Equalities

1. Background

This paper draws on available evidence to highlight issues to be considered within the formulation of the forthcoming National Strategy for Carers in Scotland. It is one of a series of papers being prepared by the National Carer Organisations (NCO’s) to be submitted to the Scottish Government. It takes a pan-equalities approach focusing on carers from BAME and LGBT communities and disabled carers accepting that there are other carer groups with one or more protected characteristics whose needs it does not address due to lack of evidence and direct experience.

2. BAME Carers

Current data on the size of the BME carer population in Scotland derived from the 2011 Census is now significantly out of date. However, it is still useful to highlight a number of trends that have emerged between 2001 and 2011 (the dates of the last two Census’s) which may be further borne out by the Census which will take place in 2022:

- Between 2001 – 2011, the size of Scotland’s BAME population has more than doubled growing from 101,677 (2.01%) to 201,996 (4%);
- This growth has been mirrored in the size of the BAME carer population increasing from 6,815 to 12,049; and,
- Of the 32 local authorities in Scotland, 24 recorded a 100%+ increase in the number of BAME carers self-identifying through the Census.

It would be reasonable to assume that the size of the BAME population is Scotland has continued to grow although the extent to which this reflects previous growth will not be known until the 2022 Census is complete.

Much of the research on BAME carers in Scotland is not current within the last 5 years but anecdotal experience strongly suggests that the issues highlighted then continue to be present now. Two recent reports looking specifically at mental health support this.

A Study¹ conducted jointly by the Universities of Glasgow and Exeter (July 2020) found that BAME men experienced a much greater deterioration in their mental health during the COVID-19 national lockdown that their White British counterparts at 14% compared to

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¹ [https://www.gla.ac.uk/schools/business/news/coronavirus/headline_733441_en.html](https://www.gla.ac.uk/schools/business/news/coronavirus/headline_733441_en.html)
6.5%. Men of Pakistani, Indian and Bangladeshi heritage showed the steepest decline in their mental health and wellbeing.

A recent report produced by the Mental Welfare Commission for Scotland\(^2\) found that BAME people with lived experience of mental health and their carers experienced a range of difficulties including: difficulties in accessing treatment and support; a lack of consistency in how services are experienced; and, discrimination and ‘being judged’ when seeking support. The role and value placed on third sector and community organisations was identified as a positive factor.

A recent, as yet unpublished paper by Carers UK, on the experiences of BAME carers during the pandemic collated the data from two surveys conducted in April and September 2020 respectively found that BAME carers were:

- **Providing more care as a result of the COVID-19 pandemic.** 80% of BAME carers reported they were providing more care (than before the pandemic) in April, and 91% reported they were providing more care (than before the pandemic) when asked in September.
- **Disproportionately impacted by the loss or reduction of local support services.** Across both surveys, BAME carers were more likely than white carers to report providing increased care as a result of local services closing or reducing.
- **Facing greater financial challenges than white carers.** Across the two surveys BAME carers were more likely to be facing higher costs as a result of the pandemic and were more likely to be worried about their finances.
- **Under intolerable pressure.** 71% of BAME carers reported being worried about how they will cope this winter, and 75% feel exhausted as result of caring through the COVID-19 pandemic.
- **Anxious about infection control, access to PPE and contingency planning.** Across both surveys a significant amount of BAME carers selected better “PPE for unpaid carers” when they were asked what would help them most in the future (53% in April and 44% in September). BAME carers were more likely to select this option than white carers in both surveys.

The recent Carers UK State of Caring Report (2021) highlighted that Black carers and BAME carers respectively placed greater importance on having their needs recognized and being supported to return to work that their White counterparts. For example, 77% of Black carers wanted greater recognition of their specific needs compared to 56% of White carers and 29% of Asian carers wanted more support to return to work compared to 13% of White British carers.

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Recommendations:

- To commission research to identify the extent to which carers with one or more protected characteristics have benefitted from the implementation of the Carers (Scotland) Act (2016);
- To require local authorities to explicitly set out in their local carer strategy, how they are meeting or intend to meet the Duties placed on them with specific regard to the equality requirements within the Carers (Scotland) Act (2016) and the Duties overall to support carers;
- To have priorities, actions and mitigations explicitly set out in the accompanying Equality Impact Assessment and the Carer Strategy Action Plan; and,
- To require local authorities to report on the above to Scottish Government annually.

3. LGBT Carers

This section was written jointly with LGBT Health and Wellbeing

No definitive data exists on the size of the LGBT population in Scotland. Estimates range from 2.2% to 7% dependent on the source. However, support agencies believe the overall figure to be significantly higher based on under-reporting and/or a refusal to answer questions and a lack of data on trans, inter-sex and non-LGB sexual identities, eg. individuals identifying as QA+. It is also not possible to provide figures on the size of the LGBT carer population in Scotland as this information has not been included in Census arrangements to date. Desk based research has also identified a lack of practice based qualitative information to better understand the nature and extent of informal caring within LGBT communities in Scotland.

Many of the issues experienced by carers within the non-LGBT community will be shared by LGBT carers such as the need for information, recognition and support. However, LGBT carers will also experience a number of additional concerns that are specific to them:

- LGBT people are more likely to be estranged from their family of origin and therefore have less extended support when they take on caring roles;
- Many LGBT people are not out to the people they are caring for which can cause considerable stress and mean they cannot rely on their chosen family or partner for support with their caring role;
- Additionally, LGBT carers who are not out to those they are caring for may not be aware of, or benefit from, changes in policy or legislation;

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3 https://www.lgbthealth.org.uk/
• LGBT people may also be caring for people who are unsupportive of their LGBT identity and as a result regularly experience discrimination at very close quarter. For example, this might include someone misgendering or ‘dead naming’ their carer;

• LGBT carers are more likely to experience poorer mental health due to a range of factors and when combined with a caring role, this can mean they are disproportionately in need of support to ensure their mental wellbeing;

• Older LGBT people also highlight that as they are more likely to be single and childless, assumptions are made by their family of origin and/or straight/cisgender friends and neighbours that they have more time and capacity to take on a caring role;

• Bi-carers also highlight the prevalence and impact of assumptions made about their identity in the context of care and often report feeling invisible. For example, if they are caring for a partner of a different gender they are assumed to be straight and similarly, if they are caring for a partner of the same gender, it is assumed that they are gay.

“Ben is caring for his dad who has dementia. He is not out to his family – and says he never will be. His mum also cares for his father but he is becoming more aggressive and he worries about leaving his mum alone. He says it is assumed he has lots of time to care for his father because he doesn’t have children or a partner. “

Common narratives around caring may not fit the lives of many LGBT people. For example, an LGBT person may be caring for someone who is not supportive of their LGBT identity. LGBT people may have caring responsibilities in their family of choice as well as their family of origin, creating greater strains on their time, resources and wellbeing. LGBT carers might worry they will not be recognised and supported as a carer by practitioners or family members of the person that they care for. Within the LGBT community, men and non-binary people are as likely as women to provide informal care.

Practitioners working with and supporting the LGBT community also highlight specific health concerns within the community that must be taken into account both in relation to the carer and the cared for. The prejudice faced by LGBT individuals has a serious and ongoing detrimental effect on both their physical and mental health. LGBT people are more likely to smoke, drink or to take drugs. Poorer mental health is widespread with higher levels of depression, anxiety, eating disorders, self-harm and suicide. The GP survey in England (2021)\(^6\) reported that 36% of lesbian, gay and bisexual carers had a mental health condition compared to 13% of heterosexual carers.

In the same survey, 70% of lesbian, gay and bisexual carers reported a longterm health condition or disability compared to 60% of heterosexual carers. 75% of LGB carers who reported a

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6 Carers’ health and experiences of primary care Data from the 2021 GP Patient Survey, Carers UK
longterm condition stated that it affected their day to day life compared to 62% of heterosexual carers who reported a longterm health condition or disability.

A large proportion of those living with HIV are gay men who are ageing and are now having to manage not only their existing medication but new medication as they get older and experience age related illness/conditions. Trans-people who are taking hormones and have conditions that impact on their memory may forget to take their hormones or may suddenly stop altogether putting them at risk of serious health problems such as osteoporosis. Overall, individuals are more likely to delay in engaging with support services leading to more acute situations and poorer outcomes. LGBT carers who live in remote or rural areas can face additional barriers due to a lack of services which are able to respond appropriately to their needs and preferences.

The inability of local services to meet the needs of LGB carers was highlighted in the recent 2021 Carers UK State of Caring Report which found that 30% of gay and lesbian carers and 33% of bisexual carers compared to 28% of heterosexual carers.

Recent research exploring the impact of COVID-19 on LGBT+ communities found that mental health deteriorated, loneliness significantly increased and the availability of vital support networks were substantially reduced. Specifically:

- LGBT+ people were at greater risk of negative covid-19 health and economic outcomes;
- LGBT+ people reported heightened experiences of poor mental health throughout the pandemic with the number of LGBT+ people reporting “poor” or “very poor” mental health rising from 34% to 61%;
- Trans and non-binary people were more likely to be disabled and to have chronic health conditions than their cis-gendered counterparts;
- LGBT+ loneliness more than doubled throughout the pandemic at 56%. This was as a particular consequence of the loss of support networks, chosen family and stigma-free support from LGBT organisations;
- Elderly people were particularly effected by the loss of contact from LGBT+ support networks and high levels of ‘shielding’, again resulting in a loss of support. 52% of gay men over 50 live alone in comparison to 19% of heterosexual men; and,
- Digital exclusion for LGBT+ older people contributed to increased isolation due to lack of devices and connectivity.

8 Phillips (2021) https://www.bmj.com/content/bmj/372/bmj.m4828.full.pdf
9 Ibid
11 Ibid Phillips
12 Ibid LGBT Foundation
Recommendations:

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- To require local authorities to explicitly set out in their local carer strategy, how they are meeting or intend to meet the Duties placed on them with specific regard to the equality requirements within the Carers (Scotland) Act (2016) and the Duties overall to support carers;
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Carers with a Disability/Longterm Condition

There is little research evidence that explores the experiences of carers who have a disability or longterm condition themselves despite this being a significant proportion of the overall carer population. Figures from the 2011 Census record a total of 133,361 carers who self-reported having a disability or longterm condition which affected their ability to carry out day to day tasks either ‘a little’ (79,468) or ‘a lot’ (51,893). The growing number of older carers, as the population ages, may also mean that more carers are experiencing personal health issues and are having to manage these alongside those of the person they are caring for. A report published by Age UK (2017) estimated that 55% of carers aged 65+ had a long-standing illness or disability.

Findings from the 2014 Carers UK enquiry into ‘Caring and Family Finances3 highlight that carers with a disability were more likely to give up work to care and much less likely to be in paid work alongside caring than non-disabled carers. The report also notes that carers with a disability or long-term illness were significantly more likely not only to be in debt but to have considerably higher levels of debt than other carers, most notably due to their own disability related expenditure and reduced earnings.

Data taken from recent Carers UK State of Caring Report 2021 highlights that 33% of disabled carers who responded felt that the care and support services in their areas did not meet their needs.

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