This is a peer-reviewed, accepted author manuscript of the following chapter:
Hafford-Letchfield, T & Cocker, C 2024, Older LGBTQ+ people and the equality/human rights implications of inequalities in older age health/social care provision. in S Westwood & NJ Knauer (eds), *Research Handbook on Law, Society and Ageing.* Edward Elgar Publishing, Cheltenham, pp. 551-565. https://doi.org/10.4337/9781803925295.00050

CHAPTER 38

OLDER LGBTQ+ PEOPLE AND THE EQUALITY/HUMAN RIGHTS IMPLICATIONS OF INEQUALITIES IN OLDER AGE HEALTH/SOCIAL CARE PROVISION

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Abstract

The legal recognition of the human rights of lesbian, gay, bisexual, trans, queer and other diverse sexual and gender identities (LGBTQ+) in some global regions has not always transferred to the reality in the provision of health and social care services particularly affecting the ageing population. Some LGBTQ+ people still live in societies that support discrimination and inequality which is further complicated by the intersections with ageism and other marginalised identities. These are compounded by additional factors documented in cumulating research evidence on LGBTQ+ health inequalities and the ageing experience. This chapter draws on academic and practice knowledge about LGBTQ+ health inequalities impacting care experiences in later life. Writing from the UK, we engage with international research and literature and provide some examples of recognition, equality and protection through the UK legal framework and discuss the implications for equality and rights to care and support services for older adults in response.

Introduction

Burgeoning research on lesbian, gay, bisexual, trans and non-binary, queer and questioning (LGBTQ+)[1] people's experiences of ageing and care in more advanced and developed global regions have provided some benchmarks and practice evidence to guide formal systems of support in health and social care often found in advanced welfare states.[2] Older LGBTQ+ people have become more visible since gaining legal recognition in some global regions, but acceptance of them within these societies varies greatly.[3] The provision of health and social care services does not always support this legal recognition in reality and this can negatively impact the lives of older LGBTQ people.[4] The health inequalities faced by LGBTQ+ older adults are evident across poor outcomes in both physical and mental health combined with unsatisfactory and in many cases, direct discrimination and marginalisation in the provision of care services. [5] [6] Systemic silence often expressed as "there are no LGBTQ+ people here" or "we treat everyone the same" [7] can render older LGBTQ+ needs as invisible. This requires active demonstration of affirmative services to the LGBTQ+ ageing community that reflect the legislative, policy, principles, and values of care, to make explicit a commitment to inclusive LGBTQ+ care.

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[1] This chapter will use LGBTQ+ when discussing broader issues relating to care provision. Where alternatives umbrella terms are used e.g., LGB; LGBT, this indicates the range of identities in the specific research study being discussed. The + sign has been used to include the wide and diverse range of identities (queer, questioning, non-binary, gender non-conforming etc) recognising the need to be inclusive and fluid and constant evolving of terminology used to describe sexual and gender identities and the right of individuals to self-identify). Please see https://www.stonewall.org.uk/list-lgbtq-terms for further information about these terms.

[2] Karen, J. Fredriksen Goldsen et al., *Iridescent Life Course: LGBTQ Aging Research and Blueprint for the Future – A Systematic Review*. GERON 65, 253–274 (2019).

[3] Roberto Baiocco et al., *LGBT+ Training Needs for Health and Social Care Professionals: A Cross-cultural Comparison Among Seven European Countries.* SEX RES & SOC. POL 19:22–36 (2021).

[4] Maria T. Brown. *LGBT Aging and Rhetorical Silence*. SEX RES & SOC POL 6, 4. 65–78 (2009).

[5] Trish Hafford-Letchfield & Lawrence Roberts *Learning and Skill Framework for LGBTQ Ageing* Skills for Care (2023). https://www.skillsforcare.org.uk/Support-for-leaders-and-managers/Supporting-a-diverse-workforce/LGBTQ-learning-framework.aspx; Sue Westwood, et al., Older LGBT+ health inequalities in the UK: setting a research agenda. JNL EPIDEMIOL COMM HEALTH 74, 408-411 (2020).

[6]

[7] Paul Simpson et al., '*We treat them all the same': the attitudes, knowledge and practices of staff concerning old/er lesbian, gay, bisexual and trans residents in care homes* ', AGE SOCI 1-31 (2016).

This chapter draws on emerging themes from what is known about LGBTQ+ health inequalities in later life and the challenges and opportunities for improvement. Writing from the United Kingdom (UK), we provide some examples of recognition, equality and protection through the UK developing legal framework and discuss their implications for care services. We draw broadly on theoretical concepts that shape our understanding of the differences in health and social care outcomes among older LGBTQ+ people such as minority stress,[8] the life course[9] and intersectionality.[10] These are considered in the context of societal and historical changes to LGBTQ+ equality and human rights and the ongoing challenges for later life. We briefly examine what wider systemic, institutional, and other multiple barriers might be faced by older LGBTQ+ people[11] and their impact on human rights.

History and legal landmarks in the lives of LGBTQ+ communities explain why older individuals and specific groups within the LGBTQ+ umbrella face unique challenges in accessing and engaging with care services.[12] The physical and psychological impacts of growing up within institutions that criminalised sexuality and pathologised diverse sexual and gender identities have an enduring legacy.[13] During their life course, lesbian, gay and bisexual older people lived much of their lives in heterosexist and homophobic societal contexts. Some were referred to health or psychological services to "treat" or cure them of their identities. These experiences contributed to long lasting trauma and entrenched fear and distrust of care services. Those born before the 1950s, lived much of their lives in a social and political context

[8] Illan H Meyer, *Prejudice, social stress, and mental health in lesbian, gay, and bisexual populations: conceptual issues and research evidence*. PSY BULL 129 674–97 (2003).
[9] PRISCILLA DUNK-WEST & TRISH HAFFORD-LETCHFIELD, SEXUAL AND GENDER IDENTITIES AND INTIMACY RESEARCH IN SOCIAL WORK AND SOCIAL CARE: A LIFECOURSE EPISTEMOLOGY. Routledge (1st ed, 2018).
[10] Michael Adams, *An intersectional approach to services and care for LGBT elders* GENS 40 94-100 (2016).
[11] Meghan Romanelli & Kimberly D Hudson, *Individual, and systemic barriers to health care: Perspectives of lesbian, gay, bisexual, and transgender adults.* AMER JNL ORTHPSY *87*, 714–728. (2017).
[12] Westwood et al., n. 5.
[13] Karen Fredriksen-Goldsen, *The Future of LGBT+ Aging: A Blueprint for Action in Services, Policies, and Research*. GENS 40 6-15 (2016).

where their human rights were *not* protected by legislation and in many regions of the world, this remains the case. Gay men were criminalised for engaging in consensual same-sex relationships before (and since) the partial decriminalisation of homosexuality (which in the UK was 1967). Homosexuality was classified as a mental disorder in the Diagnostic and Statistical Manual of Mental Disorders (APA)[14] from 1952 – 1997. Whilst the HIV/AIDS crisis politicized homosexuality, LGBTQ+ older people, especially gay men, lost many friends with whom they had hoped to grow old.[15]

Older lesbians were subject to severe sanctions and social stigma, [16] with experience of harassment, rejection, and loss of jobs, families and their children leading to increased loneliness in later life.[17] For bisexual individuals, relationships with individuals of multiple genders can contribute to internal conflict, confusion, and felt invisibility in later life.[18] Trans life course and histories are even more complex, reflecting unique chronologiesand narratives about identity.[19] There are also limitations in UK law reflecting the nuances of trans identities for example with the exclusion of non-binary identities from the Gender Recognition Act, (GRA) 2004. The GRA came about following years of hard work by campaigners and several cases before the European Court of Human Rights. Whilst the need for reform has been debated to reduce the medicalisation of gender identity and enhance the right to self-determination, through a much simpler and more streamlined administrative process, there has been very little

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[14] American Psychiatric Association (APA), Diagnostic and Statistical Manual of Mental Disorders. https://www.psychiatry.org/psychiatrists/practice/dsm.

[15] BRIAN De VRIES & PATRICK HOCTEL, THE FAMILY-FRIENDS OF OLDER GAY MEN AND LESBIANS. In NIELS. TEUNIS & GILBERT Herdt (Eds.), SEXUAL INEQUALITIES AND SOCIAL JUSTICE (pp. 213–232). Berkeley, CA: University of California Press (2006).

[16] JANE TRAIES, THE LIVES OF OLDER LESBIANS. (Palgrave McMillan, 2018).

[17] CHRISTINE COCKER. LESBIAN PARENTING: REBELLIOUS OF CONFORMIST? In. CHRISTINE COCKER & TRISH HAFFORD-LETCHFIELD (eds) RETHINKING FEMINIST THEORIES FOR SOCIAL WORK PRACTICE. (Palgrave Macmillan, Chm, 2022).

[18] Sarah Jen & Rebecca L Jones, *Bisexual lives and aging in context: A cross-national comparison of the United Kingdom and the United States.* INTL JOURN AGING HUM DEVP, 89, 22–38 (2019).

[19] RUTH PEARCE, TRANS TEMPORALITIES AND NON-LINEAR AGEING. In A. KING et al., (eds), OLDER LESBIAN, GAY, BISEXUAL AND TRANS PEOPLE: MINDING THE KNOWLEDGE GAPS (Routledge, 61–74, 2019).

progress alongside strong anti-trans rhetoric in the media which has also been echoed or endorsed in the social and political sphere of society. [20]

The term minority stress [21] is used to describe the cumulative effect of discrimination and negative experience faced by LGBTQ+ people during the life course and is related to poor health outcomes.[22] It is important to recognise the skills that some have developed to deal with crises and any subsequent abilities to deal with future stressors.[23] Engagement in LGBTQ+ social movements, and learning how to respond, adapt and cope with discrimination all provide potential for a person to consolidate their own individual strengths and resilience.[24] Whilst studies tend to show a lack of coherence in the way in which the construct of resilience is utilised and theorised in LGBTQ+ ageing care,[25] an understanding of the mechanisms involved, including the way in which minority stress and structural issues that impact resilience is also important to help in conceptualising how to improve health and social care provision.[26]

Uniqueness of older LGBTQ+ people's care needs

The lack of systematic collection of routine large-scale quantitative data on the older LGBTQ+ population contributes to their invisibility in official statistics, in epidemiological research, and the media more widely.[27] Pervasive attitudes in society have discouraged LGBTQ+ older

[20] CHRIS DIETZ & RUTH PEARCE, DEPATHOLOGISING GENDER: VULNERABILITY IN TRANS HEALTH LAW In CHRIS DIETZ MITCHELL TRAVIS & MICHAEL THOMPSON (Eds.) A JURISPRUDENCE OF THE BODY (Palgrave Macmillan, Cham, 179-203 2020).
[21] Meyer, n.9.
[22] Westwood et al., n. 5.
[23] Billy A. Caceres & Maya O. Frank, *Successful ageing in lesbian, gay and bisexual older people: a concept analysis*. INTL JNL OLD PPl NURS. 11 3 184-93, (2016).
[24] James McParland & Paul M Camic, *Psychosocial factors and ageing in older lesbian, gay and bisexual people: a systematic review of the literature.* JNL CLIN NUR 25 23-24, 3415-3437 (2016).
[25] Anže Jurček et al., *Defining and researching the concept of resilience in LGBT+ later life: Findings from a mixed study systematic review*. PLoS ONE 17 e0277384 (2022).
[26] Agnes Higgins et al., *Building resilience in the face of adversity: navigation processes used by older lesbian, gay, bisexual, and transgender adults living in Ireland.* J CLIN NURS Dec 25 23-24 3652-3664. (2016).
[27] Brian Beach, *Raising the equality flag Health inequalities among older LGBT people in the UK*. London, ILC, UCL, Cardiff University (2019).

adults from “coming out” and being counted.[28] 'An estimated 2.7 million adults aged 50 and over in the USA currently identify as LGBT, and this is predicted to rise to more than 5 million people by 2060.[29] Obtaining an accurate picture however is problematic and contributes to an overall lack of knowledge about the lives and needs of the LGBTQ+ population, both the current older cohort and younger “(gay)by boomers”.[30] This latter generation may be stronger advocates for responsive services with higher expectations and low tolerance for gaps.

The data that *are* available lack nuance about the complexity of issues around visibility for some groups to comprehensively inform caring practices, as LGBTQ+ is not a simplistic identity category.[31] An intersectional analysis affords a greater understanding of complex biographies while still retaining a concern with wider dynamics of power.[32] Multiple identities contribute to a person’s sense of self but these are themselves potentially subject to forms of discrimination and marginalisation.[33] The weakness or absence of good-quality and reliable data is partly due to a lack of monitoring for sexual orientation/gender identity in routine public services data collection.[34] Care providers may lack awareness, and not ask, or invite discussion.[35] An understandable reluctance for individuals to share information about their identities are particularly pronounced in the older LGBTQ+ community due to life experiences and living during an era, or a geographical region, when “coming out” or being themselves could result in criminal proceedings, victimisation and discrimination.[36] Hyper-visibility may

[28] SKI HUNTER, COMING OUT AND DISCLOSURES: LGBT PERSONS ACROSS THE LIFE SPAN. (Binghamton, NY Haworth 2007).
[29] Fredrickson-Goldsen, n. 14.
[30] JESUS RAMIREZ-VALLES , QUEER AGEING THE GABYE BOOMERS ANDA NEW FRONTIER FOR GERONTOLOGY(OXFORD UNIVERSITY PRESS, 2016).
[31] Katharine Almack & Andrew King, *Lesbian, Gay, Bisexual, and Trans Aging in a U.K. Context: Critical Observations of Recent Research Literature* INT J AGING HUM DEV. 89 93-107 (2019).
[32] A. KING et al., (eds), OLDER LESBIAN, GAY, BISEXUAL AND TRANS PEOPLE: MINDING THE KNOWLEDGE GAPS (Routledge, 61–74, 2019).
[33] Beach, n.28.
[34] Westwood et al., n.5
[35] Michael Toze et al., *Applying a Capabilities Approach to Understanding Older LGBT People’s Disclosures of Identity in Community Primary Care* INT J ENVIRON RES PUB HLTH 17 20 7614, (2020).
[36] Brown, n. 4; ED OU JIN LEE et al., *Knowledge and Policy About LGBTQI Migrants: a Scoping Review of the Canadian and Global Context*. INT MIG INTEG **22**, 831–848 (2021).

give rise to becoming targets of stigma or discrimination by care providers as well as conflicts with some paid carers' fundamental religious beliefs. [37] These encounters can compromise timely help-seeking and potentially delay transfers to care, as older LGBTQ+ people avoid care services due to fear of prejudice and discrimination.[38]

Qualitative studies have captured narratives and themes on how older LGBTQ+ people's life stories and relationships can be invisible, overlooked and undervalued when they interact with care services.[39] More work is needed on how LGBTQ+ midlife and older adults find meaning in response to lifelong adversity,[40] and the on-going negative consequences for their physical and mental health as a result of discrimination lasting into their older age.[41] Orel investigated USA quantitative and qualitative data on the unique needs and concerns of LGBT older people. She identified seven areas of concern (medical/health care, legal, institutional/housing, spiritual, family, mental health, and social).[42] LGBT participants discussed whether they were "out", their sense of belonging, the networks that they tap into and who they rely on within their friendship family networks. Not having the expansive family networks of support when becoming dependent compared with heterosexual peers magnifies care needs.[43] Research contributions confirm the cumulative effects of discrimination and

[37] Sue Westwood, *"People with faith-based objections might display homophobic behaviour or transphobic behaviour": older LGBTQ people's fears about religious organisations and staff providing long-term care*, JNL RELIG SPRT AGE (2022).
[38] Roos Hoekstra-Pijpers, *Experiences of older LGBT people ageing in place with care and support: A window on ordinary ageing environments, home-making practices and meeting activities*. SEXUTS *25* 25–44 (2022).
[39] Trish Hafford-Letchfield et al., *Learning to deliver LGBT aged care: Exploring and documenting best practices in professional and vocational education through the World Café method*. AGE SOC*,* 43 105-126. (2023).
[40] BRIAN DE VRIES, STIGMA AND LGBT AGING NEGATIVE AND POSITIVE MARGINALITY.. In NANCY. A. OREL & CHRISTINE. A. FRUHAUF (Eds.), THE LIVES OF LGBT OLDER ADULTS: UNDERSTANDING CHALLENGES AND RESILIENCES (55–71). (Washington, DC: American Psychological Association. 1st EDT, 2015).
[41] Dylan Kneale et al., '*Inequalities in older LGBT people's health and care needs in the United Kingdom: a systematic scoping review* 41, 493-515 AGE SOC (2021).
[42] Nancy A. Orel, *Investigating the Needs and Concerns of Lesbian, Gay, Bisexual, and Transgender Older Adults: The Use of Qualitative and Quantitative Methodology*, JNL HOMO, 61, 53-78, (2014).
[43] Eileen Reilly et al., *Women ageing solo in Ireland: An exploratory study of women's perspectives on relationship status and future care needs*. QUAL SOC WK *19 1* 75–92. (2020).

stigma over the life course. These are made complicated by the heterosexist and cisgendered nature of care services which deter or make help seeking difficult,[44] a lack of family support, the escalating cost of health care and/or lack of knowledge about what institutions provide inclusive care and how to access these.[45]

LGBTQ+ health inequalities

Whilst LGBTQ+ older individuals may experience the same challenges as their heterosexual and cisgender peers, they also face unique ones. They report poorer health than the general population and have worse experiences of care across cancer, palliative/end-of-life dementia and/or other mental health services.[46] In the absence of systematic data, one UK study conducted a unique synthesis of data from 25 different sources (over 2,500 LGB men and women) to enable a better understanding the extent of health inequalities in later life.[47] Many studies were based on participants' own self-rated experiences of health such as, long-term illness, smoking, suicide attempts, and poor life satisfaction. The study found that there are links between formal and informal care provision and environments for LGBTQ+ older adults, and health and care inequalities. There is some evidence from the literature about LGBTQ+ older adults experiencing weaker social networks, higher risks of isolation and loneliness, and poorer health behaviours, and that this may accelerate a need for formal care. The irony is that this is the environment where LGBT+ older adults face unequal treatment.[48] Another UK scoping review of studies on LGBTQ+ ageing, identified four broad categories of concern: physical health and access to health care; access to social care and end-of-life care; experiences around loneliness, social isolation and mental health problems; and experiences of violence.[49]

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[44] PRISCILLA DUNK-WEST & TRISH HAFFORD-LETCHFIELD, n.10.
[45] Illgim Dara Benoit et al., *Senior sexual and gender minorities' perception of healthcare services: A phenomenological approach*, INTL JOU HLTH MGMT 14, 1002-1010, (2021).
[46] Sue Westwood, n 5.
[47] Dylan Kneale et al., n. 43.
[48] Dylan Kneale et al., n.43, 510.
[49] Beach, n.28

This review suggests that older LGBTQ+ people are more likely to engage in harmful health behaviours like drug use, frequent alcohol consumption, or smoking as well as examples of some positive behaviours, such as regular exercise.[50] MacDermott et al. have since stressed the importance of contextualising this evidence on health inequalities within current policy discourse to challenge the "it's getting better" narrative[51] which depoliticises and denies such unjust social relations that produce inequalities.

The right to inclusive and affirmative care

These dynamics challenge the achievement of human rights in LGBTQ+ people's lives and directly contradict the United Nations Principles for Older Persons (for independence, participation, care, self-fulfilment, and dignity)[52]. For LGBTQ+ people living with dementia, cognitive impairment often heightens and multiplies challenges for them and their carers in specific ways.[53] For example, the loss of an LGBTQ+ identity as one loses one's own self within care settings can render people doubly invisible.[54] Dementia highlights the intersectionality of sexuality, stigma, and sickness leading to greater isolation.[55] Elevated levels of stress hormones have also been associated with accelerated brain ageing and cognitive decline, suggesting that some older LGBTQ+ people experiencing chronic minority stress may be at increased risk of dementia .[56] However, there is an absence of studies that directly examine dementia prevalence or cognitive functioning in LGBTQ+ older people regardless of

[50] Beach, n28.
[51] Elizabeth McDermott et al., *The Politics of LGBT+ Health Inequality: Conclusions from a UK Scoping Review*. INT JN ENV RES PUB HLTH, 18, e826 (2021).
[52] United Nations Principles for Older Persons General Assembly resolution 46/91/ https://www.ohchr.org/en/instruments-mechanisms/instruments/united-nations-principles-older-persons (1991)
[53] Justin McGovern *The forgotten/: dementia and the aging LGBT community*. J GERON SOC WK 57 845-57 (2014).
[54] Ibid.
[55] Andrew King, *Queer futures? Forget it! Dementia, queer theory and the limits of normativity*. JNL AFE STUD 63 e100993 (2022).
[56] Mark L Hatzenbuehler, *Structural stigma: Research evidence and implications for psychological science*. AM PSYCHOL. 71 8 742-751 (2016).

relationship status.[57] A scoping review of empirical research on the lived experience of LGBT+ people with dementia and their care partners[58] found only one study which included trans people.[59] None focused explicitly on intersex, non-binary or queer people, thus obscuring the nuance and distinctions between the experiences of older LGBTQ+ people with dementia.

Despite increased global ageing demography, the provision of long-term care has not addressed sexuality- and gender- diversity. Advocacy and support for people is needed for transition into long-term care[60] as "coming out" within closed care environments can be extremely stressful and may exacerbate anxiety around "who knows what." [61] In some circumstances, displays of same-sex affection can jeopardize people's friendships and relationships, potential or actual, with other residents and care staff.[62] Alarmingly, some trans people have described being open to euthanasia as a strategy to avoid residential care where the level of fear of being misunderstood, misgendered and ridiculed is so great.[63] Westwood's study of older lesbians and gay men articulated nuances where the wish to die can be impacted by an increased risk of feeling that life is not worth living and the inadequacy of both informal and formal social support. [64]

Advanced care planning is important for future care and providing protection for partners and significant others who might otherwise not be recognised. Being able to nominate

[57] Anthony N Correro, & Kirsty A Nielson, *A review of minority stress as a risk factor for cognitive decline in lesbian, gay, bisexual, and transgender (LGBT) elders*, JNL GAY LES MENT HLTH 241 2-19 (2020).
[58] Louisa Smith et al., 'Investigating the lived experience of LGBT+ people with dementia and their care partners: a scoping review' AGE SOC 1-24 doi:10.1017/S0144686X22000538 (2022).
[59] Catherine Barrett et al., *Understanding the experiences and needs of lesbian, gay, bisexual and trans Australians living with dementia, and their partners*. AUS JNL AGING 34 34–38. (2015).
[60] Trish Hafford-Letchfield et al., *Developing inclusive residential care for older lesbian, gay, bisexual and trans (LGBT) people: An evaluation of the Care Home Challenge action research project* HLTH SOC CARE COMM 26 2 e312-e320 (2021).
[61] Elizabeth Price, *"Pride or Prejudice? Gay Men, Lesbians and Dementia*." BRIT JNL SOC WK 38, 7 1337-52 (2008).
[62] RICHARD WARD ET AL, LESBIAN GAY BISEXUAL AND TRANSGENDER AGEING: BIOGRAPHICAL APPROACHES FOR INCLUSIVE CARE AND SUPPORT (Jessica Kingsley, 2012).
[63] Andrea Walling et al., *Experiences of informal caregiving among older lesbian and gay adults in Australia* AUS JNL AG 41 3 424-430 (2020).
[64] Sue Westwood, Older Lesbians, Gay Men and the 'Right to Die' Debate: 'I Always Keep a Lethal Dose of Something, Because I don't Want to Become an Elderly Isolated Person.' SOC LEG STUD 26 606–628 (2017).

"important others" as next of kin may impact on same-sex partners or significant friends. In the UK, Makita et al., found that healthcare providers are more likely to consult with family of origin/heterosexual partners about healthcare decisions, rather than the people who are most significant/important to LGBTQ+ people. [65] In some cases, this means keeping family of origin at a distance or explicitly not wanting family of origin involved.[66] For transgender people, concerns were expressed about being buried by family of origin under their assigned gender at birth, despite having legal protection of their gender identity. Older transgender people waiting for gender-affirming medical/surgical interventions can find themselves in limbo are subject to waiting lists for gender affirming interventions which affect their choices in later life.[67] Further, another complication can arise when trans people experience impaired recent memory in the early stages of dementia and this may result in an individual reverting back to an expression of identity from their earlier life.[68] An individual's abilities to make complex decisions can be compromised with cognitive decline [69] and neuropsychological evaluation protocols are based on binary gender categorization which lack cultural sensitivity. [70] An Australian study found that a disproportionate percentage of its LGBT respondents did not have advance care planning (ACP) discussions with their desired surrogate decision-maker, or advance care directives.[71] Some ACP had been deliberately withheld by those empowered with substitute decision-making responsibility, particularly enduring powers of attorney (EPoA) for finances, and/or there was a lack of precise and accurate ACP legal advice to address relationship status.

[65] M Makita et al., *The role of sexual orientation, age, living arrangements and self-rated health in planning for end-of-life care for lesbian, gay and bisexual (LGB) older people in the UK*. SEX 25 99-116 (2022) . .
[66] Ibid. p4.
[67] Pearce, n. 20
[68] Jeannie Marshall et al., *Gender dysphoria and dementia: A case report.* JNL GAY LES MTL HLTH, 19, 112-117 (2015).
[69] Ibid.
[70] Elyssa A. Scharaga et al., *What happens when we forget our own narrative: Transgender dementia case study,* CLIN NEUROPSYCHOLOGIST, 35:8, 1485-1497 (2021). 5
[71] Mark Hughes & Colin Cartwright *Lesbian, gay, bisexual and transgender people's attitudes to end-of-life decision-making and advance care planning.* Australasian JNL AG. 34, 39-43 (2015).
(2015).

Estimates indicate 3% of informal carers are LGBTQ+ but this is likely to be an underestimation.[72] Services do not take account of older LGBTQ+ carers' information needs. There is a dearth of provision and lack of tailoring in existing services. Carers' relationships may be misunderstood or insensitively questioned by care providers. Partners of LGBTQ+ people with dementia for example, are not only having to grapple with the challenges of care giving and anticipatory grief, but have to fight for their relationships to be recognised and valued at all.[73] King [74] questioned the way that dementia is understood culturally and how heteronormative and cisgendered framing and silences, obscure the experiences of LGBTQ+ people. Informal carers of LGBTQ+ people are left to educate providers but not all LGBTQ+ people have someone "fighting" for them.[75] Since some older LGBTQ+ adults systemically lack access to informal care that families and kin expect in heterosexual and cisgender family networks, they may be particularly susceptible to requiring long-term care.[76] Whilst it might be a protective strategy to not to "come out" or to "out" those people in their lives (such as same-sex partners), ironically, these key informants could help professionals and services understand their care needs better. A review of trans people's parenting experiences[77] documented a lack of knowledge and skills to work with the full range of issues impacting on families with trans parents, grandparents and carers, including recognising and discussing feelings of loss and grief related to parental gender transition and its cumulative effect. Transphobia impacts on trans people's relationships outside of family life and its consequences for later life such as poverty, near poverty and cumulative material disadvantage are not

[72] Makita et al., n.67
[73] Smith, n. 60.
[74] Andrew King, *Queer futures? Forget it! Dementia, queer theory and the limits of normativity*. JNL AGE STUD (2021).
[75] Paul Willis et al., *Reluctant educators and self-advocates: Older trans adults' experiences of health-care services and practitioners in seeking gender-affirming services*. HLTH EXPEC 23 1231–1240 (2020).
[76] Hannah Kia, *(In)Visibilities that Vary: The Production of Aging Lesbian, Gay, Bisexual, Transgender, and Queer Subjects in Chronic Care*. THE ACT 12 1 -20 (2019).
[77] Trish Hafford-Letchfield et al., *What do we know about transgender parenting?: Findings from a systematic review* HLTH SOC CR COM 27 1111-1125 (2019).

acknowledged by policy makers, service providers and informal carers, when anticipating or considering the later life care needs of trans people[78].

Implications for human rights of older LGBTQ+ people with care needs

The inability to be or express oneself authentically for fear of, or following actual, experiences of discrimination from providers, staff, other peers and service users, their families and friends,[79] all contribute to affronts and contradictions in expression of human rights such as independence, participation, care, self-fulfilment and dignity.[80] LGBTQ+ older people frequently report the anticipation or experience of discriminatory attitudes among care providers in the form of heterosexism, homophobia, biphobia and transphobia. These fears and experiences in turn contribute to a lower uptake of services which further impacts health and wellbeing.[81] Where carers are coming into LGBTQ+ older people's home spaces, this can change the meaning and safety of those spaces and these 'spatial inequalities'[82] are particularly difficult for older people whose homes are a refuge from wider social marginalisation.

Lack of understanding about how older LGBTQ+ people experience health and care trajectories in the UK needs more targeted research to explore how these patterns differ across the spectrum of the LGBTQ+ acronym and across different health and care outcomes. For example, bisexuality in later life could provide more context for understanding differences and disparities through a discursive life course approach within its complexity and cultural context.[83] One of the few studies about intersex people[84] highlighted inadequate understandings

[78] Ibid.
[79] Danika Burke Sharek et al., *Older LGBT people's experiences and concerns with healthcare professionals and services in Ireland*, INTL JNL OD PPL NURS, 10, (3), 230-240 (2015).
[80] UN, n54
[81] Willis et al., n. 77
[82] Sue Westwood, *LGBT* ageing in the UK: spatial inequalities in older age housing/care provision*. JNL POV SOC JUS 24 63-76. (2016).
[83] Jen & Jones, n. 19
[84] Peter Hegarty et al., *Understanding of intersex: The meanings of umbrella terms and opinions about medical and social responses among laypeople in the United States and United Kingdom*. PSY SEX ORIE GEND DIV, *8* 1 25–37 (2021).

of identities outside of medical interpretation. There are human rights infringements on the right to bodily integrity and self-determination when irreversible medical interventions are performed without consent for socially normalizing or cosmetic reasons not medically essential. [85] Within trans and non-binary (TNB) research on ageing care, both Pearce and Toze assert the importance of employing an alternative chronology to make sense of TNB later lives.[86] This refers to unique experiences that arise at the intersection of chronological age and trans trajectory. Discrimination faced at the intersection of age involves not being given choice and support in later life that affirms gender identity and wellbeing.[87] This is also true for ageing with other LGBTQ+ identities, where later life transformations confound normative understandings of changes to health and wellbeing in later life.

The UK regulatory context

The UK Equality Act 2010[88] prohibits discrimination on the grounds of nine protected characteristics, including religion, sexual orientation, and gender reassignment (this has been expanded by case law to include trans identities more broadly).[89] The Act applies to all organisations that provide services to the public and the Public Sector Equality Duty[90] places a duty on public authorities to consider how their policies or decisions affect people who are protected under the Act by actively removing or minimising disadvantages and taking steps to meet their needs where these are different or their participation is disproportionately low. An example of promoting these principles is the development of Joint Strategic Needs Assessments (JSNAs) to specifically address the need of the older LGBTQ+ London

[85] Amnesty International *First Do no harm* https://www.amnesty.org/en/latest/campaigns/2017/05/intersex-rights/ (2017).
[86] Pearce, n. 20; Toze, no 26
[87] Pearce, ibid.
[88] The Equality Act, 2010, n. 13. Acts of Parliament, 2010 (UK).
[89] Ms R Taylor v Jaguar Land Rover Ltd. ET 1304471/2018 [2020].
[90] The Equality Act, 2010, S149. Acts of Parliament, 2010 (UK).

population in planning and auditing services.[91] Other examples of legislative changes in the UK include the Civil Partnership Act 2004 (HMG, 2004),[92] allowing same-sex couples to legally enter binding partnerships, similar to marriage, the Marriage (Same-Sex Couples) Act 2013[93] allowing same-sex couples in England and Wales to marry with subsequent legislation in Scotland[94] and Northern Ireland.[95] The Gender Recognition Act 2004[96], gave trans people full legal recognition, allowing them to acquire a new birth certificate with limited options either "male" or "female". In 2018, the English Government consulted the public on reforming the Act which has not since taken place. In Scotland. new legislation via The Gender Recognition Reform (Scotland) Bill was introduced in 2022, but controversy led to this being blocked by the UK government. At the time of writing this blocking is being challenged by the Scottish government, via judicial review. Regardless of legislation, there are long delays for gender affirming interventions in the UK combined with inconsistencies in trans-inclusive care provided by healthcare workers.[97]

Other regulatory contexts include the Care and Support Statutory guidance [98] which supports the implementation of the English Care Act, 2014.[99] The guidance defines discriminatory abuse as: '[. . .] forms of harassment, slurs or similar treatment because of race, gender and gender identity, age, disability, sexual orientation, religion.'[100] Discriminatory abuse is a category within the Safeguarding Adults policy referring to forms of abuse motivated by prejudice or bias, including against those who have protected characteristics. It links with

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[91] Opening Doors, *Joint Strategic Needs Assessments Assessing provision for the older LGBTQ+ population of London*. Opening Doors & Ashurst. https://www.openingdoors.lgbt/news/joint-strategic-needs-assessments-assessing-provisions-for-the-older-lgbtq-population-of-london (2022).
[92] Civil Partnership Act, 2004. Acts of Parliament, 2004 (UK).
[93] Marriage (Same-Sex Couples) Act, 2013. Acts of Parliament, 2013 (UK).
[94] Marriage and Civil Partnership (Scotland) Act, https://www.legislation.gov.uk/asp/2014/5/contents/enacted
[95] Northern Ireland (Executive Formation etc) Act, 2019. Acts of Parliament 2019 (UK).
[96] Gender Recognition Act, 2004, Acts of Parliament, 2004 (UK).
[97] Willis et al., 77
[98] Department of Health and Social Care, *Care and support statutory guidance* (2022). https://www.gov.uk/government/publications/care-act-statutory-guidance/care-and-support-statutory-guidance
[99] The Care Act, 2014, Acts of Parliament, 2014 (UK).
[100] Department of Health and Social Care, n. 146, s14.17.

hate crime and other features of discrimination that may feature in care services such as neglect as a result of ageism, or financial abuse by carers. Professional standards for registered and regulated social work professionals also mandate non-discriminatory practice.[101] Professional codes for UK Nursing and Midwifery do not specifically reference LGBTQ+ people or issues but contain clear standards which are aimed at "person centred" values or care. [102]

These legislative provisions, powers and duties enable service providers to take positive steps to promote equality, for example by developing service standards that inform improvements and can be measured. The Care Quality Commission, the independent regulator of health and social care in England, has included LGBTQ+ issues in its regulatory inspection and review themes. [103] In 2017, the UK Government conducted a national survey of LGBT+ people resulting in 108,000 people providing information on the stark and continuing inequalities for the LGBT+ population.[104] The subsequent action plan and appointment of a National Advisor for LGBT Health and NHS England was a first step in painting a more precise picture of LGBT+ people's needs and their diverse characteristics to help to provide a comparison with other groups in the UK population.[105] There has been little focus on older LGBT+ people within these initiatives. Over the last decade, a range of good practice guides and resources have been developed from research and knowledge exchange to support

[101] Scottish Social Services Council, *Codes of Practice for Social Service Workers and Employers* https://socialworkscotland.org/wp-content/uploads/2022/01/SSSCCodesofPractice2016.pdf (2020); Social Care Wales, *Code of professional practice for social care.* https://socialcare.wales/cms_assets/file-uploads/Code-of-Professional-Practice-for-Social-Care-web-version.pdf (2017); Social Work England, Professional Standards. https://www.socialworkengland.org.uk/standards/professional-standards/ (2021).

[102] Nursing and Midwifery Council, *Nursing and Midwifery Council submission of evidence to the House of Commons Women and Equalities Select Committee inquiry into Health and Social Care and LGBT communities. https://www.nmc.org.uk/globalassets/sitedocuments/consultations/nmc-responses/2019/nmc-evidence-to-house-of-commons-wec-lgbt-inquiry.pdf* (2019).

[103] Care Quality Commission, *Promoting sexual safety through empowerment: A review of sexual safety and the support of people's sexuality in adult social care*. https://www.cqc.org.uk/publications/major-report/promoting-sexual-safety-through-empowerment (2020).

[104] Government Equalities Office, *National LGBT Survey: Research Report* (2018) https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/721704/LGBT-survey-research-report.pdf (2018).

[105] Office for National Statistics *Sexual orientation, UK: Bulletin. (2020).* https://www.ons.gov.uk/peoplepopulationandcommunity/culturalidentity/sexuality/bulletins/sexualidentityuk/2020 (2020).

organisations, its stakeholders and workforce to demonstrate affirmative and inclusive services as well as eliminating discrimination and harassment.[106] Initiatives targeting staff training, improving the collection of data and discussions about whether to develop specific services to address the health and social care inequalities faced by LGBTQ+ people have started to emerge.[107] In summary, there are a range of legal provisions available to support people in later life when accessing and using care services to specifically address different barriers within the public care system itself and for individuals and their supporters/carers interacting with it.

The limits of regulation in addressing LGBTQ+ health and social care?

Kia accounts for the role of neoliberal society in constructing some of the normative conditions, particularly those related to ageing, family, and health, that help shape the interactions of ageing sexual and gender minorities with systems of chronic care.[108] Ekmecki notes that whilst international declarations of human rights and national legislations may provide a basis for the right to health, they are not sufficient to ensure the macro- and micro- allocation of resources.[109] The broadened definition of health and the inclusion of the social determinants of health as illustrated in what we know about LGBTQ+ health inequalities and the need to improve outcomes, are therefore very complex. Some of this was illustrated in the positioning of LGBTQ+ older people during the COVID-19 pandemic wherein the prioritisation of scarce resources, central government responses exposed structural disadvantages and discrimination faced by many marginalised communities.[110] Research on the experience of LGBTQ+ older people demonstrated how their voices were not promoted in the general media response and in

[106] Hafford-Letchfield & Roberts, n.5.
[107] Beach, n. 28.
[108] Kia, n. 78
[109] Perihan Elif Ekmekci. *Do we have a moral responsibility to compensate for vulnerable groups? A discussion on the right to health for LGBT people*. MED HLTH CARE PHILOS 20 335-341.(2017)
[110] Hanna J Swift and Alison L Chasteen, *Ageism in the time of COVID-19. Grp Proc & Intergroup Re*, *24* 2 246–252. (2021).

some reactionary narratives towards trans people. [111] A snapshot of the impact of restrictions on the lives of older LGBTQ+ people living in the UK in the context of the pandemic[112] also painted a positive narrative of increased social kindness and inclusion: “we are all in this together”. Restrictions and lack of access to the usual LGBTQ+ community networks, and restrictions had potentially severe consequences for some. Examples included not being able to access care (from fear of discrimination/being transferred into care homes with no physical or emotional support), increased mental health issues due to isolation, and loss of support from significant others.

The lack of affirmative care has been linked to a “one size fits all” approach in some areas[113] where greater awareness and knowledge of the lifestyles and cultural needs of LGBTQ+ older people could lead to better tailoring of care. This has been addressed in two ways: firstly via directly engaging with people with lived experience and their advocates about specific issues for LGBTQ+ people; and secondly by the routine collection of additional data about sexual identity and gender identity across health and social care settings as an inclusive standard of practice.[114] The use of inclusive language and symbols such as those incorporated into mainstream service literature, posters, pins and lanyards within care environments can signal welcoming environments,[115] but not necessarily lead to systemic change. Others have pointed to tackling conflicting religious and cultural beliefs in the social care workforce, and

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[111] Michael Toze et al., *Social Support in Older Transgender and Gender Diverse Communities in the United Kingdom and Australia: A Comparative Study During COVID-19*, JNL GERON SOC WK 66 381-399, (2023). Alexander Moreno, Salima Belhouari, and Alexane Dussault. "A Systematic Literature Review of the Impact of COVID-19 on the Health of LGBTQIA+ Older Adults: Identification of Risk and Protective Health Factors and Development of a Model of Health and Disease." *Journal of Homosexuality* (2023): 1-35.
[112] Trish Hafford-Letchfield et al., Unheard Voices: *A qualitative study of LGBT+ older people experiences during the first wave of the COVID-19 pandemic in the UK* HLTH SOC CARE COM 30 e1233-e1243 (2022).
[113] Simpson et al., n. 7.
[114] Hafford-Letchfield et al., n. 62; Kristin Cloyes et al., *Providing home hospice care for LGBTQ+ patients and caregivers: Perceptions and opinions of hospice interdisciplinary care team providers*. PALL SUPP CARE 1–9. (2022).
[115] Canceres et al., n.24

ageist attitudes in relation to sexuality, gender, and ageing.[116] The participation and contribution of LGBTQ+ older communities and their advocates within any learning strategies used within organisations providing care and support to LGBTQ+ people are strongly recommended.[117]. LeCompte et al. suggest that there is a lack of explanation about what inclusive practices are, with very few or no explicit examples of the behaviours, attitudes and skills that promote inclusion. [118] Alongside defining these, there is a role for institutions in adapting their administrative, political and social structures to allow for the development of such practices, and to link learning activities to broader cultural competency initiatives at organisational and professional levels that foster and support systemic change.

The reality is that for most older LGBTQ+ people, care and support is often delivered through networks of community-based providers, including informal caregivers. The recruitment and funding challenges facing the sector can place additional demands on caregivers and isolate them from formal service systems, due to a lack of choice and homophobia and transphobia inherent within formalised care systems.[119] LGBTQ+ people themselves contribute substantial care and support to ageing parents, partners, friends and others[120] and the broader ecology of care in LGBTQ+ communities.[121] Improvement could build on the capacity of the strength and range of care practices and networks that LGBTQ+ older people have already in place, through the funding and support of community-based organisations and tailoring and supplementing mainstream services.[122] Supporting self-care by

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[116] PAUL WILLIS & TRISH HAFFORD-LETCHFIELD, SEXUALITY AND RIGHTS IN LATER LIFE In SANDRA TORRES & SARA DONNELLY (Eds.) CRITICAL GERONTOLOG FOR SOCIAL WORKERS (81-96). BRISTOL UNIVERSITY PRSS (2022).
[117] Hafford-Letchfield et al., n. 62
[118] Maude Lecompte et al., *Inclusive Practices toward LGBT Older Adults in Healthcare and Social Services: A Scoping Review of Quantitative and Qualitative Evidence*. CLIN GERON 44 210-221 (2021). .
[119] Mark Hughes & Sue Kentyln, *Older LGBT people's care networks and communities of practice: A brief note* INTL SOC WK 54 3436–444 (2011).
[120] Shari Brotman et al., 'Coming Out to Care: Caregivers of Gay and Lesbian Seniors in Canada', Gerontologist 47 490–503 (2007).
[121] Arnold H Grossman et al., *Caregiving and care receiving among older lesbian, gay, and bisexual adults.* JN L GAY LES SOC SV 18, 15–38. (2007).
[122] Hafford-Letchfield et al, n121.

those who have nurtured and enriched relationships with their families of choice is important, using strengths-based approaches as commonly articulated in UK health and social care policy.[123] The variety of care networks through LGBTQ+ specific organisations, informal friendships with other LGBTQ+ people, and with neighbours and local communities have demonstrated great adaptability and capacity particularly where these are vulnerable to fragmentation, not to mention the medium of political activism.[124] Where older LGBTQ+ people who are not at a point in their lives when they need any type of intervention or care, many of them have definite ideas about what their housing should look like in the future, resulting in a growing movement for targeted provision. Integrated housing with care support specifically for LGBTQ+ older people is one example offering mixed or 'integrated' opportunities for meeting and socialising, communal areas for activity and conversations, the opportunity for intergenerational socialising and the support to enable 'continuation of lifestyle and identity.'[125] These can expand older people's social networks, specifically rekindle their ties in the LGBTQ+ community. Further, mainstream supported housing could be more progressive by considering how they are "LGBTQ+ friendly" by ensuring that all support staff and carers are trained in all aspects of equality and diversity and increase the wider understanding of LGBTQ+ cultures.[126]

Conclusion

In LGBTQ+ ageing populations, generations have witnessed extraordinary legal change and protections unlike those before or after them. Younger cohorts have lifetime exposure to the

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[123] Ann Cronin & Andrew King, *Only connect? Older lesbian, gay and bisexual (LGB) adults and social capital*. AGE SOC, 34 258-279 (2014).
[124] Trish Hafford-Letchfield et al., *Navigating inequalities during challenging times: A case study of UK LGBT+ organisations.* JNL SOC. 61 41-59. (2022).
[125] Daniel P Swiatek et al., *Older Adults in an LGBT Residential Community: Impact of a Safe Space on Occupation and Well-Being.* OP JNL OCC THER 9 1-14. (2021) .
[126] Tina Wathern, *Building a sense of community: Including older LGBT in the way we develop and deliver housing with care.* Housing Learning and Improvement Network https://www.housinglin.org.uk/_assets/Resources/Housing/Support_materials/Viewpoints/HLIN_Viewpoint39_LGBT.pdf (2013).

social history of LGBTQ+ human rights and movements and will assert their rights and needs more than ever before.[127] The human rights of LGBTQ+ people vary globally and any vulnerabilities and dependencies in later life can result in transgressions as highlighted by the United Nations.[128] Discrimination based on a person's sexual orientation, gender identity and sex characteristics is contrary to international human rights law as set out in the Universal Declaration of Human Rights (1948). This position has been repeatedly confirmed in general guidance issued by the United Nations Human Rights Committee and other treaty bodies[129]. Despite this, over 70 countries worldwide criminalise adult same-sex relationships. In progressive regions such as the UK, there is a catalyst to improve care provision alongside incremental change learnt from research and activism and enabled by legislation. Older LGBTQ+ adults are not a homogenous group with many factors influencing their choices and experiences as a result of education, employment history, income, geographical location, housing, and personal characteristics such as class, ethnicity, disability and gender. These affect the way in which people navigate changes and transitions throughout their lives.[130] More research should investigate the impact and mechanisms of lifelong minority stress to inform the mitigation and prevention of ill-health and costs of targeted care and to maintain quality of life for LGBTQ+ people in later life.[131] Respecting human rights should include Black and minoritised people of colour, and poorer and immigrant LGBTQ+ people, who continue to struggle with limited access to services. Training, meaningful participation and engagement, organisational change and resource allocation combined with robust data about LGBTQ+

[127] Kia n. 78.
[128] United Nations A/HRC/29/23: *Discrimination and violence against individuals based on their sexual orientation and gender identity. Thematic Report*. https://www.ohchr.org/en/documents/thematic-reports/ahrc2923-discrimination-and-violence-against-individuals-based-their (2015)
[129] United Nations International Human Rights Law and Sexual Orientation & Gender Identity: Fact Sheet. Available online from https://www.unfe.org/wp-content/uploads/2017/05/International-Human-Rights-Law.pdf https://www.unfe.org/wp-content/uploads/2017/05/International-Human-Rights-Law.pdf (not dated)
[130] Beach, n.28.
[131] Meyer, n.9.

people in later life are essential to inform and drive changes in care, to improve the health and wellbeing of further marginalised groups such as trans, intersex and non-binary people.