS

HCBS allow persons who are elderly or disabled to receive care in their home or community.\(^4\) State Senator Kevin Kelly, for example, lauds HCBS, both for the potential it holds in cost-savings\(^5\) and the ability to improve quality of life for residents.\(^6\) Residents also favor these programs\(^7\) because they do not have the negative connotations of institutional care and provide a greater sense of autonomy and independence. LGBT elders are no different than their peers in that they too would prefer to age in their home or in a community-based setting.\(^8\) Unfortunately, this desire for home and community-based care clashes with the realities of present HCBS programs.

In 1983, Congress created HCBS waivers through section 1915(c) of the Social Security Act (SSA)—allowing states to circumvent the Medicaid requirements for institutional long-term care.\(^9\) The PPACA now incentivizes states to expand HCBS through Section 1115 Research and Demonstration, or Section 1915(i) Home and Community-Based Services


\(^6\) See Senator Kelly: Community-Based Care Would Improve Quality of Life for Connecticut Seniors, CONN. SENATE REPUBLICANS (last visited Mar. 7, 2013), http://ctsenaterepublicans.com/2013/03/senator-kelly-community-based-care-would-improve-quality-of-life-for-connecticut-seniors/#.UXbMkSuFSCK (stating that “[a]ging in place and community-based care have the potential to transform and improve life for members of our aging population.”).

\(^7\) See Tracy Bach, Choices For Care: Consumer Choice and State Policymaking Courage Amid Medicaid’s Shifting Entitlement to Long-Term Care, 9 MARQUETTE ELDER’S ADVISOR 269, 274, 276 (2008).

\(^8\) See Knauer, supra note 3, at 55.

\(^9\) Home & Community-Based Services, supra note 4.
State Plan waivers. As a result of those incentives, the majority of states are currently increasing the availability of HCBS programs. Through the present system, states can submit amendments for review to change their state plans and create a 1915(i) HCBS benefit. These mechanisms—1115, 1915(c), and 1915(i)—allow states to expand coverage for services to elders in their homes and communities, as opposed to the more traditional, institutional setting. It is this expansion – and the amplifying effect it may have on the unique health and economic factors in the LGBT community – that raises concern.

II. UNIQUE HEALTH AND ECONOMIC ISSUES AMONG LGBT ELDERS

The dangers posed to LGBT elders by HCBS arise from some of the specific health and economic trends that impact the LGBT community. The CDC notes that the overall LGBT population is medically underserved and suffers from significant health disparities. Among the LGBT elderly, there are elevated rates of chronic health problems, including “asthma, diabetes, HIV/AIDS, obesity, rheumatoid arthritis and certain illnesses such as cancer.” While Medicare coverage mitigates health access issues among the uninsured once they reach the age of 62, there are still persistent health issues among the LGBT elderly that would be exacerbated by

11. Id. (referring to the twenty-nine states in 2011 and twenty-seven states in 2012 that expanded HCBS programs).
12. Id.
15. MO. FOUND. FOR HEALTH, supra note 13, at 12.
increase HCBS.

These health issues are further impacted by economic circumstances. The lack of dual incomes from a partner or the economic support from adult children leaves many LGBT elders without an adequate support network. Additionally, pension and spousal plans usually do not extend survivorship benefits to same-sex partners. As a disproportionate number of LGBT elders are without traditional support systems, many who enter long-term care institutions are reliant upon state and federal aid, like Medicaid. These factors indicate why LGBT elders are vulnerable to emotional and physical abuse by their caregivers in an institutional long-term care setting.

III. POSSIBLE BENEFITS OF HCBS TO LGBT ELDERS

Over the past decade there has been repeated discussion of the development of LGBT-specific long-term care facilities. In theory, HCBS waivers create greater opportunities for like-minded people to live together and insulate themselves from discrimination in these kinds of living-arrangements. Unfortunately, there are not many success stories in the LGBT long-term care market. While there have been several successful non-profit LGBT developments that cater to lower-income residents, these represent a small subset of U.S. markets and they have significant waiting

16. MO. FOUND. FOR HEALTH, supra note 13, at 23.
21. Id.; see Lade, supra note 18 (noting that most attempts at LGBT-specific long-term care have failed).
In theory, the expansion of HCBS funding could create new opportunities in urban communities to provide LGBT-specific housing for elders covered by Medicaid.\textsuperscript{23} The problem with this theory though, is that while the potential of community-based care is emphasized by many LGBT rights groups, present and planned LGBT-specific housing do not meet demand.\textsuperscript{24} The financial constraints that have limited growth of LGBT specific long-term\textsuperscript{25} care may be aided by increased HCBS funding, but this is not the best course\textsuperscript{26} and will not correct the overarching dangers posed to LGBT elders by the expansion of HCBS.

IV. DANGERS POSED TO LGBT ELDERS BY HCBS

This move towards community-based care has benefits in diverse, urban communities where LGBT elders can elect to live with other LGBT residents. In most circumstances, though, HCBS may pose danger to LGBT people. Due to the sustained contact and the importance of the resident-caregiver relationship, intolerance or ignorance on the part of the caregiver has a significant impact upon the quality of care for LGBT residents.\textsuperscript{27} In smaller, rural communities, or in instances where elders are placed into care without their input, this could create greater potential for harm and isolation.

As there is an increased likelihood of isolation in a home-based

\begin{itemize}
\item \textsuperscript{22} Lade, \textit{supra} note 18.
\item \textsuperscript{23} See Home & Community-Based Services, \textit{supra} note 4.
\item \textsuperscript{24} Knauer, \textit{supra} note 3, at 55.
\item \textsuperscript{25} See Lade, \textit{supra} note 18.
\item \textsuperscript{26} See Hovey, \textit{supra} note 20, at 114-15 (stating that “these housing options are often too expensive for many,” and, “private alternative housing for LGBT seniors, while a nice idea, is clearly not going to solve the problem of discrimination for many older members of the gay community who cannot afford it.”).
\item \textsuperscript{27} Ritter, \textit{supra} note 1, at 1000.
\end{itemize}
program, and as isolation creates the potential for inadequate care, the risk of inferior care for LGBT elders receiving HCBS is very real. Placement in nursing care is often rushed and last-minute and there may be no opportunity to self-select for a more welcoming environment. This is especially worrisome in light of mental capacity issues where elders are placed into care quickly and with little research. In states with weaker or non-existent LGBT discrimination laws, moving LGBT elders into decentralized care like HCBS may amplify current problems with discrimination and abuse. These same states are also unlikely to create LGBT-centered care because it would be politicized and stigmatized, thus eliminating on the key benefits of HCBS to LGBT elders.

**A. Mistreatment of LGBT Elders**

Mistreatment is broadly defined as constituting physical, emotional, or sexual abuse, or neglect and abandonment by caregivers. LGBT elders are especially vulnerable to mistreatment because, as a stigmatized minority, they are often “the first targets of abuse, neglect, and discrimination in nursing homes.” This vulnerability is exacerbated by the “invisibility” of LGBT elders, and subtler forms of discrimination.

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28. Knauer, supra note 3, at 10 (referring to the fact that LGBT elders are more likely to live alone than straight peers, isolation is a clear danger).

29. Ritter, supra note 1, at 1005.

30. Hovey, supra note 20, at 111 (stating “the decision may not be theirs to make”).


35. See id.
Unfortunately, there is little reliable data on LGBT elder mistreatment. As of 2009, existing surveys did not account for LGBT people, which has created greater reliance upon anecdotal accounts.

LGBT elders experience mistreatment in the form of verbal and physical harassment by staff and residents, refusals to honor medical power of attorneys (POAs), and even the failure to provide basic care or medical care because of bias. LGBT elders fear long-term care settings because they anticipate that on the basis of their identity, they will be subject to discrimination from care providers and other residents, and receive substandard care. Recent data shows that these are pervasive concerns and that there is a significant risk of mistreatment that could arise in the HCBS setting.

LGBT patients’ previous experience of discrimination and anticipation of bias may cause residents not seek out adequate care, communicate risks to their care provider, or delay needed care. Additionally, LGBT individuals may fail to take necessary planning steps—advance directives or POAs—because they fear that doing so would invite bias or discrimination on the part of providers or their employers. Even when the proper planning is in place through the creation of a POA for an LGBT individual, these measures are sometimes ignored by long-term care providers or family

36. Knauer, supra note 3, at 52.
37. See, e.g., Nat’l Senior Citizens L. Ctr., supra note 18.
39. Id. (referencing a chart showing many forms of discrimination, from Nat’l Senior Citizens L. Ctr., LGBT Older Adults in Long-Term Care Facilities (2010)).
41. See id.
members. In long-term care this can create pressure to conceal individual LGBT status to avoid discrimination, which in turn fosters a sense of isolation and negatively impacts health outcomes.

Subtler discrimination may include the tendency among long-term care providers to ban non-relatives from electing to live together. This may not be explicitly intended to bar LGBT people from living with their spouses or partners, but it has that effect and concomitant impact upon LGBT residents’ mental health. Much of the blame may lie with the taboo placed on elder sexuality and the perception of LGBT people as hypersexualized. This creates significant pressure to hide LGBT sexuality to avoid judgment or danger, especially as there is a higher incidence of homophobia among the elderly non-LGBT population. This attempt to hide LGBT identity in turn fuels isolation and visibility problems, as hiding may only foster the false impression that the average long-term care facility doesn’t have LGBT residents.

V. CURRENT MEANS TO COMBAT PROBLEMS FACING LGBT ELDERS

A. Cultural Competency

One of the barriers to quality care for LGBT residents is that long-term care providers lack the requisite cultural competency to provide services that do not insult the dignity of LGBT residents. Cultural competency can contribute greatly to appropriate, high quality care for individuals of

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43. Knauer, supra note 3, at 39.
45. See Knauer, supra note 3, at 39.
46. Id. at 38.
47. Id. at 38-39.
49. See Knauer, supra note 3, at 38-41; Hovey, supra note 20, at 122.
different cultures. Of those institutions that are willing to respond to questions about their treatment of LGBT residents, few have protections or programs in place that train their staff on the needs and rights of LGBT residents.

In one instance where cultural competency training could have prevented harm, a long-term care resident (who was gay) hung himself after his facility placed him in a dementia ward because of complaints from other residents and their families. Unfortunately, LGBT patients are frequently moved due to complaints from other residents and staff. While long-term care providers struggle with the competing interests of protecting LGBT residents, and the morality of being forced to move patients because of bias, the outcome of these moves is a “faster pathway to depression, failure to thrive and even premature death.”

The fear of biased care and a lack of confidence in long-term care professionals among LGBT elders further emphasize this need for cultural competency. Cultural competency programs would train staff to monitor their own biases that may impact the quality of care, and reduce the likelihood of creating a “hostile or confusing environment.” This training would prevent subtler, inadvertent discrimination, and put biased staff on notice that discriminatory and substandard care is unacceptable.

Cultural competency training would additionally help caregivers to

50. INST. OF MED., supra note 40, at 65.
53. Id.
54. Id. (quoting Dr. Melinda Lantz, chief of geriatric psychiatry at Beth Israel Medical Center in New York).
55. Knauer, supra note 3, at 38.
56. MO. FOUND. FOR HEALTH, supra note 13, at 13.
57. Ritter, supra note 1, at 1015.
understand that LGBT elders need to continue relationships with loved-ones in the long-term care environment.\textsuperscript{58} Efforts to combat similar issues in the health care setting have caused advocacy groups, medical associations and the federal government to push for greater cultural competency among health care professionals.\textsuperscript{59} While competency training may help prevent subtler forms of bias, it does not hold caregivers accountable for overt acts of discrimination on the basis of LGBT status and raises further concerns with HCBS.

\textbf{B. Private Right of Action under the Nursing Home Reform Act}

In theory, there are protections in the Nursing Home Reform Act (NHRA) of 1987 that shield LGBT residents in Medicaid-sponsored long-term care like HCBS from discrimination.\textsuperscript{60} In relevant part, the NHRA states that a long-term care provider that takes Medicaid funds is required to “care for its residents in such a manner and in such an environment as will promote maintenance or enhancement of the quality of life of each resident,”\textsuperscript{61} and “to provide services and activities to attain or maintain the highest practicable physical, mental, and psychosocial well-being of each resident in accordance with a written plan of care.”\textsuperscript{62} Courts have differed in their treatment of these two provisions of the NHRA—whether they create a private right to sue long term-care providers who fail to provide an appropriate level of care.\textsuperscript{63}

\begin{itemize}
\item \textsuperscript{58} Evelyn M. Tenenbaum, \textit{Sexual Expression and Intimacy Between Nursing Home Residents with Dementia: Balancing the Current Interests and Prior Values of Heterosexual and LGBT Residents}, 21 Tem.
\item \textsuperscript{59} See Inst. of Med., \textit{supra} note 40, at 65-66.
\item \textsuperscript{60} See Natalie Chin et al., \textit{Asserting Choice: Health Care, Housing and Property—Planning for Lesbian, Gay, Bisexual, and Transgender Older Adults}, Clearinghouse Rev.
\item \textsuperscript{61} 42 U.S.C. § 1396r(b)(1)(A) (2011).
\item \textsuperscript{62} 42 U.S.C. § 1396r(b)(2) (2011).
\item \textsuperscript{63} Grammer v. John J. Kane Regional Health Centers-Glen Hazel, 570 F.3d 520, 532
\end{itemize}
Under Section 1983 of the Civil Rights Act of 1871, a citizen can sue for the violation of “a right secured by the constitution or laws of the United States.”64 The “quality of life” provision in the NHRA, a federal law, may afford residents greater rights to control aspects of their lives and choose to room with a person of their choice if both parties consent.65 Additionally, the creation of a private right demanding providers insure resident quality of life gives added protections in the event that there is discriminatory or substandard care on the basis of LGBT status.

The private right to sue under the NHRA could create additional protections that go beyond what is available under tort and contract law, as well as counter the inadequacy of the public-enforcement mechanism.66 Discretionary leeway under the present system creates little incentive to combat abuse and remedy quality problems.67

The private cause of action would remedy these inadequacies. It makes little sense to deny the private right on the basis of a broken public adjudication mechanism and there are positive examples where private suits against long-term care providers have proven successful in effecting change.68 Without greater clarity on resident rights, there are significant dangers posed to LGBT elders in the HCBS setting that raise red flags.


64. Ritter, supra note 1, at 1012.
65. Chin et al., supra note 60, at 527.
66. Ritter, supra note 1, at 1013.
67. Ritter, supra note 1, at 1015.
68. See Knauer, supra note 3, at 310-11 (recounting the story of Clay and Harold, whose settlement with Sonoma County over their mistreatment cause Sonoma County to change their conservatorship procedures to prevent future incidences).
C. Oversight and Reporting

Oversight is also a significant difference between the HCBS and institutional settings. As emotional abuse is often the byproduct of “underpaid, overworked staff, or [a] family member with little training and few resources forced to endure poor working conditions,” the threat of improper or inadequate training and the concomitant stress could create significant dangers for LGBT elders in a community care environment, where there are fewer workers and little oversight. The more training and oversight there is, the greater the expense, and the greater pressure there is on the bottom line for community-based care. While a significant incentive for community-based care is the cost-saving potential it holds, lack of oversight and training standards are certainly concerns that caution against rapid expansion of HCBS.

For a decade, audits of HCBS expansion have found that there is inadequate oversight over the waiver system and the programs that are put in place. In a 2012 study, the Department of Health and Human Services (HHS) found that “seven of the twenty-five states we reviewed did not have adequate systems to ensure the quality of care provided to beneficiaries.” Three of the states that HHS notified of deficiencies failed to correct them in a timely manner. Even with the most recent reforms in long-term care, and movements for greater accountability, serious complaints get delayed or

69. Hovey, supra note 20, at 98.
70. See Harrington et al., supra note 5.
72. U.S DEPT. HEALTH HUM. SERV., supra note 71.
73. Id.
inadequate responses.\textsuperscript{74} As there are still significant quality-control and reporting issues, the expansion of HCBS and these significant unknowns could have a disastrous impact upon the well-being of LGBT elders.

VI. CONCLUSION

While there may be cost savings and psychological and health benefits to LGBT elders who are able to get HCBS catered specifically to the LGBT community, these services are limited and do not mitigate the dangers posed to LGBT elders under the majority of HCBS programs. These dangers primarily lie in a system that lacks substantive oversight or remedial power over abuse and may not afford rights to sue.

\textsuperscript{74} U.S. Gov’t Accountability Office, supra note 71.