Carers
Australia SA

Supporting Family Carers

LGBTI - CARERS
ISSUES AND CHALLENGES

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THE HUB – STUDENT PLACEMENT PROJECT
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Introduction

Who Are LGBTI Carers?

LGBTI[1] carers for the purpose of this report can be anyone who provides unpaid care for a friend or relative where either the carer or the person(s) receiving care, or both, identify as LGBTI. Anyone at any time can be a carer; however, for the purposes of this report, LGBTI carers are considered to be over 25 years of age, as 'young carers' (under 25 years) have additional difficulties and challenges in addition to their LGBTI identity.

The LGBTI population in Australia is estimated to comprise between 2% to 11% of Australia's population (Policy and Community Development Division 2014, p.7). There are currently 2.7 million unpaid carers in Australia, so it follows that a significant portion of this group identify as LGBTI (Barrett & Crameri 2015, p.4). With Australia's population continuing to age, it seems reasonable that this number will continue to grow.

This report presents some discussion on three of the most significant challenges uniquely faced by LGBTI carers:

- Barriers to entry, which involve LGBTI carers avoiding accessing support services due to perceived or expected discrimination from those services.
- Various forms of conflict encountered in their caring role, leading to isolation and 'layers of grief' for the carer.
- Heteronormativity prevalent in care environments, another cause of isolation for LGBTI carers, who are often unable receive support that meets their needs.

These challenges are faced by LGBTI carers in addition to the challenges shared with other carers, and as such, LGBTI carers can be seen to hold an "extra degree of difficulty" in their caring role (Barrett & Crameri 2015, p.5).

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[1] In Australia, the Commonwealth Government uses the initials '**LGBTI**' to refer collectively to people who are lesbian, gay, bisexual, trans, and/or intersex. Some organisations or individuals prefer the initials 'LGBTIQ' to specifically add a reference to people who identify as queer.

Barriers to Entry

Some of the most crucial issues facing LGBTI carers are related to accessing support services. Barrett and Crameri (2015, p.7) identify a multitude of 'Barriers to Entry' preventing LGBTI carers from receiving appropriate support.

Expectations of Discrimination

These barriers are for the most part tied to LGBTI carers' expectations of discrimination from support services and institutions. There is little doubt that much of this expectation of discrimination is a direct result of experience of discrimination among LGBTI people, with 80% of LGBTI individuals surveyed in 2012 identifying discrimination as affecting their involvement with the wider community (Policy and Community Development Division 2014, p.7). When examining experiences of support services, it becomes clear that one of the most common types of discrimination encountered by LGBTI care partnerships, is an unwillingness on the part of support services to recognise a carer's LGBTI identity (Cartwright, Hughes & Lienert 2012, p.542). One of the most common examples of this is seen in service providers' refusal to address LGBTI carers with titles such as 'partner', instead referring to them as a 'friend' or identifying them as a family member such as a sister or mother (Scott 2016).

> "*We don't have gay packages.*"
> Barrett and Crameri 2016, p.10

Discrimination can however, be far more overt. Barrett and Crameri (2015, p.10) note that in some cases, LGBTI carers are outright blocked from accessing services. An example of this are some faith-based organisations arguing they are exempt from providing support to LGBTI carers, citing the "…psychological hazards for [staff] dealing with LGBTI people as it is against their religion" (Barrett & Crameri 2015, p.10). Barrett and Crameri also suggest that organisations may be hesitant to support LGBTI care partnerships due to the ethnic diversity of staff and clients, and an unwillingness to risk appearing culturally offensive.

In many cases, discrimination is born not of malignant intent, but rather through heteronormativity embedded within an organisation's institutional culture. This is most typically seen in documentation supplied by the institution based on the prevailing "…implicit assumption that all clients are heterosexual" (Kimmel 2014, p.49). This perhaps most notable in forms not accounting for same-sex couples, for example:

Relationship

Married ☐
Unmarried ☐

Barrett & Crameri (2015, p.10) identify the need for additional options in forms to allow LGBTI carers to receive appropriate acknowledgement:

Relationship

Married [De facto]	
Unmarried	
Other	

These barriers to LGBTI identity disclosure are seen by Hughes and Kentlyn (2011, p.439) as a major factor contributing towards LGBTI carers' fear of discrimination from support services. McGovern (2014, p.853) notes a lack of awareness of LGBTI preferred terms (Appendix A) is commonplace in many support institutions, which is particularly noticeable in the limited options provided on forms. This contributes to LGBTI carers feeling marginalised by these organisations. Additionally, carer support and advisory services often reflect heteronormative values in their media (such as advertising, posters and brochures) by a lack of representation of LGBTI care partnerships leading LGBTI carers to feel ignored (Ludwin 2016; Barrett & Crameri 2015, p.13).

Material provided by support services often does not provide first-hand experiences of other LGBTI carers. Additionally, LGBTI carers express frustration over the lack of coverage of LGBTI issues (McGovern 2014, p.852).These issues include:

- Decisions about identity disclosure
- Complex family dynamics
- Availability of specialised services (for example LGBTI support groups)\
- Dealing with care providers

Statements intended to encourage groups such as LGBTI carers can also be perceived as discrimination. Many organisations advertise their equal treatment of all carers, however, this does not always have the desired effect. Hughes, Harold and Boyer (2011, p.671) argue that such statements give organisations a mandate to overlook LGBTI carers. Peel and McDaid (2015, p.15) support this, suggesting that to

> **"Treating everyone equally"**
> …means treating everyone according to heteronormative values and expectations.

an LGBTI person, "treating everyone equally" in reality, means treating everyone according to heteronormative values and expectations. Furthermore, some service providers use 'equal treatment' as a way to block attempts by LGBTI carers to discuss any unique needs they may have as an LGBTI person. Labelling these needs as 'special treatment' allows institutions to avoid obligations to LGBTI carers (Price 2010, p.163). Therefore, efforts must be made to emphasise the institution's commitment to meeting the needs of the individual. "Your needs matter" and similar statements better serve to present an organisation as approachable, as they avoid implying that individuals will be dealt with according to predetermined categories.

Forms of discrimination:

- Lack of recognition of LGBTI identity.
- Service withheld on basis of LGBTI identity.
- Heteronormativity in support services
  - Assumptions
  - Incorrect terminology
  - Lack of representation in support organisations
- Mixed messages – '*equal treatment*'

Delaying Accessing Support

As a result of these expectations of discrimination, LGBTI carers are often unwilling to approach support services (Price 2012, p.518). Cartwright, Hughes & Lienert (2012, p.539) identify older LGBTI carers as particularly susceptible to this, developing fear, mistrust and wariness of support services based on a combination of life experiences and expected discrimination. Increasingly, LGBTI carers have delayed or entirely avoided accessing support, which Barrett and Crameri (2015, p.7) identify as a crucial factor contributing towards carer isolation. Closeted care partnerships are another group that often avoids seeking support services, preferring seclusion rather than risking encountering discrimination. However, isolated care partnerships tend to result in carer burnout, as the lack of support puts enormous strain on the carer (Cartwright, Hughes & Lienert 2012, p.540). By addressing the types of discrimination detailed above, organisations can help to reduce

Conflict and Layers of Grief

Another significant issue for LGBTI care partnerships is caused by conflict encountered in their caring role. Conflict can occur between the carer and the person they care for, as well as with family members, friends and even other (formal) support service providers.

Conflict with Person being Cared for

In many cases, LGBTI people care for family members who are not accepting of their LGBTI identity. As a result, the carer may struggle to live with the consequences of homophobia displayed by the person being cared for, leading to erosion of the carer's self-esteem and straining same sex relationships for the carer (Barrett & Crameri 2015, p.6). The increased closeness and interdependence required in a care partnership is extremely significant for some carers, as they struggle to cope with the disapproval by the person being cared for (Barrett & Crameri 2015, p.15). However, this may only comprise one of many 'layers of grief' brought about by the situation. Many carers describe difficulties encountered in dealing with the shock caused by a rapid change in the relationship dynamic between themselves and their loved one. A common example being that

> "*Before I was retired, in love, happy with the person I had found to be my life partner. After a diagnosis of dementia things had to change and through no fault of ours and with no cure, we were headed in one direction - Of course things changed*"
>
> LGBTI carer quoted in Barrett & Crameri 2015, p.9

carers "…feel more like a servant" than a person of equal status, a partner or child of the person being cared for (Barrett & Crameri 2015, p.8). In many cases, this further compounds pre-existing conflict, and LGBTI carers are particularly affected by this due to their reluctance to access support services.

Conflict with Family

Conflict can also develop between the carer and the family of the person being cared for, especially when the carer identifies as LGBTI and the person being cared for may not, or where families of either carer or person being cared for face barriers to accept their LGBTI status

Cartwright, Hughes and Lienert (2012, p.539) describe situations in which biological family members of the person being cared for take control of all decision making for the person receiving care (in a way denying the validity of an existing partnership). This is encountered by many LGBTI care partnerships, as the person being cared for is in many cases extremely vulnerable due to their illness or disability. Some carers even experience the breakdown of their relationship with their partner due to such conflict (Barrett & Crameri 2015, p.10). In many cases, the lack of legitimacy of particularly same sex care partnerships afforded by support services and health care providers contributes to this conflict. Often, carers are not consulted by health professionals on matters concerning their person being cared for, as they are not biologically related (Cartwright, Hughes and Lienert 2012, p.545). Peel and McDaid (2015, p.13) note that another key challenge for LGBTI care partnerships arises when services sometimes refuse to acknowledge a carer's power of attorney, citing the need to speak to a relative.

> *"An in-home visitor took the person I cared for out of home while I was in hospital.*
> *My friend was taken to her solicitor and our power of attorney was canceled because I was deemed an unsuitable person.*
> *The home visitor also attempted to have my friends Will changed... It cost us several thousands of dollars to undo the [mess] and it damaged my relationship with my friend."*
>
> *LGBTI carer quoted in Barrett & Crameri 2015, p.9*

Altogether, this conflict serves to further isolate LGBTI carers, affecting their wellbeing, their relationships with family and friends and the quality of care they are able to provide.

Heteronormative Care Environments

Some attention has already been given to heteronormativity in support organisations. However, heteronormativity also plays a part in defining the services these organisations provide.

Support Groups

Support groups are an area that LGBTI carers often struggle to relate to. Whilst LGBTI carers do share many of the same hardships as heterosexual carers, existing support groups have difficulties understanding the unique issues and challenges faced by LGBTI carers, for example dealing with HIV/AIDS (Barrett & Crameri 2015, p.10). McGovern (2014, p.853) argues that there is a "…identifiable need for LGBTI-affirmative environments" in which LGBTI carers can be at ease and talk to people with which they have a shared common ground. However, such groups are rare and Hughes, Harold and Boyer (2011, p.670) suggest that this creates a "perception of invisibility" among LGBTI carers.

Some LGBTI carers purposefully attempt to remain invisible in support groups. As heteronormative environments, for many carers, a general carer support group is perceived as not being the safe place it should be. LGBTI carers attending such environments remain 'closeted', limiting their interactions with the group to avoid the trauma of the forced disclosure of their LGBTI identity in a [potentially] hostile space (McGovern 2014, p.851). This is noted as a particularly important issue for older LGBTI carers, who have often experienced considerable discrimination and prejudice as a

young adult; Price (2012, p.518) notes that LGBTI communities have been known for "…caring for their own". If this was the case, it would be easy to assume that LGBTI carers were already part of extensive social networks which could fill the gaps left by heteronormative support groups. However, in order to access quality care for the people they care for, many LGBTI carers have "…uprooted themselves from networks they felt safe in" (Barrett & Crameri 2015, p.6). This is commonly seen when LGBTI care partnerships must move from rural areas to be closer to hospitals and other services. In these situations, it can take considerable time and effort for a carer to re-establish links with local LGBTI communities, time that a carer seldom has available to dedicate to activities unrelated to their caring role (Barrett & Crameri 2015, p.11). Furthermore, many LGBTI carers are older adults, often isolated with limited connections to LGBTI community groups and similar organisations. As such, it is difficult for community focussed groups to support older LGBTI individuals, who may not be willing to involve themselves with groups that are clearly identifiable as LGBTI for fear of being outed by association (Scott 2016).

Obligations and Expectations

As part of heteronormative care environments, LGBTI carers are often expected to accept a much larger portion of the caring role than other family members. In many families, there exists a preconceived understanding that LGBTI family members have fewer commitments, as they are often unmarried, without children of their own (Barrett & Crameri 2015, p.14). As a consequence, there is an expectation that LGBTI family members will assume the majority of caring obligations, accepting a much greater responsibility than other heterosexual family members who could potentially provide support or become a carers to the person requiring care (Hughes & Kentlyn 2011, p.438). As a consequence, LGBTI family carers often have difficulty balancing their caring obligations with maintaining their social networks (especially LGBTI networks). Older men are particularly vulnerable to such social isolation, which is identified as a significant issue by Hughes and Kentlyn (2011, p.439).

Recommendation

Persons in LGBTI caring relations experience discrimination and often fear discrimination which can severely infringe access to services.

Appropriate training for service provider staff is important to achieve an increased understanding of the specific needs and experiences of those persons in LGBTI caring relationships.

Providing a visibly welcoming environment, respectful and inclusive service practices and culture, as well as supporting staff with specifically relevant training are core foundations for encouraging the access of services and support.

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Appendix A – Inclusive Language in Documentation

Included below are some collated recommendations for maintaining inclusive language in forms and allowing LGBTI individual's scope to detail their preferred terms.

Creating a clear distinction between sex and gender

It is important to maintain a distinction between both an individual's sex and gender, as for an LGBTI person, a selection in one category does not preclude a different selection in another.

Including non-binary options in forms

It is recommended to avoid binary options in matters pertaining to an individual's gender and sex. Providing only two options limits an individual's control over their identity in documentation (Victorian Government 2016). One method is to provide additional fields in form sections such as below.

Gender identity? Please [tick/mark/select] as applicable	
	Male
	Female
	Transgender
	Other, please specify _____

Note the following:
- Inclusion of transgender as a distinct field. Miller and Weingarten (2005, p.3) stress the significance of this, as it presents the implication to transgender people that they are welcome.
- "Please tick as applicable" avoids forcing an LGBTI individual to select only one option.
- Gender *identity* – indicates institution respects the individual's right to self-identify.

Similar guidelines apply to titles:

Title [tick/mark/select] as applicable :
❑   Mr
❑   Mrs
❑   Ms
❑   Miss
❑   No title

"No title" allows LGBTI people to avoid titles they do not feel comfortable using.

Names

Providing both a legal first name and preferred name allows for greater control over an individual's self-identification. Miller and Weingarten (2005, p.5) recommend the following template:

Legal First Name	
Preferred First Name*	
Last Name	
*All mail and non-legal documents will use this name unless you request otherwise.	

Also note: 'Inclusive Language Guide', Government of Victoria, available online via:
http://www.vic.gov.au/equality/inclusive-language-guide.html.

Appendix B – LGBTI support services in South Australia

Name –   **Bfriend**
Services –   Mentoring support, information and referral services for people coming out as LGBTI
Website –   https://www.facebook.com/BfriendUC
                    http://www.unitingcommunities.org/find-a-service/services/bfriend/
Contact –   Phone: 8202 5805 or 8202 5192.
                    Email: bfriend@unitingcommunities.org

Name –   **Carrousel Club SA**
Services –   Social and peer support network for transgender people, their partners, families and friends.
Website –   http://www.carrouselclubofsouthaustralia.com.au/
Contact –   Email through their website:
                    http://www.carrouselclubofsouthaustralia.com.au/contact

Name –   **Catalyst Foundation**
Services –   Senior LGBTI information and activities
Website –   http://www.catalystfoundation.com.au/?s=LGBTI
Contact –   Phone: 08 8168 8776
                    Email: information@catalystfoundation.com.au
                    Location: Level 2/345 King William St, Adelaide, SA 5000

Name –   **Feast Queer Youth Drop In**
Services –   Bi-monthly drop-in support group for LGBTI youth (15-25).
Website –   https://www.facebook.com/feastdropin
Contact –   Email: ypo@feast.org.au

Name –   **Gay and Lesbian Community Services SA**
Services –   Provides LGBTI support information, resources and counselling services.
Website –   http://www.glcssa.org.au/
Contact –   Support hotline: (08) 7222 9152
                    Email: glcs@glcssa.org.au

Name –   **Murray Bridge QYouth**
Services –   Murraylands support group for LGBTI youth (16-25)
Website –   https://www.facebook.com/mbqyouth/
Contact –   Email: budeljesse@gmail.com or kaisha.wyld@flinders.edu.au

Name –   **Pride of the South - LGBTIQ Onkaparinga**
Services –   Create opportunities for LGBTIQ people to enjoy family-friendly community events in
                    the South. Promote and foster togetherness and goodwill
Website –   N/A
Contact –   Email: prideofthesouth15@gmail.com or mobile: 0481 830 452

Name –   **QLife**
Services –   Online and telephone counselling and referral service for LGBTI people
Website –   https://qlife.org.au/
Contact –   Access online chat: https://qlife.org.au/support/
                    Hotline: 1800 184 527

Name –   **Southern Fleurieu Q+**
Services –   LGBTI support group for young people in the Southern Fleurieu region
Website –   https://www.facebook.com/SFQPlus
Contact –   Email: ludcounselling@gmail.com

Note:
- *The information of these examples of services provided was correct at the time of printing.*
- *The Directory of SA Community Services: http://sacommunity.org may be of additional assistance in sourcing services based on council areas.*

Appendix C – Glossary[2]

Ally:
An ally is typically straight and/or Cis person who is openly supportive of LGBTIQ people.

Asexual:
Asexuality is an absence of sexual attraction to anyone or anything, although does not preclude romantic attraction.[3]

Bisexual or Bi:
A person who is sexually and emotionally attracted to men and women[4].

Binary:
A term that describes when two things oppose each other. For example, the literature may refer to the gender binary man/woman or homosexual/heterosexual. The use of binaries limits other ways of thinking about such categories.[5]

Cisgender or Cis:
A term used to describe when a person's gender identity matches social expectations given their sex assigned at birth.[6]

Coming out:
The process through which an LGBTIQ person comes to recognise and acknowledge both to self and to others, their sexual orientation, gender identity or intersex status.[7]

Gay:
A person whose primary emotional and sexual attraction is toward people of the same sex. The term is most commonly applied to men although some women use this term.[8]

Gender:
Characteristics that are often believed to be innate or biologically determined but include roles, behaviour, activities and attributes that a particular society considers appropriate for women and men. Note: 'Man and 'woman' are gender terms; male and female are sex terms, derived from biology and relate to anatomical and chromosomal attributes.[9]

Gender Fluidity:
Gender fluidity does not accept the prevalence of two rigidly defined genders 'Female' and 'Male'. People who describe themselves as gender fluid accept no defined boundaries and reject the fulfilling of expectations associated with any particular gender.

Gender expression:
The term 'gender expression' refers to the way in which a person externally expresses their gender or how they are perceived by others[10].

Gender Identity:
A person's sense of identity defined in relation to the social roles, attributes and behaviours customarily ascribed by society to 'women' and 'men'. For most people, biological sex and gender identity (birth assigned) are aligned, but for some (e.g.

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[2] Courtesy of Department of Community and Social Inclusion (South Australia)

[3] Smith E, et al, *From Blues to Rainbows, the mental health and wellbeing of gender diverse and transgender young people in Australia,* Australian Research Centre in Sex, Health and Society, Melbourne, 2014, p. 6

[4] Butler M, *National lesbian, gay, bisexual, transgender and intersex (LGBTI) ageing and aged care strategy*, Australian Government Department of Health and Ageing, Canberra, 2012, p.18

[5] Smith E, et al, loc.cit.

[6] ibid, p. 6

[7] Hillier, L, et al, *Writing themselves in 3: the third national study on the sexual health and wellbeing of same sex attracted and gender questioning young people*, Australian Research Centre in Sex, Health and Society, Melbourne, 2010, p. Vii

[8] ibid, p. Vii

[9] Butler M, loc.cit.

[10] Australian Human Rights Commission, *Resilient individuals: sexual orientation gender Identity & intersex rights national consultation report, 2015,* p. 5, 2015

transgender people) they are in conflict. Others identify as androgynous (as both man and woman) and some reject any gender labels entirely.[11]

Gender Queer: A person who does not subscribe to conventional gender distinctions but identifies with neither, both, or a combination of male and female genders.

Heteronormative: Describes the systemic privileging of the social models of binary sex, binary gender and binary sexuality that normalise heterosexuality.[12]

Heterosexual / Straight: Refers to a person who has an emotional, romantic and/or sexual orientation towards people of the opposite gender.

Homosexual: This might be considered a more medical term used to describe someone who has an emotional romantic and/or sexual orientation towards someone of the same gender. The term 'gay' is now more generally used.[13]

Homophobia: Fear of and/or prejudice against lesbians and gay men and their sexual desires and practices which often leads to discriminatory behaviour or abuse.[14]

Intersex: Intersex people are born with sex characteristics that do not meet medical and social norms for female or male bodies. Intersex traits include a wide range of hormonal, genetic and gonadal differences that may be diagnosed prenatally, at birth, at puberty, when trying to conceive, or through random chance. Intersex bodies and identities are diverse. Intersex people have a range of gender identities. Often these align with the sex assigned at birth, while some intersex people have chosen other identities.[15]

Lesbian: A woman whose primary emotional and sexual attraction is towards other woman.[16]

Pansexual: Refers to sexual or romantic attraction that is not based on a person's gender identity or sex.[17]

Sex: The biological and physiological characteristics associated with 'female' and 'male'. This includes chromosomal configuration, hormonal profile, reproductive organs, and secondary sex characteristics such as breast, body hair and voice.[18]

Sexual orientation: The term 'sexual orientation' refers to a person's emotional or sexual attraction to another person, including, amongst others, the following identities: heterosexual, gay, lesbian, bisexual, pansexual, asexual or same-sex attracted.[19]

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[11] Butler M, loc. cit.

[12] Smith E, et al, loc.cit.

[13] Stonewall UK, Glossary of terms viewed at http://www.stonewall.org.uk/help-advice/glossary-terms on August 18 2016

[14] Leonard, W and Mejia-Canales, D., *Something for them: meeting the support needs of same sex attracted and sex and gender diverse (SSASGD) young people who are recently arrived, refugees or asylum seekers*, La Trobe University, Monograph Series No. 107, Melbourne, p.12, 2016

[15] Organisation Intersex International Australia Limited Submission to the Australian Bureau of Statistics on proposed sex and gender identity standards, December 2015, viewed on 21 December 2016 at https://oii.org.au/30225/submission-to-the-australian-bureau-of-statistics-on-proposed-sex-and-gender-identity-standards/ December 21 2016

[16] Hillier, L, et al, loc.cit.

[17] Smith E, et al, op.cit, p. 7

[18] Butler, M., op.cit, p. 19

[19] Australian Human Rights Commission., loc.cit.

Sistergirls and Brotherboys:	Some Aboriginal and Torres Strait Islander peoples use the term Sistergirl (sometimes Yimpininni in the Tiwi Islands) to describe the male-assigned people who live partly or fully as women and Brotherboy to describe female-assigned people who live partly or fully as men. In some regions, Sistergirls have unique societal roles.[20]
Transgender:	An umbrella term including transsexual and transgender, used to describe a broad range of non-conforming gender identities and/or expressions. Usually includes all transgender people, but some transsexual people and members of the gender diverse community prefer not to use this term.[21]
Transphobia:	A fear of and/or prejudice against people who are transgender which often leads to discriminatory behaviour or abuse.[22]
Queer:	A sexual or gender identity that is non-conforming to heterosexual or gender binaries. It is also a historically located political term used to resist homophobia. Further this term also refers to academic theory and method that resists normative ways of exploring and understanding social phenomena (i.e. queer theory).[23]

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[20] Smith E et al, loc.cit.

[21] Ibid.

[22] Mejia-Canales, D. and Leonard, W., loc.cit.

[23] Smith E, et al, loc.cit.