

DYING ALONE? DO-IT-YOURSELF CAREGIVER AGREEMENTS FOR GAYBY BOOMERS AND OTHER AGING AMERICANS[†]

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I. A Problem for Older LGBT Americans: Dying Alone

Liberal society seeks to create a world in which everyone can live flourishing lives, but little discussed is the idea of a flourishing end-of-life.¹ Led by my colleagues Anne Alstott and Nina Kohn, legal academic attention is now turning to law and aging.² Although many Americans find their silver years to be periods of happiness and flourishing, others do not.³ Thus far unmentioned in legal discourse is *Kodokushi*, the

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1. See Anne Alstott, *Law and the Hundred-Year Life*, 26 ELDER L. J. 131, 132–33 (2018) [hereinafter Alstott, *Hundred-Year*].

2. See generally *id.*; Nina A. Kohn, *A Framework for Theoretical Inquiry into Law and Aging*, 21 THEORETICAL INQ. L. 187, 188–89 (2020).

3. See Anne Alstott, *A New Deal for Old Age*, 97 B.U.L. REV. 1933, 1935 (2017); Naomi Cahn, Clare Huntington & Elizabeth Scott, *Family Law for the One-Hundred Year Life*, 132 YALE L.J. 1691, 1704–06 (2023).

Japanese term for “lonely death.”⁴ A lonely old age and death are the fate for millions of Americans as well.⁵

The Kingdom of Sand (2022), a novel by Andrew Holleran, is an exploration of the challenges facing lesbian, gay, and bisexual Americans over the age of sixty-five.⁶ Casey Parks is an openly lesbian journalist, whose journey story is told in *Diary of a Misfit* (2022).⁷ Her coming out as a lesbian in the small-town South is accompanied by the knowledge that the boy who lived across the street from her grandmother—Roy Hudgins—was assigned female at birth.⁸ Parks’s book is her detective work to uncover Roy’s life while at the same time recovering her own family ties and learning much about southern small-town life in the closet.⁹ The characters in these recent books—two aging gay men, a lesbian, and a long-deceased transgender person—reflect an important social reality.

Although substantially ignored in the family law literature, including the burgeoning literature on aging,¹⁰ older lesbian, gay, bisexual, transgender, queer, and otherwise gender nonconforming (LGBTQ+)¹¹ Americans are a significant demographic group.¹² In 2018, the Movement Advance Project and Sage (Advocacy and Services for LGBT Elders) estimated that there are around 1.1 million Americans

4. Florian Kohlbacher & Tim Tiefenbach, *The Rise of Solitary Deaths*, MAG. BRIT. CHAMBER COM. JAPAN, ACUMEN (May 2015), <https://bccjacumen.com/the-rise-of-solitary-deaths/>.

5. Ben Steverman, *Americans Face a Rising Risk of Dying Alone*, BLOOMBERG (Oct. 9, 2017, 4:00 AM), <https://www.bloomberg.com/news/articles/2017-10-09/americans-face-a-rising-risk-of-dying-alone#xj4y7vzkg>; see generally Holly Nelson-Becker & Christina Victor, *Dying Alone and Lonely Dying: Media Discourse and Pandemic Conditions*, 55 J. AGING. STUD. 100877 (2020).

6. See generally ANDREW HOLLERAN, *THE KINGDOM OF SAND* (2022).

7. See generally CASEY PARKS, *DIARY OF A MISFIT* (Knopf 2022).

8. See generally *id.*

9. See generally *id.*

10. Cf. Cahn et al., *supra* note 3, at 1713 (lengthy article on family law and aging but with one sentence referring to “LGBTQ seniors”).

11. This Article uses the broad term LGBTQ+ but will refer to LGBT persons when describing or relying on survey data which does not extend beyond LGBT persons. Most of my generalizations and proposals would apply to intersex, nonbinary, and “queer” as well as LGBT Americans.

12. MOVEMENT ADVANCEMENT PROJECT & SAGE, UNDERSTANDING ISSUES FACING LGBT OLDER ADULTS 1 (2017), <https://www.lgbtmap.org/file/understanding-issues-facing-lgbt-older-adults.pdf> [hereinafter MAP & SAGE].

over the age of sixty-five who identify as LGBT.¹³ About one in five are older LGBT persons of color.¹⁴ One-third of these older LGBT persons live at or below 200% of the federal poverty line;¹⁵ the likelihood of living in poverty is much higher for LGBT persons who are transgender, African American, or Hispanic American.¹⁶

Like Roy in *Diary of a Misfit* and the narrator and Earl in *Kingdom of Sand*, aging LGBT persons are significantly more likely to live alone than almost any other demographic group, and their old age is freighted with much greater distress and isolation than has been observed for the average American or for most other demographic classes.¹⁷ Gay men such as Earl and transgender persons such as Roy are much more likely to live and die alone than lesbian or bisexual women such as Casey Parks, who found happiness and marriage with another woman during her journey into Roy's life.¹⁸ The reasons for this distinctive status are deeply embedded in the nation's longtime hostility and persecution of sexual and gender minorities.¹⁹

"Gayby Boomers" (roughly, those born between 1946 and 1964) who realized in their teenage or college years that they were lesbian,

13. *Id.*; *Diversity and Cultural Competency*, ADMIN. FOR CMTY. LIVING (May 15, 2023), <https://acl.gov/programs/strengthening-aging-and-disability-networks/diversity-and-cultural-competency> (estimating between 1.75 and 4 million LGBT Americans over the age of 60).

14. MAP & SAGE, *supra* note 12, at 1.

15. *Id.* at 10.

16. See M.V. Lee Badgett, Laura E. Durso & Alyssa Schneebaum, *New Patterns of Poverty in the Lesbian, Gay, and Bisexual Community*, WILLIAMS INST. 4 (June 2013), <https://williamsinstitute.law.ucla.edu/wp-content/uploads/Poverty-LGB-Jun-2013.pdf>; see also Hyun-Jun Kim & Karen I. Fredriksen-Goldsen, *Disparities in Mental Health Quality of Life Between Hispanic and Non-Hispanic White LGB Midlife and Older Adults and the Influence of Lifetime Discrimination, Social Connectedness, Socioeconomic Status, and Perceived Stress*, 39:9 RSCH. AGING 991, 995 (Oct. 2017).

17. SOON KYU CHOI & ILAN H. MEYER, WILLIAMS INST., UCLA SCH. L., LGBT AGING: A REVIEW OF RESEARCH FINDINGS, NEEDS, AND POLICY IMPLICATIONS (Aug. 2016), <https://www.lgbtagingcenter.org/resources/pdfs/LGBT-Aging-A-Review.pdf> [hereinafter CHOI & MEYER] (summarizing empirical studies); SOON KYU CHOI, KRISTAL KITTLE & ILAN H. MEYER, WILLIAMS INST., UCLA SCH. L., AGING LGB ADULTS IN CALIFORNIA 11 tbl.1 (2018), <https://williamsinstitute.law.ucla.edu/wp-content/uploads/Aging-LGB-CA-Aug-2018.pdf> [hereinafter CHOI ET AL.]; see generally HOLLERAN, *supra* note 6; PARKS, *supra* note 7.

18. STEVEN P. WALLACE, SUSAN D. COCHRAN, EVA DURAZO & CHANDRA L. FORD, UCLA CTR. FOR HEALTH POL'Y RSCH., THE HEALTH OF AGING LESBIAN, GAY AND BISEXUAL ADULTS IN CALIFORNIA 2 exhibit 1 (Mar. 2011), <https://healthpolicy.ucla.edu/publications/Documents/PDF/aginglgbpb.pdf> [hereinafter WALLACE ET AL.]; CHOI ET AL., *supra* note 16, at 11 tbl.1; see generally HOLLERAN, *supra* note 6; PARKS, *supra* note 7.

19. MAP & SAGE, *supra* note 12, at 11.

gay, bisexual, transgender, or in other respects gender-nonconforming had to cope with pervasive societal homophobia, sexism, and transphobia, the legacy of which often haunts the old age of these persons.²⁰ Out of fear and shame, they typically remained in the closet about their sexual or gender identity—and most remained in the closet even after the Stonewall riots of June 1969 triggered movement by many of their age cohort to “come out” and aggressively challenge anti-queer stigmas.²¹

Closeted LGBT persons were unlikely to have life partners and highly unlikely to have raised children.²² Because marriage rights were denied to lesbian and gay, as well as many bisexual and transgender, Americans, even openly LGBT persons were much less likely to form long-term partnerships than their straight, cisgender neighbors.²³ Holleran’s earlier book, *Dancer from the Dance* (1978), suggested that many of the out-of-the-closet gay and bisexual men, especially those in New York and San Francisco, enjoyed sexual liberty without partnered commitment.²⁴ Those who did find partners often lost them to the AIDS epidemic that swept those same urban areas soon after the publication of *Dancer*.²⁵ On the other hand, AIDS caregiving and the lesbian baby boom of the 1990s fueled interest in committed relationships for this age cohort; although significantly fewer than the norm for older straight, cisgender persons, as many as half of older LGBT adults do have cohabiting partners or spouses.²⁶ But the other half do not.²⁷ Older transgender persons such as Roy Hudgins are especially prone to social

20. See Jesus Ramirez-Valles, Jessica Dirkes & Hope A. Barrett, *GayBy Boomers’ Social Support: Exploring the Connection Between Health and Emotional and Instrumental Support in Older Gay Men*, 57 J. GERONTOLOGICAL SOC. WORK 218, 219 (2014).

21. CHOI & MEYER, *supra* note 17, at 5–6.

22. MAP & SAGE, *supra* note 12, at 12.

23. *Id.* at 12 fig.7.

24. See generally ANDREW HOLLERAN, *DANCER FROM THE DANCE* (1978) (reissued with an introduction by Alan Hollinghurst, 2019).

25. *Id.*; see also Dana Rosenfeld, *The AIDS Epidemic’s Lasting Impact on Gay Men*, BRIT. ACAD. (Feb. 19, 2018), <https://www.thebritishacademy.ac.uk/blog/aids-epidemic-lasting-impact-gay-men/>.

26. See generally WILLIAM N. ESKRIDGE JR. & CHRISTOPHER RIANO, *MARRIAGE EQUALITY: FROM OUTLAWS TO IN-LAWS* (2020); MAP & SAGE, *supra* note 12, at 3; *A Survey of LGBT Americans*, PEW RSCH. CTR. (June 13, 2013), <https://www.pewresearch.org/social-trends/2013/06/13/a-survey-of-lgbt-americans/> (stating that many LGBTQ+ persons are partnered, married, or wish to be, but generally are fewer than the cisgender straight population).

27. MAP & SAGE, *supra* note 12, at 12 fig.7.

isolation.²⁸ Many lost their spouses and contact with their families after coming out and, even more, transitioning.²⁹ Indeed, for trans persons of my generation, medical professionals often advised them to end their marriages and cut previous ties in order to start life anew.³⁰

So it is that many older LGBT Americans have ended up in the same situation as *Kingdom of Sand*'s narrator and his friend Earl or Roy in *Diary of a Misfit*. All three lived alone, none had had a long-term partner or children or relatives that lived close by.³¹ Although Earl has retired from the field of sexual adventure, the narrator has sex buddies and fantasizes about other possibilities, but the novel does not suggest a deep engagement.³² Roy lived in such fear of his community that the author of *Diary* doubts he ever enjoyed a romantic relationship.³³ In 2011, a survey by the Institute for Multigenerational Health found that 60 percent of older LGBT persons felt a lack of companionship, and more than half reported that they felt isolated from others.³⁴ Such feelings were most prevalent among gay men, bisexual men, and (especially) transgender persons—but lesbian and bisexual women feel much greater isolation than straight women and men.³⁵

Kingdom of Sand is a sensitive depiction of the “shared loneliness” of the fictional narrator (born at the tail end of the Baby Boom) and Earl (born twenty years earlier).³⁶ In his eighties, largely immobile, and with swiftly declining health, Earl is a roadmap for the narrator’s own descending life arc, as he watched “what happened when old age gets its claws in you, or at least puts you to sleep in your chair, like a man overcome with carbon monoxide in a closed garage.”³⁷ Myself quite elderly and having avoided both AIDS and COVID, I read the novel with both

28. CHOI & MEYER, *supra* note 17, at 6.

29. *Id.*

30. Loree Cook-Daniels, *Transgender Aging: What Practitioners Should Know*, in *THE LIVES OF LGBT OLDER ADULTS: UNDERSTANDING CHALLENGES AND RESILIENCE* 193, 195-215 (Nancy A. Orel & Christine A. Fruhauf, eds., 2015).

31. *See generally* HOLLERAN, *supra* note 6; PARKS, *supra* note 7.

32. *See* HOLLERAN, *supra* note 6, at 253.

33. *See* PARKS, *supra* note 7, at 29.

34. KAREN I. FREDRIKSEN-GOLDSSEN, HYUN-JUN KIM, CHARLES A. EMLET, ANNA MURACO, ELENA A. ERO SHEVA, CHARLES P. HOY-ELLIS, JAYN GOLDSSEN & HEIDI PETRY, *THE AGING AND HEALTH REPORT: DISPARITIES AND RESILIENCE AMONG LESBIAN, GAY, BISEXUAL, AND TRANSGENDER OLDER ADULTS* 28 (2011) [hereinafter FREDRIKSEN-GOLDSSEN ET AL.].

35. *Id.*

36. *See* HOLLERAN, *supra* note 6, at 117.

37. *See id.* at 122.

recognition and sadness. Although both characters cope intelligently with their situations and neither is afflicted with the financial destitution that often accompanies old age, their end-of-lives leave much to be desired.³⁸ As Holleran puts it, “growing old, they say, is not for sissies, and neither is living alone.”³⁹

To begin with, aging alone is perilous to one’s health and well-being. Medical experts tell us that regular social interaction and cohabiting with a congenial partner are good for your physical as well as mental health.⁴⁰ Their relative isolation may help explain why older LGBT Americans are more likely to be depressed, extremely anxious or psychologically distressed, significantly disabled, obese, afflicted with high blood pressure and heart disease, compared with older heterosexual and cisgender adults.⁴¹ In *Kingdom of Sand*, Earl’s declining health and mental state are associated with his increasing isolation; each contributes to the other in a swiftly descending spiral.⁴² At the end, Earl succumbs to cancer, but others face even greater end-of-life sadness.⁴³ Impoverished, Roy Hudgins spent his last years alone in a nursing home that refused to accommodate his medical needs; no one visited him in that institution, not even his neighbors Mark and Cheryl King.⁴⁴ Almost two-fifths of older LGBT Americans (including almost three-quarters of older transgender persons) report seriously considering suicide.⁴⁵

Isolation without regular social interaction has more tangible risks, for it renders the elderly person more vulnerable to fatal accidents inside the home, to delays in receiving emergency medical care, and to ineffective care in a hospital.⁴⁶ When Earl enters the hospital to treat his last, ultimately fatal illness, the narrator is frustrated that he, as a friend, cannot provide comfort or protection for Earl.⁴⁷ (Understaffed hospitals tend to ignore the patients who have no one to advocate for them, as I

38. *See id.* at 96.

39. *Id.*

40. *See* CHOI & MEYER, *supra* note 17, at 25–26; FREDRIKSEN-GOLDSSEN ET AL., *supra* note 34, at 49–50; WALLACE ET AL., *supra* note 18, at 5 exhibit 3.

41. CHOI & MEYER, *supra* note 17, at 25–28; FREDRIKSEN-GOLDSSEN ET AL., *supra* note 34, at 49; WALLACE ET AL., *supra* note 18, at 9 exhibit 3.

42. HOLLERAN, *supra* note 6, at 142.

43. *Id.* at 233.

44. PARKS, *supra* note 7, at 146, 164.

45. FREDRIKSEN-GOLDSSEN ET AL., *supra* note 34, at 27.

46. *Id.* at 49–51.

47. HOLLERAN, *supra* note 6, at 230.

learned from sitting with and advocating for my late Mother while nurses ignored other patients [whose cause I sometimes took up].) “Who was I to Earl? The nurses could refuse me information,” and ignore or even expel the friend, “because I was not a blood relative” or a spouse.⁴⁸ There was no one to advocate for Roy Hudgins in his nursing home, whose neglect contributed to his death after a serious fall.⁴⁹

Especially important, in my view, is that aging alone slowly strangles one’s emotional life. Humans are social animals, and even the introverts among us need personal interaction to flourish. One devastating cost of the closet is that it estranges LGBT people not only from their families and relatives, but also from others who could become friends, allies, lovers, and partners.⁵⁰ The ensuing estrangement and anger are psychologically destructive to the closeted or self-stigmatizing minority person and do society no good, either.⁵¹ As one’s arc of life is on the downswing, the existential anguish of such estrangement can be particularly acute.⁵² Holleran’s narrator laments that he is one of those “people who don’t come first in anyone’s life.”⁵³ He follows that observation with an account of a “recurring nightmare in which I found myself standing in front of a door I knew I had to open and walk through, though I did not know what I would find on the other side: a room full of familiar faces, or nothing.”⁵⁴

Even lonelier was the life of Roy Hudgins.⁵⁵ In the culmination of her investigation, Casey Parks finally gained access to Roy’s personal diaries that had been entrusted to his neighbors Mark and Cheryl.⁵⁶ The most poignant passage is the following:

I’m the town misfit, and I live here all alone
 I’ve got no friends or family, nothing to call my own
 I’m always broke and hungry, and lovely as can be
 I’m the town misfit, nobody cares for me
 * * *

When my life on earth is over, and it’s time for me to die

48. *Id.* at 232.

49. PARKS, *supra* note 7, at 144.

50. See FREDRIKSEN-GOLDSSEN ET AL., *supra* note 34, at 10.

51. *See id.* at 19.

52. *See id.*

53. HOLLERAN, *supra* note 6, at 134.

54. *Id.* at 135.

55. PARKS, *supra* note 7, at 208–09.

56. *Id.* at 334.

No one here will miss me. There will be no one to cry.
If I make it up to heaven, will I then find a friend?
Or will I still be a misfit, with no place to fit in?

Roy entitled the poem "The Town Misfit."⁵⁷

While family law and its commentators usually offer an excessively cheery depiction of old age, the account above veers too far in the other direction and requires correction. Although I found *Kingdom of Sand* sad and depressing, the characters cope reasonably well with old age, in part because they enjoy financial comfort, sufficient social support, and mental stimulation.⁵⁸ Until he dies at the ripe age of 88, Earl lives in his own home; he is attended by his handyman and is surrounded by the music he loves.⁵⁹ The narrator kvetches about how culturally arid Hawthorne, Florida is and feels left out of the Great Chain of Being, but he enters old age with a robust income, lives in the house he was raised in and his beloved mother died in, and maintains an active fantasy life.⁶⁰ Armed with fewer resources and friends, Roy Hudgins also lived a productive independent life in his own home, until broken by his experiences in the nursing home.⁶¹ The MAP/Sage study found that "LGBT elders show remarkable resilience given that many of their life experiences as young people were in a time when being LGBT was less accepted—or worse, criminalized."⁶²

Like the characters in *Kingdom of Sand* and perhaps even *Diary of a Misfit*, most LGBT Americans, including many who live alone, cope reasonably well with old age—but on average they cope differently than straight, cisgender Americans.⁶³ While the latter group typically relies on marital and biological ties (i.e., spouses and children) for their continued well-being, aging persons in the former group are more likely to rely on what Kath Weston calls "families we choose:" friends, partners, former lovers, neighbors, paid professionals, and LGBTQ-friendly churches.⁶⁴

57. *Id.* at 347–48.

58. See HOLLERAN, *supra* note 6, at 258.

59. See *id.* at 61–64.

60. See *id.*

61. See PARKS, *supra* note 7, at 241.

62. See MAP & SAGE, *supra* note 12, at 5.

63. See *id.* at 11; see generally HOLLERAN, *supra* note 6; PARKS, *supra* note 7.

64. See generally KATH WESTON, FAMILIES WE CHOOSE: LESBIANS, GAYS, KINSHIP (1991), brilliantly reviewed by Ellen Lewin, *Lesbian and Gay Kinship: Kath Weston's "Families We Choose" and Family Anthropology*, 18 SIGNS 974 (1993), and

In *Kingdom of Sand*, for example, the narrator and Earl enjoy a friendship that provides for each man some companionship, enjoyment of mutual activities (mainly, watching movies on Earl's jumbo TV), and the existential joy of not being alone.⁶⁵ When the narrator would pass Earl's house, "if Earl's lights were on, I was not alone, there was no reason to be afraid of the dark, of the town, of death itself—even though there weren't many lamps on."⁶⁶ "[W]hen one comes to the end you have to find help where you can—the aide in a nursing home, the man who used to fix your screens," and so it is that Earl's primary caregiver at the end of his life is his handyman.⁶⁷ Trusty John evolves from Earl's Mr. Fixit to his driver, then his chef and butler, and finally his heir and the guardian of Betty, the hound who survives Earl.⁶⁸

The narrator and Earl are gay men whose old age is lonely—but most sexual and gender minorities face an even bleaker old age. Lesbian and bisexual women over age sixty-five are much less likely to have even the modest financial resources commanded by the narrator, and LGBTQ persons of color are even less well-off financially.⁶⁹ Transgender persons such as Roy Hudgins are subject to more pervasive discrimination and social humiliation than these older white gay men.⁷⁰ As many as 14 percent of all older gay and bisexual men are HIV-positive; this subgroup faces more severe health challenges as well as continuing discrimination.⁷¹

For most older LGBTQ+ Americans, the social support system is not nearly as good as it is for the gay men in *Kingdom of Sand*.⁷² And that has serious consequences for their end of life. **First**, their physical health care needs are not met, and they are at great risk of unnecessary injury and premature death.⁷³ **Second**, they are likely to suffer emotionally and are more likely to be depressed and consider suicide.⁷⁴ **Third**, even the elementary details of what Liz Emens calls "life administration" fall

discussed in WILLIAM N. ESKRIDGE JR., *GAYLAW: CHALLENGING THE APARTHEID OF THE CLOSET* (1999)).

65. See HOLLERAN, *supra* note 6, at 80.

66. *Id.* at 137.

67. *Id.* at 218.

68. *See id.*

69. See MAP & SAGE, *supra* note 12, at 2.

70. *See id.* at 4.

71. See FREDRIKSEN-GOLDSSEN ET AL., *supra* note 34, at 23–24; *see also* CHOI & MEYER, *supra* note 17, at 27–28.

72. See CHOI & MEYER, *supra* note 17, at 19.

73. See MAP & SAGE, *supra* note 12, at 19.

74. See CHOI & MEYER, *supra* note 17, at 25.

by the wayside, as their lives slide into chaos and confusion.⁷⁵ Unfortunately, American family law and its scholars have pretty much ignored this significant minority group.⁷⁶

II. Potential Legal Assistance: New Forms of Relationship Recognition

As for other older Americans, the LGBTQ+ elderly rely on a complicated social safety net that includes loved ones and neighbors; the financial support of pensions, Social Security, and Medicare or Medicaid; and their own resourcefulness.⁷⁷ What sets them apart is not only the ongoing mental and physical health consequences of homophobia, sexism, and transphobia, but also a greater vulnerability than other cohorts and continued exclusion from portions of the social safety net that others enjoy.⁷⁸

Consider some examples of discrimination or exclusion that have harmed older LGBTQ+ Americans:

- Until 2013, Social Security and Medicare did not protect married or partnered LGBT families; Medicaid did not protect them until 2015.⁷⁹ Hence, spousal survivors typically enjoy lower or no benefits, and surviving unmarried partners enjoy no benefits whatsoever.⁸⁰ In response to a class action judgment in 2020, the Social Security Administration has for a brief period opened up survivors benefits to those who can prove they would have been married and qualified for benefits, had their states not unconstitutionally refused to recognize their unions when their partners died.⁸¹
- Many gay, lesbian, and bisexual persons who served their country in the armed forces but received less-than-honorable discharges before 2011, pursuant to anti-gay executive orders and the 1993 Don't Ask, Don't Tell statute, do not have access

75. See generally ELIZABETH EMENS, LIFE ADMIN: HOW I LEARNED TO LESS, DO BETTER, AND LIVE MORE 3 (2019).

76. See Cahn et al., *supra* note 3, at 1742–43.

77. See FREDRIKSEN-GOLDSSEN ET AL., *supra* note 34, at 5.

78. See CHOI & MEYER, *supra* note 17, at 12.

79. See *id.* at 8–9.

80. See *id.*

81. See *Thornton v. Comm'r Soc. Sec.*, 570 F. Supp. 3d 1010, 1019 (W.D. Wash. 2020) (complying with and going beyond the Court's order, the Commissioner opened the process for survivors to demonstrate that they would have qualified for benefits but for their states' discriminatory marriage laws); see also *Notice Of Class Action Order: Thornton v. Commissioner of Social Security*, SOC. SEC. (Oct. 15, 2021), <https://www.ssa.gov/thornton/> [hereinafter *Notice of Class Action Order: Thornton v. Comm'r*].

to veterans' benefits.⁸² Transgender persons were not eligible to serve based upon departmental memoranda that were abrogated under President Obama and reinstated under President Trump; under President Biden they have been terminated one final time.⁸³ Veterans' benefits can include caregiving expenses for qualified persons and their families.⁸⁴

- Veterans' benefits do not cover medical treatment relating to gender confirmation.⁸⁵ After a recent update, Medicare may provide such coverage, but there is no national policy and its availability may depend on whether it is deemed medically necessary by the person's plan.⁸⁶ As administered by a large majority of states, Medicaid does not cover such treatment and procedures, even if medically necessary.⁸⁷
- The Older Americans Act of 1965 provides funding for local programs to help the elderly with the "greatest economic or social need."⁸⁸ The LGBTQ+ elderly have not been so designated.⁸⁹
- Most older Americans realize they may need care in an assisted living facility or nursing home, but LGBTQ+ elderly are discouraged from that option by fears of discrimination—fears that have been borne out by surveys documenting anti-LGBTQ+ discrimination in admission to such facilities, verbal

82. The Biden Administration is trying to rectify this problem. See Kayla Williams, *Tenth Anniversary of the Repeal of Don't Ask, Don't Tell*, VA NEWS (Sept. 20, 2021), <https://news.va.gov/94920/tenth-anniversary-of-the-repeal-of-dont-ask-dont-tell/>.

83. *Trans Troops Return to Era of 'Don't Ask, Don't Tell' as Trump Policy Takes Effect*, GUARDIAN (Apr. 12, 2019, 8:44 PM), <https://www.theguardian.com/us-news/2019/apr/12/transgender-ban-military-trump-take-effect-dont-ask-dont-tell>; Gautam Raghavan, *10 Years Later: Looking Back at the Repeal of "Don't Ask, Don't Tell"*, WHITE HOUSE (Sept. 20, 2021) <https://www.whitehouse.gov/ppo/briefing-room/2021/09/20/10-years-later-looking-back-at-the-repeal-of-dont-ask-dont-tell/>.

84. See *The Program of Comprehensive Assistance for Family Caregivers*, U.S. DEPT VETERANS AFF. (Feb. 22, 2023), <https://www.va.gov/family-member-benefits/comprehensive-assistance-for-family-caregivers/>.

85. See MAP & SAGE, *supra* note 12, at 16–17.

86. See *id.*; see also Center for Medicare & Medicaid Servs., HHS, Medicare and Medicaid Programs: Changes to the Hospital and Critical Access to the Hospital Conditions of Participation to Ensure Visitation Rights for All Patients, 75 Fed. Reg. 70,831 (Nov. 19, 2010).

87. See MAP & SAGE, *supra* note 12, at 16; see Medicare and Medicaid Programs: Changes to the Hospital and Critical Access Hospital Conditions of Participation to Ensure Visitation Rights for All Patients, 75 Fed. Reg. 70,831 (Nov. 19, 2010) (to be codified at 42 C.F.R. pts. 482, 485).

88. See 42 U.S.C. § 3001 et seq. (2020); see also CONG. RSCH SERV., OLDER AMERICANS ACT: OVERVIEW AND FUNDING 5 (June 23, 2022) [hereinafter OLDER AMERICANS ACT: OVERVIEW].

89. See OLDER AMERICANS ACT: OVERVIEW, *supra* note 88, at 5.

and even physical harassment, restrictions on visitors, and denial of basic services or medical care.⁹⁰

- Since 2011, hospitals receiving Medicare or Medicaid funds are required to allow visitors designated by patients and are barred from discriminating because of sexual orientation or gender identity.⁹¹ In practice, this mandate has not been completely implemented. Unless the patient is married or files a form with the hospital, their domestic partner or best friend has no rights to assist or make medical decisions if the patient is incapacitated.⁹²

These and other burdens have long been ignored or minimized, but the Biden Administration's Social Security Administration and Department of Veterans Affairs have responded positively to these inequities.⁹³

Moreover, President Biden's 2022 Executive Order on Advancing Equality for LGBTQI Individuals directed the Secretary of Health & Human Resources to "address discrimination, social isolation, and health disparities faced by LGBTQI+ older adults," including discrimination by long-term care facilities and exclusion from the Older Americans Act.⁹⁴ Within weeks, HHS issued a notice of proposed rulemaking that would interpret the Affordable Care Act to require nondiscrimination against LGBTQ persons.⁹⁵ Initiatives such as those by the Biden Administration and by state agencies are very important and deserve full support.

This Article will focus on a modest contribution that family law can make for the benefit of aging LGBTQ+ Americans. I start with a word about the evolution of family law itself.

Family law's traditional focus on lifetime marriage between one man and one woman had no room for most LGBTQ+ Americans, except

90. MAP & SAGE, *supra* note 12, at 17.

91. Medicare and Medicaid Programs: Changes to the Hospital and Critical Access Hospital Conditions of Participation to Ensure Visitation Rights for All Patients, 75 Fed. Reg. 70,831, 70833 (Nov. 19, 2010) (to be codified at 42 C.F.R. 482, 485).

92. See Garrett Riou, *Hospital Visitation and Medical Decision Making for Same-Sex Couples*, CAP (Apr. 15, 2014), <https://www.americanprogress.org/article/hospital-visitation-and-medical-decision-making-for-same-sex-couples/>.

93. See *Notice of Class Action Order: Thornton v. Comm'r*, *supra* note 81; see also Williams, *supra* note 82.

94. Exec. Order No. 14,075, 87 Fed. Reg. 37,189, 37,193 (June 15, 2022).

95. Nondiscrimination in Health Programs and Activities, 87 Fed. Reg. 47,824, 47,824, 47,931 (Aug. 4, 2022) (to be codified at 42 C.F.R. pts. 438, 440, 457, 460 and 45 CFR pts. 80, 84, 92, 147, 155, 156).

as closeted spouses in unhappy traditional marriages.⁹⁶ But in the last century family law has expanded spousal choice within marriage, abandoned marriage's monopoly on recognized relationships, opened up marriage rules to contract-based modification, and made it easier to dissolve marriage and other legal relationships.⁹⁷ In short, American family law has moved away from an inflexible morals-based marital regime toward a pluralistic choice-based regime.⁹⁸ This revolution in American family law reflects our recognition that the best role for government is to respect the relationship choices of adults.⁹⁹ Rather than criminalizing disapproved relationships and forcing romantic partners into a traditional mold, till death do they part, government seeks to facilitate choice through a more flexible family law regime grounded on consent and mutual support rather than blood or status.¹⁰⁰

For LGBTQ+ Americans, the biggest change is that procreative civil marriage no longer enjoys a legal monopoly over intimate relationships.¹⁰¹ Traditionally, sexual relations that were not both marital and procreative were felonies in America.¹⁰² Fornication and consensual oral sex are no longer crimes, and adultery is at most a misdemeanor; birth control is legal.¹⁰³ Hence, as a matter of law, sexual intercourse no longer has to be marital, and no longer has to be procreative.

Not only has civil marriage lost its monopoly on sexual intercourse but the state now recognizes a menu of relationship options,

96. William N. Eskridge Jr., *Family Law Pluralism: The Guided-Choice Regime of Menus, Default Rules, and Override Rules*, 100 GEO. L.J. 1881, 1899–1901 (2012) [hereinafter Eskridge, *Family Law Pluralism*].

97. See ANDREW J. CHERLIN, *THE MARRIAGE-GO-ROUND: THE STATE OF MARRIAGE AND THE FAMILY IN AMERICA TODAY* 29–32 (2009); Herma Hill Kay, *From the Second Sex to the Joint Venture: An Overview of Women's Rights and Family Law in the United States During the Twentieth Century*, 88 CALIF. L. REV. 2017, 2019 (2000); Carl E. Schneider, *Moral Discourse and the Transformation of American Family Law*, 83 MICH. L. REV. 1803, 1847 (1985) (describing the transformation of family law in terms of abandonment of morals-based reasoning and adoption of psychology-based reasoning).

98. Eskridge, *Family Law Pluralism*, *supra* note 96, at 1893–96.

99. *Id.* at 1894.

100. *Id.* at 1928–29.

101. See *id.* at 1900.

102. See generally WILLIAM N. ESKRIDGE JR., *DISHONORABLE PASSIONS: SODOMY LAWS IN AMERICA, 1861–2003* (2008) [hereinafter ESKRIDGE, *DISHONORABLE PASSIONS*] (describing the historical trajectory from non-marital and/or non-procreative sex as felonies to state respect for nontraditional sexual relations and unions).

103. See RICHARD A. POSNER & KATHARINE B. SILBAUGH, *A GUIDE TO AMERICA'S SEX LAWS*, 155–206 (1996) (updated by ESKRIDGE, *DISHONORABLE PASSIONS*, *supra* note 102, at 483).

each regulated with a bundle of legal benefits and duties.¹⁰⁴ Sexual cohabitation is now legal, and most jurisdictions afford cohabitants some protections and basic rights.¹⁰⁵ Some states have created statewide civil unions or domestic partnerships and have endowed those institutions with the same legal rights and responsibilities of marriage, but not the name.¹⁰⁶ Most relevant for my purposes is that a handful of states have created a voluntary form of family-lite association for “beneficiaries.”¹⁰⁷

The AIDS epidemic motivated many gay and bisexual men—men like the Gayby Boomers in *Kingdom of Sand*—to form caregiving relationships with their dying partners.¹⁰⁸ In California, this demand generated municipal “domestic partnership” legislation in the 1980s.¹⁰⁹ Under those laws, the registered domestic partners of municipal employees could be added to their health insurance, and both partners were assured hospital visitation rights.¹¹⁰ Because statewide “gay marriage” was politically impossible, gay and lesbian activists focused on domestic partnership laws at the city level—and by the end of the millennium domestic partners had been recognized in Seattle (1989), San Francisco (1990), New York City (1990, later expanded), Washington D.C. (1992, later expanded), Atlanta (2000), Los Angeles (County, 1999; City, 1998), Boston (1993), Philadelphia (1998), Denver (1999), and dozens of counties and other cities after 2000.¹¹¹

In 1991, lawsuits challenging same-sex marriage bars were filed in the District of Columbia and Hawaii. Surprisingly, one appeals judge ruled in favor of the plaintiffs in D.C. (but in dissent),¹¹² and a Hawaii

104. See generally WILLIAM N. ESKRIDGE JR., *EQUALITY PRACTICE: CIVIL UNIONS AND THE FUTURE OF GAY RIGHTS* (2002) (providing a detailed analysis of the emerging menu of state-recognized relationship options) (updated in ESKRIDGE & RIANO, *supra* note 26, at 718–19).

105. ESKRIDGE & RIANO, *supra* note 26, at 717–719.

106. *Id.*

107. *Id.* at 719.

108. See *id.* at 629.

109. See *id.* at 62–65; S. F., CAL. ADMIN. CODE, § 62.1 (1990).

110. See ESKRIDGE & RIANO, *supra* note 26, at 62–69.

111. See *id.* at 65–70, 327; see e.g., SEATTLE, WASH., MUN. CODE § 4.30.020 (1989); S. F., CAL., ADMIN. CODE § 62.1 (1990); N.Y.C., N.Y., N.Y. COMP. CODES R. & REGS. TIT. 9, § 2500.2 (1990); D.C. CODE § 32-702 (1992); ATLANTA, GA., ORDINANCE 94-133 (2000), § 3; L. A. COUNTY, CAL., CAL. ADMIN. CODE § 2.210.010 (1999); BOS., MASS. MUN. CODE CH. 12, § 12-9A.1 (1993); PHILA., PA., PHILA. CODE § 17-1902 (2011); DENVER, COLO., CODE OF ORDINANCES § 28-200 (1999).

112. *Dean v. District of Columbia*, 653 A.2d 307, 309 (App. D.C. 1995) (Ferren, J., dissenting).

trial judge struck down the marriage bar in Hawaii.¹¹³ While the Hawaii judgment was on appeal, a tremendous backlash motivated the Clinton-Gingrich regime to pass the Defense of Marriage Act in 1996 and frightened the Hawaii Democratic Party into placing the marriage issue on the 1998 ballot.¹¹⁴ Almost 70% of the voters in the tolerant Aloha State supported a state constitutional amendment allowing the Legislature to limit civil marriage to one man, one woman.¹¹⁵

Paired with the resolution placing the marriage amendment on the Hawaii ballot, however, was the Reciprocal Beneficiaries Act of 1997.¹¹⁶ At the same time the Hawaii Legislature was advancing a proposal to reaffirm the traditional limit of marriage to different-sex couples, it acknowledged that “there are many individuals who have significant personal, emotional, and economic relationships with another individual yet are prohibited by such legal restrictions from marrying.”¹¹⁷ Hence, the Legislature determined that “certain rights and benefits presently available only to married couples should be made available to couples comprised of two individuals who are legally prohibited from marrying one another.”¹¹⁸ Marriage equality supporters hated the new law because it was, at best, marriage-lite, a second-class version of marriage rights, and because the law’s premise seemed to be nonsexual relationships.¹¹⁹

For that reason, few Hawaiian couples registered as reciprocal beneficiaries, but it was an important innovation for some of the reasons the same-sex marriage supporters felt betrayed.¹²⁰ To begin with, the law valorized relationships of reciprocity.¹²¹ The law took account of the fact that lesbian, gay, and transgender couples cared for one another, and that their relationships were not only legal (Hawaii had repealed its consensual sodomy law in 1972) but also valuable.¹²² That close relatives and even friends could be reciprocal beneficiaries

113. *Baehr v. Miike*, CIV. No. 91-1394, 1996 WL 694235, at *22 (Haw. Cir. Ct. Dec. 3, 1996).

114. See David Orgon Coolidge, *The Hawai'i Marriage Amendment: Its Origins, Meaning and Fate*, 22 U. HAW. L. REV. 19, 20, 38 (2000).

115. Eskridge & Riano, *supra* note 26, at 104.

116. 1997 Haw. Sess. Laws 1211. The legislative history of the law is set forth in ESKRIDGE & RIANO, *supra* note 26, at 94–105.

117. HAW. REV. STAT. §572C-2 (1997).

118. *Id.*

119. ESKRIDGE & RIANO, *supra* note 26, at 105.

120. *Id.*

121. See *id.* at 104–105.

122. See *id.* at 108 (discussing 1972 Haw. Sess. Laws 90).

suggested that this institution was aimed at caregiving more than sexual intimacy.¹²³ That incurred the anger of same-sex marriage advocates but renders it more relevant today for unmarried persons of all orientations and identities who are growing old alone.¹²⁴

The 1997 law assured reciprocal beneficiaries a few dozen important legal rights.¹²⁵ Some of the reciprocal rights of special interest to older persons would include inclusion in some “family coverage health benefit plan[s]”; a requirement that reciprocal beneficiaries have “the same rights as a spouse with respect to [hospital] visitation and making health care decisions for the patient”; recognition of joint ownership of property; entitlement to “family leave” to care for one’s reciprocal beneficiary; rights to inherit in the event a beneficiary dies without a will; entitlement to bring a wrongful death action for loss of the loved one due to negligence of a third party; rights to funeral leave and death benefits enjoyed by spouses; the right to demand a post-mortem examination and to make an anatomical gift after a beneficiary’s death; the right of a beneficiary who is hospitalized upon order of a doctor to call their reciprocal beneficiary and for the beneficiary to be treated as a “relative” for purposes of a commitment hearing or personal counseling and therapy.¹²⁶

In 2000, the Vermont Legislature created a similar institution—also called “reciprocal beneficiaries” and also limited to couples who were ineligible to marry—when it enacted legislation recognizing “civil unions” for same-sex couples.¹²⁷ In 1999, California adopted a statewide “domestic partnership” regime in lieu of marriage for same-sex couples; in the next four years, the Legislature added benefits and protections until in 2003 it was the virtual equivalent of marriage.¹²⁸ Legislatures in Maine, Maryland, and Wisconsin created modest “domestic partnership” regimes similar to reciprocal beneficiaries in Hawaii and Vermont.¹²⁹

123. *Id.* at 105.

124. *See id.*

125. *See id.* at 104–05.

126. 1997 Haw. Sess. Laws 1211.

127. 2000 Vt. Acts & Resolves 91.

128. ESKRIDGE & RIANO, *supra* note 26, at 156–57.

129. An Act To Promote the Financial Security of Maine’s Families and Children, 2004 Me. Laws 1579 (codified in various parts of Me. Laws) (new institution of “registered domestic partners”); 2009 Md. Laws ch. 602; 2008 Md. Laws chs. 590, 599 (new institution of “domestic partnership”); Wis. Stat. § 770 (2011) (new institution of “domestic partnership”).

In May 2004, Massachusetts became the first state to issue valid marriage licenses to same-sex couples¹³⁰—but the second would not come until 2008.¹³¹ As in the 1990s, there was a nationwide legal response to the marriage equality movement.¹³² The Bush Administration unsuccessfully supported a Federal Marriage Amendment that would have constitutionalized DOMA.¹³³ With much greater success, traditional marriage groups in 2004 and 2006 won dozens of ballot initiatives to amend state constitutions to bar same-sex marriages and (for most such initiatives) civil unions and (for a few states) domestic partnerships.¹³⁴

One such state was Colorado.¹³⁵ In 2006, Focus on the Family, domiciled in the state, won a ballot initiative to amend the state constitution to bar same-sex marriages.¹³⁶ Seeking middle ground, the Gill Action Fund had supported a parallel initiative to recognize civil unions, but their initiative narrowly lost.¹³⁷ Gill's Ted Trimpa and Pat Steadman of Equal Rights Colorado devised a new institution, "designated beneficiaries."¹³⁸ With bipartisan support, acquiescence from the Conference of Catholic Bishops, and muted opposition from Focus on the Family, the Designated Beneficiaries Agreement Act passed the Legislature and was signed into law on April 9, 2009.¹³⁹

As with reciprocal beneficiaries, designated beneficiaries can be related to one another and must not be married; sex is irrelevant, so the institution is available to unmarried straight, gay, bisexual, transgender, nonbinary, or queer persons over the age of 18.¹⁴⁰ At the option of the participants, designated beneficiaries enjoy important rights or protections under Colorado law, including those involving (1) joint interests in real and personal property, (2) trust benefits, (3) the

130. ESKRIDGE & RIANO, *supra* note 26, at 519.

131. *Id.* at 282.

132. *Id.* at 175.

133. *See id.* at 256–60.

134. *Id.* at 273–75.

135. *See id.* at 328–29.

136. *Id.* at 331.

137. *Id.* at 330–31.

138. *Id.* at 332.

139. *Id.*; H.B. 09-1260, 67th Gen. Assemb., Reg. Sess. (Colo. 2009); 2009 Colo. Sess. Laws 428; *see* COLO. REV. STAT. § 15-22-102(d)(2023) (describing the legislative purpose), & COLO. REV. STAT. § 15-22-105(3)(2023) (listing rights and responsibilities of designated beneficiaries).

140. *See* COLO. REV. STAT. § 15-22-104 (2023) (defining the requirements for a designated beneficiary agreement).

right to receive benefits from retirement or pension plans, (4) life and health insurance benefits, (5) priority for appointment as a guardian or personal representative, (6) hospital or nursing home visitation rights, (7) the right to file a complaint for wrongful acts by a nursing home, (8) the right to be a surrogate decisionmaker for medical care decisions, (9) notice of withholding of life-sustaining procedures for one's partner, (10) the right to challenge the validity of the partner's declaration as to medical treatment, (11) agency for making or revoking anatomical gifts, (12) the right to inherit if the partner dies without a will, (13) standing to receive benefits from the state worker's compensation program, (14) standing to sue for wrongful death, and (15) the right to dispose of the partner's last remains.¹⁴¹ The statute includes a form that the parties complete, with each party designating which rights they choose.¹⁴²

Given its origin in the campaign for recognition of same-sex relationships, Colorado's institution of designated beneficiaries has been overshadowed in that state by its 2013 civil unions statute¹⁴³ and its recognition of marriage equality by judicial decree in 2014.¹⁴⁴ I am deeply disappointed that state and local governments have not made older Coloradans aware of this institution, for it offers an off-the-rack legal regime that people can enter without the expense of lawyers but with assurance that they are creating legal benefits and responsibilities that are potentially useful and even life-saving for older LGBTQ+ persons like Roy Hudgins in *Diary of a Misfit* or the narrator and Earl in *Kingdom of Sand*.

First, a designated beneficiary agreement provides off-the-rack rules for surrogate decisionmakers, and it does not require the elderly to retain lawyers and do other paperwork.¹⁴⁵ For married couples, your spouse is the presumptive decisionmaker if you are incapacitated and cannot make medical decisions or provide informed consent for life-saving procedures.¹⁴⁶ Your spouse has standing to challenge medical decisions or documents purporting to direct medical care at the end of

141. COLO. REV. STAT. § 15-22-106 (2023).

142. *Id.*

143. See Colorado Civil Union Act, S.B. 13-011, 69th Gen. Assemb., Reg. Sess. (Colo. 2013).

144. Burns v. Hickenlooper, No. 14-cv-01817-RM-KLM, 2014 WL 3634834, at *5 (D. Colo. July 23, 2014), stayed pending appeal (lifted Oct. 7, 2014).

145. COLO. REV. STAT. § 15-22-106 (2023).

146. COLO. REV. STAT. § 15-18.5-104 (2023).

life.¹⁴⁷ If you die, your spouse has presumptive authority to arrange for your funeral and the donation of parts of your body to help others.¹⁴⁸ Designated beneficiaries have all these spousal rights.¹⁴⁹ All of these surrogate decision-making rights can be trumped by valid documents¹⁵⁰—but documents very few Americans have created.¹⁵¹

Second, a designated beneficiary agreement facilitates a process whereby the elderly person can negotiate a deal with a caregiver to provide daily care etc. in return for being the automatic heir, joint property owner, and/or beneficiary after death.¹⁵² In short, the statute and its standard form allow do-it-yourself deals that benefit the aging person and the caregiver. In *Kingdom of Sand*, Earl changes his will to leave his house to John, the handyman-caregiver.¹⁵³ Many Americans do not have wills;¹⁵⁴ a designated caregiver agreement can efficiently (i.e., without the expense of a lawyer) facilitate such arrangements.¹⁵⁵

Third, a designated beneficiary agreement can vest the friend, relative, or caregiver with legal status to assure access to the aging LGBTQ+ person in a hospital or nursing home and information from those institutions, as well as legal standing to press complaints against nursing homes.¹⁵⁶ More generally, such an agreement can give the aging person some assurance that they have someone whom they can depend on and who will stand up for them in dealing with medical institutions and other third parties.¹⁵⁷ In *Diary of a Misfit*, Roy's neighbor Mark King might have played this role if there had been a legal mechanism available.¹⁵⁸ He was an uneven caretaker of Roy's diaries but is depicted as a helpful and decent ally to Roy.¹⁵⁹

147. *Id.*

148. COLO. REV. STAT. § 15-19-106 (2023).

149. *See id.*

150. *See id.*

151. Nicole C. Berg, *Designated Beneficiary Agreements: A Step in the Right Direction for Unmarried Couples*, 2011 UNIV. ILL. L. REV. 267, 289 (2011).

152. *See* Adam Hofri-Winogradow & Richard L. Kaplan, *Property Transfers to Caregivers: A Comparative Analysis*, 103 IOWA L. REV. 1997, 1999 (2018).

153. HOLLERAN, *supra* note 6, at 217.

154. *See* Berg, *supra* note 151, at 289.

155. *See* COLO. REV. STAT. § 15-22-106 (2023).

156. *See id.*

157. *See generally id.* (providing a list of rights and protections offered by a designated beneficiary agreement).

158. *See* PARKS, *supra* note 7, at 139.

159. *See generally id.* at 149–55.

These are potential virtues of the Colorado approach—but its statutory scheme was not designed for older persons in the twilight of their lives.¹⁶⁰ Consider some limitations.

First, designated beneficiary agreements can be terminated by either party, and neither party has fiduciary duties.¹⁶¹ Most caregiving arrangements work fine when the parties know one another and have a preexisting familial relationship or friendship, such as that between Earl and John.¹⁶² But such agreements leave room for strategic behavior and cheating in those relationships, especially when there are not social or legal guardrails or monitors.¹⁶³ Thus, once they secure inheritance rights, caregivers might neglect or even abuse the older person. Or the older person might secretly create a will that excludes the caregiver from promised inheritance; under Colorado law, wills supersede the terms of the designated beneficiary agreement.¹⁶⁴

Second, these designated beneficiary agreements are probably most useful for aging persons with modest incomes who cannot or do not want to pay for a lawyer—but they are less useful for aging persons in poverty, such as Roy Hudgins.¹⁶⁵ Because of race, sex, sexual orientation, and/or gender identity discrimination, a disproportionate number of LGBTQ+ seniors are destitute.¹⁶⁶ They may certainly benefit from having surrogate decisionmakers and friends who can have access to them in a hospital or nursing home, and if they are lucky their beneficiary can help them with Medicaid or Medicare paperwork, but their biggest problem may be lack of resources.¹⁶⁷

Third, these designated beneficiary agreements remain obscure.¹⁶⁸ Few states have created such an institution, and legislators are no longer motivated to replicate the Colorado statute, which was a compromise between an insistent marriage equality movement and

160. See COLO. REV. STAT. § 15-22-106 (2023).

161. See generally *id.*

162. HOLLERAN, *supra* note 6, at 154.

163. See *Caregivers Can Provide Undue Influence on an Elderly Person*, GOLDMAN, MONAGHAN, THAKKAR & BETTIN, P.A. (Oct. 16, 2020), <https://www.hmtlaw.com/blog/2020/10/caregivers-can-provide-undue-influence-on-an-elderly-person/>.

164. See COLO. BAR. ASS'N, COLORADO'S DESIGNATED BENEFICIARY AGREEMENT ACT 1 (Jan. 2012), https://www.cobar.org/Portals/COBAR/Repository/publicDocs/Colorado's%20designated%20beneficiary%20act_web.pdf?ver=2012-07-27-130730-947.

165. See Berg, *supra* note 151, at 280.

166. See CHOI & MEYER, *supra* note 17, at 10.

167. See Berg, *supra* note 151, at 289–90.

168. See ESKRIDGE & RIANO, *supra* note 26, at 731–34.

religion-based skeptics who were open to a nonsexualized alternative.¹⁶⁹ Even in Colorado the designated beneficiaries law has received virtually no publicity and has had very little uptake.¹⁷⁰ Indeed, Beatrice Pollard (my research associate) and I could not even extract basic information and statistics from the state and local authorities. To be sure, some of the advantages of such agreements (such as inheritance and surrogate decision-making) can be secured through private contacts and wills—but they usually require legal assistance.¹⁷¹

III. Do-It-Yourself Designated Caregivers

The Colorado Designated Beneficiaries Act potentially facilitates caregiving arrangements by either generational peers (similar to marriage and civil unions) or intergenerational loved ones (similar to parent-child or other younger relatives).¹⁷² In my view, other state legislatures ought to enact similar statutes and ought to give that new family form the kind of publicity that Colorado, Hawaii, and Vermont have not provided for their laws. I also join LGBTQ+ advocacy groups in seeking congressional and state legislative measures that would facilitate caregiving arrangements.¹⁷³

Unfortunately, these are precisely the kind of academic proposals that die on the vine. Federal and state legislators have little incentive to adopt such laws unless a powerful group such as the AARP gets behind it, and even an AARP-backed proposal would have to fight its way through the crowded legislative docket.¹⁷⁴ In Congress and many state legislatures, religion-based lobbies might raise a fuss about a

169. See Nausica Palazzo, *Marriage Apostates: Why Heterosexuals Seek Same-Sex Registered Partnerships*, 42.1 COLUM. J. GENDER & L. 186, 255 (2021).

170. See ESKRIDGE & RIANO, *supra* note 26, at 37–40.

171. See Berg, *supra* note 151, at 304.

172. See John Culhane, *Colorado Built the Perfect System to Protect Unmarried Couples of All Stripes*, SLATE (June 27, 2023, 5:50 AM), <https://slate.com/news-and-politics/2023/06/colorado-designated-beneficiary-agreement-unmarried-couples-law.html>.

173. See Family Caregiver Alliance & Helene V. Wenzel, *Legal Issues for LGBTQ+ Caregivers*, FAM. CAREGIVER ALL. (2015), <https://www.caregiver.org/resource/legal-issues-lgbt-caregivers/>.

174. See generally Naveh, *The Paradox of Regulating Lobbying through Legislation*, HOFSTRA L. REV. 705, 711 (2018).

designated beneficiaries law if they interpreted it to offer an alternative to traditional marriage.¹⁷⁵

A more realistic idea is one that is inspired by my collegial work with Dean Jennifer Gerarda Brown, a distinguished alumna of the University of Illinois School of Law, and her professor and mentor, Richard Kaplan: caregivers' agreements.¹⁷⁶ Lawyers already draft "personal care" agreements, often between family members, but increasingly between aging persons and nonfamily caregivers.¹⁷⁷ Because many older persons cannot afford a lawyer to help them plan and to execute legal agreements, this is an area where law school clinical programs or attorney pro bono networks can contribute to their communities.¹⁷⁸

Another approach to such agreements would establish a website that folks can visit to create their own agreements, tailored to their circumstances just like the Colorado template anticipates.¹⁷⁹ Reflecting advances in technology that have already come into practice, the website should have the following features:

- After the principal and potential caregiver(s) create secure password-protected accounts, the website would pre-screen them with a series of simple explanations, questions, prompts, and confirmations that would provide some assurance that each party is well-informed about what a contract is and what duties and responsibilities each would be agreeing to. Importantly, the website should be trained to raise red flags with moderators based on anomalous responses that suggest the principal is confused or may not be competent or that the caregiver is evasive or providing inaccurate information. This

175. Tom Gjelten, *Some Faith Leaders Call Equality Act Devastating; For Others, It's God's Will*, NPR (March 10, 2021, 5:01 AM), <https://www.npr.org/2021/03/10/974672313/some-faith-leaders-call-equality-act-devastating-for-others-its-gods-will>.

176. See IAN AYRES & JENNIFER GERARDA BROWN, *STRAIGHTFORWARD: HOW TO MOBILIZE HETEROSEXUAL SUPPORT FOR GAY RIGHTS 2* (2005); Richard Kaplan, *Formalizing the Informal: Family Care Agreements in Canada and the United States*, 1 *CAN. J. ELDER L.* 52, 53–54 (2008).

177. Hofri-Winogradow & Kaplan, *supra* note 152, at 1999–2002; Nina A. Kohn, *For Love and Affection: Elder Care and the Law's Denial of Intra-Family Contracts*, 54 *HARV. C.R.-C.L. L. REV.* 211, 214–17 (2019) [hereinafter Kohn, *For Love & Affection*] (arguing that personal care contracts are valuable for aging persons and fair to family caregivers who can ill afford financial sacrifices for unpaid work).

178. See Lorie Konish, *Half of Single Seniors Can't Pay for the Basics. Here's Why Social Security's Not Enough*, CNBC (Jan. 13, 2020, 2:32 PM), <https://www.cnbc.com/2020/01/13/why-its-hard-to-for-retirees-to-get-by-on-social-security-benefits.html>.

179. See *COLO. REV. STAT.* § 15-22-106 (2023).

could operate similar to the machine learning algorithms utilized for credit card fraud detection.¹⁸⁰

- Following a checklist patterned after the 2009 Colorado law, the website would then offer the principal and designated caregiver(s) a series of options, each of which would be explained (and with more detailed explanations available if prompted).¹⁸¹ Specifically, the website would ask the principal whether they want a designated caregiver (1) to have access to them and the capacity to act for them in hospitals and nursing homes; (2) to be their surrogate decisionmaker for medical and after-death decisions; and (3) to have a power of attorney, perhaps a limited one, to manage the principal's financial and other affairs.¹⁸² The power of attorney would be accepted by the website only after a grace period had elapsed, relatives and other designated persons had been notified, and the principal returns to the website to confirm their option. As my description suggests, the caregiver for Item (3) might be a different person than the caregiver(s) for Items (1) and (2).
- The website would also offer a path for the principal and the caregiver(s) to enter into a contract to compensate the caregiver(s) for specified services, including emergency services and extra care during hospitalization. As before, the website should be trained to raise red flags with moderators based on a pattern of responses that suggest the principal is confused or may not be competent or that a caregiver is evasive or providing inaccurate information.¹⁸³ The contract would combine standard terms (such as termination by either party), but also would be tailored to meet the needs of the principal and the designated caregiver.
- Like Earl in *Kingdom of Sand*, elderly persons might find it in their interest to exchange inheritance or property interests for caregiving services.¹⁸⁴ So the website might provide information that would allow the principal and caregiver to work out a simple arrangement where the principal could transfer a share of their property to (1) a trust for the benefit of the caregiver, (2) joint tenancy with the caregiver (who would automatically inherit the property upon the principal's death or vice-versa), or (3) tenancy in common (without a right of survivorship).¹⁸⁵ The website might recommend the principal and

180. See Jonathan Kwaku Afriyie, Kassim Tawiah, Wilhemina Adoma Pels, Sandra Addai-Henne, Harriet Achiaa Dwamena, Emmanuel Odame Owriedu, Samuel Amening Ayeh & Josh Eshun, *A Supervised Machine Learning Algorithm for Detecting and Predicting Fraud in Credit Card Transactions*, 6 DECISION ANALYTICS J. (Mar. 2023) at 1–2.

181. See COLO. REV. STAT. § 15-22-106 (2023).

182. See *id.*

183. See Afriyie et al., *supra* note 180, at 2–6.

184. See HOLLERAN, *supra* note 6, at 217.

185. See COLO. REV. STAT. § 15-22-106 (2023).

caregiver seek an attorney for this plan, but if they proceed on the website with precautions such as those noted above,¹⁸⁶ the website can guide the contracting parties, prepare their documentation, and file the needed documents with the register of deeds.

- Every time a designation is made or a contract or property transfer accomplished, the website would send the relevant information and documentation to relatives, friends, doctors, hospitals, banks, local officials, and so forth, as appropriate. The website would offer a process by which interested persons or institutions could raise questions or challenge designations, contracts, and property transfers. With the aid of artificial intelligence, the website could also automatically challenge anomalous actions and render preliminary judgments that would be reviewed by human adjudicators.¹⁸⁷
- With emerging technology (e.g., health monitoring devices), the website could be a resource for following and monitoring the principal's health and welfare—and the operation of the caregiving agreement.

Who would create and maintain such a website? Experimentation with different institutions might be useful. I'd focus on the state or even county level, which would be more manageable for starters. A state or county health department could create and operate the website—but other possibilities are the AARP, the University of Illinois or another distinguished institution of higher learning or research, or a local program funded by the Older Americans Act. Whichever institution would establish such a website, it would need to work with the state bar association to make sure that it was not violating the state's unauthorized practice of law rules.¹⁸⁸

Overall, do-it-yourself caregiving agreements, managed with new technology, have great potential for helping older LGBTQ+ and other Americans because they are (1) an efficient and cost-effective mechanism (2) for helping older persons make well-informed choices that might brighten their twilight years, but with (3) guardrails and monitoring that could flag problems and potential abuses.¹⁸⁹ In *Kingdom of Sand*, Earl could have eased into a do-it-yourself caregiving agreement with his handyman with greater assurance that he would not be exploited, and the narrator could have benefitted from initiating a

186. See generally Afriyie et al., *supra* note 180.

187. See Sciforce, *Anomaly Detection—Another Challenge for Artificial Intelligence*, MEDIUM (June 27, 2019), <https://medium.com/sciforce/anomaly-detection-another-challenge-for-artificial-intelligence-c69d414b14db>.

188. See e.g. COLO. R. PROF'L COND. 5.5.

189. See *supra* notes 145–71 and accompanying text.

similar process.¹⁹⁰ Indeed, the process of investigating the possibility of a caregiving agreement and then working out the details with a friend, relative, or neighbor would ease the loneliness felt by many aging LGBTQ+ and other persons.¹⁹¹ The narrator's existential laments of loneliness and alienation from his neighbors might well have eased through the process of identifying a potential caregiver, discussing the arrangement with them, and actually working through the website, perhaps over a period of weeks or months.¹⁹²

Another advantage of this proposal is that it would not require legislation—but its contractual relationship might fit into existing statutory schemes. For a simple example, the Obama Administration created a rule requiring hospitals receiving federal funds to make all patients aware that they can designate unrelated caregivers as well as family members who cannot be denied visitation and access to the patients.¹⁹³ The do-it-yourself caregiver agreements would not only satisfy the new visitation rule, but hospitals with secure access to caregiver information from the website could automatically notify medical personnel, with little or no additional notice from patients.¹⁹⁴

For another example, Medicaid officials are suspicious of caregiving compensation agreements among family members, because they are viewed as mechanisms to deplete the older person's resources so that they qualify for Medicaid; these officials are needlessly penalizing the elderly and their caregivers.¹⁹⁵ Armed with emerging technologies that are already deployed in important contexts such as fraud detection and medical diagnosis, the caregiver website can provide statistical assurance to Medicaid officials that caregiver compensation is not only fair in the abstract but also in operation (the monitoring feature of the website).¹⁹⁶ Impecunious persons such as Roy Hudgins in *Diary of a Misfit* could benefit from this.¹⁹⁷ His neighbors Mark and Cheryl might

190. See HOLLERAN, *supra* note 6, at 164.

191. See CHOI & MEYER, *supra* note 17, at 6–7.

192. See HOLLERAN, *supra* note 6, at 135.

193. Medicare and Medicaid Programs: Changes to the Hospital and Critical Access to the Hospital Conditions of Participation to Ensure Visitation Rights for All Patients, 75 Fed. Reg. 70831, 70835 (Nov. 19, 2010).

194. See *id.*

195. Kohn, *For Love and Affection*, *supra* note 177, at 214–16 (noting that personal care contracts are too often incorrectly viewed as fraudulent transfers under the Medicaid program).

196. See *supra* note 182 and accompanying text (discussing how AI could be used to monitor activity on websites).

197. See Parks, *supra* note 7, at 147.

have been advocates for him in the nursing home where he was neglected and died.¹⁹⁸

Likewise, the caregiving website might be linked with state and local programs. Florida, the home for the characters in *Kingdom of Sand*,¹⁹⁹ has a government network that is largely invisible to its older LGBTQ+ residents.²⁰⁰

Florida's Department of Elder Affairs is the central agency in this network and administers the National Family Caregiver Support Program, which informs and assists caregivers such as those designated in a caregiver agreement.²⁰¹ Florida's Home Care for the Elderly (HCE) program provides support for older residents in home caregiving (rather than nursing home) settings.²⁰² The program provides a basic subsidy for all participants as well as discretionary subsidies for services or supplies.²⁰³ Florida's Community Care for the Elderly (CCE) program "provides community-based services organized in a continuum of care to help functionally impaired older adults live in the least restrictive yet most cost-effective environment suitable to their needs."²⁰⁴ Under the CCE program, caretakers provide their patients with day-to-day services, including but not limited to, respite care, personal care, and shopping assistance.²⁰⁵ A Participant Direct Option (PDO) under Florida's Statewide Medicaid Managed Care Long-Term Care Program also permits functionally impaired older adults and their representatives to hire care providers; even spouses and adult children of the

198. *See id.* at 151.

199. *See* HOLLERAN, *supra* note 6, at 1.

200. *See infra* note 201–208 and accompanying text (showing how support systems in Florida do not specifically cater to elderly LGBTQ).

201. *National Family Caregiver Support Program*, ELDER AFF. FLA. (Apr. 3, 2023), <https://elderaffairs.org/programs-services/caregiving/national-family-caregiver-support-program/>; *How to Become a Paid Caregiver for a Family Member: 6 Steps to Uncovering Assistance Options for Family Caregivers*, CAREFORTH (Oct. 20, 2023), <https://careforth.com/blog/how-to-become-a-paid-caregiver-for-a-family-member-6-steps-to-uncovering-financial-assistance-options-for-family-caregivers/#Florida>.

202. *Home Care for the Elderly (HCE) Program*, ELDER AFF. (Apr. 3, 2023), <https://elderaffairs.org/programs-services/caregiving/home-care-for-the-elderly-hce-program/> [hereinafter *HCE*]; CAREFORTH, *supra* note 201.

203. *HCE*, *supra* note 202; CAREFORTH, *supra* note 201.

204. *Community Care for the Elderly (CCE) Program*, ELDER AFF. FLA. (Apr. 3, 2023), <https://elderaffairs.org/programs-services/caregiving/community-care-for-the-elderly-cce-program/> [hereinafter *CCE*]; CAREFORTH, *supra* note 201.

205. *CCE*, *supra* note 204; CAREFORTH, *supra* note 201.

older adult may be hired and compensated for providing caregiving services under the PDO.²⁰⁶

Not least important, a caregiving website deployed in Florida could offer its users direct links to Access Florida (for applications to receive Medicaid assistance), to the local Aging and Disability Resource Center (for information on applying for the HCE program), and the Florida Department of Veterans Affairs (for information on applying for VA benefits).²⁰⁷

206. *Florida Statewide Medicaid Managed Care Long-Term Care (SMMC-LTC) Program: Benefits & Eligibility*, AM. COUNCIL ON AGING (Mar. 19, 2023), <https://www.medicaidplanningassistance.org/florida-medicaid-smmc-ltc/>; CAREFORTH, *supra* note 201.

207. AM. COUNCIL ON AGING, *supra* note 206; CAREFORTH, *supra* note 201.

