

LGBTQA+ Communities and Mental Health Caring Relationships

Focus Group Consultation Paper to the Royal Commission into Victoria's Mental Health System
drummond street services | queerspace - supported by tandem carers

July 2020



queerspace
our health in our hands



drummond street services
wellbeing for life

tandem
representing Victorian mental health carers



We acknowledge the traditional owners of the land where we work and pay respects to elders past, present and future.

Key Recommendations

Recommendation 1: Government fund and resource whole of family and care relationship prevention, early intervention and response programs with the goal to reduce risk of family/care relationship conflict, increase resilience, and strengthen relationships; particularly during 'coming out' processes (sexuality and gender identity) and subsequent whole of family/care relationship transitions/adaptations.

Recommendation 2: The Commission propose Government invest in further adaptation and exploration of cost effective, evidence-based therapeutic and psychoeducation modalities which show positive outcomes for consumers and families (e.g. Multiple Family Group, Behavioural Family Therapy and Open Dialogue) to determine the best ways of working with LGBTQA+ communities and their family forms. **These should address both common and unique mental health risk and protective factors for each LGBTQA+ cohort.**

Recommendation 3: Provide additional investment in the capacity of services currently struggling to meet the needs of LGBTQA+ people in care relationships and LGBTQA+ people who are experiencing poor mental health and comorbidities. Ensuring these services:

- Are designed and delivered in ways that meet intersectional needs
- Reflect the service seeking trends of each sub-cohort
- Place emphasis on collaborative care (including care relationships/families, broader support networks and communities)
- Are funded to match statistical need and thorough LGBTQA+ population data analysis

Recommendation 4: The Government and the Collaborative Centre for Mental Health initiate research in consultation with LGBTQA+ carers/consumers and key specialist service providers to better understand experiences of caring between non-family members, and how LGBTQA+ community resilience can be built where circles of care may have developed.

Recommendation 5: Government resource the Collaborative Centre for Mental Health to implement the technical capacity to undertake an independent, critical examination of international and local evidence to identify effective whole of family/care relationship/s approaches to mental health. As a key part of this process; identify promising outcomes in the prevention and early intervention of mental illness for people of intersectional experiences (including diverse sexuality, genders, race, ethnicity, faith, abilities, experience of trauma among others).

Recommendation 6: The Commission propose an additional \$1 million increase, (from \$1.6 to \$2.6 million) to the Carer Support Fund to restore currency to the Fund and assist an extra 2,000 mental health carers engaged with clinical mental health services.

Recommendation 7: State Government resource more stringent monitoring of LGBTQA+ competency among mental health service providers and develop sector education resources that includes: content on the differing health and wellbeing outcomes between the range of LGBTQA+ cohorts and the impacts of intersectional discrimination.

Recommendation 8: Government fund an increase in targeted Peer Lived Experience initiatives and support groups for LGBTQA+ carers - to address and mitigate the psychological and wellbeing impacts of unsupported caring - as well as reduce the stigma and discrimination towards marginalised LGBTQA+ carers experiencing poor mental health.

Key Recommendations continued:

Recommendation 9: State Government invest additional funds to **create targeted population programs and services** to support the psychosocial and recovery needs of those Victorians not covered under the NDIS and who are 'hard to reach' including LGBTIQ+ populations.

Additional investment and expansion of these services should:

- Ensure they are designed and delivered in a way that meets intersectional needs
- Reflect the service seeking trends of particular cohorts (and sub-cohorts)
- Place emphasis on collaborative care that includes care relationships/families, broader support networks and communities.
- Ensure targeted procurement processes reflect the service seeking needs of diverse LGBTIQ+ populations
- Be funded to match statistical need and thorough LGBTIQ+ population data analysis

This will build on EIPSR and the NPS-M (National Psychosocial Support Measure), to address current gaps.

Recommendation 10: Government resource the expansion of Lived Experience Peer workforce reforms in collaboration with specialist LGBTIQ+ services to create sector guidance which responds to the intersectional concerns of LGBTIQ+ mental health carers and consumers. This includes the intersectional and complex needs of those who seek a range of services beyond clinical mental health settings (e.g. family violence response and recovery, sexual abuse counselling/support, homelessness and unemployment services/supports etc).

Recommendation 11: Government resource whole of family/care relationship prevention, early intervention and response programs which adopt broader community understandings and meanings attributed to poor mental health (beyond a diagnosis); and which can be integrated beyond clinical mental health settings to address the source of poor mental health and consumer/carer priorities (e.g. family violence response and recovery, sexual abuse counselling/support, homelessness and unemployment etc).

Recommendation 12: The State Government provide flexible funds to a range of programs and services to support NDIS access for those with multiple/complex needs; including 'hard to reach' populations who require intensive approaches and more time to build rapport with services. This should include additional investment to current community trusted specialised services (that are co-designed, co-produced); and who are well placed to assist 'hard to reach' LGBTIQ+ consumers/carers and families access the required assessments to prove NDIS eligibility.

Recommendation 13: Continued investment by State Government in NDIS education for mental health professionals and other services, to increase awareness and capacity to support consumer applications and better understand NDIS psycho-social disability access requirements, systems and processes.

Executive Summary

Thank-you for accepting this focus group consultation paper regarding the needs and experiences of LGBTQA people in care relationships from **drummond street/queerspace** and **tandem**.

We welcomed the opportunity to extend our support to the Royal Commission through holding a small focus group of LGBTQA+ (and ally) carers. The goal of this focus group was to increase current understandings about the needs of LGBTQA+ people in care relationships, their help seeking behaviour and the impacts of poor mental health on individuals and families. This paper is a report of this focus group's findings.

During this consultation the following key themes emerged.

- While some challenges and barriers experienced by the group were shared with non LGBTQA+ carers; there were others unique to sexuality and gender diversity.
- Lived experience of intersectionality and the nexus of multiple identities resulted in unique forms of discrimination and stigma for carers.
- Impacts on care relationships, families and consumers were raised due to a lack of resourcing for LGBTQA+ competent services.
- LGBTQA+ services could also lack in responding to whole family, care relationship or intersectional needs.
- Family context and strengthening capacity for reciprocity in care relationships was viewed as important for LGBTQA+ people in care relationships but was often overlooked.

It should be noted that while the numbering of the recommendations is consistent in this document that the order is different within the text due to efforts made to reflect the order of questions posed in the focus group discussion.

About Our Organisations

drummond street services provide mental health and wellbeing services that focus on whole-of-family early intervention, prevention and response. Over the past decade drummond street has been at the forefront of developing innovative responses to marginalised populations with complex trauma histories. These populations include children and adults with experiences of intimate partner/ family violence (IPFV) and sexual assault, refugee and humanitarian entrants, whole families where mental illness and comorbidities are present, LGBTQA+ communities and institutional child sexual abuse victims.

Our work aims to:

- Reduce the prevalence of mental health burden
- Address early risks of poor mental health outcomes
- Support families to create and maintain positive family/parent-child relationships and home environments
- Support children and young people's emotional wellbeing

drummond street's **queerspace** service is the first federally funded (and largest Victorian provider) of LGBTQA+ community specialist mental health and recovery services. Alongside our lead role in the 'w|respect' LGBTQA+ family violence service; queerspace provides support for individuals, families, children and young people. We work to the principle 'for communities/by communities' and are committed to partnerships with a range of grassroots LGBTQA+ capacity building organisations and innovation in Lived Experience peer led recovery service models.

drummond street services are well placed to explore the unique needs arising for people and families impacted by care relationships. As part of our services drummond street|queerspace provide carer support initiatives for: LGBTQA+ carers, carers of a person who has experienced institutional abuse and people in care relationships impacted by the Royal Commission into the Abuse, Neglect and Exploitation of People with a Disability. Our wrap around case management, whole of family assessment model and mental health recovery support includes identification of both consumer and carer needs.

Tandem is the Victorian peak body representing organisations and individuals advocating for family and friends of people living with mental illness. Tandem leads campaigns and lobbies to improve Victoria's mental health system for family and friends; co-ordinates sector wide best-practice response to carers; undertakes carer research and policy development; trains carers and professionals; and provides direct support services to family and friend carers. Other tandem activities include:

- Advocacy for carer involvement in planning, care, system change and supports
- Promotion of - and support for - the development of the mental health carer workforce
- Informing and empowering mental health carers to access the NDIS
- Raising community awareness about the role of families and carers in mental health recovery
- Administration of the Carer Support Fund which provides financial assistance to families, friends and carers of people registered with Victorian Area Mental Health Services
- Operation of the State-wide Tandem Carer Support and Referral Line 1800 314 326
- Communicates regularly with members and stakeholders via regular e-news, website and meetings via a range of online platforms and in person across Victoria

tandem have expanded their advocacy in collaboration with drummond street|queerspace and other community groups to include the needs of diverse carer cohorts including LGBTQA+ populations.

While this paper has been written by drummond street services|queerspace, the project has been a collaborative effort. drummond street|queerspace gratefully acknowledge tandem's work to; transcribe and analyse participant interviews, co-write recommendations, provide expertise on mental health carer advocacy/rights and policy issues, assist organising the consultation and support participants, as well as help with the public release and promotion of this paper and its findings. Finally, we gratefully acknowledge tandem's ongoing community, sector and government facing advocacy on behalf of families and carers impacted by mental illness has contributed greatly to key reforms.

Background

Mental health carers and families play a major role in providing support and care to people with mental illness. Their caring role is critical to client support and recovery, with an estimated 240,000 Australians providing informal care to an adult with mental illness. Of these, 54,000 were primary carers¹. Despite this significant contribution, too frequently carers are not respected, acknowledged or included in a range of health, mental health and other service settings. The Victorian Carers Recognition Act 2012² and the Commonwealth Carer Recognition Act 2010³ was created with the objective to officially recognise care relationships and the role of carers in our community; however, the goals of this legislation are yet to be fully realised in practice.

It is suggested between 15-30% of LGBT people are currently in caring roles⁴. It has also been noted carers from LGBTQ+ communities experience unique circumstances which increase the likelihood of caring depending on which subset cohort of LGBTQA+ acronym a person sits within, for example some research indicates lesbians, bisexual and trans women spend more hours caring than other groups⁵. In 2019, queerspace conducted survey of more than 800 people as part of queerspace's Midsumma Festival activities of which carers made up one fifth of the respondents. 43 per cent of those carers reported caring for someone due to a mental health condition.

Furthermore, 390 (15%) of responses (out of 2,603) to an Equality Australia survey of LGBTIQ+ communities during COVID indicated the 'provision of unpaid personal or domestic care to another person'. Care was most commonly provided to parent(s), followed by partners, children, a friend and another family member. Recent events in relation to COVID -19 may also have impacted the prevalence of caregiving which some have suggested has not only risen, but has had variable effects on caring stresses among LGBTIQA+ people. 'Around half (53.6 and 48.5% respectively)' of the caregivers who responded to the Equality Australia survey indicated 'COVID-19 and its associated restrictions had affected their ability to provide personal or domestic care, or increased their caring responsibilities'⁶.

Research on the physical and mental wellbeing of LGBTIQA+ populations identifies LGBTIQA+ people face distinct difficulties and barriers to good health. These can include physical and/or psychological abuse, oppression and/or financial disadvantage. These barriers can influence a range of public life domains (e.g. employment, education, criminal-justice law and relationship recognition); and can be directly linked to discriminatory societal responses to diverse sexuality/gender identity or expression and also include exclusion or discrimination in personal spheres, such as significant interpersonal relationships⁷. In our view, this is highly relevant to the wellbeing of these communities and considerations for service design targeting LGBTIQA+ people in care relationships.

Eligibility and scope of the invitation to participate

Eligibility for participation in our carer focus group was for people 16 years and over who:

- *Provides ongoing or episodic informal (unpaid) care to a person with a mental illness, or who experiences poor mental health/high distress.*

- Provides ongoing or episodic informal (unpaid) care or support to a person with a mental health diagnosis ('mental illness')
- Provides informal or episodic (unpaid) care or support to a person with poor mental health/high distress who has a drug and alcohol problem
- Provided support for a significant period of time in the more recent past (e.g. previously a carer 2 years prior to an elderly parent who experienced episodic poor mental health/high distress but who is now deceased)

We invited two cohorts of carers:

- **The first cohort were people** who meet the criteria above and who are **from one or more of the LGBTIQ+ communities.**
- **The second were people who were not from any of the LGBTIQ+ communities but who supported or cared for a person who was.**

Other terms used in this submission are “people in care relationships” and “LGBTQA+ people in care relationships”. These refer to carers as above, but also to LGBTQA+ people *receiving care*.

We had 6 respondents in this focus group who described themselves and person they supported (and the person’s health conditions) in multiple ways:

Carer gender/sexualities	Care Relationship characteristics identified in focus group	The descriptions of support provided focus group carers include:	The conditions of people receiving care due to a mental illness included the following descriptions:
Asexual/pansexual, Gender diverse female identifying, Gender fluid, sexuality unsure Cis – heterosexual man, Lesbian cis woman, Bi+ transmasculine nonbinary	<ul style="list-style-type: none"> - Support multiple people in family of origin/ across a range of ages, - supports a lesbian sibling - Supports a queer housemate - Supports a TGD child - supports a child - supports their child, spouse, and parents - one was unspecified 	<ul style="list-style-type: none"> - Emotional support - making decisions (e.g. nominated persons forms, advance care directives, enduring power of attorney) - community access - life skills - navigating services (NDIS, my aged care) - liaise/advocate with emergency services (police, hospitals, legal services, mental health system, medical providers etc) - resolving discrimination - supporting exercise, diet & wellbeing - finding housing - help with sourcing material aid - financial support, (including banking) - Shopping - Transport life admin - home-schooling, letter and email writing, - advocacy in mental health system, - advocacy with employers - attend emergencies resulting from episodic mental illness 	<p>Mental health challenges</p> <ul style="list-style-type: none"> - Bipolar disorder - PTSD - Social Anxiety, - Psychosis - Depression - Severe mental illness, - Psycho-social disabilities - Dissociative disorder - Borderline personality disorder <p>Additional challenges</p> <p>Cognitive disability learning disability intellectual disabilities dementia, Autism, deafness, cancer, complex medical conditions, physical disabilities, Parkinson's symptoms, vision loss, hearing loss, brain injuries, ASD</p>

Scope and limitations

This group is a small snapshot demonstrating the diversity of experiences of LGBTQA+ people in care relationships; and highlights some of the shared experiences, concerns and barriers faced by carers of

LGBTQA+ people. It is our hope this paper acts as a prompt to explore a range of issues not yet addressed by carer or consumer targeted initiatives or services targeting LGBTQA+ populations. We recognise this paper is not a complete catalogue of LGBTQA+ carer cohort issues.

Family vs friend care and ‘family of choice’

Some research indicates high value ascribed to friends as possible caregivers among LGBT communities⁸, and we recognise the appeal of care relationships with friends or partners where family of origin and formal services are, or perceived, as unsafe⁹. Language is important. For example, the survey of LGBTIQ communities during COVID by Equality Australia¹⁰ found almost *1 in 5 respondents reported providing care to a friend*, who is not a partner and not a family member. Some of these caregivers felt discouraged by COVID-19 restrictions that were framed around ‘households’ and ‘family’, demonstrating the importance of communications which speak to the diversity of family/relationship forms in LGBTIQ+ communities¹¹. However, more exploration of friend and ‘family of choice’ caregiving is required¹² to understand the expectations associated with - and preference for - these terms among LGBTIQ+ communities.

Furthermore, we use ‘family of choice’ cautiously to define non-family of origin relationships in LGBTIQ+ populations for reasons including:

- Changes to legislation – these now recognise the marriages of LGBT people resulting in an increase of familial status ascribed to partners and children.
- ‘Partner’ should not be viewed lesser than ‘spouse’ where people - for either personal or political reasons - have no desire for the State to assign status to their relationship.
- Youth in supportive families of origin have better wellbeing outcomes¹³. While a child coming out can be a challenge for some families, families can play a key role enhancing the well-being of LGBTQ youth with the right support¹⁴. Any focus on ‘families of choice’ should not divert attention from the potential of mental health practice models that *shift paradigms* from *engaging individual young people as the centre of interventions*, to one that *engages their families* as an important resource to their resilience.
- We need to ensure terms associated with relationships in LGBTIQ+ communities do not inadvertently alienate LGBTIQ+ people who desire/or mourn relationships with estranged family of origin.
- Not everyone experiences the social capital required to build and maintain family type relationships, or have friends that will step in (or are able) to provide extensive support for things such as preconceived threats of old age^{15, 16}.
- The use of this term may vary among culturally diverse LGBTQ+ populations and Aboriginal and Torres Strait Islanders¹⁷ who may place importance on kinship. Where culturally appropriate terms are used among diverse populations, these should be used.

We also note that during the focus group relationships were more frequently referred to based-on their characteristics such as ‘housemate’ and ‘friend’.

Recommendation 4: *The Government and the Collaborative Centre for Mental Health initiate research in consultation with LGBTIQ+ carers/consumers and key specialist service providers to better understand experiences of caring between non-family members, and how LGBTIQ+ community resilience can be built where circles of care may have developed.*

Intersex people and LGBT identities

References we make to L, G, B, T, Q, A+ people in this submission are made with recognition that some LGBTQA+ people are intersex and not all intersex people are LGBT¹⁸. As we did not have any respondents

disclose as intersex, ‘LGBTI’ would be inappropriate to use in this paper. Therefore, ‘intersex’ is deliberately excluded from the acronym throughout *except* where any literature referenced includes it, or when recommending actions where we believe intersex populations should also be considered.

Conflation of intersex and LGBT issues is problematic. While there is overlap of sexuality and gender related issues among some intersex people, significant differences between intersex experiences, sexuality and transgender issues must be acknowledged^{19,20}. These include types of violence and discrimination intersex people experience such as non-consensual surgeries.

Key findings

1. General Challenges and Barriers

Question: “Thinking of the full range of services you have sought to support either your mental health, or that of the person you cared for; what have been some of the challenges or issues you have experienced?”

“I managed expectations with my son around waiting. There was frustration, anxiety and I had to manage and hold him in that space... that’s a carer thing I guess”

Focus group participants noted significant challenges and barriers to care relationships that mirrored those of non-LGBTQA+ carers or carers of non-LGBTQA+ people. This included impacts due to a lack of services, which reflects research highlighting inadequacies in the mental health treatment and support system increases the experience of informal care burden²¹.

The disabling nature of mental illness, alongside inadequate recognition and identification of psychosocial disability in the human services sector was raised. This made some carers in the group feel invisible, or that services did not put appropriate support in place. A lack of knowledge about support available among those staffing universal platforms like Centrelink services for example, was highlighted as an additional burden. Subsequently, there was a belief that responsibility fell on carers and consumers – not service providers - to identify supports and pathways for people in care relationships.

“...There wasn’t help until I looked and went absolutely out of my way to find these services for her, services that actually recognised poor mental health was disabling... or recognised it as a ‘disability’. Only when I suggested another provider, did the service inform us about other things available to us. Then we could go out and look into these services together. There was no help. It was upon us - not upon the system to get help.”

1.2 Poor experiences of treatment

Similar to research findings on the experiences of other carers, our LGBTQA+ focus group participants raised a lack of adequate information of their loved one’s treatment (including discharge information and information about treatment orders) as a frustration, and relayed experiences in acute support settings they believed were harmful. Carers at the focus group also shared stories of having to manage distress of those they supported which related to service provision including:

- Distress of the consumer over long periods in Emergency waiting rooms
- Distress triggered by experiences/and things the person saw in acute mental health wards
- Distress due to early discharge from services before the person was adequately stabilised
- Distress the person experienced/expressed in the home in-between mental health supports

- Distress of those they supported caused by poor or disrespectful service delivery

Other general issues focus group participants raised about mental health services included:

- Poor acknowledgement of carers emotional needs and strain (prolonged caring)
- Confusing systems and service pathways
- Wait times or eligibility criteria that were unclear or change due to funding
- Poor understanding of privacy, rights and responsibilities and how this impacts carers
- Geographic distance to services was prohibitive to accessing them.

“Services still don’t connect with me, even though I am listed as next of kin. From hospitals, when she [care recipient] has agreed, I hear nothing from them. They just send her around in circles, in and out of hospitals.”

1.3 Financial Strains on Carers

The financial strain on mental health carers, is well documented and was again highlighted during the consultation. Participants reported providing considerable financial support as part of their caring role, in addition to community access, emotional, psychosocial and advocacy support. However often the latter supports relied on financial resources for carers to achieve them.

The Mental Health Carer Support Fund supports families and friends connected with Area Mental Health Services, who are likely experiencing the most acute economic, social and emotional distress, to access practical assistance to support their health and wellbeing and reduce financial strain. The Fund, however, has remained static for over a decade in spite of need increasing by over 50%. Additional investment is required to increase access to crisis support payments to vulnerable carers/families who require immediate relief.

Recommendation 6: *The Commission propose an additional \$1 million increase, (from \$1.6 to \$2.6 million) to the Carer Support Fund to restore currency to the Fund and assist an extra 2,000 mental health carers engaged with clinical mental health services.*

2. LGBTQA+ Specific Challenges and Barriers

Question: “Have attitudes about groups of people influenced your experiences of services or influenced the type of support you received (or didn’t)”.

Experiences unique to the LGBTQA+ carers in the focus group were also identified, and viewed strongly as contributing adversely to poorer wellbeing and their own mental health (in addition to the general issues above). Some of these were also shared by the cis heterosexual male carer of a trans child. He identified concerns related to delays accessing LGBTQA+ specific services, with the long wait for gender affirmation services being an issue and the lengthy, truncated processes associated with these supports.

Anxieties about waiting periods for drug and alcohol services, as well as long waits for housing services were also a significant concern. drummond street|queerspace and tandem believe this should be a consideration in relation to LGBTQA+ people in care relationships given the higher representation of some LGBTQA+ populations in drug and alcohol misuse and homelessness data.

The experiences raised by LGBTQA+ focus group participants included:

- *Being judged by services because of sexuality or gender characteristics*

- *Hiding their LGBTQA+ identities or the identities of the person they cared for to protect themselves or the other person from discrimination*
- *High levels of emotional labour educating services - particularly during a crisis which left some participants feeling vulnerable, exasperated, exhausted or unwell*
- *Heteronormative and cis-normative service delivery*
- *Feeling emotionally unsafe before even walking into a service*
- *Being mis-gendered - including in front of the person they support - therefore undermining key understandings between themselves, the person they cared for and other family members*
- *Not having their intimate partnerships/ family forms identified or acknowledged*
- *Educating service providers that cost time which should otherwise be spent getting the services resulting in more appointments, expense and slower progress*

Question: “How safe have you felt discussing your identity or that of the person you care for to service providers? Could you share some more about that?”

Carers would at times and where possible seek private services to mitigate the impacts of inappropriate public service responses to sexual or gender diversity. However, one non LGBTQA+ carer spoke about going to ‘meet services first’ to be sure they would treat their transgender child ‘appropriately and with respect’ and that it was a ‘trust thing’.

Another transmasculine carer shared their experience:

“I have to do my research to see who are going to take what I say seriously. I have to educate them [services] about my gender identity. I have to interview services to see if they are appropriate and LGBTIQ friendly. It’s bloody hard work”.

Where people cared for multiple family members, having to travel or do extra work to ensure respect of LGBTQA+ needs meant this burden impacted the care they could provide to other family members. This could run risk of creating family conflicts where LGBTQA+ people in care relationships have mixed acceptance of their sexual or gender identity in their families and exacerbate resentments.

It was emphasised that even ‘good intentions from services to understand LGBTQA+ communities’ and be ‘accepting’ were detrimental to equitable care. As one participant identified, it was not only that educating services was emotionally draining for carers, but this could also reduce their child’s access to a service and increase the financial cost, because it took up valuable time in appointments which should otherwise focus on the care recipient.

...once they go down that path of “Oh I really care about your gender identity and I really want to know all about that” I have to educate them. Then all of a sudden the consultation time is over and my kid has not got what they need; or I have to make another appointment.”

Carers also raised that some approaches to mental health treatment models excluded particular family forms by default. A lesbian, cis woman carer discussed how this creates inaccurate assumptions about the best treatments or consumer and family needs. She said;

“In inpatient settings, staff ask your history. I had to say he is not my biological son, but my partners...because they kept asking about my parent’s mental health and jumping to assumptions based on a biomedical model. It’s a way of staff interacting with you that they default to and I was always having to clarify that...”

Recommendation 7: *State Government resource more stringent monitoring of LGBTIQ+ competency among mental health service providers and develop sector education resources that includes: content on the differing health and wellbeing outcomes between the range of LGBTIQ+ cohorts and the impacts of intersectional discrimination.*

3. Intersectionality: needs at the nexus of multiple identities and experiences

Intersectionality is a way of thinking about identities and their relationships to power²². Understanding the implications of differences in race, ethnicity, culture, socioeconomic status, and age among LGBTIQ+ people using an intersectionality lens is important (i.e. examination of the multiple identities and the ways in which they interact²³). drummond street|queerspace and tandem agree; the intersection of people’s care relationships with other lived experiences related to identity are an important consideration for designing person centred responses to their needs.

The Victorian Government recently began using the term ‘Intersectionality’, similarly defining it as ‘the ways in which different aspects of a person’s identity can expose them to overlapping forms of discrimination and marginalisation’²⁴. While intersectionality was originally used as a term to describe how race and gender could intersect creating unique types of oppression, it later expanded to include additional considerations — such as sexual orientation, nationality, class, disability²⁵, and trans/gender diversity among others.

As stated already, LGBTQA+ people in care relationships, may experience unique hardships due to the intersecting experience of providing or receiving informal support to or from another person, and adversities related to societal responses to diverse sexual and/or gender diversity. This can result from direct stressors, dynamics of the care relationship, or conditions arising within a person’s family, community, economic or socio-political context²⁶. Therefore, people from LGBTQA+ communities with concurrent identities may experience disproportionate barriers.

This was reflected in feedback from participants throughout the focus group. The participants identified service experiences they saw as deeply rooted in other people’s attitudes and assumptions related to either LGBTQA+ status or due to assumptions of heterosexuality and cis gender status. However, there were also instances of discrimination they saw as being driven by ableism, racism or anglo-centric concepts of faith. We highlight some other intersections of experience raised in the focus group below. These intersected with their sexuality or/and gender identity; *and* their identity as a mental health carer to create unique barriers that are not universally shared by *all* carers, nor *all* people from L, G, B, T, Q, A+ populations.

3.1 Each identity, each characteristic should not mean extra barriers

Ethnicity and faith: Assumptions people from LGBTQA+ communities do not exist within faith or ethnic communities can be widespread within these communities or originate beyond them⁽²⁷⁾. Carers in the focus group identified situations where services responded in ways they believed disregarded faith requirements - despite the expression of these faiths being intrinsic to the mental health of the person they supported (or themselves). Concerns were also raised that services did not understand the needs of ethnically diverse people from LGBTQA+ communities. Carers who required ethnic cultural literacy, and competency around LGBTQA+ issues experienced greater barriers accessing services, and they expressed a strong desire for services that could meet needs arising from the nexus of sexual, gender, faith and ethnic identities.

Ableism: Over half of the focus group participants disclosed they experienced chronic illness, poor mental health/mental illness or physical disabilities of their own. Some believed this resulted in discrimination against them as a carer (this included discrimination against parent and close sibling carers). Furthermore, despite mutual consent to the care relationship being expressed by the 'consumers', these carers views and knowledge about the people they supported were not listened to or respected in ways which they strongly believed were related to discrimination regarding their own disability, or presentation.

In one instance a carer who was an NDIS recipient who reported conflict with their package planner, was advocating for the person they cared for using a pseudonym and advocating through others. This was because they did not want adverse outcomes for the person they supported. NDIS plans need to consider a person's caring responsibilities. This person was caring for multiple family members and it was distressing to them that their capacity to support family members was not seen as a reasonable or necessary part of their lives, or in fact that they were viewed as capable of assisting others. This mirrors similar discriminatory views against many parents with a disability and disproportionate scrutiny of their parenting capability (28, 29).

Differential 'LGBTQA+ service' experiences among L, G, B, T, Q, A+ cohorts: Experiences of discrimination related to sexuality and gender (homophobia, bi-phobia, transphobia) are unique and specific in the ways they harm and infringe people's right to health safety and wellbeing. The importance for services to ensure the eradication of unconscious or deliberate discrimination and exclusion for all people from these communities ('not just one or two') was recognised by participants.

Standards of 'LGBTQA+ appropriate' care were identified by one focus group participant as variable depending on what cohort/s of the LGBTQA+ acronym consumers and family members may be from. This carer reflected on personal experience with a private 'Rainbow Tick accredited' service and said:

"...despite being accredited with the Rainbow Tick, staff were still incredibly transphobic/or homophobic ... I honestly don't know how they got accredited. We need imbedded ongoing education ... Just because this happens...it doesn't necessarily make it a safe service from all staff."

drummond street services|queerspace raised in our earlier submission to the Royal Commission that different LGBTQ+ populations can experience very variable mental health and wellbeing outcomes for reasons unique to each cohort in the acronym and these statistics continue to emerge³⁰. Our service data found variable and increased rates of mental health distress, social isolation and financial distress on analysis of all our baseline measurements among our LGBTQA+ cohorts (31). This highlights the need attached to getting training and monitoring of service competency right. More research and data collection on these variables and identities is also required and drummond street and tandem would support further research in this area.

Age: The father carer of a young trans child also raised age as a barrier to services – citing this restricted access to, and interest from some services in being involved with the young person's care. There was ambivalence around the seriousness to which a child was able to express their gender and understand what they were feeling. This resulted in this father paying money to meet and screen professionals prior to his child undergoing treatment and support.

The sense was that carers were not 'either/or' and it simply was not an option for people to overlook one of their identities to meet the needs of another. Any determination of what makes 'LGBTQA+ services', 'for and by LGBTQ+ communities' needs to consciously consider methodologies of co-design, co-production, co-implementation, strategies and actions that respond to lived experiences of 'intersectionality' which go beyond diverse genders and sexuality. This is key to ensuring the needs arising from these nexuses are addressed.

3.2 Summary: Participant Themes and Issues

- *Unmet need due to an absence of appropriate services for LGBTQA+ people with diverse needs (services being for one identity or another)*
- *Anxiety and anticipating difficulties with/or discrimination by services due to gender, sexuality, disability, faith, race, ethnicity etc (“feeling as though you have to gear up for a fight”)*
- *Services carers accessed were not knowledgeable about LGBTQA+ needs, and burden fell on carers to educate them*
- *There is need for LGBTQA+ education and training programs for mental health staff - and other related services LGBTQA+ populations need. Particularly services addressing comorbidities where LGBTQA+ populations are overrepresented in the data on them.*
- *There needs to be stringent, ongoing, monitoring and review of mental health and other services’ accreditation; to ensure inclusive and safe practices for LGBTQA+ people (Mental Health Service Standards and Rainbow Tick Accreditation were mentioned)*

Recommendation 8: *Government fund an increase in Peer Lived Experience initiatives and support groups for LGBTQA+ carers - to address and mitigate the psychological and wellbeing impacts of unsupported caring - as well as reduce the stigma and discrimination towards marginalised LGBTQA+ carers experiencing poor mental health.*

Recommendation 5: *Government resource the Collaborative Centre for Mental Health to implement the technical capacity to undertake an independent, critical examination of international and local evidence to identify effective whole of family/care relationship/s approaches to mental health. As a key part of this process; identify promising outcomes in the prevention and early intervention of mental illness for people of intersectional experiences (including diverse sexuality, genders, race, ethnicity, faith, abilities, experience of trauma among others).*

*Issues in this section also addressed by Recommendation 6

4. LGBTQA+ carers and families can have unique emotional, physical and mental health support needs

Question: “Have your needs/the needs of your family or the needs of the person you support been met or not?”

Question: “What would make you feel seen/appropriately responded to as a whole person in a care relationship?”

“In inpatient settings, never once has anyone ever talked about my own needs. EVER! It didn’t matter how stressed or burnt out I was. Even after my son had a suicide attempt... They have policies to engage [with carers and families] but nothing’s enacted.”

An estimated 56% of carers experience (at minimum) moderate depression, and one fifth experience severe depression in addition to high levels of anxiety, psychological distress as well as lower perceptions of self-worth and personal well-being overall³². Stigma for carers in mental health settings, negative or dismissive perceptions of their caring role, as well as guilt or shame can also hinder their own help-seeking.

This experience has been reflected in service evaluations for a prior LGBTQA+ carers group program run in collaboration with queerspace, the City of Melbourne and Carers Victoria. Participants in this

program expressed high needs for, and satisfaction with supports that reduced stigma or low confidence; and addressed primary social/emotional needs. 92% of participants indicated sharing experiences with other carers was a key benefit. The next most commonly indicated benefit, (75% of participants), was 'having the chance to relax'. Reduced social isolation, learning more about carer issues and/or supports, taking time away from the caring role, gaining a fresh perspective from others, gaining a sense of belonging and being understood, and knowing it is okay to feel frustrated, were also highly regarded by the group (67% of participants).

Likewise, our focus group carers anticipated great benefit from meeting more LGBTQA+ carers in safe spaces, where they could be self-expressive (about gender identity, sexuality, ethnicity, faith etc); and share issues they faced related to caring. Feedback on the focus group also included some expression of relief and feelings of validation due to a heightened awareness of how much they were doing for others and why they were so tired and down.

Focus group participants also raised insufficient medical, counselling and health services (such as gender affirmation services, LGBTQA+ specific health and counselling services), as an issue for themselves - not only people they supported. This was identified as a barrier to self-care, which was already suffering due to limited support to their caring role. Some raised the issue that identifying themselves as a carer had the negative outcome of service staff assuming they didn't need assistance. One focus group member said *"I have had things denied for me as a carer because they think you don't need anything because you are capable..."*

Another focus group participant stated relationship building with providers was a lot slower when providers had little competency around LGBTQA+ issues or where the practitioner was not from one of the communities themselves. This highlighted the risk for people accessing counselling sessions using mental health plans would have more of sessions taken up 'explaining or building rapport' than other clients would.

"I wasn't getting the support I needed. My housemate is the same way - when they tell their experiences to the professionals they have gone to... they always have to explain terms and go into details about definitions/scientific things (about gender) rather than going through how that stuff is for them on an emotional level"

4.1 Summary: Participant Themes and Issues

- Focus group members believed more LGBTIQ+ specific Lived Experience staff are required to provide carer and consumer services (e.g. trans and gender diverse peer support services, mental health services, drug and alcohol, housing etc)
- Focus group members agreed more LGBTIQ+ Peer Lived Experience supports are needed
- Recognition and acknowledgment of carer mental health needs has to improve
- Care relationship needs can be overlooked or ignored by health and human service providers (including 'LGBTIQ+ services') - just as much as needs related to sexuality/gender).

Recommendation 10: Government resource the expansion of Lived Experience Peer workforce reforms in collaboration with specialist LGBTIQ+ services to create sector guidance which responds to the intersectional concerns of LGBTIQ+ mental health carers and consumers. This includes the intersectional and complex needs of those who seek a range of services beyond clinical mental health settings (e.g. gender services, LGBTIQ+ services, family violence response and recovery, sexual abuse counselling/support, homelessness and unemployment services/supports etc).

5. Caring, services need to support family and relationship context

Question: "What needs to change/improve/would be helpful for you/what does a good mental health system look like?"

Recent submissions to the Royal Commission into Victoria's Mental Health System have outlined the many negative experiences of families and carers within clinical settings and a lack of inclusion³³. The application of Standards of Practice when working with families of people with a mental illness has also been well articulated³⁴.

Interventions aimed at increasing family/carer knowledge and capabilities are noted to be among the most helpful and effective. These include interventions that reduce feelings of 'burden', distress, and provide psychological/emotional support; or those which increase coping/crisis management skills, improve quality of life and raise self-esteem³⁵. When offered early, these types of interventions help both carers and those receiving care to improve the quality of their relationships, overall family functioning and promote recovery from symptoms of poor mental health.

Focus group participants noted similar issues to other cohorts of carers such as inflexible services and difficult navigation. This often intersected with 'issue siloing' that subsequently underplayed the role of carers in a broader family context. It is harder to achieve positive outcomes for LGBTQA+ people in care relationships when their families and context are not holistically supported.

For example, the experience of one participant (with a physical disability) included family violence - which had also impacted other family members they were caring for. They explained how services told them they should 'give up' on their family of origin and 'walk away'. This was distressing to the carer who had built care responsibilities into their safety planning and that of other family members. They had been doing all they could to keep everyone safe for a long time and this was part of 'caring'.

This story illustrates the risks to people with disabilities as abusers may use care relationships to leverage threats, coercion and power against them. It is also concerning if services cannot identify and understand the wider impacts of family violence on care relationships. While there has been some attention given to (and rightfully so) on the use of violence towards people with disabilities by people assigning themselves as 'carers'; there is limited exploration on how abusers may use people with disabilities (including psychosocial) as a means to control a carer partner, or others they are being violent towards.

5.1 Unique impacts of LGBTQA+ service shortages on care relationships/families

Some LGBTQA+ carers in the focus group were seeking the same or similar services as the person they supported. This added unique complexities and difficulties to the care relationship dynamics. Particularly where these services had long waiting lists, and options were limited.

One participant highlighted how inequity of service access between two people in a care relationship, could create additional burden and feelings of guilt. This carer reported stress and frustration because they were accessing an LGBTQA+ service that a person they cared for was unable to. The carer continued to use the service, but said the care recipient was 'struggling' and their wellbeing declined since they were told they could not access it. The carer said an increase in their care responsibilities quickly undid the benefits of the support they got themselves. This carer believed the 'relationship would be better' if aided by mutual access, and that the person should receive the service to prevent significant impacts on their wellbeing.

Finally, focus group conversations and remarks about family indicated where there is risk of conflict around sexuality and gender identity (and where safe and appropriate to do so), it would be particularly useful to support whole families of LGBTIQ+ people in care relationships. drummond street/queerspace have heard similar issues arise while working with parent allies of trans and gender diverse children; for example, where parents experience resistance or animosity from other family members who disagree with their support of the child's self-expression.

In 2015, drummond street|queerspace conducted a research project, funded by Beyond Blue 'Building the Evidence Base; Risk and Protective Factors in the LGBQ Community'. This was based on an in-depth clinical file audit of non-heterosexual clients aged 18+ years, undertaken over a three-year period. drummond street|queerspace examined common risk and protective factors that impact an individual's mental health and wellbeing. These audit findings highlighted the need to better support families who have a child/loved one who is questioning their sexuality/gender. Ongoing support is needed for the families facing difficulties assisting or accepting a relative/or child - as well as the relative or child themselves ³⁶. It is reasonable to suggest that doing this would only enhance the family environment required for healthy mutual supportive care relationships.

Recommendation 11: *Government resource whole of family/care relationship prevention, early intervention and response programs which adopt broader community understandings and meanings attributed to poor mental health (beyond a diagnosis); and which can be integrated beyond clinical mental health settings to address the source of poor mental health and consumer/carer priorities (e.g. family violence response and recovery, sexual abuse counselling/support, homelessness and unemployment etc).*

Recommendation 1: *Government fund and resource whole of family and care relationship prevention, early intervention and response programs with the goal to reduce risk of family/care relationship conflict, increase resilience, and strengthen relationships; particularly during 'coming out' processes (sexuality and gender identity) and subsequent whole of family/care relationship transitions/adaptations.*

5.2 Summary: Participant Themes and Issues

- *Genuinely engage with/and support carers and families so their needs are addressed ('enact service policies') to support 'whole of family recovery' and 'relationship recovery'.*
- *Reinstate community mental health services that ceased with the introduction of the NDIS*
- *Reform service systems to better assist people with severe mental illness and who have overlapping complex needs, the answer to their mental health distress may be found in better housing, employment, escaping violence etc*
- *Increase flexibility in mental health service provision, particularly when it comes to people who are homeless, have a physical disability or comorbidity issues such as substance abuse*
- *Increase respite services for carers so they can have a break and recharge [i.e. practical support such as in-home support as well as respite programs for LGBTIQ carers]*
- *Enable equitable access to services between people in care relationships to support the quality of their relationship*
- *Increase transparency and improve system coordination so local support pathways to psychosocial disability services are more easily identified*

6. Reciprocal care, capacity within care and family relationships

Question: “How might the service system recognise, support and promote healthy family and care relationships, what can the system do? ...”

“I’m the motivation driver. We realise we both have to go there because we know it’s not going to go perfectly. Actually, we are each other’s motivators”

Some focus group members identified instances where needing the same services brought about a shared understanding of adversity that contributed to the foundation of the relationship, and resulted in some reciprocity of ‘moral support’.

One carer for example, told of supporting a person facing similar difficulties accessing LGBTQA+ services and they had been on the same waiting lists. Although both coped differently with the circumstances, the carer identified some reciprocity of care where they ‘would advocate for and provide support to each other’. The carer went on to describe an element of friendship which was expressed when they attended appointments with GP’s and gender identity support services. The carer said they ‘always went together as much as possible’ - simply so they could ‘find the energy to face a service provider’ but ‘it worked and was really helpful’.

Other carers in the focus group simply raised again that barriers to services impacted the role carers and others in their trans and gender diverse communities could play. They highlighted;

“There’s high anxiety, there’s self-harm and just resigning. There needs to be more funding, more paediatricians, clinical psychologists for gender diverse people. If we had this, we would be taking better care of our community.”

Reciprocity has been identified as a protective factor against carer stress and it is important for services to recognise and support³⁷. drummond street|queerspace and tandem would support more research focusing on LGBTIQ+ communities to understand the experiences of caring between non-family members, and how community resilience can be built where circles of care may have developed.

Finally, many carers said they experienced a lack of time or energy to be as emotionally reciprocal in ways they would like to; and that they desired to express more everyday aspects of their relationship with the person they supported (for example a parent/child relationship). This may also impact their ability to reciprocal in other family relationships. One carer remarked they were so exhausted from housework, medical, life administration responsibilities and driving people around that they had nothing left in them to experience relationships in other every-day ways.

‘Particularly where there’s discharge from acute services, when the person returns home still unwell – it requires a lot of energy to support them, they are still hyper-aroused, hyper talkative, scared, vigilant, sort of manic...lockdown caring during COVID, this has impacted my health a lot. There’s no respite. Even just half an hour of peace... It’s hard to function in other ways, to be a partner, friend, parent...’

Another carer said, *“It’s not just during the day, you’re woken up during the night...Even someone to just clean the house – even that would help. It would help so much...”*

6.1 Summary: Participant Themes and Issues

- *Services need more funding for supports to carers and families [‘there is little or no funding, so there are no services, when carers become unwell - it will all fall apart’]*
- *Some LGBTIQ+ carers need the same or similar services to the people they support and have helped each other find these services and advocated for each-other*
- *Less support to carers had an impact on people’s ability to play other roles in their families and reciprocate emotionally in ways they would like*
- *Some people assisted each other with either separate (life admin help in return for moral support) or similar things (accessing LGBTQA+ support groups/health services)*
- *Funding should be allocated to both consumer **and** carer support automatically and be costed in ways to enable equal access to services.*

Recommendation 2: *The Commission propose Government invest in further adaptation and exploration of cost effective, evidence-based therapeutic and psychoeducation modalities which show positive outcomes for consumers and families (e.g. Multiple Family Group, Behavioural Family Therapy and Open Dialogue) to determine the best ways of working with LGBTIQ+ communities and their family forms. **These should address both common and unique mental health risk and protective factors for each LGBTIQ+ cohort.***

Recommendation 3: *Provide additional investment in the capacity of services currently struggling to meet the needs of LGBTIQ+ people in care relationships and LGBTIQ+ people who are experiencing poor mental health and comorbidities. Ensuring these services:*

- *Are designed and delivered in ways that meet intersectional needs*
- *Reflect the service seeking trends of each sub-cohort*
- *Place emphasis on collaborative care (including care relationships/families, broader support networks and communities)*
- *Be funded to match statistical need and thorough LGBTIQ+ population data analysis*

6.2 Discussion on decreased service access since the NDIS

The lack of awareness or recognition of psychosocial disability was raised alongside concerns about fewer services for people with mental illness or poor mental health; particularly since the introduction of the National Disability Insurance Scheme (NDIS). This is despite the development of the NDIS Psychosocial Disability Support Pathway (in October 2018) which was created with the goal to improve people’s access to psychosocial supports available through the scheme.

In an attempt to address a range of issues experienced by consumers and their carers/families, the NDIS Psychosocial Disability Support Pathway implemented measures to improve access and quality of support plans. This included the training and employment of specialised NDIA planners and Local Area Coordinators (LACs), and the facilitation of stronger connections between NDIA staff, their partners and the mental health sector³⁸. Further to this, in March 2019, the Federal Government announced, as part of a funding package, an extension of supports to June 30, 2020 for clients connected to the three Commonwealth mental health programs (Partners in Recovery (PiR), Personal Helpers and Mentors (PHaMs) and Support for Day to Day Living in the Community (D2DL) to support their transition to the NDIS.³⁹

Despite reforms, issues of access remain as many people with severe and enduring mental illness continue to be declined support under the NDIS⁴⁰. There remains a lack of knowledge and understanding amongst clinicians of how to produce evidence framed in NDIS language to meet access criteria⁴¹. Furthermore, the time needed to source information and complete an access request application is time very few clinicians have. The task is made increasingly difficult where the consumer has a history of moving around, is largely disconnected from - or sporadically involved with - mental health services, in which case, they will not likely have the evidence they need to prove eligibility⁴². If the consumer is not connected with an area mental health service, access to assessments necessary to prove permanency are costly or otherwise difficult to source.

Focus group participants felt the impacts of this heavily, as they attempted to navigate and understand the NDIS system and processes in the absence of adequate service support. It was agreed by those present that further investment in programs and services to support NDIS access for those with multiple and complex needs, including 'hard to reach' populations (such as vulnerable LGBTIQ+ people) is required and that additional resources be added to State funded programs to enable flexible case management to facilitate this.

Recommendation 12: *The State Government provide flexible funds to a range of programs and services to support NDIS access for those with multiple/complex needs; including 'hard to reach' populations who require intensive approaches and more time to build rapport with services. This should include additional investment to current community trusted specialised services (that are co-designed, co-produced); and who are well placed to assist 'hard to reach' LGBTIQ+ consumers/carers and families access the required assessments to prove NDIS eligibility.*

Recommendation 13: *Continued investment by State Government in NDIS education for mental health professionals and other services, to increase awareness and capacity to support consumer applications and better understand NDIS psycho-social disability access requirements, systems and processes.*

Increased services to support access to required assessments to prove eligibility were also deemed as useful, particularly for people or families who require more intensive approaches or time to build trust or rapport with agencies. We believe LGBTIQ+ populations would benefit from this approach. Particularly also given histories of pathologizing diverse sexualities and gender within the mental health system⁴³ and as already raised in the Royal Commission hearings the reluctance of significant numbers of LGBTQA+ people to access mainstream service platforms⁴⁴.

Furthermore; at full scheme, the NDIS will support 64,000 people with a psychosocial disability (14 per cent of total participants)⁴⁵. Out of the 184,000 Victorians with severe mental illness, only 15,000 will be eligible for the NDIS once it is fully rolled out, leaving many tens of thousands who will have to rely on non-NDIS community mental health services for support⁴⁶.

The gap left by the Victorian Government's decision to decommission community mental health services and transfer funds over to the NDIS further compounded issues of an already fragile system⁴⁷. The subsequent decision by the Victorian Government to provide short-term, limited funds over two years through the Early Intervention Psychosocial Support Response (EIPSR) program was welcome. However, this program targeting adult clinical mental health service users with severe mental illness; who are either ineligible for the NDIS or waiting for an access decision - only partially meets the broader need⁴⁸.

Without adequate funding to support the psychosocial and recovery needs of Victorians living with severe mental illness; pressure on acute services, carers and families will continue as people become increasingly unwell, not to mention the broader longer-term impacts on the Victorian economy.

It is important however to note that focus group participants thought investment and expansion of services for people ineligible for the NDIS, or who are waiting for an access decision should include an emphasis on targeting 'hard to reach' populations including LGBTQA+ communities and use Lived Experience peer workers that understood the challenges they faced.

It is drummond street | queerspace and tandem's view that this also means services should be designed, commissioned and delivered in a way that meet intersectional needs. In addition; that they reflect the service seeking trends of targeted cohorts, place high value on collaborative care that includes families, and people's broader support networks and communities.

This also requires Government and others guiding mental health reform processes to reach out to and resource services who have built community trust, who have histories specialising in the delivery of cohort specific (codesigned and co-produced) services, who use (diverse intersectional) Lived Experience peer workforces and who face significant increasing demands. The feedback of the focus group, combined with the authoring agencies practice and sector experience has informed the paper's recommendation 11 in response to these considerations.

Recommendation 9: *State Government invest additional funds to **create targeted population programs and services** to support the psychosocial and recovery needs of those Victorians not covered under the NDIS and who are 'hard to reach' including LGBTQA+ populations.*

Additional investment and expansion of these services should:

- *Ensure they are designed and delivered in a way that meets intersectional needs*
- *Reflects the service seeking trends of particular cohorts (and sub-cohorts)*
- *Place emphasis on collaborative care that includes care relationships/families, broader support networks and communities.*
- *Ensure targeted procurement processes reflect the service seeking needs of diverse LGBTQA+ populations*
- *Be funded to match statistical need and thorough LGBTQA+ population data analysis*

This will build on EIPSR and the NPS-M (National Psychosocial Support Measure), to address current gaps.

Website Links

<https://www.queerspace.org.au>

<https://ds.org.au>

<https://www.tandemcarers.org.au>

Endnotes

- 1 Diminic, S., Hielscher, E., Lee, Y., Harris, M., Schess, J., Kealton, J. and Whiteford, H. 2017, *The Economic Value of Informal Mental Health Caring in Australia: Summary Report*, Mind Australia, Melbourne (p. xiii).
- 2 Carers Recognition Act 2012, No. 10 of 2012
- 3 Commonwealth Of Australia. (2010). Carer Recognition Act 2010 No. 123.
- 4 Carers Victoria, LGBTI Carer Facts, (accessed online via Carers Victoria website on 4.6.20)
<https://www.carersvictoria.org.au/media/1107/lgbti-carer-facts-infographic.pdf>
- 5 Carers Victoria, LGBTI Carer Facts, (accessed online via Carers Victoria website on 4.6.20)
- 6 Equality Australia, *Inequality Magnified*, (2020) NSW p. 32
- 7 Aleksandrs, G., cites Rosenstraich, 2013; Moleiro & Pinto, 2015 in Aleksandrs, G. (2019). Working With Lesbian, Gay, Bisexual, and Transgender People in Care Relationships. In *Mental Health Policy, Practice, and Service Accessibility in Contemporary Society* (pp. 177-178). IGI Global.
- 8 Croghan, C. F., Moone, R. P., & Olson, A. M. (2014). Friends, family, and caregiving among midlife and older lesbian, gay, bisexual, and transgender adults. *Journal of Homosexuality*, 61(1), 79-102
- 9 Fredriksen-Goldsen, K. I., Kim, H. J., Muraco, A., & Mincer, S. (2009). Chronically ill midlife and older lesbians, gay men, and bisexuals and their informal caregivers: The impact of the social context. *Sexuality Research and Social Policy Journal of NSRC*, 6(4), 52-64.
- 10 Inequality Australia, *Inequality Magnified*, (2020) NSW pgs. 31- 32
- 11 Equality Australia, *Inequality Magnified*, (2020) NSW pgs. 31- 32
- 12 Fredriksen-Goldsen, K. I., Kim, H. J., Muraco, A., & Mincer, S. (2009). Chronically ill midlife and older lesbians, gay men, and bisexuals and their informal caregivers: The impact of the social context. *Sexuality Research and Social Policy Journal of NSRC*, 6(4), 52-64.
- 13 (Beyond Blue), PEOPLE, Q. Y. Families like mine.
- 14 Asakura, K. (2016). It takes a village: Applying a social ecological framework of resilience in working with LGBTQ youth. *Families in Society*, 97(1), 15-22.
- 15 Orel, N. A. (2014). Investigating the needs and concerns of lesbian, gay, bisexual, and transgender older adults: The use of qualitative and quantitative methodology. *Journal of homosexuality*, 61(1), 53-78 (p.15)
- 16 Aleksandrs, Gabriel. "Working With Lesbian, Gay, Bisexual, and Transgender People in Care Relationships." *Mental Health Policy, Practice, and Service Accessibility in Contemporary Society*. IGI Global, 2019. 177-204.
- 17 Hill, T., Cass, B., Newton, B., & Valentine, K. (2012). Indigenous carers. *Social Policy Research Paper No. 45*.
- 18 OII Australia. (2012). Intersex for allies. Melbourne: OII Australia. Retrieved from <https://oii.org.au/21336/intersex-for-allies>.
- 19 Aleksandrs, G., cites Rosenstraich, 2013; Moleiro & Pinto, 2015 in Aleksandrs, G. (2019). Working With Lesbian, Gay, Bisexual, and Transgender People in Care Relationships. In *Mental Health Policy, Practice, and Service Accessibility in Contemporary Society* (pp. 177-204). IGI Global p.179
- 20 Darlington Statement: Joint consensus statement from the intersex community retreat in Darlington, March 2017. (2017). Working Paper. Sydney, NSW: QUT
- 21 Diminic, S., Hielscher, E., Lee, Y. Y., Harris, M., Schess, J., Kealton, J., & Whiteford, H. (2017). The economic value of informal mental health caring in Australia. *MIND Australia*. p.103
- 22 Kimberlé Crenshaw, *Washington Post* September 25, 2015 (accessed online <https://www.washingtonpost.com/news/in-theory/wp/2015/09/24/why-intersectionality-cant-wait/>)
- 23 Orel, N. A. (2014) cites (Crenshaw, 1989; Institute of Medicine, 2011) in Investigating the needs and concerns of lesbian, gay, bisexual, and transgender older adults: The use of qualitative and quantitative methodology. *Journal of homosexuality*, 61(1), 53-78 (p.15).
- 24 DHHS, Victorian Government (accessed online <https://www.vic.gov.au/understanding-intersectionality>)
- 25 Christine Emba, *Washington Post* September 25, 2015 (accessed online <https://www.washingtonpost.com/news/in-theory/wp/2015/09/21/intersectionality-a-primer/>)
- 26 Aleksandrs, G., cites Rosenstraich, 2013; Moleiro & Pinto, 2015 in Aleksandrs, G. (2019). Working With Lesbian, Gay, Bisexual, and Transgender People in Care Relationships. In *Mental Health Policy, Practice, and Service Accessibility in Contemporary Society* (p. 177). IGI Global.
- 27 Aleksandrs, G., cites Rosenstraich, 2013; Moleiro & Pinto, 2015 in Aleksandrs, G. (2019). Working With Lesbian, Gay, Bisexual, and Transgender People in Care Relationships. In *Mental Health Policy, Practice, and Service Accessibility in Contemporary Society* (pp. 177-204). IGI Global p.185
- 28 Swain, P., Goodfellow, J., Lee, J., Cameron, N., & Bennett, W. (2002). *Pride and prejudice: A snapshot of parents with disabilities experience of the child protection system in Victoria*. pii.
- 29 Tarasoff, L. A. (2015). Experiences of women with physical disabilities during the perinatal period: a review of the literature and recommendations to improve care. *Health care for women international*, 36(1), 88-107. (pgs 92-93)
- 30 National LGBTI Health Alliance Snapshot of Mental Health and Suicide Prevention Statistics, February 2020
- 31 drummond street services/queerspace submission to the Victorian Government's Mental Health Royal Commission (p.20).
- 32 Carers Victoria (2019) 'Initial Submission Royal Commission into Victoria's Mental Health System July 2019', Melbourne, p. 4
- 33 Tandem (2019) Royal Commission into Victoria's Mental Health System p. 12
- 34 Standards of practice for the adult mental health workforce: Meeting the needs of families where a parent has a mental illness Melinda Goodyear,1,2 Terri-Lee Hill,3 Becca Allchin,4 Francis McCormick,5 Rochelle Hine,6 Rose Cuff 2 and Brendan O'Hanlon2 1 School of Rural Health, Monash University, Moe, 2 The Bouverie Centre, La Trobe University, 3 Latrobe Regional Hospital Mental Health Services, Traralgon, 4 Eastern Health Adult Mental Health Program, Melbourne, 5 Psychiatric Services, Bendigo Health, Bendigo, 6 Mental Health Services, Southwest Healthcare, Warrnambool, Victoria, Australia
- 35 Schumacher, K., Beck, C. A., & Marren, J. M, 2006, FAMILY CAREGIVERS: caring for older adults, working with their families. *AJN The American Journal of Nursing*, 106(8), 40-49
- 36 Lysenko, N., Pryor, R., Leung, R., Field, K. & Toumbourou, J., 2015, 'Building the evidence base of risk and protective factors for depression and anxiety within the LGBQ Community', drummond street services.
- 37 del-Pino-Casado, R., Frías-Osuna, A., & Palomino-Moral, P. A. (2011). Subjective burden and cultural motives for caregiving in informal caregivers of older people. *Journal of Nursing Scholarship*, 43(3), 282–291. PMID:21884374

38 NDIA, ‘Government announces improved NDIS mental health support’, accessed online: <https://www.ndis.gov.au/news/400-government-announces-improved-ndis-mental-health-support>.

39 Department of Social Services, ‘Extension of Commonwealth programs transitioning to the National Disability Insurance Scheme’, accessed online: <https://www.dss.gov.au/disability-and-carers-transitioning-to-the-ndis/extension-of-commonwealth-programs-transitioning-to-the-national-disability-insurance-scheme-ndis-frequently-asked-questions>.

40 N. Hancock, J. Smith-Merry, ‘It’s hard for people with severe mental illness to get in the NDIS, and the problems don’t stop there’, January 21, 2020, accessed online: <https://theconversation.com/its-hard-for-people-with-severe-mental-illness-to-get-in-the-ndis-and-the-problems-dont-stop-there-130198>.

41 Ibid.

42 Ibid.

43 Aleksandrs, G., cites Rosenstraich, 2013; Moleiro & Pinto, 2015 in Aleksandrs, G. (2019). Working With Lesbian, Gay, Bisexual, and Transgender People in Care Relationships. In *Mental Health Policy, Practice, and Service Accessibility in Contemporary Society* (pp. 177-204). IGI Global p.186 - 187

44 Rizmal, Z., ‘LGBTQI people under-reporting mental illness due to ‘distrust and fear’, royal commission told’ (accessed online 13.7.20) <https://www.abc.net.au/news/2019-07-17/lgbtqi-services-need-to-be-better-mental-health-royal-commission/11318240>

45 Mental Health Victoria, ‘Saving Lives, Saving Money: The Case for Better Investment in Victorian Mental Health’, June 2018, p. 13, accessed online: <https://www.mhvic.org.au/policy-publications/policy-submissions>.

46 Mental Health Victoria, Victorian Healthcare Association, ‘Joint Submission to the Royal Commission into Victoria’s Mental Health System’, July 2019, p. 29, accessed online: <https://www.mhvic.org.au/policy-publications/policy-submissions>.

47 Mental Health Victoria, ‘Saving Lives, Saving Money’, p. 4.

48 MHV, VHA, ‘Joint Submission to the RCVMHS’, p. 29.