



More Than Ticking A Box: LGBTIQA+ People With Disability Talking About Their Lives

Understanding experiences in Healthcare and
Community to Improve Services For All

Findings and Recommendations from a
Victorian Research Project



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Foreword

This project came about at the initiative of Pride Foundation Australia whose philanthropic work supports charitable activities that benefit LGBTIQ+ people and allied communities in Australia. As part of their priority focus on LGBTIQ+ people with disability, Pride Foundation Australia formed an advisory committee of people with lived experience and/or professional experience in the field to advise it on priority areas of need. Pride Foundation Australia accepted the advice that policy and practice needed to be informed by a better understanding of barriers for LGBTIQ+ people with disability in fully participating in Australian society. Informed by Inclusion Melbourne's collaborations with Pride Foundation Australia and Deakin University, the Disability & Inclusion team at Deakin University was approached to co-create a qualitative research project to explore these issues.

This project developed from a shared recognition of the limited research or policy knowledge that is grounded in the everyday lives of LGBTIQ+ people with disability in Australia. As a small project, its scope was limited to the state of Victoria as an Australian case study. The Deakin University team committed to an additional goal for the project – to include LGBTIQ+ people in meaningful ways and, from this, to grow their capacity to engage with, and produce, research about the health and wellbeing of LGBTIQ+ people and people with disability. This feature of the project reflects the values of Pride Foundation Australia, and was enthusiastically embraced and supported.

Suggested citation

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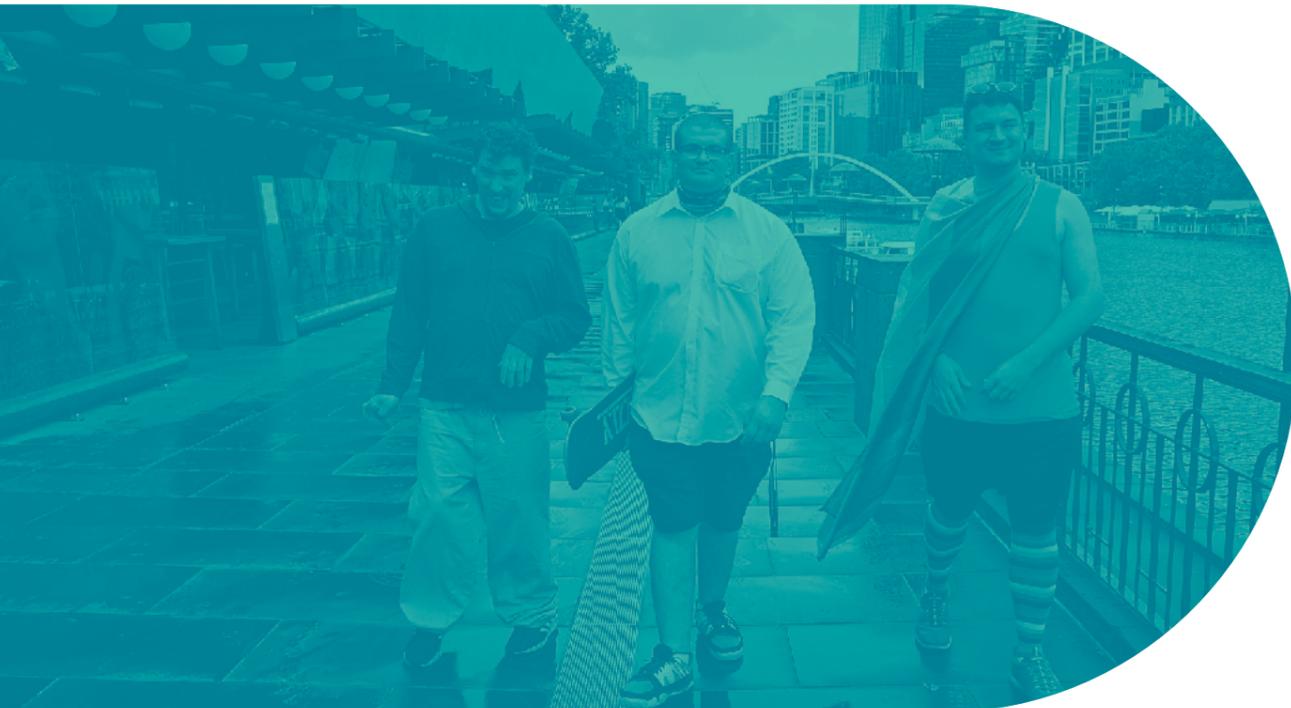


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The project was funded by a consortium of interested parties led by Pride Foundation Australia, which also includes Snow Foundation, Broadtree Foundation and the Victorian Government.

We recognise the Traditional Owners of the Aboriginal lands on which this research took place: the Wurundjeri, Boon Wurrung, Wadawurrung, Taungurong, and Dja Dja Wurrung people of the Kulin Nation. We pay our respects to the past, present and future Elders and acknowledge that Indigenous sovereignty has never been ceded.

A note on terminology and our approach

All research is underpinned by a set of beliefs about its topic. In the sometimes contested and culturally specific case of sexuality, gender identity and disability, it is particularly important to clarify how we have understood and used these concepts.

LGBTIQ+ sexuality and gender identity

The acronym LGBTIQ+ stands for lesbian, gay, bisexual, transgender (or trans), intersex, queer/questioning, asexual, HIV positive and other terms (such as non-binary and pansexual) that people use to describe or express their sex, gender, sexuality, and relationships. Intersex people are born with physical sex characteristics that don't fit medical norms for female or male bodies (Intersex Human Rights Australia, 2020). The term 'queer' is often used as an umbrella term to refer to sexually and gender diverse people and communities. Although historically used as a pejorative, LGBTIQ+ people have reclaimed the term as an expression of resistance, solidarity and sense of belonging to a broad community (Drummond & Brotman, 2014). As with many terms used to describe identity, the language used to describe sexual and gender diversity is constantly changing. Sexual and gender identities are complex, dynamic and constantly evolving and, as we address in this report, situationally particular in response to external factors (e.g., see Latham, 2017b). There is no one preferred term used by all sexually and gender diverse people; people often have multiple, overlapping identities, and many people and communities also have unique ways of describing their identities, histories and experiences (National LGBTI Health Alliance, 2016). We did not ask participants which identity category or categories best describes their experience of sexual and gender identity.

Disability

Definitions of disability vary across contexts and are influenced by various cultural and political perspectives. A *medical model* of disability frames disability in relation to the individual and focuses primarily on bodily impairment and medical conditions (Mckenzie & Macleod, 2012), an approach that also informs how people with intersex variations are understood. We

acknowledge the work of both disability and intersex advocates in challenging the pathologising effects of the medical model (see for example Carpenter, 2018; Oliver, 1995), which tends to see disability as a problem to be fixed. In comparison, a *social model* of disability recognises that a range of social factors impact on how disability is experienced, and focuses instead on how attitudes, practices and structures within society lead to oppression and exclusion of people with disability (Oliver, 1990). In this sense, the social model of disability places responsibility for access, equity and inclusion, not on the individual, but on how broader social structures are set up in ways that limit access to people with disability.

The United Nations Convention on the Rights of Persons with Disabilities (CRPD) provides an international human rights framework for the protection of the fundamental rights and freedoms of people with disability. It is underpinned by a bio-psycho-social perspective of disability (World Health Organization, 2002) which recognises disability as a multidimensional and evolving concept. In this view, disability occurs resulting from the interaction between people with impairments and attitudinal and environmental contexts that restrict their full and equal participation in society (United Nations, 2006). This is similar to sociologist Tom Shakespeare's interactional model (Shakespeare, 2006; Shakespeare, 2013) which understands disability as a complex and dynamic interaction between the individual and their environment. Bio-psycho-social and interactional models of disability are clear that "people with disability" are not one homogenous group, and experiences of disability are different for everyone (Goodley, 2017). Throughout this report, reference to disability includes physical, cognitive, psycho-social, sensory, and/or forms of neurodiversity. We recognise that disability may be episodic or consistent, acquired or congenital, single or plural. We did not ask participants to report the details of their disability.

An intersectional approach

To understand the lives and experiences of LGBTIQ+ people with disability we were informed by the work of American legal scholar Kimberlé Crenshaw's theory of *intersectionality* (Crenshaw, 1990). An intersectional approach means examining the experiences of minority groups as facing multiple and overlapping oppression (Crenshaw, 1990). Critical disability scholars have found this work effective, as Dan Goodley (2017) writes, because "A body or mind that is disabled is also defined by race, gender, trans/national location, age, sexuality, religion and class ... Intersectionality is about not simply bringing together these markers and the theoretical responses but also considering how each supports the constitution of one another" (p. 44). An intersectional approach has also been used in LGBTIQ+ research, including older LGBT people (Westwood, 2019), mental health for LGBT people (Ruth, 2017) and LGBT people of colour (Ramirez et al., 2018).

"they want us to tick a tick box, but we want to slide a slider"

1. Background

The purpose of this project was to explore the experiences of LGBTIQ+ people with disability in Victoria, Australia¹, especially in relation to:

- ▶ Accessing health and social services
- ▶ Connecting with LGBTIQ+ and disability identities and communities

In doing so the project aimed to also identify and propose recommendations for improvements to ensure services are more inclusive and responsive to the contemporary needs of LGBTIQ+ people with disability.

Historical oppression and social inequalities are key factors influencing the experiences and lowered health outcomes of both LGBTIQ+ people and people with disability. For LGBTIQ+ people with disability, experiences of discrimination and oppression are compounded by multiple social identities, leading to multiple minority stress (McConnell et al., 2018). 'Minority stress' refers to how marginalised groups experience stress that arises from experiences of stigma and discrimination, which leads to increased negative physical and mental health and social wellbeing outcomes (Carrera & Nielson, 2020).

An intersectional perspective is therefore critical to understanding the way multiple social identities and discriminatory processes and systems interact to shape the lived experiences of LGBTIQ+ people with disability, their health and wellbeing, and access to services, community and support. The project approached this intersection at the collective levels of *disability* and *LGBTIQ+* because this is where most policy and service provision is positioned. However we also acknowledge, and within the scope available have made attempts to avoid, assumptions of homogeneity or generalisation, while also leaving space for more intersecting experiences of marginalisation.

¹ We have prioritised Australian literature and service contexts wherever possible, although there is by necessity some extrapolation of comparable international data.

There has been increasing recognition of the importance of including people, particularly members of marginalised groups, in research. In LGBTIQ+ communities, we recall the work of queer people in community-based HIV/AIDS and other health promotion work (Dowsett et al., 2001). The practices of inclusive research led by academics working with people with intellectual disability form another backdrop to this project (Johnson & Walmsley, 2003). In this research, we draw on both histories and a cumulative and deepening understanding of meaningful and authentic research participation in sexuality research with LGBTIQ+ people and people with disability (Frawley & O'Shea, 2020; O'Shea & Frawley, 2020).

1.1 Health status and inequities

People with disability are more likely to have poorer overall physical and mental health than people without disability (Dispenza et al., 2016), while people with intellectual disability have lower life expectancy and higher rates of avoidable deaths at over twice the rate of the general population (Reppermund et al., 2020; Trollor et al., 2017). Research has also shown that lesbian, gay and bisexual people have increased likelihood of disability, poor mental health, and substance use than their counterparts (Fredriksen-Goldsen et al., 2013). Further research on LGBTIQ+ ageing demonstrates the cumulative effects of this marginalisation over the life course, as older LGBTIQ+ people have higher rates of disability, depression, anxiety and loneliness than the general community, as well as less social support (Cramer

People with intellectual disability have
2x
the rate
of avoidable deaths than
the general population

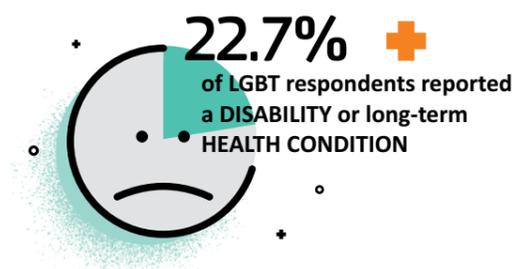


et al., 2015). People with intersex variations may be coerced into medical interventions to normalise sex characteristics in ways that do harm, especially in regards to sexuality and sexual health (Latham & Holmes, 2018). The effects of iatrogenic trauma and ongoing stigma related to intersex sex characteristics also produce poorer health outcomes for people with intersex variations (Carpenter, 2018). For trans and gender diverse people, the classification of their experiences as a mental disorder ('Gender Dysphoria') can also produce an antagonistic relationship with medical professionals, and a reluctance to access health and other social services (Latham, 2017a).

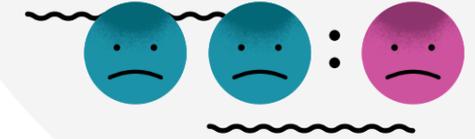
Mental health is an important element of overall health and wellbeing. A recent report by the National LGBTIQ Health Alliance (2020) on the mental health of LGBTIQ+ people showed that compared to the general population, LGBTIQ+ people are more likely to:

- ▶ Have thoughts of suicide
- ▶ Attempt suicide in their lifetime
- ▶ Have engaged in self-harm in their lifetime
- ▶ Experience and be diagnosed with depression and anxiety
- ▶ Experience psychological distress

As most national datasets do not collect information on diverse sexual and gender identities, the available data on the health status of LGBTIQ+ people with disability is severely limited. The influential *Private Lives 2: The second national survey of the health and wellbeing of gay, lesbian, bisexual and transgender (GLBT) Australians* (Leonard et al., 2012) includes some information on people with disability. The most recent report details that:



LGBT people WITH DISABILITY have
TWICE the rates of ANXIETY
and PSYCHOLOGICAL DISTRESS
than LGBT people without



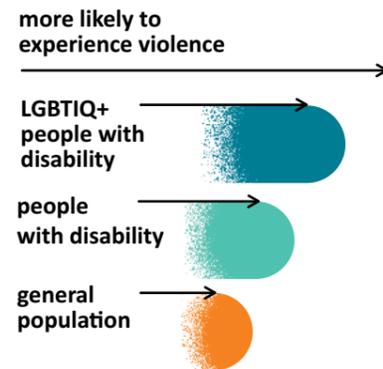
- ▶ 22.7% of LGBT respondents reported a disability or long-term health condition
- ▶ Females were more likely than males to report having a disability or long-term illness
- ▶ LGBT people with disability were more likely to have poor self-rated health
- ▶ LGBT people with disability reported higher levels of psychological distress than those without
- ▶ LGBT people with disability have twice the rates of anxiety and psychological distress than LGBT people without
- ▶ Rates of anxiety and psychological distress were considerably higher for trans people (Leonard et al., 2012)

1.2 Experiences of discrimination, violence and abuse

Experiences of discrimination, violence and abuse have a significant impact on the health and wellbeing of LGBTIQ+ people and people with disability. People with disability are more likely to experience violence and discrimination than people without disabilities (Frawley et al., 2015), and the incidence among LGBTIQ+ people with disability is recognised to be even higher, despite issues of under-reporting (Leonard & Mann, 2018).

The risks of violence, including family/domestic violence and sexual violence are higher for women with disability (Disabled People's Organisations Australia, 2017). LGBTIQ+ people with disability may also be at increased risk of abuse from carers and support workers. For example, one third of participants in a UK study reported experiences of discrimination or poor treatment by their personal assistant or care workers because of their sexual

orientation or gender identity (Abbott, 2017). Some participants also reported experiences of verbal, physical and sexual abuse by their personal assistants or care workers (Abbott, 2017).



In addition to broad societal discrimination, LGBTQIA+ people with disability may also experience discrimination from within the LGBTQIA+ and disability communities, compounding their sense of social marginality and isolation (Abbott, 2017; Leonard & Mann, 2018). Discrimination also leads to internalized stigma and victimisation, which have been shown to be predictors of disability and depression among queer people (Fredriksen-Goldsen et al., 2012).

The rights of people with disability were elucidated in the United Nations Convention on the Rights of Persons with Disabilities (United Nations, 2006) which was ratified by Australia on 3 May 2008. However, while it codifies the right to form a family (Article 23), rights for women with disability, and refers to the right to sexual health education and reproductive health care (Article 25), the Convention fails to explicitly refer to sexuality, gender identity or intersex status (Jaramillo Ruiz, 2017; Schaaf, 2011; Shah, 2017). This is an omission which itself tells of the contentious nature of sexuality in people's lives and which leaves holes in the opportunities for people with disability to have their sexual rights acknowledged and supported (Frawley & O'Shea, 2019). Without support for the right to be sexual, other rights codified in the

Convention are weakened. It was not until General Comments 6 and 7 that sexual orientation, gender identity and sex characteristics were specifically written into the interpretive architecture around the Convention (United Nations, 2020).

1.3 Inclusion and exclusion within communities

LGBTQIA+ people and people with disabilities experience higher levels of social exclusion across a range of settings, including schools, workplaces, social events, general community settings, and healthcare (Frawley et al., 2015; Social Inclusion Unit Department of the Prime Minister and Cabinet, 2009; United Nations, 2016; Waling et al., 2019).

Social support and networks have been shown to be protective factors against poor general health, disability and depression among lesbian, gay and bisexual people (Fredriksen-Goldsen et al., 2012). However, LGBTQIA+ people with disability experience marginalisation and exclusion within both queer and disability communities (Dispenza et al., 2016; Leonard & Mann, 2018; Vaughn et al., 2015) and therefore report experiencing lower social support from, and connection with both communities (Leonard & Mann, 2018).

People with intellectual disability are a group often left out of wider disability advocacy and research. We draw on the early results of a consultation with members of Rainbow Rights, the self-advocacy organization of LGBTQIA+ people with intellectual disability in Victoria (Rainbow Rights, 2020). LGBTQIA+ people with intellectual disability described a number of barriers to inclusion including lack of access to health services, negative (ableist, homophobic or heterosexist) attitudes of health professionals, income inequality and under diagnosis of mental illness. They call for social, economic, political and civic inclusion for LGBTQIA+ people with intellectual disability, describing it as:

“everyone being able to participate fully in social, economic, political and civic life; by getting a good education, receiving an adequate income, having a job, being politically aware and being connected to family, friends, the LGBTQIA+ and mainstream community”

(Rainbow Rights, 2020 p.3)

In the recent consultation conducted by The Social Deck to inform the next national disability plan, LGBTQIA+ participants reported that being LGBTQIA+ and having a disability increases experiences of discrimination, and that people were not always accepted in one group or the other. They also highlighted the cross impacts for people who identify as LGBTQIA+ with disability, and additional barriers to being included and feeling a sense of belonging (The Social Deck, 2019).

1.4 Access and engagement with services

A number of systemic barriers impact on access to and utilisation of services by LGBTQIA+ people with disability, including the discriminatory and stigmatising attitudes held by professionals working in the health, social and disability sectors (Leonard et al., 2012; Mulé et al., 2009). Similarly, professionals often lack the knowledge, skills and confidence to deliver inclusive and responsive services to LGBTQIA+ people with disability, and are not provided with adequate training, resources and other supports to improve their practice (Leonard & Mann, 2018).

² Religious Discrimination Bill 2019, Religious Discrimination (Consequential Amendments) Bill 2019, Human Rights Legislation Amendment (Freedom of Religion) Bill 2019



One study showed that 34.6 per cent of LGBTQIA+ participants in a Victorian survey reported occasionally or usually hiding their sexuality or gender identity when accessing services (Leonard et al., 2008). For example current religious exemptions give some religious private schools in Australia “permission to discriminate against transgender and gender diverse students” (Smith et al., 2014 p.49). In the same study, 27% of trans and gender diverse respondents stated that they avoid religious institutions due to actual and/or potential experiences of discrimination. The current Religious Freedom Bills² propose unprecedented protection of the religious beliefs of some, over those of others including those of no faith. This is of significant concern to both LGBTQIA+ and disability communities, for example section 41 of the Religious Discrimination Bill, which would “allow people who wish to express prejudiced, harmful or dangerous views about women, people with disabilities, LGBTQIA+ people and others” (Equality Australia, 2019 p.2).



There is a lack of understanding among health professionals and disability services regarding the LGBTIQ+ community, which appears to be a particular issue in regional and rural areas, and some faith based institutions (Barrett et al., 2015; Leonard et al., 2012). The consultation report also noted the need to better understand the experiences LGBTIQ+ people with disability and the way policy decisions impact on them (The Social Deck, 2019).

The most recent Private Lives Survey (Leonard et al., 2012) found that compared to LGBTIQ+ people without disability, LGBTIQ+ people with disability were:

- ▶ Less likely to have private health insurance
- ▶ More likely to have a regular GP, and to see them more often
- ▶ More likely to see a counsellor, psychologist or social worker
- ▶ More likely to access psychiatric services
- ▶ Slightly less likely to have pap or mammogram screening
- ▶ Less likely to have ever had a HIV test

An earlier report on the service access experiences of LGBTIQ+ people with disability described how:

- ▶ LGBTIQ+ people with disability experience exclusion from mainstream disability services
- ▶ Trans and gender diverse people with disability experience greater discrimination when accessing services than other LGBQ people with disability
- ▶ LGBTIQ+ people with disabilities from culturally diverse backgrounds experience multiple and intersecting forms of discrimination and barriers to accessing services (Mann et al., 2006). This is particularly significant given that the 2016 Census identifies that 49.1% of Victorians, or one of their parents, were born outside Australia (Australian Bureau of Statistics, 2017).

1.5 National disability service system

Issues of sexuality and relationships are largely medicalised and otherwise overlooked in health-based disability services such as acquired brain injury or rehabilitation (O’Shea et al., 2020). We focus here on the National Disability Insurance Scheme (NDIS) as the primary locus for disability services and supports.

In 2011 the Productivity Commission conducted a national enquiry into the National Disability Long-term Care and Support Scheme, which found that the disability support system was under funded, fragmented and inefficient, that services were not being provided equitably, and that it was failing to meet the needs of many people with disabilities and their families (Productivity Commission, 2011). A key recommendation of the report was the introduction of a national insurance scheme that provides funding for long-term high quality care and support for all people with significant disabilities.

The NDIS was first introduced in Australia with the passing of the *National Disability Insurance Scheme Act* (2013) and the subsequent establishment of the National Disability Insurance Agency (NDIA) (National Disability Insurance Agency, 2020b). The purpose of the NDIS is to support the independence and social and economic participation of people with disability, and empower them to exercise choice and control over their support needs and goals (Department of Health and Human Services, 2018).

Rollout of the NDIS commenced in 2016, with nearly 380,000 people currently accessing the NDIS, including nearly 84,000 people living in Victoria (National Disability Insurance Agency, 2020a). Within the next five years it is expected the NDIS will provide \$22 billion per year to an estimated half a million people with ‘permanent and significant’ disabilities (Department of Health and Human Services, 2018).

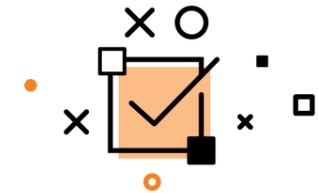
The NDIA does not currently collect data that supports monitoring of LGBTIQ+ demographics. While data is collected on participants’ “sex”, information is not collected regarding gender identity or sexuality, meaning that the number of LGBTIQ+ people accessing the NDIS is not known.

- ▶ In late 2019 a review of the NDIS legislation examined participants’ experiences of the NDIS and opportunities to improve systems and processes. Specifically, it focused on the legislative changes required to improve participants’ experiences with the NDIS, rather than the broader range of operational and implementation issues (Tune, 2019).

In relation to LGBTIQ+ people with disabilities, the review recommended that any amendment to the legislation should include amendments to the principles of the NDIS Act to acknowledge the unique experiences of women and LGBTIQ+ people with disability, as agreed previously by Council of Australian Governments (COAG) in 2016. The review also set out the proposed elements of a Participant Service Guarantee, which is to be legislated through NDIS rules in July 2020. ‘Respect’ was identified as one of six key engagement principles of the Guarantee, which includes a commitment to ensuring staff have a high level of training in diversity, including on practices for working with LGBTIQ+ people (Tune, 2019).

Despite acknowledging that experiences of discrimination and social exclusion are significant barriers to people accessing and navigating the NDIS, LGBTIQ+ people have not been identified as a priority community for assertive outreach or enhanced access support (Tune, 2019). Other marginalised communities are represented in such strategies, including Cultural and Linguistically Diverse people, and in the Rural and Remote, and Aboriginal and Torres Strait Islander Strategies (National Disability Insurance Agency, 2020c). Some research has been undertaken to inform approaches to workforce needs including the ‘Out

together’ project that developed a peer support approach, training and a toolkit resource to develop capacity in the NDIS workforce. Further current NDIS research grants identify LGBTIQ+ people with a disability as a core cohort for funding for community capacity building. The absence of an overall plan to guide work and to clearly articulate a commitment to addressing the specific needs of LGBTIQ+ people with disability is a current issue for the sector.



1.6 National policy context and implications

Current policy and practice guidelines on disability care and support in Australia do not adequately acknowledge the unique experiences of LGBTIQ+ people with disabilities, or outline actions and strategies to address specific support and care needs.

The National Disability Strategy (“the Strategy”) was developed in partnership between the Commonwealth, State and Territory Governments through the Council of Australian Governments. The Strategy set out a ten-year plan for improving the lives of people with disability, their families and carers, by guiding activities across mainstream and disability specific areas of public policy, and driving improvements in performance and outcomes for people with disability (Commonwealth of Australia, 2011).

Although the Strategy acknowledges that a range of personal characteristics, including gender and sexuality, intersect with disability to shape people’s needs, priorities and perspectives, it is not sensitive to these factors. Instead, the Strategy adopts a

universal approach to its policy directions, goals and intended outcomes. In a recent review of the implementation of the Strategy, meeting the specific needs of diverse groups was identified as a key gap and priority for future policy development and implementation (Davy et al., 2018). The review also emphasised the importance of ensuring that representatives from diverse groups are involved in all aspects of policy design and implementation.

While policy statements acknowledging the unique experiences of LGBTIQ+ people with disability have symbolic importance and may increase their visibility among service providers and the broader community, clear policy actions and practice guidelines are required to ensure services are inclusive of and responsive to the needs of LGBTIQ+ people with disability. The NDIS Quality and Safeguards Commission is responsible for registration and regulation of NDIS service providers. Independent third party auditing and certification are conducted using the new NDIS Practice Standards, representing an important element in monitoring and assuring LGBTIQ+ inclusive practice. While a number of the standards are relevant and applicable to LGBTIQ+ people with disability there is a lack of meaningful reference to their rights. However, in light of repeated references to diverse characteristics such as age, cultural background, religious background, and abilities in the Practice Standards, there is a conspicuous lack of specific reference to 'LGBTIQ+', 'queer', 'sexual orientation', 'gender identity' or 'intersex status' in any of the NDIS Practice Standards and supportive guidelines. Requiring Approved Quality Auditors (AQA) to infer or elucidate such considerations rather than providing explicit reference and indicators means that the capacity of the scheme to effect and drive change is limited (N.Despott, personal communication, June 22, 2020). As of early 2020, the mandated training course for AQAs includes no references to LGBTIQ+ people.

Furthermore, despite references to LGBTIQ+ and the sexual/gender rights of people with disability across a range of regulatory frameworks and laws (including equal opportunity and anti-discrimination legislation, NDIS Practice Standards, Disability services legislation, and the Victorian Charter of Human Rights and Responsibilities), there are no intersectional statements that combine LGBTIQ+ and disability in any of these frameworks or laws. In particular, there are no clauses that specifically require the application of such rights and practice to people with intellectual disability, a population often quietly excused from domains such as the expression of sexuality and gender due to underlying assumptions about capacity.

The Victorian State Disability Plan (2017) included detailed action points specific to LGBTIQ people. Although such Plans are not formal regulatory frameworks, this resulted in specific grant funding targeting LGBTIQ projects, and encouraged LGBTIQ inclusive practice in services. The Plan is currently under review, the consultation paper for which acknowledges that people with disability may often experience less control over their intimate lives (Department of Health and Human Services, 2017). Clearly, persistent advocacy has been effective but is required to retain this focus and to develop specific guidelines, indicators and directives.

The development of the next National Disability Strategy, and ongoing reforms under the NDIS present significant opportunities to prioritise the needs of LGBTIQ+ people with disabilities in public policy. Policy responses should be co-designed with LGBTIQ+ people with disabilities, and should specify actions that address service delivery needs/priorities, effective communication and information provision, increasing the competence/capability of the workforce, and improving data collection, monitoring and evaluation.

RECOMMENDATIONS

The following recommendations are suggested in order to address gaps in the inclusion of LGBTIQ+ people with disability in a range of community settings.

1. Publicly funded services should be required to create and make public their statements and plans for equal access for LGBTIQ+ people with disability, supported with relevant academic research
2. LGBTIQ+ people with disability should be acknowledged as a priority community for focussed outreach or enhanced access support within the NDIS. This may occur within the NDIS and through funding advocacy services.
3. An opportunity to discuss and review the NDIS LGBTIQ+ Strategy should be arranged at local or state government levels as a matter of priority. This could be trialled within one region to determine how to best ensure access and cultural safety
4. Create state-based working groups with the assistance of experienced practitioners on LGBTIQ+ people with disability, to bring together health service providers, LGBTIQ+ organisations, disability services and LGBTIQ+ people with disability to learn from each and share ideas on inclusive practice. The work of LGBTIQ+ people with disability within these groups should be appropriately recognised and remunerated. These groups will:
 - 4.1 Establish clear channels for policy reform across all levels of government
 - 4.2 Create connection and peer development for LGBTIQ+ people with disability
 - 4.3 Advise services and departments on inclusive practices for LGBTIQ+ people with disability
 - 4.4 Promote opportunities in collaborative research development, including grant funding support
 - 4.5 Organise workshops, seminars and other events to develop ideas and share resources more broadly
5. Further research by tertiary institutions and independent research bodies into the experiences of people with disability and LGBTIQ+ people committed to developing the research capacity of LGBTIQ+ people with disability as an integral part of these research projects
6. Any funded project connected to disability or LGBTIQ+ topics should expressly aim to include LGBTIQ+ participants, and report against this outcome

2. Methodology

An overarching commitment to developing and using an inclusive research approach guided the methods of this project. Inclusive research is guided by an evolving set of practices which encompass a range of approaches and methods (Nind, 2014). The significant element of inclusive research is that people who were traditionally considered the objects of research are instead active in roles including the instigation of ideas, and the collection and analysis of data. From the outset, this project centred LGBTIQ+ people with disabilities in a number of roles, not simply as research participants, but as members of the Research Advisory Group, as peer researchers,³ and through attempts toward meaningful opportunities for participants to access and engage in data collection, analysis and the project's outputs.

Academic work reflecting on the development of inclusive research has recognised the importance of making its practices available for critical scrutiny (Johnson & Walmsley, 2003; O'Shea, 2016), hence we present these in detail within this report.

Drawing on Participatory Action Research (PAR) methodologies, the research aimed to take an iterative and action-focussed approach across the project planning, research (data collection, analysis) and outcomes being undertaken iteratively. Like inclusive research, PAR represents a range of theoretical orientations and methods that "promote pluralism and creativity in the art of discovering the world and making it better at the same time" (Chevalier & Buckles, 2019 p. 3). PAR aims to effect change within queer and disability research, as it promotes self-advocacy, facilitates a critical-consciousness raising, encourages analysis

of social structures and subverts power dynamics within traditional research (Carmack, 2018; Owen & Friedman, 2017).

Strong feedback loops to the research environment were built into the project ensuring findings were being co-developed and used to inform subsequent action research cycles of the overall project. Deakin University Human Research Ethics Committee provided approval for the project (2019-2027).

2.1 The research team

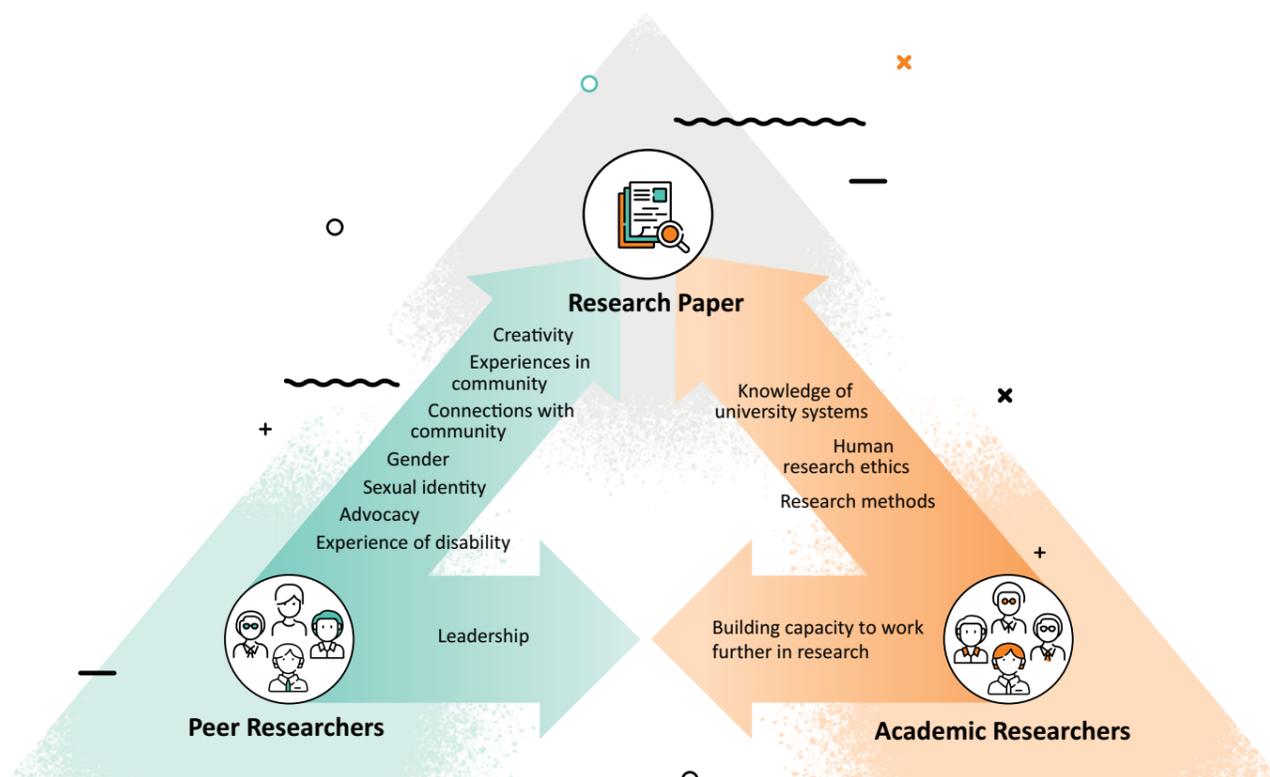
This research project was conducted by a team comprised of academic researchers and peer researchers employed by Deakin University. The academic research team was led by Dr Amie O'Shea with Dr J. R. Latham and Associate Professor Patsie Frawley, and additional research assistance from Dr Anita Trezona. The peer researchers on the team were Sherrie Beaver, Jake Lewis, Ruby Mountford and Mellem Rose. The team was formed to reach across a breadth of lived and professional experiences, genders, sexualities and research knowledges.

Peer researchers brought their leadership, creativity, experiences and connections with diverse communities across gender, sexual identity, advocacy,⁴ and various experiences of disability. Academic researchers brought their knowledge and experience of university bureaucracies, research methods, human research ethics, and a commitment to building the capacity of peer researchers to ensure the 'nothing about us without us' dictum of inclusive disability research was practiced in this project. This report was led by the academic researchers with input from the

³ We use the term 'peer researchers' to describe LGBTIQ+ people with disability to capture the significance of shared experience. Other commonly used terms include 'community researcher' or 'co-researcher'.

⁴ We acknowledge advocacy work comes from funded disability advocacy organisations, self-advocacy (a term in the academic literature often referring to advocacy when performed by people with intellectual disability in particular), and the individual advocacy that people engage in which is often not funded, but comes as part of engaging with services and systems which construct them





whole research team and Research Advisory Group. Reflections by the peer researchers on this project can be found at 4.6 of this report.

The academic researchers were committed to the peer researcher project, in part with the knowledge that inclusion and opportunities created during this project have the potential to feed directly back into communities. In order to recognise the strengths and contributions of each team member, we spent time getting to know each other and hearing about our work in the shared spaces of LGBTIQ+ and disability advocacy, community organising, activism and research. We became familiar with the way that professional-personal boundaries are dismantled by holding multiple forms of knowledge as valued, and asked questions of each other to understand our different perspectives and areas of expertise. In practice this meant that elements of the research method were led by different members of the research team. The focus groups were run by peer researchers with academic researchers present for support if needed. Writing this report was led by the academic team with consultation and feedback from the peer researchers and the Project Advisory Group.

Key tasks of the peer researchers included

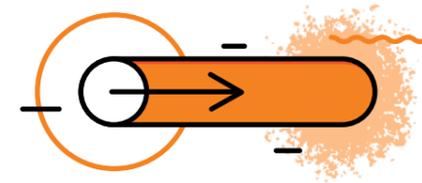
participant recruitment, which involved the design of written information and the creation of information in Auslan as well as its subsequent circulation online and through established networks. The peer researchers worked in pairs to plan focus groups: identifying the location, venue, date and time, catering and in deciding if/when they would like support from the academic researchers during the focus group. In order to ensure the research complied with Human Research Ethics, the academic researchers managed the consent process and operating digital voice recorders used for producing transcripts of the focus groups. Peer researchers also advised on access needs including the provision of suitable Auslan-English interpreters, accessible venues, establishing focus group guidelines, making available a 'quiet room' for if/when participants needed a break, and the use of a 'talking stick' to ensure all participants were able to contribute.

During data collection, peer researchers facilitated the focus groups in pairs, with the exception of one Deaf⁵ focus group, which was facilitated in Auslan by one peer researcher. In all cases, members of the academic research team attended the focus group to provide support as needed. In recognition

⁵ We follow the convention of capitalised Deaf when referring to people who identify as members of a cultural and linguistic minority, who use Auslan Ladd, P. (2003). Understanding deaf culture: In search of deafhood. Multilingual Matters.

of peer researchers' dual role within the research team and their identification with the participant group, opportunities to debrief were prioritised. Peer researchers participated in a short debrief with academic researchers immediately after the focus group, and a more detailed debrief 2-4 days after each focus group, to reflect on the issues raised, share concerns as they arose, and access support in solidarity.

Peer researchers also attended the Research Advisory Group meetings, to present their work and to hear reflections and feedback from the group. Several significant elements of the project came from these discussions, including the idea of a Deaf focus group in Auslan, and the production of the final report in easy language. Below we detail the peer researchers' roles in data collection and analysis. In particular, the development of guidelines for the focus groups by the peer researchers was critical to this project's methodology, as well as its success in recruitment.



2.2 Study participants

Research participants were people aged 18 years or over who self-identified as LGBTIQ+ people with disability. In line with the definitions given earlier in the report, there were no additional or more specific eligibility criteria. There were 29 people who participated in focus groups for this project, recruited online and through personal networks of the research team. Recruitment was iterative, with additional guidance from the Research Advisory

⁶ Formerly the Victorian AIDS Council and Victorian Deaf Society respectively

Group of focus areas and possible recruitment opportunities.

2.3 Data collection

Data collection was conducted through four focus groups conducted by the peer researchers. Two focus groups were held in the Melbourne and one in Bendigo, which were conducted in spoken English. Peer researchers identified the location for focus groups with an eye to cultural and community familiarity, using venues provided by the City of Melbourne's Multicultural Hub, Thorne Harbour Health and Expression Australia.⁶

One focus group was conducted in Auslan by Sherrie Beaver and Amie O'Shea in recognition of the recruitment connection to the Deaf community made possible by peer researcher Sherrie Beaver and academic researcher Amie O'Shea (a fluent Auslan user and interpreter). Drawing on the creativity and flexibility afforded within an inclusive PAR methodology, Sherrie and Amie worked together to plan this focus group. All other focus groups invited people with any experience of disability, and while we do not differentiate the data analysis on disability type, we note here that this included people who identified with various sensory, physical, intellectual disability as well as neurodiversity, acquired brain injury and complex communication needs. We actively resisted any perceived hierarchy of disability, or privileging of cognition and sought to consider all perspectives and contributions as equally valued. We did not ask participants to outline their experience of disability, or their identification within LGBTIQ+. The main reason we made this decision was political: we know that people with disability are often required to explain their disability and its effects, to their own detriment, and that people who identify within the acronym LGBTIQ+ can feel pressured to justify their inclusion within a particular category. We sought to avoid these pressures, and

instead focussed our limited time together around experiences of health and community services. Lastly, we recognise the vast differences which can come within disability and LGBTIQ+ identities such as family support, congenital or acquired disability, and level of engagement with services. Factors outside these identities which also inform their experiences include cultural background, age, location and so on.

The focus groups were supported by guidelines developed in response to requests from the peer researchers. The guidelines provided a rundown of events (Acknowledgement of Country, consent forms, introductions, and a list of potential interview questions and topics). The guidelines also included notes for various scenarios, such as what to do if group discussion went 'off track', if someone arrived late to the group, or if discussion stalled. The guidelines included a suggested list of themes for discussion, such as employment, housing, finances, relationships, services, and disability/LGBTIQ communities. Ethical and safety considerations were also addressed in line with discussion from the Research Advisory Group, and included how to support a participant who became distressed, and how to maintain confidentiality. The question style was open, allowing participants to guide the discussion and share the issues of most significance to them. The first question was 'what brought you here today?', which was followed by open ended questions such as 'what do you think is the most important thing we need to know?' and ending with 'is there anything else you'd like to tell us?'

Focus groups were digitally recorded for the production of typed transcripts. Participants were provided with a pen and paper if they wanted to make notes, or write any extra reflections to share with the research team. Some participants and some peer researchers chose to follow up their contribution in writing, which was included in the analysis process described below.

2.4 Data analysis

Qualitative data analysis of focus group transcripts and follow up contributions was conducted using thematic analysis and iterative categorisation across three rounds described below. The process was designed to facilitate a collaborative development of meaning and the analytic process of progressive focusing (Srivastava & Hopwood, 2009). Thematic analysis provides a flexibility which accommodates the needs of the research project, to capture a complex range of sexual, gender and disability identities. By embracing researcher subjectivity, it recognises the researchers' active role within the research (Braun & Clarke, 2013) which recognised our position on valuing the voices of peer researchers within the study. Iterative categorisation is a technique emerging from addiction studies (Neale, 2016) which was adapted here to allow for its collaborative approach and the dual expertise of peer researchers.

This use of iterative categorisation meant that analysis of the transcripts freely involved reflections of the peer researchers, who could identify their own connections with the source material to expand our understanding. Informed by the work of Voronka (2019) it also meant that peer researcher engagement was not limited to a pseudo 'professional' self, which required elimination of other equally valued selves or to further question the 'authenticity' of peer identities. Instead, it reflected the concept of praxis put forward by Friere (1986) in his work on liberation for the oppressed as 'reflection and action upon the world in order to transform it' (p. 33).

The approach taken to iterative categorisation can be seen in this section.

Unstructured qualitative data such as focus group transcripts often requires some organisation or order before deeper work can commence (Neale, 2016). Accordingly, round 1 was led by the academic research team and led to the broad identification of overarching topics. An accessible

summary of each theme was then sent to peer researchers for their review and comment. Although full transcripts were available, peer researchers preferred to work with the summary, leaving it to function as both an access modification and in scaffolding the upcoming process of analysis.

Round 2 involved a half-day workshop with the whole research team. The four peer researchers had each worked with one of the early overarching topics, and prepared their comments to some prompt questions to share with the group. This approach was requested as having time to develop ideas and present their thoughts was experienced as more accessible by members of the peer research team. The prompt questions asked them to: explain the theme to the others, giving some examples from the focus group; reflect on how this theme came out in the focus groups they attended; share any other thoughts on the theme. The notes from this workshop were presented as issues listed in bullet points, which were then circulated to the team in advance of round 3 of analysis.

For round 3, peer researchers reviewed the notes from round 2 on their own identified theme and one chosen other. At another half day workshop with the whole research team, peer researchers again summarised the bullet points and were asked to identify the most pressing or highest priority issues. This led to a further distilling of the topics, identified emergent cross-topic themes and provided more direction for the research findings.

The entirety of this report reflects and expands insights from these analysis workshops. The recommendations were developed after the rest of this report had been drafted; when the research team was able to view the project as

a whole. In this they were supported by each others' knowledges and experience, also drawing on the expertise in lived experience, policy and professional experience held by members of the Research Advisory Group. Our processes at this point were affected by the situation surrounding the COVID-19 pandemic and social isolation regulations introduced by the Victorian Government on the 21st of March 2020, which precluded in-person project meetings. Instead, we completed this part of the report via email or video call, rather than in a group face-to-face meeting as planned.

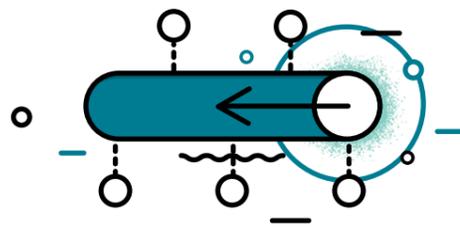
This reflexive approach to analysis was designed to incorporate the multiple experiences held by peer researchers as they related across axes of disability, gender and sexuality. We sought to encourage engagement with and reflection on the data in a way which would maximise involvement and recognise these layers of expertise.

Many things were discussed, including visible versus invisible disabilities, experiences of recent diagnosis, and what can happen when access needs for one group may make things more difficult for another. The peer researchers talked about their need for a space in which it was safe for them to express anger, grief and pride as we worked through the analysis of the focus group transcripts. At these times it was the role of the academic researchers to hold that space open and reflect on what could be learned not only about the topic at hand, but about facilitating meaningful inclusion.

RECOMMENDATIONS

The following recommendations are suggested in order to strengthen the research approaches which aim to focus on – and include – LGBTIQ+ people with disability.

7. Future research about LGBTIQ+ people with disability should meaningfully include them at all stages of the research process, including design, data collection and analysis, write up and dissemination.
8. Research and evaluation claiming co-design or similar approaches should be required to demonstrate rigor and transparency about processes towards inclusion.



3. Findings

These findings are presented according to the overarching topics that emerged from the preliminary analysis of the focus group transcripts and follow up content, the analysis workshops, and through our reflections on engaging with research participants and with each other in the collaborative research environment of this project. Because of the small and connected nature of the LGBTIQ+ disability community and to preserve the anonymity of participants we have chosen not to include identifiers on quotes provided in this report. Due to the iterative and developmental nature of the data gathering process, we have stated at which focus group the data was contributed, indicated in chronological order.

Our analysis did not differentiate by disability or sexual/gender identity for two main reasons. Firstly, because of the relatively small sample size and the large number of intersecting identities available between disability/ies and gender/sexual identities. Secondly, the entire research team felt strongly that in an environment where the onus is often on individuals to ‘prove’ their disability or that sexual/gender identity is sufficient for the label, participant identification as an *LGBTIQ+ person with disability* would be clearly positioned as valid and sufficient. We note the same view of self-identification is taken by First Peoples Disability Network Australia in their work on community-driven research (Avery, 2018), This approach was subsequently supported by the concerns expressed by participants that services would not recognise their identities as discussed later in this report.

We did not approach data collection with the idea that people could be reduced to labels, or boxes, to describe their identity unless this was something

that they chose to do in their contributions to the focus group. However our experience with the Deaf focus group indicates there is potential for more disability-specific LGBTIQ+ research, which could build on the findings presented here.

The key topics emerging from the research were: i) identity ii) community; iii) mainstream services; and iv) the NDIS. All quotes presented are taken from focus group transcripts unless otherwise stated.

3.1 Managing multiple identities



The data presented the many layers of identity held by participants. We conceptualise identity as

‘how I am, and how I am known’, noting there may be a discrepancy between those elements (Goffman, 2009; Orne, 2013). Identity was central to the discussion, beginning with the peer researchers’ introduction of themselves and followed by each of the participants who variously described their

disability identity, their sexual/gender identity, their pronouns, their cultural identity, and so on. Rural or regional locations added complexity to finding community. While people may have some experiences in common, there is a need to recognise the diversity within communities and that people have their own unique identities and experiences.

‘It’s a redneck town, and being a lesbian, or a rainbow community member, it’s a huge thing. Also, added to that is that I’m Deaf, and so there’s so many layers to that’.

(Focus group 4)



A common discussion among participants was the concept of *masking* and *closeting* identities. They noted that just as LGBTIQ+ people with disability have to come out and/or explain themselves in multiple ways, they also have to mask or keep hidden different parts of themselves in different contexts.

Participants described the stress of constantly having to make decisions about whether or not to hide an aspect of their identity, how to go about doing so and anticipating what the consequences of disclosing or masking might be. At times this meant having to strategically decide which parts of themselves to reveal, which could mean deciding whether to disclose information about their gender, sexuality or disability.

A number of participants acknowledged that they hide aspects of their identity in anticipation of how others might respond to, or treat them, or based on what the consequences of disclosing might be:

“I think it’s important to highlight the diversity of experience between various identity groups and communities. There’s going to be a lot of different experiences that can’t be related to by every single person, based on unique challenges faced by these different communities; like trans, versus this experience, and monosexual versus multi-sexual, physical versus invisible disability, neurodiverse and neurotypical, all of that kind of stuff I think is important to highlight”.

(Focus group 3)

Participants also acknowledged that having multiple, intersecting identities means LGBTIQ+ people have to ‘come out’ many times, in different ways, in many different contexts, and that this can be a lifelong process. As one participant noted:

“We don’t come out once in our life; most of us come out every day, and I have to keep doing that around my sexuality, but also around my disability. My disability is very non-visual; it’s in here, and it’s the things that I can do and the things that I can’t do... but it is difficult, in a workplace, to cover both of these things at once”.

(Focus group 1)

“Yes, I’m a lesbian.” Yes. But I always watch who I tell, because where I work, there’s a lot of [gossiping noise], and not a lot of people understand what gay is, what lesbian is, and what every other sexuality is”

(Focus group 3)

“This idea of me happily telling the world about my relationship is not real. It’s all a big secret, which is like going back in the closet all over again, because I need financial stability. I need financial independence, so that I can feel like I’m my own person,

and have autonomy over myself, and my life. But to do that, I have to hide who I am, including my relationship, no matter who it's with".

(Focus group 3)

For some participants the decision to mask or closet has been influenced by their comfort with their own identity. For example, one participant said:

"My experience, when I was younger, I wasn't sure about my identity, I was really confused. I didn't know – I just pushed that side of myself down. I didn't want people to tease me, I didn't like that. I put a mask on, straight away. I wasn't comfortable with who I was. But later, when I was older, I saw in my Deaf community that I was accepted. You know, why am I so worried about it. Why was I pretending to be straight?"

(Focus group 4)

For others, the decision was influenced more by fear about not having their identity acknowledged and affirmed by others:

"Well, for instance, I think often it's easier to be one or the other, and you don't often get to be both. You either get to be the person with a disability, and you don't always disclose, as others have said; or you get to be the gay person, but you don't

get your disability side of you actually acknowledged, or sort of... I don't know. I think you often get split between the two, or between however many there are".

(Focus group 2)

The experience of being 'split' suggests that the participant quoted above felt they could not remain whole, or present their authentic self. It can be difficult to present an integrated set of identities, and feeling forced to present only certain aspects of oneself in certain settings. What makes some settings feel safe or appropriate for presentation of the self was not made clear, however has been explored elsewhere (Orne, 2013).

In contrast, some participants reported feeling pressure to be visible, particularly within their own communities and in relation to their professional roles, which often have an advocacy component. These participants described the personal toll that comes with having to be visible and 'perform' their identities as huge, and the way this leads to questioning themselves.

"And that doesn't mean I'm not proud - it just means I get to choose."

(Focus group 3)

Some participants also emphasised the importance of supporting their agency to decide when and how to disclose parts of their identity, or not, including people working as disability and/or queer advocates. In the case of some disability groups, such as people with cognitive impairment, agency in disclosure of sexual identity is often incorrectly taken for a lack of understanding or knowledge (Rakidzic & O'Shea, In Press).

3.1 Community



"Community" is a somewhat disingenuous term as there is not one singular "disability community" or "queer community." Rather, "community" serves as shorthand for people who have in common particular identities. As with all groups of people, while they might share some experiences and values, they do not represent a homogenous group.

A prominent theme discussed in relation to community was the role in promoting a sense of belonging and acceptance, and the importance of peer connection for instilling pride and counteracting shame. For example, one participant described the positive impact of discovering their interpreter was also part of the queer community:

"I got the vibes from them that they're one of us, and I was sort of thinking, how long have they been part of the LGBTI community, and they said that they're gay, so we had that camaraderie, and we were able to talk to each other about it, and I could add my sass, and I could hear him using that sort of language when he was interpreting for me, and I really loved that"

(Focus group 4)

Participants also discussed the role of community in building resilience and capacity, and as an important source of relevant, tailored information. Online communities were seen as particularly important for LGBTIQ+ people with disability, where they were able to find community led, accessible information, especially for people who may not be able to connect in physical spaces.

Online spaces were also described in terms of providing people with security over what and how much they reveal about their identities.

"First time I ever saw another LGBTI person with disability was actually on Grindr. I'd never actually met anyone. I never actually knew there were other people out there; and when it started to show up on Grindr, that was when I was like, "Wow, there are actually other people out there." Which is a really powerful thing".

(Focus group 2)

"I find a lot of Facebook groups really helpful. There are really specific identity-based Facebook groups, and also ones that are specifically tailored to different political leanings and things like that, so you can feel accepted in multiple facets of identity at once. Those are all our own voices, community-based spaces - they're not set up by other people. It's all ourselves".

(Focus group 3)

Participants also recounted how opportunities to connect offline with peers can be limited for people with multiple identities, and that this is compounded for people who live in regional and rural areas and already experiencing social isolation.

“You get to meet many people in the Deaf world, but out in regional areas, you’re the only one, essentially, so being a woman, living out there and being a lesbian, there’s not a lot of options for me out there. It’s very limiting”.

(Focus group 4)

A key point discussed was difficulties relating to access and inclusion within communities, where competing accessibility needs or the values and aspirations of particular groups often clash.

“Just because you’re disabled doesn’t mean that you’re inclusive to people with all different types of disability, and sometimes little cliques can form”.

(Focus group 1)

Participants stressed the importance of understanding the breadth and variety of access needs, emphasising that ‘one access size’ does not fit all people. We encountered an example of this during the research process, when there were participants with sensory sensitivity (requiring dim lighting) and vision impairment (requiring bright lighting). In this instance, we were conducting two focus groups simultaneously and could divide the participants into two differently lit rooms. Participants also drew attention to the complexity of psycho-social disabilities, where access needs could be harder to describe and less likely to be understood. Many participants lamented that terms such as “accessibility” and “inclusion” could

be slapped onto events or organisations without being relevant, and participants reported on the implications of misusing them.

“Inclusive really isn’t inclusive yet. So a lot of places are being advertised as an inclusive event, yet they’ve not actually done any research in regards to finding out about disabilities and what inclusive changes need to happen for people with disabilities to access those services. So yeah, it kind of... it raises the question of going, “Okay, well, all of these things are being promoted as accessible for us, yet they’re not”.

(Focus group 2)

In many cases participants saw this as evidence of a lack of consultation with people with disability. Participants acknowledged that effort had been made by some event organisers to improve some aspects of accessibility, but highlighted the importance of ensuring that more community events and spaces are accessible to more people, taking into account physical, financial and social access barriers. In particular, they spoke of the need for organisers of LGBTIQ+ events to plan for and provide access for people with disability, and the positive impact of doing so.

“I think actually the best example of accessibility within the LGBTI community I think has to go to Midsumma, because they are proactively starting to make that information available

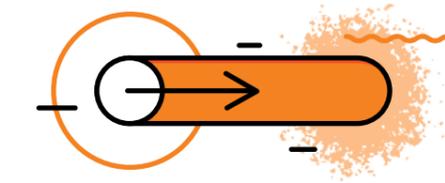
in events and booklets. So when you open up the booklet, they’re starting to include wheelchair access, they’ve got Auslan there, breakout spaces, and things like that.”

(Focus group 2)

Many participants described experiencing mistreatment within their own communities, including homophobia, biphobia and transphobia within disability communities, and ableism in LGBTIQ+ communities. Participants described the despair that accompanied feeling like it was necessary to erase aspects of their identities across several communities. For many, this left them feeling excluded, marginalised and unsafe within their own communities, in addition to the broader exclusions and discrimination experienced elsewhere.

“Two things that jump out most to me, in my experiences with disability and LGBTIQ+ communities is binarism in disability spaces, constant reminders that they don’t acknowledge me and my identity, and I don’t feel particularly welcome. And ableism in LGBTIQ+ spaces. I’m not often able to fully participate and feel comfortable in those spaces either, because they don’t cater for my needs at all”.

(Focus group 3)



“I think there’s so many social barriers, in terms of people’s ableism and negative attitudes around disability, within the broader community, but also within the LGBTI community... there’s so many assumptions about people with disabilities, around our sexuality, our desire. Being viewed as not desirable or less than other people. You know, trying to find a relationship, but also trying to find a pash on a Saturday night is really hard”.

(Focus group 2)

3.1 Accessing Services



A key topic of discussion with participants was their experiences of engaging with what were often termed “mainstream services.” For example, Centrelink or a non-specialist health service designed for everyone. A number of participants expressed fears and concerns about not having their identities understood or respected when navigating and engaging with services and individual providers, and again described the stress of trying to ascertain whether it was safe to disclose.

“I have to go back to my gynaecologist soon, because it’s time for my next check-, since the last one five years ago, and since then, I’ve explored my gender, and come out, and things like that; so I’m sort of wondering if there’s any point in disclosing my trans identity, or if I should just closet myself. Because is there any point in doing the work to educate them? Because it’s almost certain they won’t know already. Or is that energy better spent on just getting through the whole experience?”

(Focus group 3)

This was a concern for participants when navigating specific disability services, where they were unsure if it was safe to discuss their gender and/or sexuality. Participants also described uncertainty and tension around trying to access LGBTIQ+ services or events.

“So if I want to get autistic services, I don’t really talk about sexuality; if I want to go into queer spaces, I can’t really talk about disability and access. Or there’s not an understanding; there’s not a whole lot of cross-education”

(Focus group 1)

For LGBTIQ+ people with disability, these concerns mean having to constantly decide on information to prioritise or share with providers, balancing decisions about what they think their provider needs to know about their identities, with the potential physical and emotional toll of having to explain themselves.

“A disproportionate number of disabled people are on Newstart, rather than DSP, unfortunately; and that can be a really difficult landscape to navigate, as both a queer person, and a trans person, and all that kind of stuff, as well as a disabled person; because I have to disclose all those parts of identity as well as my access needs, police that they’re being met, police that I’m being gendered correctly, all of that kind of jazz; which makes every other part of life more difficult”.

(Focus group 3)

Participants also described the burden associated with having to ‘come out’ repeatedly. At times this was the result of individual providers not respecting or appropriately responding to particular needs, or of systems not having the capabilities to accurately record information, such as gender and pronouns.

“I recently tried coming out to my disability employment services provider, because they have really not known a lot, so I think they’ve tried to take note of what I said, but there is no place on their system where they can note my pronouns, or my actual gender, or my preferred name. My actual name that I use, rather than my birth name”

(Focus group 3)

Services labelling themselves as “LGBTIQ+ friendly” was seen as useful, but participants described wariness about whether this was a marketing ploy with little substance, as well as experiences of negative treatment at such services.

“I still have anxiety about sharing my sexuality, and I live in a sexually and gender diverse household; I’m the carer of someone else with disability, and when I look for services, I actively search to see if they are LGBTI friendly; and even when I do find that they say they are, if they treat you really badly or discriminate based on

the disability, I don’t then feel comfortable sharing the other part”.

(Focus group 2)

In addition to concerns about their identities and needs not being understood, participants also expressed fear of being discriminated against when accessing and engaging with services, and of providers not knowing what to do to support them appropriately. For some people, fear of discrimination or receiving poor quality care resulted in them avoiding or delaying engagement with some services.

“I want to start study soon... but I’m afraid for two reasons, because I don’t know what level of support I’ll have with access needs, and things like that, because they’re not very explicit about that before you enrol. And I’m also worried about if my trans identity will be accepted”.

(Focus group 3)

Another issue discussed in relation to services was poor accessibility, both in terms of information and service-provision. Participants described how information is often not provided in accessible formats (i.e. Auslan or plain English) or other languages, and often contains medical and technical jargon that is difficult to understand. Participants lamented how people with disability are frequently expected to cover the additional costs of having information made accessible to them, and how this can be a significant barrier to receiving the information and supports they need.

“Access to health information shouldn’t just be about the cost, it should be about – we’re part of a minority group, and we are well behind. We have poorer health outcomes, because we don’t have access to that information, so there is no equality there”.

(Focus group 4)

The “costs” described were not only financial, but also related to the burdens of dedicating the time, energy and resources needed in order to access services.

“Then means that as a person with a disability, we’re the ones always making the phone calls, reaching out, trying to find out how we can just access for an everyday service, rather than just being able to go out the door and access them”.

(Focus group 1)

With regard to service access, participants reported a lack of service options for people living in regional and rural areas, as well as the lack of information about services that do exist. This was particularly evident in relation to queer specific services, with some participants recounting that they had never heard about or used a queer specific service.

“I didn’t grow up here, and I find that I don’t have access to all services, and that hidden or invisible disabilities aren’t recognised. I think that we should have an opportunity to be able to feed in designs of what we want as housing options, or health options, or whatever; because we don’t get that chance. We’re left out of the loop”.

(Focus group 2)

Participants emphasised how LGBTIQ+ people with disability had fewer options the more minority identities they belonged to, and/or the more specific their health or access needs are. This picked up on the ongoing theme of fragmentation, or having to ‘split’ oneself rather than present as a whole person, whether that be in community interactions or within services.

“Whenever I need to get medical care, or therapy, or anything like that. You need to sort of pick which part is most important immediately, because there’s almost never any option that covers all the bases at once”.

(Focus group 3)

The availability of Auslan interpreters, particularly in rural and regional areas, was highlighted as a key area of concern by Deaf participants. Participants outlined how this has implications for their right to privacy, and the ability to maintain their privacy.

“We have a big problem out regionally, because going to the doctor, or going to the hospital, there’s only the local interpreters there... I mean, I grew up with you [an interpreter] teaching - through my education life, I had you there interpreting, and I don’t want you being in this part of my life, so sometimes, I have to be assertive and say no”.

(Focus group 4)

Recently I was in a meeting, and there was an interpreter there, a Centrelink person, and we were talking about serious things, like mental health, and I didn’t feel comfortable talking in front of the interpreter, as well. You know, I never thought about that before, but really, I started talking about it – you know, [if] she’s the right person, and I just don’t feel comfortable in that scenario”.

(Focus group 4)

Participants also described the additional burden and stress associated with having to determine whether a service can meet their access needs and advocating to have these needs met, which often also means incurring the additional financial costs of receiving access supports. This idea of responsibility – of who had to take responsibility for making identities visible, for enabling holistic

care, and facilitating access – currently rests largely with the individual. However participants made clear that this experience was exhausting, and they called for services and community to take some responsibility, to reach out beyond simply recognising they exist but to actively include them.

This was important finding given the specific experiences of LGBTIQ+ people with disability at intersections of at least two significant points of oppression. It also meant that ‘access’ looked differently for different people, pointing to the need for a holistic and comprehensive understanding of how access needs can be conceptualised and met.

“Knowing your accessibility needs can be really difficult sometimes, when disability is defined by what makes us frustrating for other people, as opposed to what our experiences of it actually are”.

(Focus group 1)

This is reminiscent of a discussion in the 2006 report “Swimming Upstream” (Mann et al.) which highlighted the need to reframe the common term of ‘hard to reach’ populations, to services which are ‘hard to access’. This distinction removed the victim blaming approach and moved the responsibility for reaching out onto services.

Another significant barrier to access was the high costs of some services, particularly mental health and psycho-social services. Some participants were critical of the lack of financial support available via Medicare subsidises in order to access these services.

“While the government has the mental health care plan, which gives you 10 [subsidised] sessions, so many people charge \$220-odd for their sessions, which means [the government contribution of] \$80 towards that really doesn’t actually make it an affordable session... makes it a really difficult one to find ongoing and trustworthy connections within your healthcare team”.

(Focus group 2)

Financial equity was highlighted across several focus groups, with the lack of sustainable income to meet the ‘costs of being disabled’ an important theme.

Participants also discussed the lack of integration and coordination between public, private and NDIS funded services. Many described the frustration and confusion about finding out which services they are eligible for, and the processes involved in gaining access to them. Participants pointed out that this ultimately leads to gaps in service provision, with some people unable to navigate these complex bureaucratic systems and therefore unable to access services they need and are entitled to.



3.1 The National Disability Insurance Scheme (NDIS)



Some participants reported having had positive experience with the NDIS, and acknowledged that they are now able to access supports and services that were not available to them previously

“I’m just grateful for the NDIS. I’m just grateful, because in the past, going to private hospitals... how would we have paid for [the supports we need]? How would we have been able to access the information that we needed?”

(Focus group 4)

“I guess I am lucky, and I am grateful to receive NDIS funding, because I never fitted into any of the boxes before then, or I didn’t know I was being funded before...”

(Focus group 3)

Other participants expressed optimism about the potential of the NDIS to improve the delivery of care and support for people with disability and the benefits it will bring in future.

“And that’s not to say I haven’t been incredibly grateful for the support that NDIS has given me, now that we’re kind of working out the bugs with it; and in about 10 years’ time, it will be a fantastic system”

(Focus group 3)

Many participants, however, were critical of the NDIS system, and reported negative experiences and challenges accessing and engaging with the NDIS that were similar to the issues described in relation to other services. For example, participants described experiences with National Disability Insurance Agency (NDIA) employees and NDIS providers who did not understand and respect their identities, and were not able to respond appropriately to meet their needs.

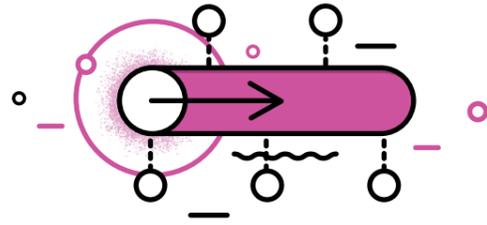
“So now that included getting a support coordinator; which brings me to this, which is I’m stuck trying to find a support coordinator, and trying to decide which part of my identity am I wanting to prioritise in getting this. Do I go with someone who I know is LGBTIQ+ ready, in front of them, because I know if religious reforms come through, that potentially I can have more active discrimination against me? Or do I choose someone that maybe understands more about my psycho-social disability, or my autism, or my other complex needs? It’s left me really stuck, because I’m having to do all this extra work, and try and make a decision on which part of my identity is the most important thing for me to get the best outcomes”

(Focus group 3)

Here, the idea of fragmentation earlier described as being ‘split’ can be contrasted with the idea of comprehensive access, and integration. It led one peer researcher to comment of the NDIS:



“they want us to tick a tick box, but we want to slide a slider”



This quote resonated with the research team during analysis and inspired the title of this report. It captured the desire to resist a binary yes/no option and instead be represented within systems that could encompass multiple or fluid responses and identities.

Participants also reported that NDIA planners, and previously Local Area Coordinators (LACs), who are responsible for working with NDIS participants to develop their NDIS funded plan, often have limited knowledge of disability. This led to plans being developed that did not identify and secure the adequate and appropriate supports and services people needed. Some participants also described challenges in finding support workers that they felt understand and respect people with disability. This was experienced as a lack of respect for people with disability also held within the NDIS system. As one peer researcher reflected during the subsequent analysis process:

“We are just an equation they have to work out how little they can get away with spending on us”

Some participants reported delaying their engagement with the NDIS due to a lack of confidence in the system to recognise their identities, and the ability of NDIS providers to offer safe spaces and services. Participants pointed out

how organisations may promote inclusion and diversity, yet LGBTIQ+ people with disability could still experience discrimination from individual providers.

“I’m really terrified of it going badly the first time... If [my application] gets in the system with me being misgendered, or with my pronouns not being noted, or something like that, or if not all my documents are consistent across how they describe my identity, there could be an issue going forward with them getting it wrong for the rest of the time I’m on the NDIS”.

(Focus group 3)

Others reported concerns about the way gender diversity and sexuality were being addressed more broadly by the National Disability Insurance Agency in terms of the planning and delivery of the NDIS, including administrative systems and processes (i.e. the ability to record pronouns), and specific strategies to ensure the needs of LGBTIQ+ people with disability are adequately prioritised and addressed.

“They [the NDIS] are really shit with recognising our sexualities, and we still have no strategy around that, for the community... And even recognising people with disabilities as sexual beings... We worked for three years, me and some others, [on a] NDIS

LGBTI strategy, but we have seen nothing⁷”.

(Focus group 3)

Another key issue raised by participants was the complexity of the NDIS and therefore how difficult it is for people to access. They noted that many people with disability do not understand the system, how to apply to become an NDIS participant or what they are able to get funding for. They felt that information can be difficult to find and understand, and that the information tends to be too general, rather than tailored to specific disabilities or service needs.

“I also feel like a lot of people with disabilities don’t understand what NDIS is... Yeah, and no one knows what they can get funding for...”

(Focus group 3)

Participants reported that even once they were able to become an NDIS participant, the system is confusing and time-consuming to navigate. There is also a significant burden on participants to provide proof of their disability, and to advocate for adequate funding to cover the costs of the services and supports they need. This creates additional and ongoing difficulties for people, as for many it requires significant learning or developing of skills, such as the ability to plan and manage a complex budget.

“Looking at it in terms of this stupid neoliberalism around the user has to pay for everything, and all of a sudden you’re the expert because you get your own budget. It’s like, “Well, that’s stupid.”

(Focus group 3)

“I’ve actually found NDIS themselves to be a barrier to work. They wouldn’t fund very basic maintenance for a very basic piece of equipment for me. I’ve been fighting them for a year. Imagine what I could have done with that year, if I hadn’t had to fight them”

(Focus group 1)

A further funding related barrier is the way supports and services are categorised across the health and disability systems and sectors. Participants reported instances in which they were not eligible for services in the public health system, whilst also not being eligible to access them through their NDIS funding. Participants also discussed their perception that the shift from block funding to individual funding under the NDIS has reduced the funding available to disability advocacy organisations, which has subsequently reduced organisations’ capacity to provide navigation and advocacy support to individuals.

⁷ The NDIA LGBTIQ+ Strategy was subsequently released during production of this report in August 2020 and can be accessed on the NDIS website.

4. Discussion

There are three key themes that work across the topics presented in this report, which we will integrate into this discussion: visibility, multiple identities and understanding access and inclusion.

4.1 Visibility

Visibility was an overarching subject affecting all four topics, which we found most constructive for analysis when encapsulated in a question: “am I seen here?” Being ‘seen’ had both literal and figurative meanings:

- ▶ “Am I seen for who I am – as LGBTIQ+ and a person with a disability?”
- ▶ “Am I seen in the way services advertise and respond to me?”
- ▶ “Can I see others like me within this community/group?”

To be ‘seen’ in this context included many positive actual or desired elements when engaging with community and services such as: correct use of pronouns, a rights-based and sex positive approach to disability, and visible markers of inclusion at an organisational level. The consequences of not being ‘seen’, particularly by services and organisations, were described by participants as ‘uncomfortable’, ‘unwelcoming’, ‘worrying’, and ‘terrifying’.

Visible markers included the rainbow flag, academic literature has identified how the rainbow flag can be a visual indicator which answers these questions for LGBTIQ+ people with intellectual disability (Marks et al., 2020). For Deaf participants in this study, seeing an Auslan interpreter present at events such as Midsumma carnival served a similar function. Interestingly, the Auslan interpreter is most likely⁸ to be a hearing person, but the connection was felt through the presence of Auslan rather than the individual interpreter. However,

⁸ Deaf interpreters are increasingly being used however this remains in the minority

the practice of many queer organisations and good interpreter booking agencies to request LGBTIA+ interpreters and the nature of the small Deaf community meant that many times the interpreter is also known to Deaf people as a fellow LGBTIQ+ individual. Articulating this duality was made possible through the analytic work conducted by the research team, and reflects an intersectional example of understanding visibility for LGBTIQ+ people.

The importance of being ‘seen’ within the NDIS in particular points to the importance of the LGBTIQ+ Strategy. The team discussion of this element of our analysis led to an additional research output, a poster intended for wide distribution to voluntary, community and statutory agencies who engage with LGBTIQ+ people with disability to encourage them to consider taking on some of the responsibility in managing access and inclusion, and making their work visible.

4.2 Multiple identities

The experience of managing multiple identities featured across the topics we have discussed, and was strong within the data overall. People talked about feeling ‘split’, about ‘binarism’ in disability spaces, and feeling the effects of a lack of ‘cross-education’ between the disability and LGBTIQ+ sectors. They described ‘masking’ and ‘closeting’ and the work which was required to anticipate the consequences of disclosure of LGBTIQ+ or disability identities. Yet, it was at the intersection of these experiences that people saw their authentic and complete self, and for which services and communities should be seeking to create space.

Participants described the impact of frequent decisions on when and how to self-identify and the impact of such behaviours on their mental health. The impact of not being able to come out safely

particularly encroaches on the home environment when it involves family or home-based care. There are potential implications to treatment, health interventions or support services which are designed without full practitioner information, particularly in a medical setting. We note that the responsibility for such implications cannot and must not rest with the individual, and existing knowledge around misdiagnosis and diagnostic overshadowing bias⁹ should be extended and applied to this group.

We recognise that there is agency in making choices about which identities to make public or to express in each setting. This is an identity management technique also described by LGBT+ people with disability in the UK (Toft, 2020). Participants celebrated the chance to explore their pride in identity through online connections, and for peer researchers in their role in this study. Taking control of one’s information and choosing when and how to share it is a legitimate choice. When it becomes burdensome, when fragmentation is forced or necessary for safety, this is the point at which it becomes obstructive.

One example of the impact of multiple identities can be seen in a discussion of guardianship in Victoria as it may effect LGBTIQ+ people with disability, using the NDIS system as an example. There are a range of types of guardians in Victoria: guardians, administrators, supportive guardians, and supportive administrators, with varying powers of attorney (such as financial powers and medical decision making), including supportive attorney appointments that are specifically predicated on supported decision making (Carney, 2015). In addition to guardianship, there are other arrangements that can inadvertently confer guardianship-like powers to people in the lives

⁹ Diagnostic overshadowing bias occurs when an individuals’ mental illness is not diagnosed, instead misunderstood as part of their intellectual disability. This is often attributed to a lack of training in intellectual disability in Australia resulting in low clinician confidence (see for example Jamieson & Mason, 2019; Weise & Trollor, 2018).

¹⁰ “Cared accommodation is usually long term and may be institutional in style. It includes hospitals, residential aged care, cared components of retirement villages, hostels and group homes where a resident has been, or is expected to be, living for 3 months or more. The accommodation must include all meals for its occupants and provide 24-hour access to assistance for personal and/or medical needs.” (AIHW, 2019)

of people with disability. For example, NDIS Plan Nominees (often a family member or advocate) can be appointed to make decisions on behalf of NDIS participants.

The recent review of the NDIS noted the lack of consistency and somewhat poor interaction between the concepts of ‘nominee’, ‘guardian’, and ‘supported decision making’ as enacted in NDIS practice (Tune, 2019). If a person’s life, lifestyle, schedule or daily activities are heavily reliant on NDIS-funded services, Plan Nominees may be in a position to make influential decisions which structure the participant’s daily life. In all guardianship or guardianship-like arrangements, it is vital that LGBTIQ+ identity, needs, desires, and choices are carefully considered and free of prejudice or personal judgement on, for example, LGBTIQ+ identity or community connections. For LGBTIQ+ people with disability, guardianship is not guided by an integrated, intersectional policy and legislative framework that explicitly mandates conscientious engagement with LGBTIQ+ rights, leaving those who sit at this intersection more likely to have their rights overlooked.

4.3 Understanding access and accessibility

There is a clear need for a greater level of understanding of access and accessibility across all services, communities and agencies who engage with LGBTIQ+ people with disability. We focus on services here given the importance of both disability and specialist services, which for some, such as the 16,200 Australians living in residential care accommodation¹⁰ (Australian Institute of Health and Welfare, 2019) including the estimated

1500-6000 young people living in nursing homes (Summer Foundation, n.d; Young People in Nursing Homes National Alliance, 2020) consume all aspects of their life.

To understand access and accessibility we draw on the work of Levesque et al. (2013) in which they conceptualise five dimensions of accessibility: approachability, acceptability, availability and accommodation, affordability, and appropriateness. They distinguish *access* from *accessibility* where the former is being able to obtain services, and the latter describes the nature of the services, that is how usable they are. When what is available does not match with what an individual needs, there is a barrier to access.

Access and accessibility should not be framed as the responsibility of the individual, but of those whose role or desire it is to reach them. By shifting the focus in this way, it becomes the task of the service or organisation to consider how to reach out to LGBTIQ+ people with disability, and understand the range of access needs and supports which this may require. The best way to form this understanding is with consultation and meaningful community engagement. We developed this thinking drawing on the distinction between community presence and community participation made first by the influential work of John O'Brien (1987) which would be familiar to those with a long enough history in this field. However, O'Brien's work and indeed much contemporary service provision still requires the individual to be measured, assessed or improved. We call for services to bear this load (or indeed, this opportunity) instead, through policy inclusion, training and active efforts towards access and accessibility.

As demonstrated in this research, people for whom access and accessibility is to be considered must be included in that process. That may mean actively seeking out LGBTIQ+ people with disability across a wide range of roles, as staff, volunteers, designers, board members, spokespeople, and more. Drawing on the work of Levesque and colleagues (2013), this strategy has been recommended by Australian research on violence and abuse and women with disability (see for example Healey et al., 2013; Robinson et al., 2020).

RECOMMENDATIONS

The following recommendations are suggested in order to strengthen the research approaches which aim to focus on – and include – LGBTIQ+ people with disability.

9. All healthcare, community and disability services should be required to presume that LGBTIQ+ people with disability both need and use their services. These services should proactively develop inclusive reforms through action plans or similar approaches which demonstrate the ways they act in order to be inclusive to everyone, and acknowledge that it is not the responsibility of the individual to educate services on how to be inclusive. The Rainbow Tick may be an appropriate initiative to achieve this recommendation.
 - 9.1 Voluntary organisations or groups within local, queer or disability communities should be funded and supported through small grant systems to develop similar plans at an appropriate level
 - 9.2 At an immediate level, all systems and services should have the capacity to accommodate information such as gender pronouns and gender neutral titles, display the rainbow flag and use inclusive and welcoming language
 - 9.3 Disability service providers should refer to the explicit list of attributes noted in rights, responsibility and diversity indicators of the NDIS Practice Standards
10. Opportunities to positively highlight the intersectional identities held by LGBTIQ+ people with disability, and to connect these individuals, should be sought. For example, a biannual conference should be funded by government to be led by LGBTIQ+ people with disability, in partnership with the University sector. The event should include streams for LGBTIQ+ people with disability may be one way to strengthen knowledge and advocacy, and a second stream for currently siloed disability, queer and mainstream support services would address this recommendation. Establishing conferences of this nature would allow for the involvement of LGBTIQ+ people with disability in what is often an environment that is restricted to academic audiences. It would further reflect the inclusive approaches taken in this project.
 - 10.1 Such an event should be informed by relevant and accessible research and best practice and run by LGBTIQ+ people with disability
11. The Victorian State government should fund advocacy, community and research partnerships to provide adequate support to LGBTIQ+ people with disability in accessing the NDIS, including:
 - 11.1 A communications campaign to raise awareness of the recently released NDIA LGBTIQ+ Strategy
 - 11.2 Training for NDIS staff, with planners as the first priority, on how to include and support LGBTIQ+ people with disability
12. The development of a federal and state government/level LGBTIQ+ people with disability strategy to articulate a whole of government approach that specifically highlights the needs of LGBTIQ+ people with disability to address the issues of access and services described in this report ¹¹

¹¹ For example, the LGBTIQ Aged Care Strategy asserts principles of inclusion, empowerment, access and equity, quality and capacity building as key sites for action.

4.4 Summary

Inclusive practice means a lot more than putting up a sticker or building a ramp. There are no easy, simple solutions to the complex ways in which LGBTIQ+ people with disability experience social exclusion and marginalisation, including in using or trying to access a host of health and advocacy services. Meaningful inclusion means from design to delivery, LGBTIQ+ people with disability work at all levels of planning and management, which values their expertise appropriately, and commits to outcomes that offer meaningful transformations in policy and practice to LGBTIQ+ people with disability.

We recognise there are significant issues affecting the lived experiences of LGBTIQ+ people with disability that result in often weighty consequences of exclusion, poorer outcomes and discrimination. LGBTIQ+ people with disability experience multiple marginalised identities which may result in a greater need for services than others, and a more developed and nuanced service system than currently exists. We also acknowledge one of the key opportunities to change this situation can be rectified by the inclusion of LGBTIQ+ people with disability in meaningful and active ways, within services, policy development and research, which recognises their capacity and right to experience the very best of life.

4.5 Limitations

The study included a relatively small number of people. It is a familiar experience for those experienced in participatory research with marginalised people that the work of creating cross-disability and LGBTIQ+ appropriate spaces (for both the focus groups and within the research team) requires more time and resources. While the small number of participants precludes generalisability, we did not and do not seek to generalise from this study. Rather, our priority was to do meaningful research that respected the experiences of LGBTIQ+ people with disability, as

both participants and researchers, create positive engagement, and produce outcomes that improve the lives of LGBTIQ+ people with disability.

While many people reflected on the position of their individual identities, there are many potential intersections contained within the concepts of disability and LGBTIQ+ that were not specifically addressed in the data or in this report. We purposefully did not identify participants in the transcripts by statements they made regarding their gender, sexuality, or disability, in part to respect the privacy and confidentiality of the small group of participants. We acknowledge that there is a need for far more research into the experiences of LGBTIQ+ people with disability that focuses on specific identity groups and experiences of disability. We hope this project will provide the foundation for funding such projects in the future, and we hope the approach to peer research we have taken will be taken up elsewhere. Such work will help with further unpacking ideas of ‘access’ and broadening our understanding of the area.

There are many potential intersections that were not addressed directly in this project. For example, no participants identified themselves as intersex, Aboriginal or Torres Strait Islander, and there was limited discussion of religion. This could be due to the open nature of the focus groups and people either choosing not to discuss the topic, or not finding it a suitable or safe space to do so. Future research should prioritise and explore these areas, drawing on the expertise of peer researchers from within these communities.

RECOMMENDATIONS

The following recommendations are made in order to address the limited engagement with LGBTIQ+ people with disability in a research capacity.

13. LGBTIQ+ people with disability should be afforded the opportunity to participate in advisory and similar roles at all levels of government. This will ensure that future activities are informed by their experiences and input.
14. There is an urgent need for further research across a host of areas that affect LGBTIQ+ people with disability, and for that research to be conducted in a way that practices meaningful inclusion.
15. Elucidation of key concepts through accessible knowledge translation documents to articulate the processes of inclusion and participation across the intersecting LGBTIQ+ and disability spectrums.
16. Ensure that the present work and the methodological capacity developed by the research team is recognised in future capability mapping
 - 16.1 Drawing on this project, we suggest the following priority research areas:
 - Further research to emphasise/highlight the diversity of experiences *within* the umbrella terms “LGBTIQ+” and “disability” We suggest that a qualitative focus on the experiences and needs of, and protective factors for, trans and gender diverse people with disability, is of particular significance and should be considered as a priority.
 - Academic evaluation of the impact on the lives of LGBTIQ+ people with disability the following initiatives:
 - LGBTIQ+ inclusive practice approaches in clinical services
 - LGBTIQ+ inclusive policies
 - Disability inclusion reforms in LGBTIQ+ services and organisations
 - Connecting with the National Disability Research Partnership to promote the importance of LGBTIQ+ disability research
 - Further exploring the experiences of LGBTIQ+ people with disability. In particular:
 - Research projects that are focussed on specific disabilities and include the intersecting experiences of LGBTIQ+ people. For example, research into the experiences and needs of neurodiverse women or Deaf men. We also note a dearth of research on intersex lived experience. Such projects should be led by teams with established connections to relevant communities, partnership across relevant sectors, and academic experience relevant to the task/s required.

4.6 Peer Researcher reflections

In addition to their contribution to the entire report, the peer researchers have contributed some additional reflections, adding another layer of representing the voices of LGBTIQ+ people with disability. We were requested to include this content at the report conclusion, when the reader has an understanding of the project in its whole, and of their central role in its conduct.

Mellem Rose:

It was a privilege to be involved in this work. I come from generational poverty, disability, and disadvantage. My upbringing meant that I was unaware that I had learning disabilities until later in life, the traumas that existed in my life meant that I was unable to pass high school and later was unable to afford a higher education.

This project was an opportunity for me to be seen by the academic community, professionals, peers, and myself as an accomplished and successful person in spite of the many challenges that life has thrown at me.

If pride is something my community connects over, then this project is something that will connect me to my community because I am proud of the work I have produced and the accomplishments my team and community has made in the authenticity of this work.

Despite the many personal hardships that I have had to endure during this work and my period of my life, I am astounded that I have come out a stronger, more determined person, and I look forward to my future endeavours of continuing my research work and getting a PhD. I would never have thought that was possible without the support of my colleagues, peers, and community and most importantly this opportunity.

Ruby Mountford and Jake Lewis:

The methodology and participation of peer researchers in this project is a positive step and was made possible by allies and supporters. Our reliance on the good will of others is still, at this point, a factor that must be acknowledged.

Participating in research such as this comes at a cost – the quotes within came from discussion that required us to sit in our experiences of oppression and indignity, to share our frustrations and our fury at injustice, and then to sift through this raw material in the name of data collection.

Thank you to everyone who came to a focus group and trusted us with your stories. This project is a testament to the resilience and determination of the LGBTIQ+ disability community and our allies.

This project is, we hope, one tiny step on the road towards a more just and equal future, and our right to self-determine. Nothing About Us Without Us.

Sherrie Beaver:

A once in a lifetime project like this needs peer researchers. It's important to bring in our life experience - together we can make the project far stronger than just one side of the story. That is what we believed in this project, and what we took into the focus groups where we welcomed people to participate in the research and share their stories. We were able to help participants feel more safe and comfortable in telling their stories.

I think these stories came to us as rich as they did, as high quality as they are, because of the way that participants saw themselves in the project, through us. This to me is evidence to anyone looking to improve their services or supports for queer people or people with disability.

For me, as a peer researcher, a Deaf queer non-binary person, I could connect with queer Deaf people to be part of the project and have their stories included. I brought my connection with the

Deaf community to our work, which meant that people came forward to share their stories - they had faith that we would do them justice, and I believe we have.

It's really important to have people involved in research who understand what it is like from the inside, who can reflect on both their subjective and objective experiences. It's always important to have a team that includes lived experience. If you don't, that work is weak, or biased - I wouldn't support that kind of work. Peer representation is such an important part of research. I hope our work will help to improve things for queer people with disability.



5. Recommendations

The overwhelming finding of this research is that there is a clear and urgent need for disability services to better understand the needs of LGBTIQ+ people, and for LGBTIQ+ services to better understand the needs of people with disability. Accordingly, centering the experiences of LGBTIQ+ people with disability in inclusive reforms will focus the development of inclusive practices that benefit more LGBTIQ+ people and people with disability. The recommendations produced within this report sit within the principles articulated in the United Nations Convention on the Rights of Persons with Disabilities which should also be taken through across all levels of policy, legislation and service delivery.

RECOMMENDATIONS

1. Recipients of public funding should be required to create and make public their statements and plans for equal access for LGBTIQ+ people with disability, supported with relevant academic research
2. LGBTIQ+ people with disability should be acknowledged as a priority community for focussed outreach or enhanced access support within the NDIS. This may occur within the NDIS and through funding advocacy services.
3. An opportunity to discuss and review the NDIS LGBTIQ+ Strategy should be arranged at local or state government levels as a matter of priority. This could be trialled within one region to determine how to best ensure access and cultural safety
4. Create state-based working groups with the assistance of experienced practitioners on LGBTIQ+ people with disability, to bring together health service providers, LGBTIQ+ organisations, disability services and LGBTIQ+ people with disability to learn from each and share ideas on inclusive practice. The work of LGBTIQ+ people with disability within these groups should be appropriately recognised and remunerated. These groups will:
 - 4.1 Establish clear channels for policy reform across all levels of government
 - 4.2 Create connection and peer development for LGBTIQ+ people with disability
 - 4.3 Advise services and departments on inclusive practices for LGBTIQ+ people with disability
 - 4.4 Promote opportunities in collaborative research development, including grant funding support
 - 4.5 Organise workshops, seminars and other events to develop ideas and share resources more broadly
5. Further research by tertiary institutions and independent research bodies into the experiences of people with disability and LGBTIQ+ people committed to developing the research capacity of LGBTIQ+ people with disability as an integral part of these research projects
6. Any funded project connected to disability or LGBTIQ+ topics should expressly aim to include LGBTIQ+ participants, and report against this outcome
7. Future research about LGBTIQ+ people with disability should meaningfully include them at all stages of the research process, including design, data collection and analysis, write up and dissemination.
8. Research and evaluation claiming co-design or similar approaches should be required to demonstrate rigor and transparency about processes towards inclusion.
9. All healthcare, community and disability services should be required to presume that LGBTIQ+ people with disability both need and use their services. These services should proactively develop inclusive reforms through action plans or similar approaches which demonstrate the ways they act in order to be inclusive to everyone, and acknowledge that it is not the responsibility of the individual to educate services on how to be inclusive. The Rainbow Tick may be an appropriate initiative to achieve this recommendation.
10. Voluntary organisations or groups within local, queer or disability communities should be funded and supported through small grant systems to develop similar plans at an appropriate level
 - 10.1 At an immediate level, all systems and services should have the capacity to accommodate information such as gender pronouns and gender neutral titles, display the rainbow flag and use inclusive and welcoming language
 - 10.2 Disability service providers should refer to the explicit list of attributes noted in *rights, responsibility and diversity indicators* of the NDIS Practice Standards
11. Opportunities to positively highlight the intersectional identities held by LGBTIQ+ people with disability, and to connect these individuals, should be sought. For example, a biannual conference should be funded by government to be led by LGBTIQ+ people with disability, in partnership with the University sector. The event should include streams for LGBTIQ+ people with disability may be one way to strengthen knowledge and advocacy, and a second stream for currently siloed disability, queer and mainstream support services would address this recommendation. Establishing conferences of this nature would allow for the involvement of LGBTIQ+ people with disability in what is often an environment that is restricted to academic audiences. It would further reflect the inclusive approaches taken in this project.
 - 11.1 Such an event should be informed by relevant and accessible research and best practice
12. The Victorian State government should fund advocacy, community and research partnerships to provide adequate support to LGBTIQ+ people with disability in accessing the NDIS, including:
 - 12.1 A communications campaign to raise awareness of the recently released NDIA LGBTIQ+ Strategy

12.2 Training for NDIS staff, with planners as the first priority, on how to include and support LGBTIQ+ people with disability

13. The development of a federal and state government/level LGBTIQ+ people with disability strategy to articulate a whole of government approach that specifically highlights the needs of LGBTIQ+ people with disability to address the issues of access and services described in this report¹²

14. LGBTIQ+ people with disability should be afforded the opportunity to participate in advisory and similar roles at all levels of government. This will ensure that future activities are informed by their experiences and input.

15. There is an urgent need for further research across a host of areas that affect LGBTIQ+ people with disability, and for that research to be conducted in a way that practices meaningful inclusion.

15.1 Elucidation of key concepts through accessible knowledge translation documents to articulate the processes of inclusion and participation across the intersecting LGBTIQ+ and disability spectrums.

16. Ensure that the present work and the methodological capacity developed by the research team is recognised in future capability mapping

16.1 Drawing on this project, we suggest the following priority research areas:

- Further research to emphasise/highlight the diversity of experiences *within* the umbrella terms “LGBTIQ+” and “disability”. We suggest that a qualitative focus on the experiences and needs of, and protective factors for, trans and gender diverse people with disability, is of particular significance and should be considered as a priority.
- Academic evaluation of the impact on the lives of LGBTIQ+ people with disability the following initiatives:
 - LGBTIQ+ inclusive practice approaches in clinical services
 - LGBTIQ+ inclusive policies
 - Disability inclusion reforms in LGBTIQ+ services and organisations
 - Connecting with the National Disability Research Partnership to promote the importance of LGBTIQ+ disability research
- Further exploring the experiences of LGBTIQ+ people with disability. In particular:
 - Research projects that are focussed on specific disabilities and include the intersecting experiences of LGBTIQ+ people. For example, research into the experiences and needs of neurodiverse women or Deaf men. We also note a dearth of research on intersex lived experience. Such projects should be led by teams with established connections to relevant communities, partnership across relevant sectors, and academic experience relevant to the task/s required.

¹² For example, the LGBTIQ Aged Care Strategy asserts principles of inclusion, empowerment, access and equity, quality and capacity building as key sites for action.



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