LGBTIQ disability self-advocacy

A report on the results of a survey of LGBTIQ people living with disability in Victoria

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Purpose of the survey

The survey was part of a project to prepare for the development of a LGBTIQA+ Disability self-advocacy alliance in Victoria. The survey was designed to seek input from a broad range of LGBTIQA+ Victorians living with a disability (PWD) about the purpose and need for a self-advocacy group.

This project was coordinated by Jake Lewis at VALID and supported by GALFA (now Pride Foundation Australia), in association with an advisory group. It was made possible by a grant from the Victorian Government Disability Advocacy Sector Capacity Building Fund.

We were interested in the following questions:

- What are the existing connections and access to the LGBTIQ community for LGBTIQA+ PWD
- What are their experiences of disability inclusion in LGBTIQ communities
- What are their experiences of LGBTIQ inclusion in disability services
- What are the possible roles of a self-advocacy group – both personal benefits and community roles
- What are the preferred methods for people to connect with a self-advocacy group

Research team and advisory group

The research team consisted of

- Jake Lewis – project worker
- Ruth McNair – GP academic and Pride Foundation Australia (PFA) chairperson
- Dominic Moollan – VALID

The advisory group included:

Ian Gould (Chairperson advisory group, PFA), David Petherick (VALID), Jax Jacki Brown (disability rights consultant), Nathan Despott (Inclusion Melbourne), Michael MacKay and Peter Locke (Thorne Harbour Health), Ada Castle (Switchboard), Margherita Coppolino, Cameron Bloomfield (Rainbow Rights), Margaret Boulos (Carers Vic).

Survey development

The framework used to develop the survey was a social model of disability, and human rights as per the Convention of the Rights of People with Disability. This framework involves empowerment through respectful relationships, and a 'nothing for us without us' philosophy. We also recognised the importance of intersectionality. Our definition of disability included intellectual, physical, cognitive, and sensory disabilities.

We started with a draft set of questions based on the lived experience of the survey design team as well as recent Australian documents including:

- Leonard, W. and Mann, R. *The everyday experience of lesbian, gay, bisexual, transgender and intersex (LGBTI) people living with disability*, No.111 GLHV@ARCSHS, La Trobe University: Melbourne, 2018.
- Submission responding to the discussion paper on the Victorian State Disability plan 2017-2020, Submitted on behalf of the Gay and Lesbian Foundation of Australia (GALFA) LGBTIQ disability advisory group and the LGBTIQ Health and Human Services Working group, Victoria, July 2016
- Wilson et al A narrative review of the literature about people with intellectual disability who identify as lesbian, gay, bisexual, transgender, intersex or questions. Journal of Intellectual Disabilities 2016, 1–26

The draft survey was then co-designed with the advisory group. It was piloted with a group of 5 LGBTIQA+ disability advocates before being finalised.

The survey was written in two formats, a standard plain English version produced on the Survey Monkey online platform; and a hard copy dual read version – which included clear spacing, graphics and simple language, with space on one side of the page for a supporter to explain the questions if needed. The easy-read version responses were added to the survey monkey online survey manually by the research team.

Survey respondents were informed that they would go into a draw to receive a gift voucher prize.

1. Respondent characteristics

The survey was open from 7th February 2019 to the end of May 2019.

There were 164 survey respondents, including 15 people who completed the easy read version.

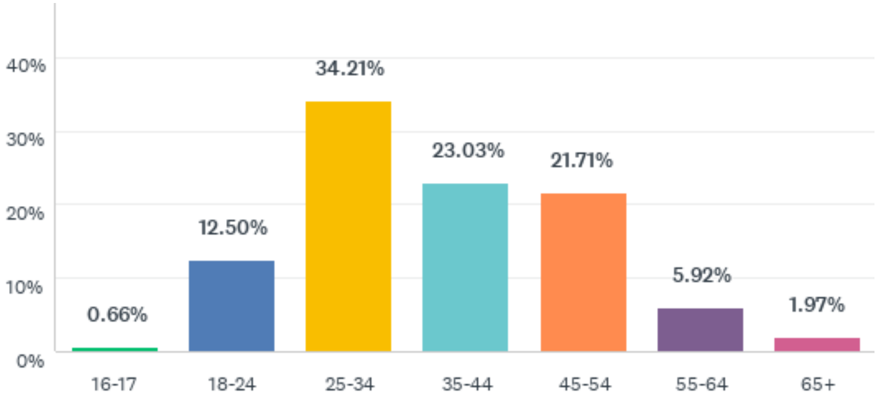
The range of respondents was broad, with ages from 18 to over 65, and a wide range of gender and sexual identities.

Just over half (81 = 55%) were assigned female at birth, and 56 (38%) were assigned male at birth.

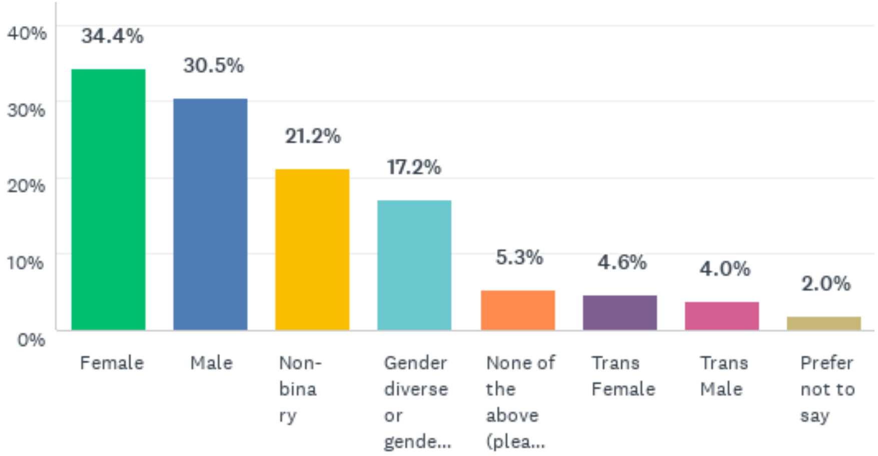
Of the 5.3% who chose the 'none' category, most were gender non-conforming. So almost 44% of the sample identified with a non-binary or gender diverse gender, which is relatively high compared to other LGBTIQ samples.

We asked respondents whether they thought it was important to express their gender identity. Of the 107 responses, 87 (81%) felt it was important. We then asked whether they felt their disability effected their freedom to express their gender identity. Thirty-one (29%) said yes, 12 (11%) were unsure, and 57 (54%) said no. Six people made comments. One example of the difficulty expressing their gender:

Age



Gender identity



More than one answer was possible.

> *I am supposedly unable to know who I am because I'm disabled, and thus should be forced to stick to a randomly assigned gender. It is also incredibly hard to express my gender when there is barely anything that I can use or wear as a Deafblind wheelchair user.*

Intersex variations

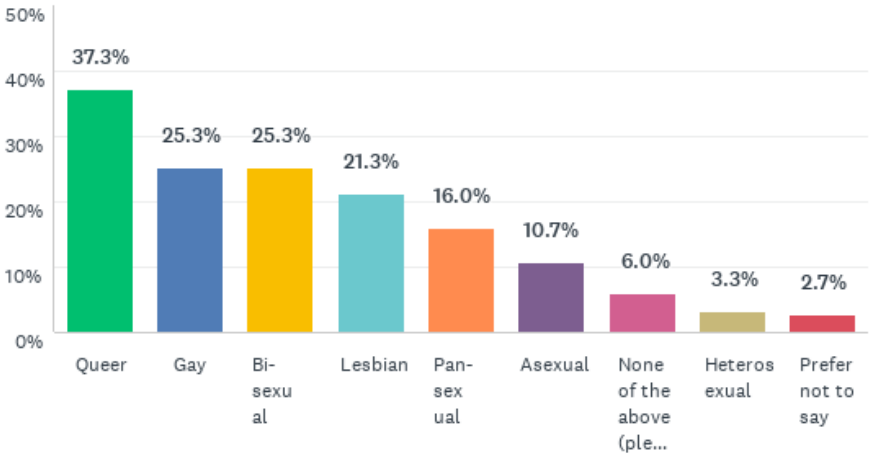
Twelve respondents (8%) had an intersex variation, and 6 (4%) preferred not to say. This compares with about 2% of people in the general population having an intersex variation.

Sexual orientation

A higher proportion selected queer, pansexual and asexual labels than would be expected in a general LGBTIQ community survey.

We asked respondents whether they thought it was important to express their sexual orientation. Of the 105 responses, 85 (81%) felt it was important. We then asked whether they felt their disability effected their freedom to express their sexual orientation. Thirty-four (32%) said yes, 22 (21%) were unsure, and 35 (33%) said no. Twelve people commented on their responses, and many of these comments related to feeling misunderstood or asexualised due to their disability. For example:

Sexual orientation of participants



More than one answer was possible.

> *Yes [it affects freedom to express] because of other people's assumptions that people with disabilities are not sexual or attractive, because of ableism not because of my impairment itself.*

> *I am frequently told that I should not be expressing myself because I cannot understand sexuality, or that I am undesirable because of my disabilities and should stay out of spaces.*

> *I'm a pretty confident person, but sometimes I feel like I'm not 100% acknowledged in gay venues and at festivals for who I am.*

> *I never know if my carers are going to be homophobic.*

Cultural diversity and ethnicity

This was a predominantly white sample of people. The majority of people (125 = 84%) were born in Australia, and most of the rest were born in either UK, New Zealand or the United States.

Just 4% (6) of the respondents identified as Aboriginal or Torres Strait Islander.

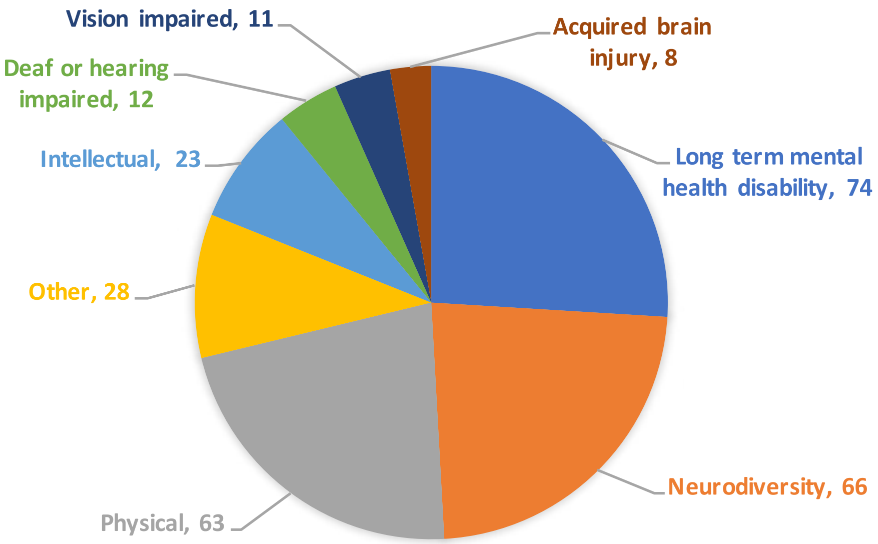
15% (22) people spoke a language other than English.

The ethnicity was a little more varied as depicted in this word cloud, with the size of the word indicating the frequency of responses:

The type of disability

Many respondents noted more than one type of disability. Long term mental health disability was the most common type amongst 51% (74) respondents. Neurodiversity, which includes Autism Spectrum, Tourette Syndrome, and ADHD was the next most common amongst 45% (66) respondents; then 43% (63) with physical disabilities. Almost 20% (28) selected 'other', with the most common types of disability described in the open-ended response being neurological (including stroke), then chronic illness, then fibromyalgia and chronic pain.

Type of disability - Number

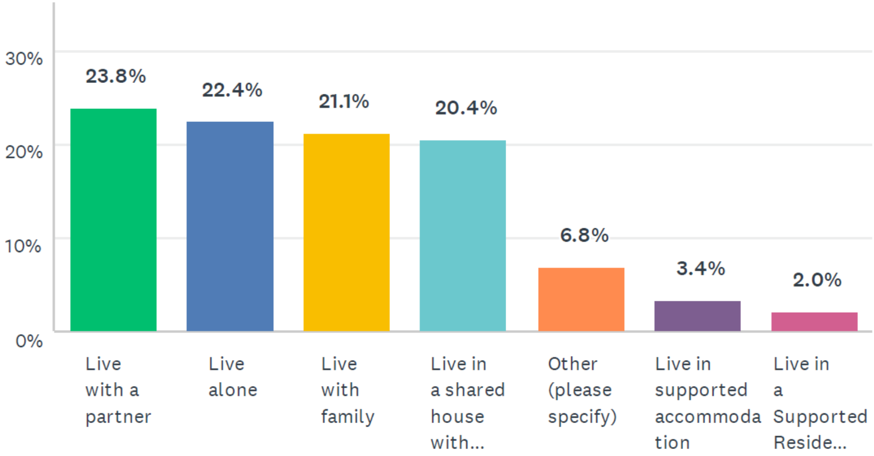


Living arrangements

Most respondents lived in Melbourne (68 = 46% in inner Melbourne, and 43 = 29% in outer Melbourne). Twenty-five (17%) lived in a regional city, and 11 (7.5%) in a town of less than 30,000.

Very few respondents lived in supported accommodation or a supported residential service (8 people = 5.4%), and none lived in a nursing home. This may reflect the lack of connection to LGBTI community for people in these living situations or difficulty being able to affirm their LGBTI status. The 10 respondents that selected 'other' were either living with children or an ex-partner or were in unstable housing such as a boarding house or couch-surfing.

Type of accommodation



Financial situation

Almost 2/3 (94 = 64%) received a Centrelink payment, including disability support pension, youth allowance, or rent assistance. Forty-three people (30%) had an NDIS support package, 4 people had an individual support package and 1 had an aged care package. However, over 2/3 (100 = 68%) did not receive a support package.

2. Connections and access to the LGBTIQ community

This set of questions had a lower response rate than the previous questions, with only 107 of the 164 (65%) answering them. This may have been partly because the questions were placed at the end of the relatively long survey. It may also reflect that for some respondents, connection to LGBTIQ community was not important or simply not possible.

A relatively high proportion (48=45%) of respondents did not feel part of the LGBTIQ community, despite the survey recruitment being largely carried out via this community.

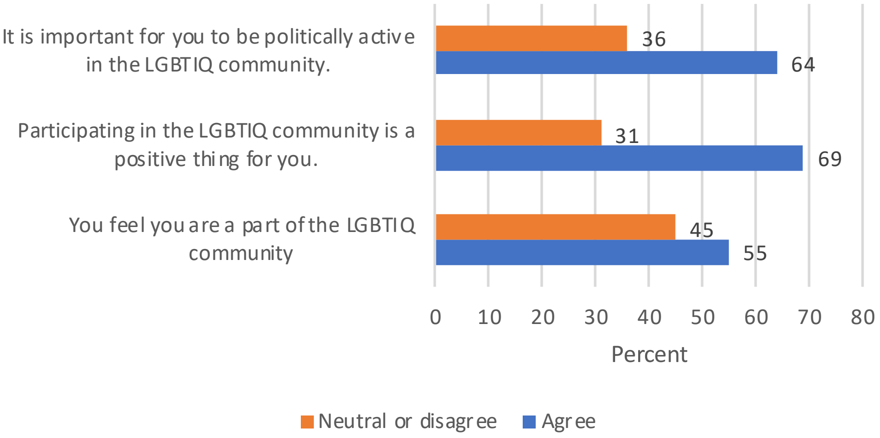
For those that were participating, almost one third (33 = 31%) did not find it a positive experience.

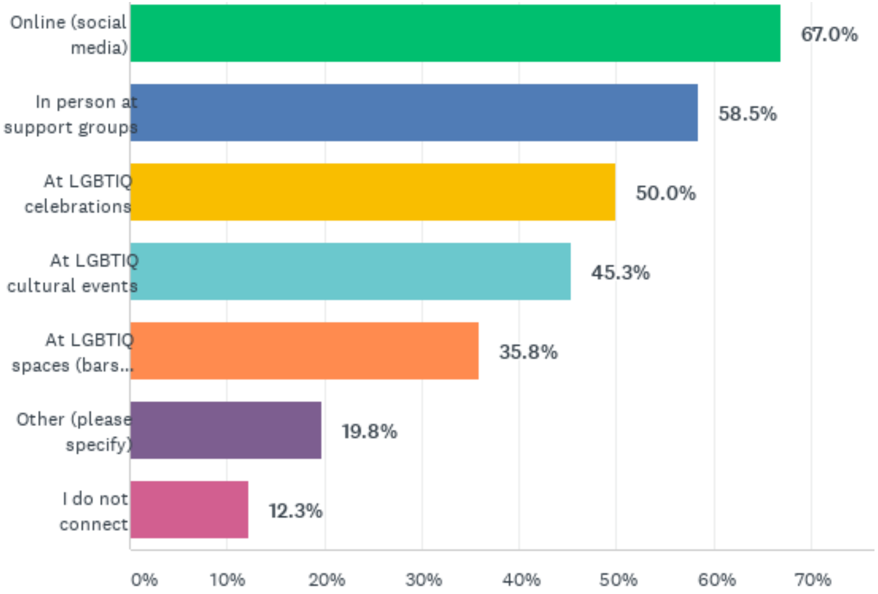
The majority of people responding to this section (88 = 83%) wanted to connect more with the LGBTIQ community.

Type of connection to LGBTIQ community

The majority (67%) of respondents connected online, and over half (58.5%) also connected in face to face social groups or peer support groups. Only around a third (38 = 35.8%) of respondents attended LGBTIQ bars and clubs. This connection was rated as the least inclusive of disability (see below) with only 3.8% of respondents experiencing them as very inclusive, Twenty-one people nominated 'other' methods. These included connection with 'chosen queer family' and individual queer friends. Individuals also mentioned sex on premises venues, queer sporting team, and being on a queer community working group. A few mentioned avoiding formal LGBTI spaces due to finding them difficult to access or not welcoming.

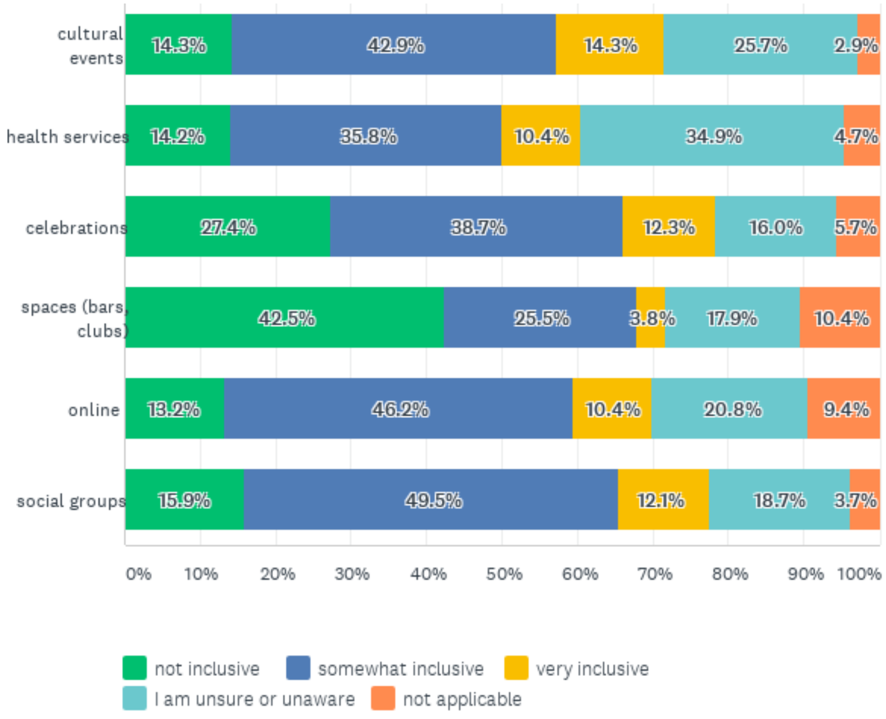
Connection to LGBTIQ Community





Level of disability inclusion in areas of the LGBTIQ community

Under 15% of respondents felt that any of the listed LGBTIQ specific areas were very inclusive. The most disability inclusive spaces were online, health services, cultural events and social groups.



Improving disability inclusion in the LGBTIQ community

We asked two open ended questions about how the LGBTIQ community includes people with disabilities, and then how this could be improved.

There were some positive experiences of inclusion, and most of the examples given were about accessibility at events such as the following comment:

> *There are some excellent event organisers who are making a real effort to provide inclusive places and events that have ASL [Auslan] interpreters, wheelchair access etc.*

Some people said they felt the LGBTI community was better than the mainstream community in accepting difference and understanding the impacts of marginalisation, for example:

> *The broader community has a lot to learn from the positive example of trans online spaces being mindful of autistic communication needs and of considering the impact of anxiety and depression in communication styles.*

However, others felt that the inclusion was very inconsistent, and more likely for certain disabilities such as mental health or autism.

At least half of the comments were negative. Twenty-one people said that the LGBTIQ community does not include PWD- point blanc, with no accessibility – “exclusion is painfully obvious”.

This was also a problem in regional areas or related to certain more marginalised disabilities:

> *People like me with a disability, people who are homebound/bedridden, the LGBTIQ community basically does not realise we even exist.*

Several people commented that inclusion is often tokenistic and not negotiated in a respectful manner:

> *Sometimes I get asked to talk about my experience or for resources and advice, but to be honest I’m afraid that I am being exploited or used as Inspiration/ Entertainment porn.*

Ideas for inclusion

Seventy-four people generously shared their ideas, which we have categorised into capacity building for inclusion, and accessibility methods.

Capacity building

- Include PWD in all planning, development and delivery of events
- Create culture change by "opposing ableism" through campaigns, increasing visibility, and education
- Funding for PWD as employees in LGBTIQ organisations
- Funding for LGBTIQ disability training

Accessibility methods

- No stairs/wheelchair access
- Auslan interpretation, subtitles
- Quiet spaces, no strobe lighting
- Daytime events
- Reserved seating
- Online events including live streaming

> *Unless disabled folks are a large part of planning, it doesn't [include PWD]. Ever. Accessibility is a huge issue, and I have been told, repeatedly, and by many different people and establishments that neither I, nor anyone like me, am welcome in LGBTQIA+ spaces, especially not offline.*

> *They can acknowledge us and actually have a conversation with us instead of standing back and staring.*

> *Education, if people don't know about the difficulties people face the problem will never solved. But also not criticising people who don't attend events or queer spaces because something like the pride parade is too much for them.*

> *Ensuring accessibility needs are met at events (wheelchair access, subtitling, Auslan interpretation, consideration of different sensory needs) Actively working with disabled people in planning of events, policies, etc.*

> *I'd like to see gay groups on FB at least catering for all sorts of disabilities, with disability specific private groups for peeps to join if they want. It is so LONELY out here.*

> *A lesser focus on very loud, crowded and often physically or sensorily inaccessible social events, and a greater focus on accessible venues and broader activities as a vehicle for bringing the community together.*

3. Experience of LGBTIQ inclusion in disability services

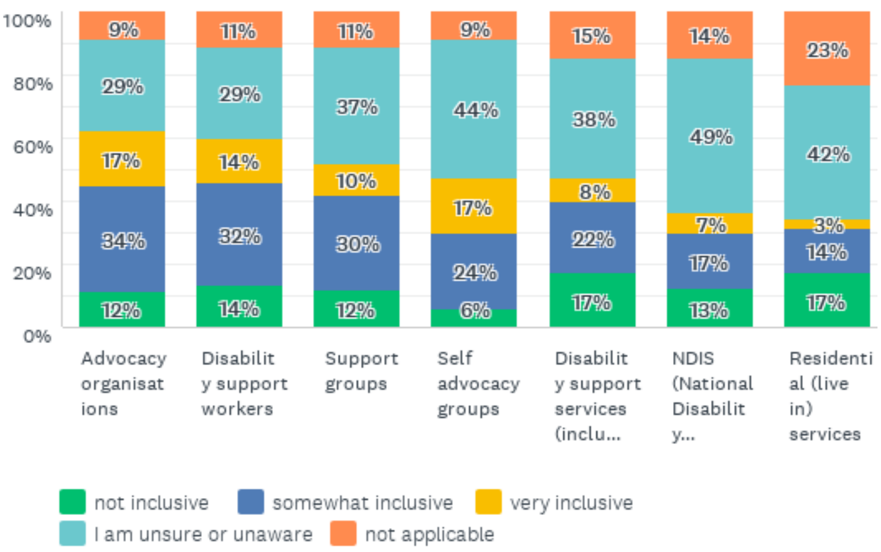
We were interested in respondents' experiences of being LGBTIQ in disability services.

Our first question was about how LGBTIQ inclusive a range of disability services were perceived to be.

Very few people felt any of the services were very inclusive, with about one quarter to one third felt they were somewhat inclusive. Most inclusive were advocacy organisations and disability support workers.

There were 13 comments, and several related to the difficulty of providing an overall rating as inclusivity differed across different people in an organisation. For example:

Inclusivity of LGBTIQ in disability services



> *Have had mixed experiences from utter contempt and disinterest in inclusiveness, to current situation with transition support and LGBTIQA peer workers*

Comfort to disclose LGBTIQ status with disability services

Importantly, a large proportion of respondents were unaware of the level of inclusion, implying that they had not disclosed their LGBTIQ status when accessing these services. Our next question was how comfortable respondents felt sharing their LGBTIQ status with disability services. Of the 104 responses, 47 (45%) were comfortable, 30 (29%) unsure, and 9 (9%) were not comfortable.

There were a few differences according to LGBTIQ status, with queer and pansexual respondents being least comfortable, compared with over two thirds of lesbian or gay people being comfortable. More culturally diverse than Anglo-saxon respondents were unsure of their comfort to disclose, and more people with intellectual disabilities or acquired brain injuries (ABI) were unsure or not comfortable. There were no significant differences according to gender identity. Respondents with intersex variations were the most comfortable in the sample, which may reflect the degree of medicalisation of their intersex status.

Eighteen people made comments about disclosure. These were mostly to clarify that the decision to disclose depends on multiple factors including whether trust has been established with a specific worker, and on the issue at hand. One person said they do not disclose in religious organisations. Another would only disclose related to physical disabilities, not mental health disabilities.

> *Depends which organisation. Definitely would not share with Centrelink or Job Seeker Organisation, only trustworthy organisations*

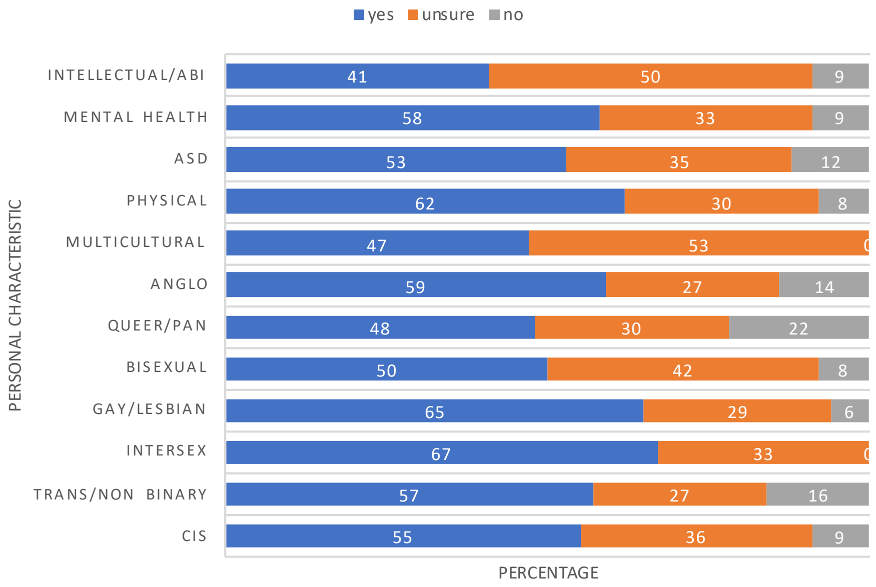
Two people disclosed as they felt it would be helpful to the organisation, and another two said they would disclose but also would have to educate the worker.

> *Yes but I know that I would have to educate them and that is stressful. It would defeat the purpose of accessing the service*

The emotional consequences of disclosure were difficult and prevented disclosure for this person:

> *If I thought there was a decent reason to. Mostly I just fly under the radar because the idea of having to educate everybody and defend my choices sounds exhausting and pointless.*

Comfort with disclosing LGBTIQ status in services



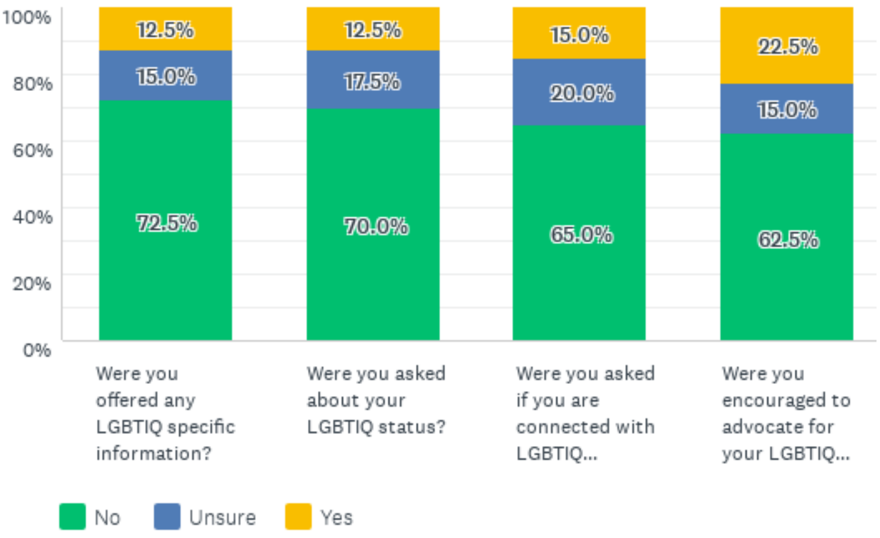
NDIS experiences

We were specifically interested in experiences of inclusion with NDIS, given the relatively recent history of these services. Only 34% of respondents had an NDIS package.

For those with a package, very few had experienced LGBTIQ inclusive practices. The most likely LGBTIQ specific support was that almost one quarter of respondents were encouraged to advocate for their LGBTIQ specific needs.

One person had had a positive experience:

LGBTIQ inclusion in NDIS services



> *From what I've seen, more NDIS service providers are speaking up and making public their own unique LGBTIQ inclusion practices.*

One respondent described a very negative experience:

> *They just pretend we don't exist. A note on my experience accessing the NDIS -I discussed at length in my planning meeting with my LAC my queerness and my partner and my connection with and work within the LGBTIQ community and how this was central to my life and goals, they wouldn't have asked me about LGBTIQ identity or issues if I hadn't brought it up and would have not funded those goals if I wasn't able to clearly articulate why they were important. My LAC was nice but had no LGBTIQ awareness or competency.*

Disability services LGBTIQ inclusion experiences

Finally, in this section we asked two open ended questions about experiences of inclusion and ideas of how they could be more inclusive.

There were several important suggestions that we have categorised under the following headings:

- Policies and organisational change
- Training workers
- Employing LGBTIQ workers, and including LGBTIQ peer support workers
- Creating a welcoming environment

Including posters, rainbow stickers, inclusive forms, actively marketing to the LGBTIQ community

- Individual workers having inclusive communication skills

Including being open, listening, non-judgemental, not making any assumptions.

Also acknowledging past experiences of discrimination and oppression.

- Enabling self-advocacy

> *They need to invest in LGBTIQ disability training by LGBTIQ people with disabilities and employ LGBTIQ people with disabilities and support us to lead meaningful change in the org and across the disability sector. They need to provide comprehensive, accessible LGBTIQ sexual health education to people with disabilities and support people to access the LGBTIQ community. They need to have knowledge and competency on trans and gender diverse issues.*

> *Some are trying but it tends to be individual staff who are progressive as opposed to at an organisational level*

> *My main disability provider is welcoming of my sexuality. I feel pretty safe with them. But being welcoming is not the same as actively engaging with LGBTIQ clients and helping and providing services that cater for their needs.*

> *It varies with the service. Some communities with known high proportions of LGBTIQA people are very inclusive, putting LGBTIQA issue front and centre, making sure people get to share their gender pronouns and not assuming sexuality - letting participants self-disclose and express as they see fit.*

4. A regional case study

One respondent highlighted the multiple layers of disadvantage LGBTI people with a disability can face when living in supported accommodation in regional areas. He identified as a gay cisgender male and had an intellectual disability.

He spoke about feelings of isolation due to the limited number of ways to connect with the LGBTI community locally.

> *There is a feeling of isolation among LGBTIQA community in country areas. I would like to feel more included. It is lacking in regional areas which leads to people [feeling] less inclined to be open about their sexuality.*

He described a lack of overt support from disability service providers for enabling his connection to the LGBTI community.

He also highlighted the need for attitudes to change within the LGBTI community towards people with a disability.

When asked, 'how can the LGBTIQ community be more inclusive of people with a disability?', he responded:

> *By changing the attitudes of people in the LGBTIQA community towards members with a disability. This might be done through more education and change of culture.*

The experiences of this respondent show the unique disadvantage that LGBTI people with a disability face; including lack of inclusion within the LGBTI community and disability support services not fully accepting the needs of LGBTI people. Ultimately, this left him isolated and feeling unsupported, and unable to fully express himself and live authentically as a gay man.

> *I feel my disability service provider discourages connection to the LGBTIQA community by not providing open access to potential partners to visit me at my residence. My current accommodation feels like an institutional environment. Disability service providers are not LGBTIQA friendly in my experience.*

5. The possible personal benefits of a Victorian self-advocacy group

Roles for personal support

We provided a list of the **possible roles of a self-advocacy group for personal support** and asked respondents to rate their usefulness.

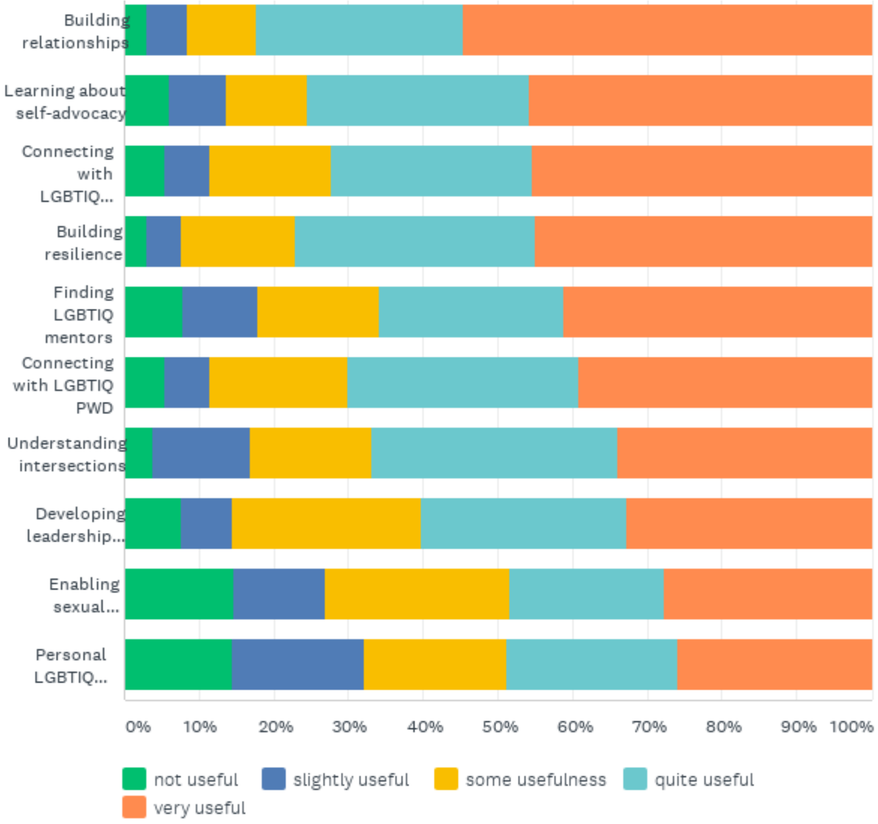
Most of the roles that were rated most useful were about connections - building relationships, connecting with LGBTIQ communities and LGBTIQ people with disabilities, and finding LGBTIQ mentors. All of these were also related to building resilience. Learning about self-advocacy was also highly rated.

Enabling sexual expression and personal LGBTIQ awareness were rated as the least useful roles.

Additional personal roles listed in the 'other' open text box included

- Developing a national LGBTIQ disability group to influence political parties
- Helping LGBTIQA+ people of colour
- Providing communication skills development

Usefulness of self-advocacy group for personal support



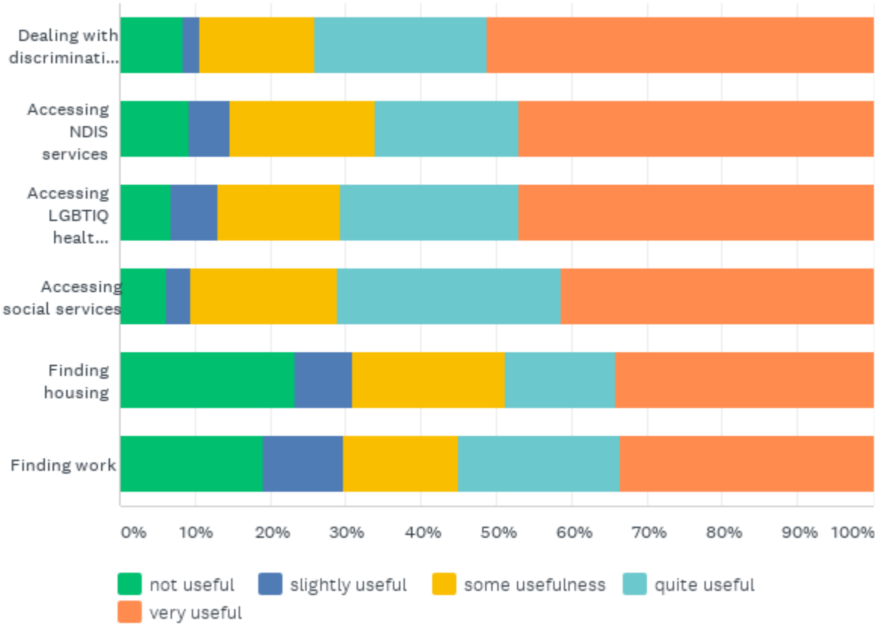
Roles to assist with access to services

We then provided a list of **possible roles of a self-advocacy group in relation to improving access to services** and asked respondents to rate their usefulness.

The most useful roles of a self-advocacy group in relation to accessing services were to access LGBTIQ health services, social services, NDIS and also dealing with discrimination, abuse and violence. A few additional ideas were written in the 'other' box including:

- Developing links between LGBT and disability worlds
- Dealing with discrimination in the LGBTIQ community
- Finding general supports such as peer support, interpreters

Usefulness of self-advocacy group for access to services



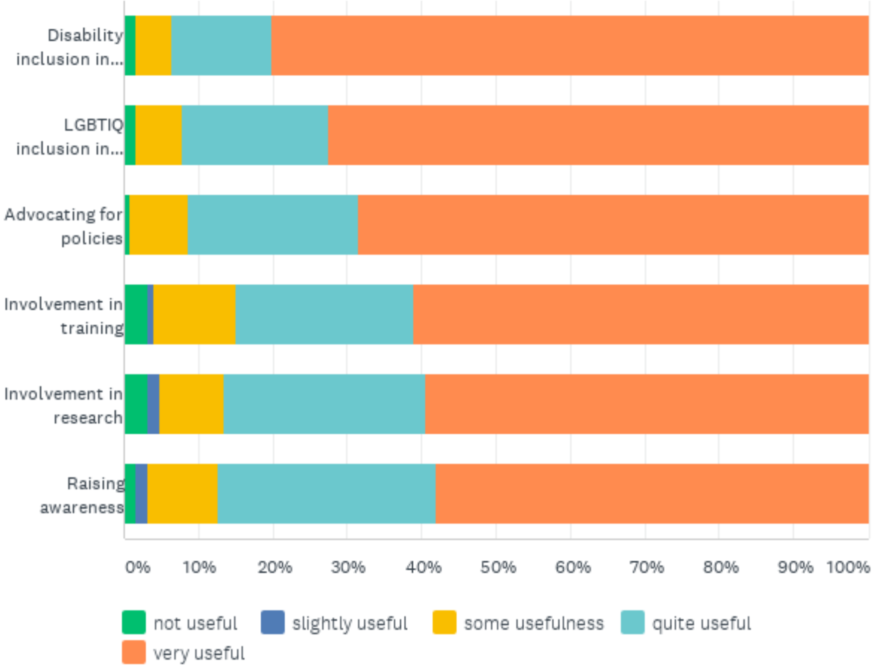
Role for wider community inclusion

Finally, we asked about the **usefulness of a self-advocacy group for a range of wider community roles**.

The roles for a group in wider community activism were strongly supported. In order of usefulness they were:

- Advocating for disability inclusion in LGBTIQ services
- Advocating for LGBTIQ inclusion in disability services
- Advocating for LGBTIQ disability inclusion in policies
- Involvement in training of services regarding LGBTIQ disability
- Involvement in research
- Raising awareness of LGBTIQ PWD in the general community

Usefulness of self-advocacy group for community inclusion



6. Possible involvement in a self-advocacy group

To test the feasibility and structure of our proposed LGBTIQ PWD self-advocacy group, we asked whether and how respondents would be involved. Eighty (63.5%) of 126 respondents to this question said they would be involved, 41 (32.5%) were unsure, and just 5 (4%) said they would not be involved.

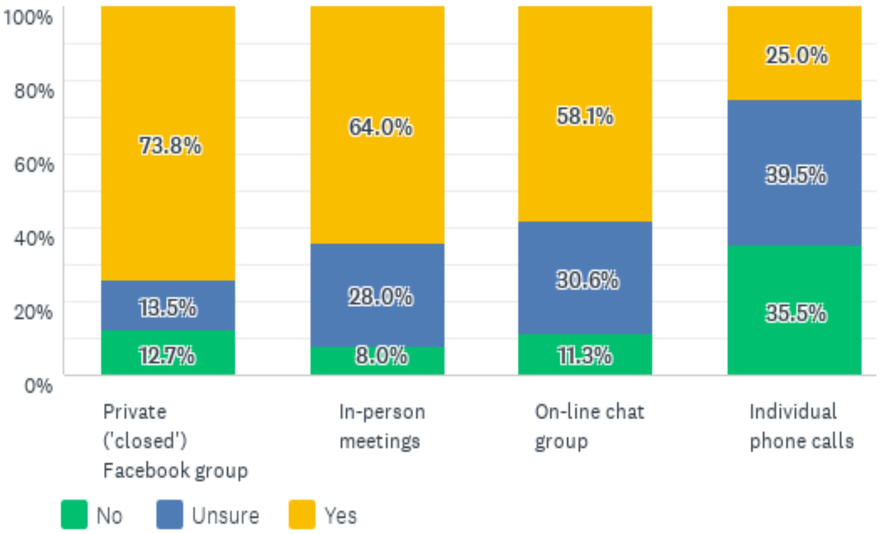
Preferred connection methods

The most popular methods of connection were a private Facebook group, closely followed by in-person meetings and online chat groups.

Thirty-eight people wrote comments about this question. It was clear that the respondents were polarised, with some preferring face-to face and other preferring some sort of online communication. This was largely based on the degree of disability and mobility.

Nine people preferred in person gatherings in small groups, but 3 people wanted to meet just one-to-one. One person wanted to have activities arranged in the group such as art therapy. Continuity for such groups was also highlighted as important:

Preferences for methods of connection



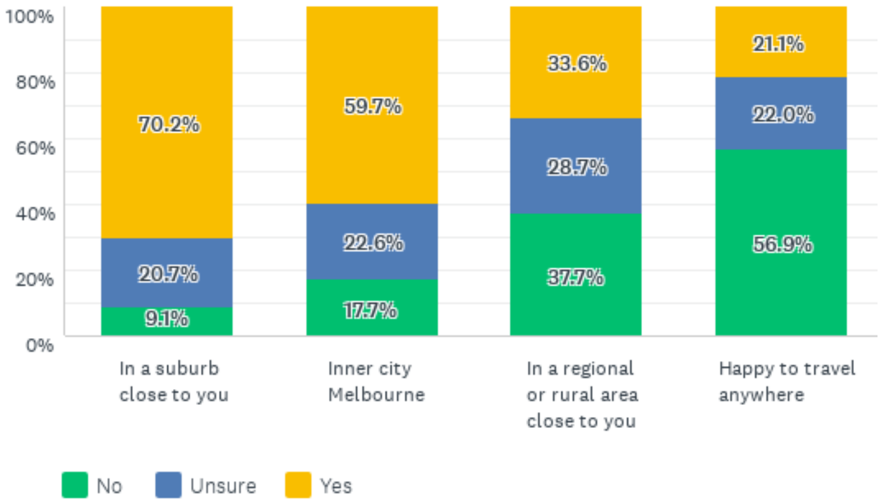
> *I used to attend a LGBTI disability self-advocacy group in [regional city], but [the facilitator} left and I haven't heard from anyone else. This job was good because it supported not only me to be more independent and proud in the community, but also the other participants in that group. I think it's really important to keep groups like these going when they are established because otherwise people lose touch with each other and confidence to be who they are.*

Sixteen people preferred online connection, the majority of these via video chat apps, 3 via email, and 2 preferred phone calls.

> *Phone calls and online chat that require me to be available at a certain time MIGHT work depending on how it lines up with times support workers are here. In-person is 100% inaccessible as I am homebound.*

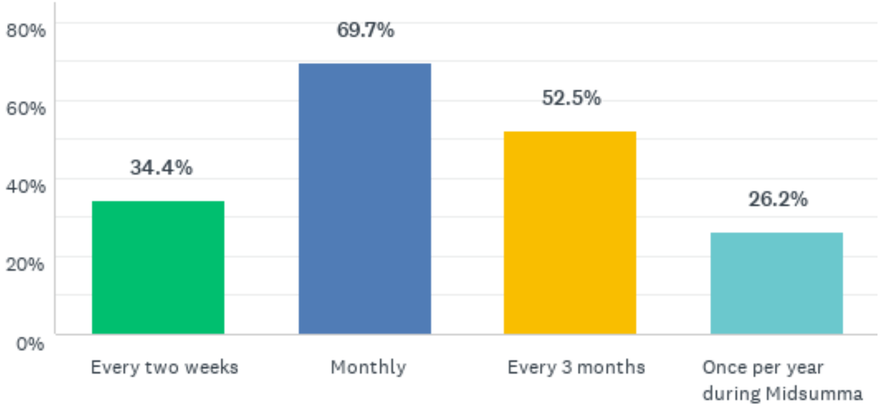
Preferred location of the group

A nearby location was the most convenient for most people, with only one fifth of respondents happy to travel anywhere.



Preferred frequency of the group

The majority of people preferred monthly or quarterly meetings.



Conclusions

There is a significant need for specific peer support and self-advocacy for LGBTIQ people living with disability In Victoria, and Australia. Such a group would have multiple roles including providing personal support for the participants' LGBTIQ identities and connections and improving their access to LGBTIQ inclusive services. However, additional roles were even more strongly supported by respondents, including advocacy for LGBTIQ inclusion, training and general awareness raising about the needs of people with disabilities within LGBTIQ events and the wider mainstream.

The logistics of such a group would need to be carefully considered, as there are varying needs for both face-to-face and online presence, and a particular need for regional and rural engagement. Also, it is crucial to enable involvement of people with intellectual disabilities, those with neurodiversity, and those confined to their homes, who have traditionally been effectively excluded from LGBTIQ community activities. There has been a heavy emphasis in the LGBTIQ community on large in-person events involving strobe lights, loud music, alcohol, drugs, and these environments are hostile to many PWD. In the post-COVID-19 world, it is likely that our new competencies in video conferencing and live streaming of events, as well as valuing of more intimate gatherings, will come into their own for self-advocacy groups, particularly for people living with disabilities with multiple access challenges.

The survey also provided a number of valuable insights into the lives of LGBTIQ PWD. First, they are a very diverse group of people, with even more gender and sexual diversity than seen in other areas of LGBTIQ community.

Second, we have a long way to go to improve the LGBTIQ community inclusion of PWD. Over 80% of respondents desired more involvement in the LGBTIQ community. An embarrassingly small proportion of LGBTIQ community events and connections were felt to be very inclusive of PWD, and the whole LGBTIQ community needs to make a commitment to improve this. The respondents provided some ideas of clear and simple methods to both improve accessibility, but more importantly, improve the capacity for true disability inclusion. First, and foremost, this involved engagement with LGBTIQ PWD at every step of planning, delivery and evaluation of activities, and on Boards and management structures.

Finally, LGBTIQ inclusion in disability services is also woefully inadequate. The respondents paint a clear picture of invisibility of their sexuality and gender diversity, and also of overtly discriminatory experiences at times. Several strategies for improving inclusivity are presented. These have their equivalents in many recent pieces of work in other sectors, including aged care, homelessness, community healthcare, family violence services, and mental health care. In particular, calls for consultation with LGBTIQ PWD consumers at all levels of organisations, and for adequately funded peer support workers must be taken seriously for serious and lasting culture change to be achieved.

So, the role for self-advocacy for LGBTIQ people living with disabilities is clear and necessary. The next step is to provide funding to enable sustainability. Then self-advocacy will take on a life of its own to improve the lives of its participants.