Supporting LGBTI Carers in Europe

Challenges, Key Lessons and Policy Insights

Eurocarers' Position Paper

EUROCARERS
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Key messages

The experience of LGBTI carers remains largely invisible in policy, advocacy and research in Europe – both in the context of the carers' movement, and LGBTI movements.

This paper aims to shed light upon their challenges and needs, as well as their distinctive caregiving approaches which offer invaluable insights for society as a whole. Understanding the uniqueness of their experience is essential for those working with and for informal care in Europe, to ensure more inclusive advocacy going forward.

To underpin this, this position paper highlights the following key messages:

It is essential to call for a holistic approach to social policy by breaking down silos and emphasising the link between LGBTI and care policies.

The current EU LGBTIQ Strategy 2020-2025 does not address long-term care, and similarly the EU Care Strategy overlooks LGBTI people and other minority groups. This disjointed approach to policy hampers the ability of social investments to respond to people's needs adequately.

More research is needed on LGBTI carers in Europe as a whole and at national level.

Currently, a lack of understanding of their experience in specific local contexts hampers efforts to address their needs in policy discussions, and results in LGBTI carers remaining invisible.

Policy, research and advocacy should focus more on the experiences of minorities and marginalised groups in informal care.

Recognising and valuing the diversity of informal care experiences is crucial for supporting individuals on their caregiving journeys and for ensuring that people can continue to care for others. This approach enhances the understanding of informal care as a complex and rich field of study, moving away from a simplistic and monolithic view of the subject.

Challenging gender norms in caregiving strengthens communities' resilience to the pressures of intensive care ...

... and fosters a more inclusive society that views care as a collective responsibility and values all who provide care to others. This may happen more organically amongst those LGBTI individuals who are prone to challenge normative assumptions about gender in all aspects of their life. Greater efforts are needed to encourage a similar paradigm shift in broader society, where 'traditional' gender attitudes still prevail, often disadvantaging women.

It is crucial to centre friend carers in discussions about informal care.

This group often takes the backseat within the carers' movement and in policy. However, the experience of how care is organised within LGBTI groups beyond the confines of the nuclear family, is a reminder that a more collective model of care is possible and desirable.

Specific provisions must be established for young LGBTI carers

Professionals interacting with young carers (including those in educational settings) should be adequately equipped to meet the needs of LGBTI youth and create safe and affirming environments, also for those who have not yet come out.

1. Introduction

Why a position paper on LGBTI carers?

An informal carer is a person who provides – usually – unpaid care to someone with a chronic illness, disability, or other long-term care needs, outside a professional or formal framework. Becoming an informal carer at one's point in life is a rather common experience: Eurofound estimates that at least 12% of people above the age of 18 (44m individuals) provide informal care at least twice a week in the EU[1]. Informal carers provide the bulk of long-term care in Europe[B], although their role and contribution are not uniformly recognised, and the level of support they are entitled to varies considerably from country to country.

It is incorrect and unhelpful to frame informal care as solely negative and burdensome: when adequately supported, and a free choice, it can be an empowering and fulfilling experience. For this to happen, however, **carers need to be supported with adequate legislation and policies – otherwise informal care risks exacerbating pre-existing vulnerabilities and inequalities.**

Informal care therefore needs to be addressed within a social protection framework. The role of social protection is to provide a safety net that ensures economic and social security for all citizens, support active inclusion and promote a fair and cohesive society. Within this framework, in 2017 the EU introduced the **European Pillar of Social Rights**, described as 'a rulebook to ensure that everyone has the same chances in life' [2]. It serves as a political compass to achieve better working and living conditions in the EU, and consists of 20 principles to support fair and well-functioning labour markets and welfare systems.

With social protection in mind, this position paper focuses on informal carers that belong to a specific minority group: LGBTI individuals. The 'LGBTI' acronym stands for 'Lesbian, Gay, Bisexual, Trans and Intersex', also including other sexual and gender minority identities[C]. The European Pillar of Social Rights addresses the topics of LGBTI equality and long-term care respectively in Principle 3 (on 'Equal opportunities') and Principle 18 (on 'Long-Term care'), regarding both as essential policy areas to build a fairer and more inclusive European Union [3].

This paper explores how being LGBTI affects experiences of informal care – both in the case of caring for other people who also identify as LGBTI, and for people who do not. To do so, it discusses specific challenges faced by LGBTI carers (Section 3), what broader society can learn from caregiving practices that exist within LGBTI groups (Section 4), what can and should be done to support them better (Section 5).

Currently the topic of LGBTI carers is still widely under-researched in Europe. We hope this position paper will encourage researchers and public authorities to better investigate their experience, and help put this topic on the policy agenda. Additionally, we hope it also inspires them to pay closer attention to the intersectionality of compounded discrimination faced by this and other minority groups in caregiving roles.

Conceptual frameworks

The aim of this paper is to promote discussions on what it means to be an LGBTI individual and a carer, from an intersectional point of view. Informal carers and LGBTI individuals are not a monolith. Within both groups coexist layers of vulnerability and privilege originating from the interplay of factors such as gender, race, class, age, sexual orientation, gender identity, disability, carer status. To analyse the experience of LGBTI carers it is therefore crucial to understand how different axes of oppression shape the lived experiences of different individuals.

This aligns closely with the concept of **'person-centred care',** which has been gaining prominence in recent years. This approach accounts for individual needs and specificities in the provision of care, as opposed to a 'one size fits all' approach. The World Health Organisation [4] and the EU Care Strategy [5] have endorsed this framework, emphasising that access to long-term care should be personalised and inclusive, ensuring that each individual's needs are met appropriately.

In these times of budget constraints on health and social care, it is even more crucial to make sure that **social investments** address people's needs adequately. Understanding the experience of LGBTI carers is the first step to ensuring they are not left behind or remain invisible.

2. Prevalence of LGBTI carers

There is a concerning lack of data on the prevalence of LGBTI carers in the EU. Some data is available for the US and the UK, where conversations on this topic are more advanced. The US National LGBTQIA+ Health Education Center [6] reports that, in 2020 the typical LGBTI carer was 42.4 years old and unmarried, and was most often caring for a parent or grandparent living within a 20-minute drive. LGBTI carers reported high-intensity caregiving situations, spending typically 28 hours a week assisting with care needs. They were more often the primary carer of their care recipient. Carers Wales reports that 16% of people who identified themselves as being LGBTI in the 2021 UK Census also identified as being a carer [7], a higher proportion than among non-LGBTI people.

Research shows that LGBTI individuals are more likely to be carers than someone who is not LGBTI [7, 8, 9]. This happens for a variety of reasons that the rest of the paper will examine in detail. For example, it is common among older LGBTI adults to need to rely on informal caregiving arrangements, as a result of a lifetime of discrimination in employment and other economic disparities. Being LGBTI makes many people afraid to enter institutionalised care due to risk of violence, harassment, or discrimination, therefore local community groups may be more likely to create care systems internally to protect LGBTI individuals needing care. Older LGBTI individuals and those living in countries with fewer civil rights are also less likely to be part of traditional family support networks, and may need to rely more on each other in times of illness, old age or crisis. Having fewer opportunities to become parents themselves can also result in more intra-community care among LGBTI individuals. Among those LGBTI individuals who openly challenge traditional gender norms, there might also be more openness towards caregiving roles, which in heterosexual and cisgender relationships are disproportionately assigned to women. For this reason, and because generally they are less likely to have parenting responsibilities of their own, LGBTI individuals may face increased and unfair pressure from biological families to become carers for their parents and grandparents during old age, or when long-term care needs arise.

3. Challenges and obstacles faced by LGBTI carers

Identity and 'coming out': what does long-term care mean as a LGBTI person?

Being an informal carer can be an all-consuming occupation that often takes up all the time and energy a person has to give. This not only hinders carers' participation in society, it also exacerbates the risk of social isolation, which can lead to rapid mental health deterioration. When they are not adequately supported – for example through respite care services and community support groups – it is quite common for carers to experience loss of personal identity, which is entirely absorbed by caring responsibilities [10, 7]. This has a tremendous impact on carers who rely largely on community support, as is often the case for LGBTI individuals. For many, being severed from their social support groups means losing a safe space to express one's identity and affirm one's sense of self. This is especially detrimental when the people in need of care are not as accepting of a carer's LGBTI identity.

At the same time, coming to terms with one's multifaceted identity as an LGBTI carer can be challenging. More attention is needed on what ageing, disabilities and long-term care entail for LGBTI individuals. Older LGBTI generations were often precluded from inhabiting these scenarios openly and proudly, having to hide their true selves due to severe homophobia and transphobia present in healthcare and social care institutions. This was especially severe during the AIDS crisis, when medical institutions were complicit in reinforcing the social stigma attached to being LGBTI. In many ways, we are currently witnessing the start of conversations about the intersection of long-term care and LGBTI identities, and a growing awareness around these topics.

Research conducted in recent years[D] shows that many LGBTI people remain invisible within older people' organisations, which often fail to investigate and address their needs due to persisting prejudice and taboos around sexuality, sexual orientation, gender identity and gender expression [11]. Older LGBTI people also face ageism within LGBTI groups. This is caused by ageist myths and beliefs that are still rooted in society, such as 'ageing leads to loneliness', 'all older people are post-sexual', 'ageing is depressing' and 'all older adults are heterosexual and cisgender' [11]. Overall, the right to enjoy consensual sexual expression and activities in old age is not always respected in today's society, an attitude that is reflected in long-term care services, and even more so when it comes to older LGBTI people and those who care for them [11].

Family relations

Informal care by definition happens in the context of social relationships that pertain to the most intimate sphere of those involved, such as family relations, romantic relations and friendships. Being LGBTI has a significant impact on these interpersonal relationships and, therefore, on the experience of providing informal care.

Prejudice, discrimination and lack of acceptance are unfortunately still common in Europe [10]. This can create complex situations when LGBTI individuals find themselves caring for a family member that is not affirming or accepting of their identity or experience. As a consequence, LGBTI carers might need to hide aspects of their lives while caring for others and potentially restrict time with people who matter to them, such as LGBTI friends or intimate partners. A quote from a queer carer[E] reported by Carers Wales [7] explains that:

> *"As a queer carer looking after someone, I've had a challenging time with regards to my sexuality. Caring put me in an uncomfortable position of more proximity to someone I found difficult to be around. Compared to other people and places where I can be my full self, I noticed that I minimised aspects of myself that would set my mum off, in a way partly retreating into the closet. The intimacy that exists between a disabled person and their carer has scope to really strengthen some relationships, but instead it made me feel unsafe and performative at times."*

At the same time, LGBTI individuals can also experience greater pressure to take up caring responsibilities if they are not married/in a civil union – which is still not possible in several countries in Europe[F] – and/or do not have children, based on the assumption that they have more time and energy to dedicate to caregiving [10]. In other cases, pressure derives from deep-seated beliefs about gender roles, which assign caring responsibilities to women and other marginalised gender and sexual identities. Willis, Ward and Fish [12] report a quote from a research participant who was assumed to be a suitable carer for his grandmother solely based on his sexual orientation as a gay man:

> *"And what I found was, first of all, the expectation. It sounds really silly, but how can I put it, the district nurse would say 'Peter come in and have a look at this, have a look at your Nan because you are going to have to clean her up later'. So, my Nan is eighty-four [years old, and is standing] there stark naked. Which is my Nan, so it's sort of ok. And it was commented on by a couple of nurses at one point, 'but you are gay so you are allowed to see it'".*

The authors of the paper reflect on the fact that a heterosexual man in the same situation would not have been expected to undertake this level of intimate care for older women in the family, nor would have been perceived as an appropriate provider of care more broadly – which is a similarly biased assumption in itself.

Historically, LGBTI individuals have been less reliant on support from their families of origin, due to prior experiences of discrimination and rejection that stem from widespread homophobic and transphobic attitudes in society [13, 14]. Same-sex marriage, registered partnerships and parental rights are not fully recognised or accessible across the whole of the EU, and in many countries these rights have only been obtained recently [15]. This discrimination has an impact on care and on the aftermath of the caregiving period – such as in the case of death of the person receiving care, bereavement and other major life transitions. The

experience of an LGBTI person caring for their spouse can vary considerably from a legal, bureaucratic, and financial point of view, depending on the extent to which their relationship is recognised in their country. A member of the Alzheimer's Society of Ireland, recounting the time when his late husband was in the process of being diagnosed with Early-Onset Alzheimer's Disease, explained [16]:

> *"The thing I found most difficult to cope with at that time is [that] we were not recognised legally. We had no legal partnership, or anything like that. So, his mother was his next of kin, and that was a huge worry for me, because I knew, even if we had not been given the diagnosis [yet], I knew there was an awful lot we would have to go through. So, when the opportunity arose in 2012, we had our CP [civil partnership] despite some reservations by his family and some pressure to postpone. But we didn't, and I'm very glad we didn't".*

For all these reasons, LGBTI individuals may rely more on support networks other than the nuclear family. 'Families of choice' (i.e. friendships networks, lovers, ex-partners, a few trusted relatives) are of great importance among this group and this is often where informal care takes place [12]. **The experience of LGBTI carers is an important reminder that more recognition and support is needed for friends and chosen families that are informal carers.** As a group, they are often sidelined in conversations about long-term care, and not always recognised on par as family members and romantic partners who take up this role [10]. Generally, they may not be able to rely on traditional sources of support for carers that have been developed for biological relatives and spousal carers, even though research shows that the two groups do not differ in levels of perceived stress or depressive symptomatology deriving from caregiving [17].

Financial vulnerability and poverty

Informal carers often face financial precarity due to income loss, reductions in paid employment, limited state income support and direct costs associated with care - such as medication, special diet, medical devices and home adaptations [18]. This reality keeps them from accessing social protection and contributes to locking informal carers (especially women) in poverty and social exclusion. According to Eurofound, 45% of non-working carers are in the lowest income quartile (compared to 25% of non-carers), while 54% of non-working carers have difficulty making ends meet (compared to 38% for non-carers) [19].

The economic impact of informal care affects more heavily those who already experience other types of vulnerability and discrimination, such as LGBTI people. According to the Center for LGBTQ Economic Advancement and Research [20], in 2019, one in four LGBTI Americans experienced financial difficulties due to their sexual orientation and, on average, LGBTI workers earn less than their heterosexual and cisgender peers. While data on socioeconomic inequalities among LGBTI individuals in Europe are limited, analysis conducted by ILGA Europe and FEANTSA [21], shows that LGBTI people often face discrimination when seeking employment and discriminatory treatment at work, leading to financial insecurity. More specifically, 10% of all respondents to the 2019 LGBTIQ Survey II conducted by the EU Fundamental Rights Agency reported being discriminated against when looking for a job on the basis of being LGBTI in the past year [21]. This is especially true for the most marginalised LGBTI groups, such as intersex people and trans women, who experience more severe financial discrimination in the workplace and other related areas, such as access to housing [21, 22, 23]. Women in same-sex relationships are also more likely to have a smaller joint income compared to women in different-sex relationships because of pay gaps between men and women, and experience greater financial difficulties due to accumulated loss of income [24].

The intersection of these different layers of discrimination is compounded for LGBTI carers. Carers UK reports that, when comparing the experiences of lesbian, gay and bisexual carers to heterosexual counterparts, the former were more anxious about their financial situation and more likely to say they were struggling financially [10]. UK research also shows that caring has a negative impact on the finances of lesbian, gay and bisexual carers. All three groups were more likely to report that they could not afford their rent or mortgage payments, and that they are or have been in debt as a result of caregiving, compared to heterosexual carers [7].

Discrimination and stereotyping

Individuals often face discrimination in the workplace and other social contexts after revealing their LGBTI identity or disclosing their role as carers. Coming out can be especially challenging for individuals who may fear discrimination based on both being a carer and being LGBTI. Carers UK reports the strain of having to continually 'come out' to care services when assumptions are made about one's sexual orientation or gender identity, or the relationship with the person receiving care [10]. Within the context of long-term care though, coming out does not always feel like a safe option. Some LGBTI carers report feeling that they need to go 'back in the closet' due to fears of discrimination or unfair treatment by social care and healthcare services and biased individuals working in the sector [10].

Willis, Ward and Fish [12] relate that several research participants did not consider overt experiences of discrimination worth reporting, because of the emotional resources required to challenge discriminatory treatment from healthcare professionals. Providing care was seen as a higher priority than challenging discriminatory treatment. In this sensitive context, the majority of carer's emotional and cognitive resources are taken up by their caregiving role [12]. The paper also describes several instances where stereotyping based on normative assumptions about gender, sexual orientation and care impacted the experience of LGBTI carers, as explored in the section on family relations. These attitudes reduce individuals to stereotypes and lead to neglecting the actual needs and preferences of both the carers and those receiving care. This clearly undermines the principle of person-centred care.

Navigating discrimination and stereotyping in long-term care can prove especially challenging for older LGBTI individuals, who have lived through times of significant prejudice and oppression at the hands of society, governments, legal systems and healthcare institutions [10, 7].

Physical and mental health

The physical and emotional strain of care can have heavy repercussions on the health and wellbeing of carers. Informal carers tend to experience poorer physical and mental health outcomes than non-carers, and are at greater risk of becoming in need of long-term care themselves [25, 26]. Evidence suggests that the burden of caregiving is most acute among marginalised groups, such as those who are socially isolated, of lower socioeconomic status, from racialised minorities and from LGBTI groups [27, 28]. This phenomenon is known as 'minority stress' [29].

LGBTI individuals experience disproportionately poorer health and mental health outcomes than their heterosexual and cisgender counterparts. The 2023 LGBTIQ III survey conducted by the EU Fundamental Rights Agency (FRA) [30] found that LGBTI people face severe difficulties in accessing healthcare, in many cases leading to forgoing treatment (5%), avoiding seeking necessary healthcare (6%) or being refused treatment by medical professionals (2%). Around 5% of respondents reported they had to change general practitioner due to negative reactions. Mental health is another sensitive domain for LGBTI people. More than one third

of respondents (37%) to the 2023 FRA survey had contemplated suicide in the year before the data collection [30]. This proportion is even higher for trans women (59%), trans men (60%) and non-binary and gender-diverse respondents (55%). It is also very high among those who are severely limited by disabilities (66%) and those who face financial difficulties (58%). Among LGBTI individuals, the likelihood of facing mental health challenges is also aggravated by experiences of abuse, discrimination and hate crimes along the life course [10, 17].

For all these reasons, informal care can be more taxing for LGBTI individuals. LGBTI carers may find that not only they are more likely to care for someone who has a physical and mental health condition, but often face considerable challenges with their own health and wellbeing at the same time [7]. UK research shows that this group is more likely to feel lonely or isolated, and to have poor mental health, compared to non-LGBTI carers [10]. A Carers UK analysis of the 2021 NHS England GP Survey found that 70% of lesbian, gay and bisexual carers reported a long-term health condition or disability, compared to 60% of heterosexual carers[10]. In addition, some people may have difficult relationships with family members who are not accepting of their being LGBTI, resulting in increased loneliness or lack of support with caregiving [10]. Some carers then may refrain from seeking mental health support due to concerns that support services are not LGBTI affirming, or simply not prepared to provide inclusive support that recognises all aspects of their identity [10].

Young carers

Young Carers are children and young people under the age of 18[G] who provide care for a parent or a relative in the community, usually within their own home. When they do not receive adequate support, this comes at **great personal expense**: they can be deprived of their childhood, miss out on educational opportunities and have few established friendships and support networks [31]. Young Carers are also at greater risk of not completing their formal education and are generally less able to access higher-education, increasing their chances of social exclusion later in life [31].

These difficulties are even more severe for young LGBTI people. Young LGBTI people face greater obstacles to advocate for themselves and their needs, due to their lack of financial and legal independence. When growing up in hostile environments (i.e. family of origin, school setting, social circles), it is more difficult for them to access safe, affirming spaces and support. In a recent publication, ILGA Europe and IGLYO [32] found that over 45% of respondents to the 2019 LGBTIQ II survey conducted by the EU Agency for Fundamental Rights[H] aged 15-17 feel discriminated against by school staff. Almost a third of young respondents (32%) indicate that they have been physically or sexually attacked, compared to 24.5% of LGBTI respondents of all ages. Exposure to attacks from a family member was particularly striking: almost 10% of LGBTI youth aged 15-17 reported that a family member had perpetrated an attack, with those experiencing intersectional marginalisation being even more likely to have familial perpetrators[I].

The experience of young LGBTI carers is noteworthy in all the areas where challenges for LGBTI carers have been identified, but their difficulties are even more pronounced. Similarly to the data gaps described earlier in the paper, there is a lack of research and data on young LGBTI carers in Europe. However, UK-based research allows us to paint a picture of the obstacles this group faces. A report by Carers Trust Scotland[33] found that almost a quarter of young LGBTI carers may or did drop out of education because of financial difficulties, and 28% have debt that causes worry. Overall, being a young LGBTI carer was found to have an impact on job prospects and the ability to build a stable future. Bullying and harassment are also major concerns, as the study found that 83% of young LGBTI carers experience bullying in school [33]. Gino, a young LGBTI carer from the Netherlands, explains that [34]:

"I was bullied a lot in both primary and secondary school. I didn't connect with my peers, I had to deal with a tough home situation and in addition I struggled with my gender identity in my teenage years. I didn't really have a place where I felt really safe, except at the youth centre where I went with my mother from a young age".

In terms of physical health outcomes, 80% of young LGBTI carers rated their own health as 'ok' or 'Poor', while over 60% do not feel safe and supported by the National Healthcare System - especially trans kids [33].

4. What we can learn from caregiving practices within LGBTI groups

Being LGBTI not only poses challenges for informal care, that need to be handled carefully, it also shapes care in positive ways that broader society can learn from.

The prevalence of LGBTI individuals caring for other LGBTI individuals beyond the confines of the nuclear family exemplifies that care does not necessarily centre around biological relations, and that community and friendships play a prominent role [13]. In this group there is a higher prevalence of friends who provide regular care to other friends, who are often left out of discussions about informal care. Looking closely at the experience of LGBTI carers allows us to shed light on a model of care that is based to a greater extent on **reciprocity and caring** as core pillars for mutual support. This is the result of a long history of adversity, discrimination and lack of support from institutions and the medical establishment, which compelled people to rely on one another for survival [13]. The AIDS crisis in the 1980s/90s for example, albeit vastly traumatic, helped to develop a culture of mutual care among LGBTI populations [35].

Present-day experiences reflect this caring legacy very clearly. One example is **care provided among trans individuals to access trans-specific healthcare** [12], which is often a very difficult and lengthy process in many countries in Europe [36]. Willis, Ward and Fish's research [12] included trans individuals who shared accounts of community-based care among this group. They found that while participants did not explicitly identify as carers, their stories described caring practices where they advocate for one another in medical settings, respond to individuals in crisis, and set up local communities of care. These roles and practices stem from a lack of suitable health and social care services available for trans individuals, which compel people to show up for one another [12]. Tim[J], an informal carer from Dutch-Indonesian background, explains that:

"My friends, my chosen family, also represent and support these important values; together we form a social support system that supports, empowers and also cares for each other. For example, in our local LGBTI community there is a trans drag activist who is always in the front line when it comes to fighting for our rights. This year she had a facial feminisation[K] surgery and couldn't work during the time of her recovery; in response the community started a crowdfunding to support her financially in that period. I think this situation illustrates beautifully how we can care for each other as a

community, and that we must take into account that one can also be an informal carer for their chosen family member; that a blood-line should not be a requirement to be recognised as an informal carer and receive support where necessary".

The widespread provision of informal mental health support among LGBTI individuals demonstrates the power of community-based care in responding to unmet needs [37]. Such unmet needs often arise from a reluctance to engage with mental health services due to the potential to experience discrimination and stigma, as well as a lack of cultural competence among mental health professionals regarding LGBTI clients. Participants in a recent study recount engaging in unpaid work outside of professional settings to support their peers' mental, emotional, and physical health in both acute and chronic situations [37]. They viewed their roles in informal mental health support as meaningful for various reasons, including a sense of purpose, aiding important people in their lives, and a desire to help other LGBTI individuals in times of need.

Lastly, the experiences of LGBTI people are also defined by the participation of some community members in political activism, which shaped their self-awareness as political actors. LGBTI individuals have a long collective history of advocating for themselves, community organising and demanding political change. This allowed to forge a transnational movement that has been able to achieve significant gains for the rights of LGBTI individuals in Europe and beyond [38]. Obtaining the same political positioning has been harder for the carers' movement as a whole, even though significant gains have been made in Europe throughout the last few decades[L]. While the active social and political marginalisation experienced by LGBTI people remains unique - including criminalisation, conversion practices, and lack of legal access to functioning identity documents to participate in society - analyses of the experience of LGBTI carers show that some of the demands of the LGBTI movement and the carers movement are converging. **This suggests a common ground for the carers movement to join forces with other civil rights movements in demanding social and political change in Europe.**

5. Recommendations to better support LGBTI carers

Actions to ensure LGBTI carers receive better support and recognition can be actioned at different levels of society, care services and policy making. Key efforts should include:

Information and training

- Carers organisations should have access to and take part in specific training and education on LGBTI issues.
- LGBTI organisations should have access to and take part in specific training and education on informal care.
- Carers organisations should provide their target audiences with training and awareness raising initiatives focusing on LGBTI individuals, and specifically the challenges and needs of LGBTI carers, in order to improve the attitudes and inclusion of this group in the carers movement. Carers organisations should also audit their services and projects to ensure they are providing an inclusive service that LGBTI carers feel they can safely access.
- LGBTI organisations should provide their target audiences with training and awareness raising initiatives focusing on the role, needs and challenges of informal carers, as well as what rights they are entitled to. LGBTI individuals are not the usual target of information campaigns on the state of play of informal care, and this should change.
- Carers organisations should provide training resources focusing specifically on the needs and challenges of young LGBTI carers. Intersectional identities should also be embedded in all educational materials, focusing on how the experience of other marginalised groups shapes informal care.
- Health and social care services should improve LGBTI awareness and competence among staff that interact with informal carers, to ensure they are well equipped to interact with LGBTI carers without bias and prejudice.

Health and wellbeing of carers

- Carers organisations and carers support services[M] should set up dedicated services and programmes for the wellbeing of LGBTI carers, addressing their specific needs and using a person-centred approach.

- Carer support services should promote initiatives that focus on prevention, positive mental health and resilience of carers, instead of providing support only in situations of crisis.
- Carer support services should assess the needs of the care recipient and informal carer as a unit, in addition to focusing on their individual needs.
- Carer support services should provide holistic assessment of the needs of young carers, including their future aspirations and life plans beyond and after caregiving.

Inclusive practices and attitudes

- Carers organisations should set up specific support groups (including peer support groups, and buddy systems) for LGBTI carers and young LGBTI carers. They could also explore the role that community centres can play in reaching minority groups and connecting social organisations that are committed to these groups.
- Carers organisations and carer support services should use inclusive paper forms and electronic records that affirm LGBTI individuals. For example, recording name changes, non-binary identities, people's pronouns and partner, even if same-sex partnerships are not legally recognised.
- Carers organisations and carer support services should provide legal resources tailored to the needs of LGBTI carers, specific to the national context.
- Health and social care services should support the creation of certifications for services that are LGBTI inclusive, for instance following the example of De Roze Loper[N] in the Netherlands, and with a specific focus on LGBTI carers.

Communication

- Carer support services should use inclusive and affirming language, respect people's pronouns and name, even when they are not legally recognised at national level. When interacting with carers, they should not make assumptions about their gender identity, pronouns, sexual orientation, family status or partners.
- Carer support services should display and publish LGBTI affirming materials: including images of same-sex couples, people stating their personal pronouns, rainbow flags and staff badges.
- Carers organisations and health and social care services should embed intersectional identities in promotional resources, including LGBTI people belonging to minority groups and young LGBTI carers.
- Carers organisations and health and social care services should create dedicated information hubs and channels specifically for LGBTI carers, with particular attention to young LGBTI carers.

Research and data

- Research institutions should increase research efforts on LGBTI carers in Europe, as the majority of studies have been conducted in the UK, US and Australia. More comparative research is needed to understand how experiences differ across countries, what are the key commonalities, and how to develop synergies at EU level.
- Researchers should collect data specifically on the experience of LGBTI carers (including young LGBTI carers) to address current gaps in research. While greater attention is dedicated LGBTI individuals in care settings and as care recipients, their experience as informal carers has not been studied as widely yet.

- Researchers should focus on the experiences of minority groups in providing informal care from an intersectional perspective, recognising the complexities that arise from overlapping identities.
- Carers organisations and health and social care services should conduct participative research, involving LGBTI carers in designing and testing support programmes and tools.

Policy

- Policy makers at EU and national level should promote a holistic approach to social policy by breaking down silos and emphasising the link between LGBTI and care policies, for instance drawing inspiration from the new Australian National Carer Strategy 2024-2034 [39]. As of now, the EU LGBTIQ Strategy 2020-2025 [40] does not address long-term care, and the EU Care Strategy [5] overlooks LGBTI people and other minority groups. It is important to establish these links in light of the upcoming EU Anti-Poverty Strategy, to address root causes of poverty and discrimination through an intersectional lens, and the new Gender Equality Strategy and EU LGBTIQ Equality Strategy.
- EU Member States should take into account the needs of LGBTI carers when implementing the Council recommendation on access to affordable high-quality LTC.
- EU Policy makers should ensure EU funding is available to support initiatives aimed at improving support and recognition for LGBTI carers.
- Policy makers at national level should amend national legislation on informal carers (where available) to ensure that LGBTI carers have the same rights as other carers, for example when creating a carer status, carers' entitlements, or carers' employment contracts.
- Policy makers at all levels should involve LGBTI carers (including young LGBTI carers) in policy making, through active participation in the design, implementation and evaluation of policies. They should regularly consult their representatives at both national and EU levels, including young LGBTI carers.
- Policy makers at all levels should utilise research and data about LGBTI carers, and young LGBTI carers, to inform evidence-based policy development.
- Educational institutions should establish inclusive policies, services and interventions to support LGBTI student carers. These actions should be inclusive and accessible to all those students that might not have come out yet.
- Employers should implement inclusive and flexible employment and training policies that accommodate LGBTI carers' needs.

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Endnotes

A. In alphabetical order.

B. When using full-time equivalents, informal carers account for close to 80% of care providers at EU level [41].

C. See the Glossary at the end of the paper (Section 7) for a more comprehensive definition of this acronym, and other terms that are specific to LGBTI groups. In this paper, the acronym LGBTI will be used unless making a reference to a narrower part of the community or quoting from the works of others using different acronyms.

D. It is important to highlight that most of it focuses on LGBTI individuals as care recipients, rather than in the role of carers.

E. Self-identified.

F. The ILGA Europe Rainbow Map provides a comprehensive overview of the rights of LGBTI people across Europe [15].

G. Several of the challenges described here apply also to Young Adult Carers, that is people aged 18-24 who provide or intend to provide care, assistance or support to another family member on an unpaid basis.

H. For the first time, the survey included the experiences of LGBTI people under 18, and determined that young people (aged 15-24) experience some of the highest levels of discrimination across all age groups included in this research [32].

I. Within the same age bracket, 12% of ethnic minority youth, 12% of youth with disabilities, 16% of intersex youth and 17% of trans men reported being attacked by a family member [32].

J. Pseudonym. The testimonial was collected anonymously by Eurocarers via an online survey.

K. A type of trans-specific healthcare.

L. Nonetheless, several carers' organisations have been founded in Europe in the last few decades (including Eurocarers), which have been driving significant achievements for the carers' movement.

M. This refers both to carer support services provided by carers organisations and by health and social care services. Applies throughout the section.

N. https://roze50plus.nl/roze-loper/

Glossary

Bisexual:
when a person is romantically and/or sexually attracted to persons of more than one gender.

Cisgender:
a term that refers to a person who does not identify as trans.

Closet/-ed:
closeted and in the closet are metaphors for LGBTI people who have not disclosed their sexual orientation or gender identity and aspects thereof, including sexual identity and sexual behaviour. This metaphor is associated and sometimes combined with 'coming out', the act of revealing one's sexuality or gender to others, to create the phrase 'coming out of the closet'.

Coming-out:
the process of revealing oneself to be LGBTI. Originally this expression was known as 'coming out of the closet'.

Gay:
refers to a person who is sexually and/or romantically attracted to people of the same gender. It traditionally refers to men, but other people who are attracted to the same gender or multiple genders may also define themselves as gay.

Gender:
refers to a social construct which places cultural and social expectations on individuals based on their assigned sex.

Gender expression:
refers to people's manifestation of their gender identity to others, by for instance, dress, speech and mannerisms. People's gender expression may or may not match their gender identity/identities, or the gender they were assigned at birth.

Gender identity:
refers to each person's deeply felt internal and individual experience of gender, which may or may not correspond with the sex assigned at birth, including the personal sense of the body (which may involve, if freely chosen, modification of bodily appearance or function by medical, surgical or other means) and other expressions of gender, including dress, speech and mannerisms. Some people's gender identity falls outside the gender binary, and related norms.

Intersex:
refers to persons who have innate sex characteristic(s) (including chromosomal, gonadal, anatomical, or hormonal) that vary from the societal and/or medical understanding(s) of typical female and male bodies. In some national contexts, intersex persons are sometimes also referred to as persons with variations of sex characteristics.

Lesbian:
refers to a person who is sexually and/or romantically attracted to people of the same gender. It traditionally refers to women, but other people who are attracted to the same gender or multiple genders may also define themselves as lesbian.

LGBTI:
acronym for lesbian, gay, bisexual, trans and intersex. In some contexts, the acronym will also explicitly include other terms such as queer, asexual, pansexual, non-binary etc. Different acronyms (such as LGBT, LGBT+, LGBTIQ) are used in various political, social and national contexts for a variety of reasons.

Non-binary:
Refers to gender identities other than male or female.

Pansexual:
When a person is romantically and/or sexually attracted to people regardless of their gender.

Queer:
previously used as a derogatory term to refer to LGBTI individuals in the English language, queer has been reclaimed by people who identify beyond traditional gender categories and heteronormative social norms. The term also refers to queer theory, an academic field that challenges heteronormative social norms concerning gender and sexuality.

Same-sex relationships or couples:
covers relationships or couples consisting of two people of the same sex.

Sexual orientation:
refers to each person's capacity for profound affection, emotional and sexual attraction to, and intimate and sexual relations with, individuals of a different gender or the same gender or more than one gender.

Time poverty:
refers to experiencing a lack of sufficient time to fulfil responsibilities, pursue interests and engage in activities that contribute to one's well-being, due to various demands on their time. This can result from factors such as heavy workloads, long commutes, unpaid domestic work or caregiving responsibilities. Sustained time poverty over time can lead to psychological distress, exhaustion and burnout.

Trans:
is an inclusive umbrella term referring to people whose gender identity and/or gender expression differ from the sex/gender they were assigned at birth.

Trans-specific healthcare:
Psychosocial support and/or medical interventions a person may opt to undergo, in order to better express their gender identity. This process may, but does not have to, involve hormone therapy or surgical procedures. A human rights-based approach to this care should be based on self-determination and informed consent.

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