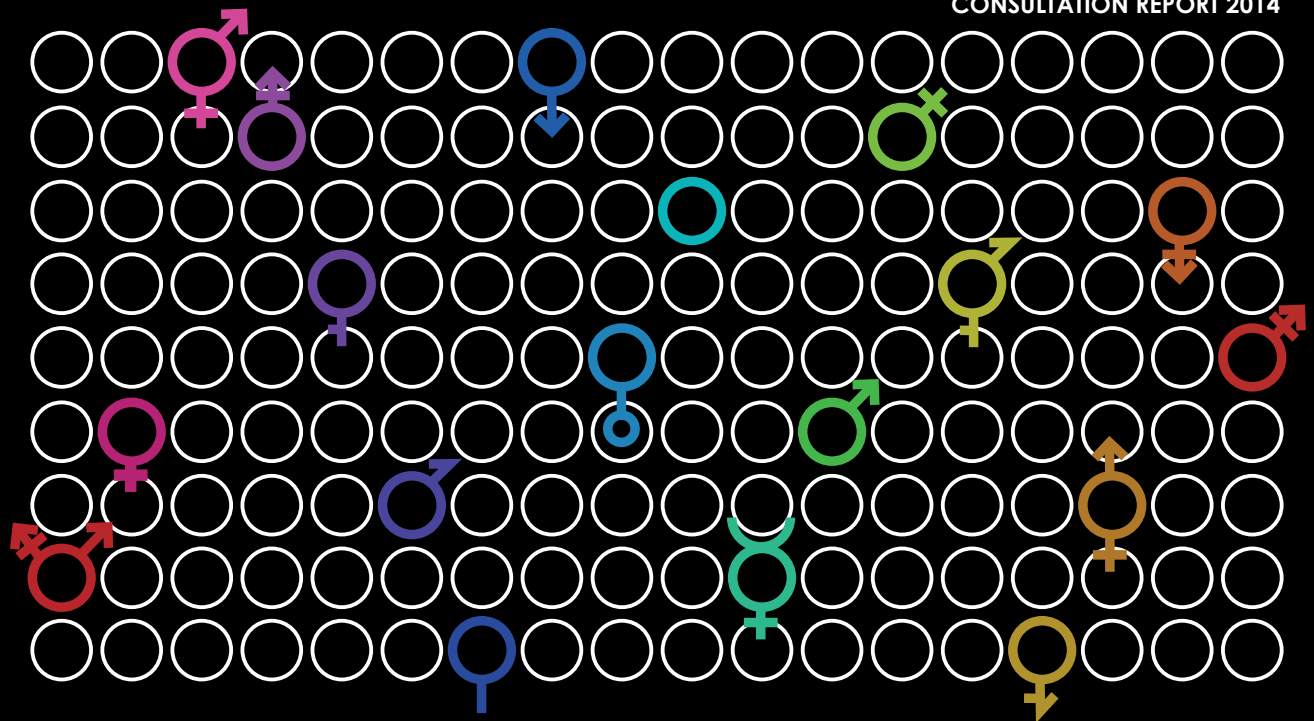
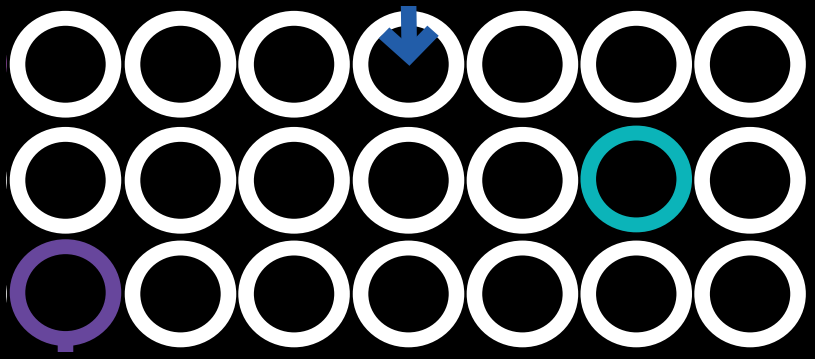
CONSULTATION REPORT 2014



Aged care issues raised by Lesbian, Gay, Bisexual, Transgender, Intersex, Queer and HIV+ people in the ACT

AGED CARE ISSUES

raised by Lesbian, Gay, Bisexual, Transgender, Intersex, Queer and HIV+ persons in the ACT



Provided by the ACT Lesbian, Gay, Bisexual, Transgender, Bisexual, Intersex and Queer (LGBTIQ) Ministerial Advisory Council

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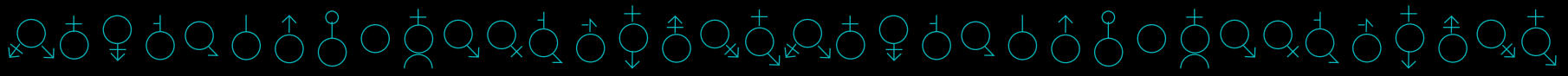
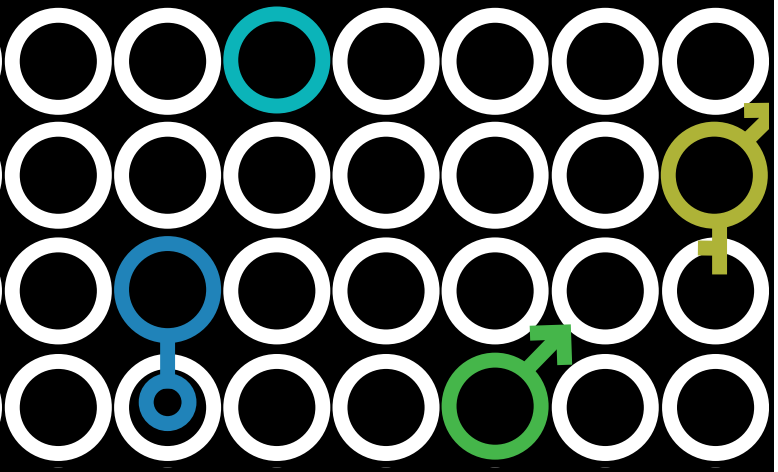


CONTENTS

EXECUTIVE SUMMARY



Background

In its role of providing advice to the Minister on issues affecting lesbian, gay, bisexual, transgender, intersex and queer members of the ACT community, the ACT Lesbian, Gay, Bisexual, Transgender, Bisexual, Intersex and Queer (LGBTIQ) Ministerial Advisory Council identified aged care issues as a specific area for further investigation and consideration.

This report encapsulates combined findings from a public forum held in November 2013 and a subsequent survey undertaken between December 2013 and April 2014. Whilst the approach taken was somewhat basic in its design, the results nevertheless provide an indication of, and insights into, the specific issues affecting Canberra's LGBTIQ and HIV+ communities which warrant some attention.

The LGBTIQ Ministerial Advisory Council was funded by the Canberra Gay and Lesbian Tennis Club to write the report. These funds were subsequently split between AIDS Action Council and A Gender Agenda (AGA) who each appointed a project officer to work together to develop the initial drafts of this report.

The project officers were overseen by an advisory group consisting of 2 council members and representative each from AIDS Action Council and A Gender Agenda. The Advisory group provided the final editing of this report.

The survey questions included a section about wills and enduring power of attorney, which are not addressed in this report. These issues will be considered separately and at later date.

This report will assist to increase awareness and knowledge about specific aged care issues for LGBTIQ and HIV+ people in the ACT and provide guidance for the Minister for Community Services and policy makers, members of the LGBTIQ and HIV+ communities, aged care service providers, community services more broadly and the general public to ensure that appropriate services are delivered with dignity and respect.

Aims and objectives of the consultation

The broad aim of this consultation was to ascertain the types of issues LGBTIQ and HIV+ people may have in relation to accessing aged care. This presented an opportunity for the LGBTIQ Ministerial Advisory Council to partner with community organisations with a vested interest in the area and to consult with local community members about how they feel about ageing.

The ageing of the 'baby-boomer' generation and the expectation that demand for services will dramatically increase in the future, highlights the need for a greater focus on ageing and aged care. Until comparatively recently, there has been minimal examination and inclusion of the needs of transgender, gender diverse and intersex older Australians, those who are non-heterosexual and those who are HIV+.

The LGBTIQ and HIV+ population are by no means an homogenous group, although some common needs may exist. Nor are these groups mutually exclusive. Individuals within these communities have specific social, cultural, psychological, medical and care needs. Collectively however, they are a group requiring particular attention due to their common experiences of discrimination and the limited recognition of their needs by service providers and in policy frameworks and accreditation processes.

It is hoped that the issues raised in this report will inform and improve policy and practice in aged care contexts for LGBTIQ and HIV+ people in Canberra and the region so that they are welcoming, appropriate, affordable and non-discriminatory.

Methodology

The Council began the process of engaging the community by hosting a half day public forum about aged care issues on 22 November 2013. Since the AIDS Action Council, A Gender Agenda (AGA) and Northside Community Services (NCS) were already funded to progress this issue, the obvious benefit of combining resources was recognised. As a result, AIDS Action Council identified and provided an appropriately qualified facilitator, Diversity ACT provided the morning tea and NCS provided the venue for the forum. All agencies promoted the forum broadly. The forum focussed on LGBTIQ aged care and was targeted at both consumers and professionals within this field. Almost 40 people attended, from a broad section of the community with both professional and personal interests in the area of LGBTIQ ageing and aged care.

Subsequent to the forum, the agencies worked together to develop a survey titled 'Ageing and Issues Facing Older LGBTIQ People in the ACT' for the LGBTIQ and HIV+ communities and their family/friends, in order to elicit the general level of concern and identify key issues for these groups when accessing aged care services. The survey was open for four months and widely promoted. The AIDS Action Council undertook the lead role in developing the survey and collating the responses into a format that allowed the results to be written up. The survey was first produced in hard copy and circulated through the community at events such as Fair Day. It was subsequently produced electronically through Survey Monkey. At this point the survey was refined to ensure it was suitable for an online methodology. All completed hard copy surveys were added to Survey Monkey. [See APPENDIX A: Survey instrument, Ageing and Issues Facing Older LGBTIQ People in the ACT (p. 29)].

Where there were gaps in the survey results, existing literature has been drawn upon to provide additional context, particularly in relation to issues relevant to intersex people.

Key findings

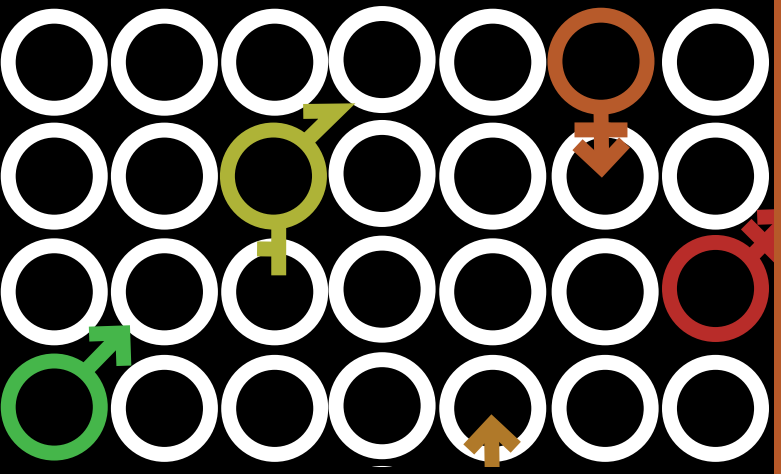
1. **Unique aged care needs:** Members of LGBTIQ and HIV+ communities possess particular needs in relation to ageing and accessing aged care. Whilst there are common overlaps and issues of discrimination and exclusion between them, distinct differences exist both on an individual basis, but also between the broader issues of sexual orientation on the one hand (as represented by the 'LGB'), and gender diversity or intersex status (as represented by the TI) on the other. It is essential that policy, service providers, and the wider community acknowledge and are aware of these differences in order to adequately cater for members of the LGBTIQ and HIV+ ageing population.
2. **Fear of discrimination:** The overriding concern was fear of experiencing discrimination, homophobia, transphobia and overall lack of awareness and understanding of LGBTIQ and HIV+ issues by organisations, staff and co-residents. There was a high level of concern regarding the adequate provision of care. This included concern about people being accepted for who they are and who they love, their significant relationships not being recognised or respected, the fact that organisations make heterosexual assumptions, discrimination and judgement, lack of adequate training for aged care workers and concern about the need to understand specific health requirements -particularly amongst transgender, gender diverse and intersex individuals and communities as well as those living with HIV.
3. **Lack of control over disclosure of personal identity or status:** The issue of disclosure is different across the LGBTIQ and HIV spectrums. The desire to conceal one's sexuality, gender identity, intersex or HIV+ status comes from a fear of discrimination and a risk is taken when a person discloses. In many cases, particularly for gender diverse, intersex and HIV+ people, the decision not to disclose is not an option. This results in additional concerns for many members of the TI and HIV+ communities due to the sometimes intimately physical nature of aged care.
4. **Social isolation:** Social circumstances for members of the LGBTIQ and HIV+ communities were in many cases identified as different to the wider population. Members of the LGB and particularly the T&I and HIV+ communities are far more likely to live alone, experience isolation, and/or have family structures which do not conform to social expectations. They may also have a biological family who do not support or understand who they are.
5. **Reliance on community and state funded care services may be disproportionately required earlier by LGBTIQ and HIV+ seniors:** Relatively lower instances of natural supports combined with financial access issues for some mean there will be some individuals less able to rely on superannuation, friends, or family for support as they age. A majority of respondents indicated that they thought they would rely on the LGBTIQ/HIV+ community at this time.
6. **General health status:** The timing and type of aged care services that LGBTIQ and HIV+ people will require as they age is dependent also on their health status. The experience of mental illness, disability and HIV status and other health issues may increase the likelihood that aged care services will be required earlier than the broader population.

Recommendations

This report identifies several areas for consideration in order to improve the situation for LGBTIQ and HIV+ older adults, based on responses to the forum and the survey. These include accountability from service providers through assessment and accreditation processes, development of educational programs, the need for advocacy and promotion of awareness of legal rights at both individual and systemic levels, development of community visiting schemes and peer support initiatives.

It is recommended that:

INTRODUCTION



It is clear from the results of both the public forum and the survey that there is a significant level of concern amongst Canberra's LGBTIQ and HIV+ community members and those around them about the appropriateness and affordability of aged care services, both now and into the future.

Whilst all citizens may rightly have some concerns about services as they age, there are particular concerns for the LGBTIQ and HIV+ cohorts which require specific attention in order to ensure that services are accessible, appropriate and contribute to positive health and wellbeing, as they age.

This report documents the findings of the consultation process undertaken by the Ministerial Advisory Council and partner organisations and highlights issues raised. It provides a degree of insight into the particular needs individuals may have and some recommended approaches to better cater for LGBTIQ and HIV+ seniors.

Since the early twentieth century substantial progress has been made for the rights of LGBTIQ people. Yet elderly members of these communities, as well as those who will seek aged care in the future, have lived experience of discrimination, abuse, and the criminalisation and/or medicalisation of homosexuality, gender diversity or intersex status. Largely due to these experiences, members of the LGBTIQ and HIV+ communities are likely to access services with trepidation about their sensitivity and appropriateness, exacerbated by their experiences of isolation, financial difficulties, health, and mental health concerns.

It is important to note that LGBTIQ and HIV+ people are not a homogenous group. Firstly some HIV+ people do not identify with being LGBTI and/or Q and additionally some transgender and intersex people may identify as heterosexual. Furthermore it is essential to understand that there is a distinction between sex and gender.

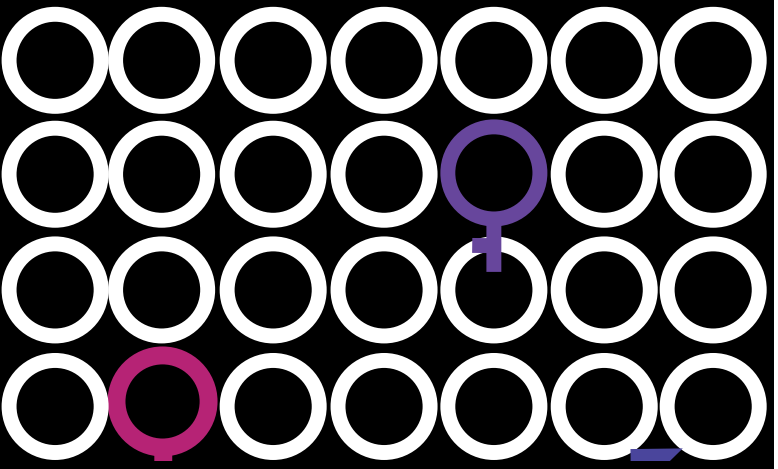
Sex is about a person's biological sex, which can be female, male or intersex. Gender is about a person's self-identification with the presentation and lifestyle of a particular sex. Increasingly, there is more fluidity between the binary genders and some identify as neither of the binary genders. Sexuality is based on relationships between any genders.

Whilst there has been some progress in recognising the human rights of lesbians and gays, and to a lesser extent for bisexuals, for gender diverse and intersex people there is still a long way to go in reducing discrimination and prejudice. Many of their most basic rights are still being fought for today and experiences of stigma, mistreatment and discrimination are heightened and all too real. In addition HIV+ community members have discrete health and stigmatisation pressures which may affect quality of care.

Across the LGBTIQ spectrum there is a diverse range of specific needs and concerns in regard to the experience of ageing. The effects of past and present experiences of discrimination, assumptions by service providers regarding identity and presentation, family structure, and healthcare needs all negatively impact on members of these communities, as their particular interests are not considered or catered for in aged care contexts.

Although significant progress has been made for LGBTIQ and HIV+ people over the past few decades, we are still learning about how to best cater for members of these communities as they age. Are there particular needs? What specific issues are raised for LGBTIQ and HIV+ people as they age? There is no single answer to these questions as a great deal of diversity of experiences and needs exist across the LGBTIQ and HIV+ spectrums, however what is at the core, is the need for awareness and education.

THE FORUM



The outcomes of the forum are a representation of views from individuals from across the LGBTIQ and HIV+ spectrums, community service and aged care service providers and other interested individuals. Disclosure of sex, gender, sexual orientation and/or health status of participants was not required or recorded.

The forum was facilitated by Kathy Hilyard from *People and Strategy and* identified and funded by the AIDS Action Council. Acknowledgement was given to the diversity of perspectives in the room and the National LGBTI Health Alliance's explanation of identities was discussed during the introduction, in order to ensure provision of a safe respectful space.

The process involved small group discussions to identify areas of concern and raise issues. These were subsequently clustered into broader areas of concern and discussed with the whole group. Similarly, ideas about ways of addressing the key areas of concern and developing possible solutions were identified.

Areas of concern

The main areas of concern about aged care with regard to LGBTIQ and/or HIV+ were identified as:

- the fear of discrimination, stigma and heteronormative assumptions across the range of aged care settings;
- many people hide their diverse identity from aged care services as a result;
- issues of sexuality at all, are often overlooked in aged care services, let alone gay, lesbian, bisexual or transgender sexualities;
- fear of lack of safety and respect;
- the reputation of some religious organisations as likely to treat members of this community poorly compared to the population as a whole;
- lack of consistency, transparency and accountability of service provision regarding treatment of LGBTIQ and HIV+ people in both residential and home care based settings;
- not being specifically considered in organisational policies, procedures and staff training;
- lack of recognition of couples or relationship status;
- the identification and role of family and carers;
- the need to understand the diversity of needs and respond to individuals rather than to which categories they may or may not fit; and
- the complexities of provision of sexual health care within the aged care services, particularly for transgender and intersex people.

Suggested solutions

Suggested solutions fell into broad categories of ways to ensure inclusion through education, ensuring appropriate quality of care in service provision and promotion of legal recognition and law reforms.

They included:

- encourage best practice by development and provision of training and educational programs about the rights and needs of LGBTIQ and HIV+ people for organisations, healthcare and aged care workers, as well as community members and co-residents in facilities;
- add modules/units to existing curriculum in CIT and other courses;
- adapt existing training of service providers to include a focus on HIV and AIDS related issues such as early onset dementia and other health complications;
- ensure recognition of non-biological family and appropriate respect for relationships of choice;
- develop an audit tool to assess or self-assess how inclusive and proactive a service provider is;
- ensure service providers have specific policies and procedures regarding working with LGBTIQ and HIV+ people;
- develop and apply formal accreditation processes and/or standards for service provider organisations to ensure they are LGBTIQ and HIV+ friendly and promote the appropriateness of these organisations through a Rainbow Tick-type program;
- Ensure that professional standards for workers include awareness of non-judgemental and non-discriminating language and action;
- ensure awareness of diversity of needs is included in all educational systems;
- address pay inequity in aged care and community services;
- consider funding targeted programs to address equity issues for LGBTIQ and HIV+ people in aged care settings;
- develop and promote LGBTIQ and HIV+ visitors schemes;
- deliver systemic advocacy and information services to community and service providers;
- develop a speakers bureau;
- contribute to law reform that ensures the human rights of LGBTIQ and HIV+ people are enshrined and respected; and
- promote and increase awareness of legal rights within and external to the LGBTIQ and HIV+ community using social media and other marketing tools.

The Survey

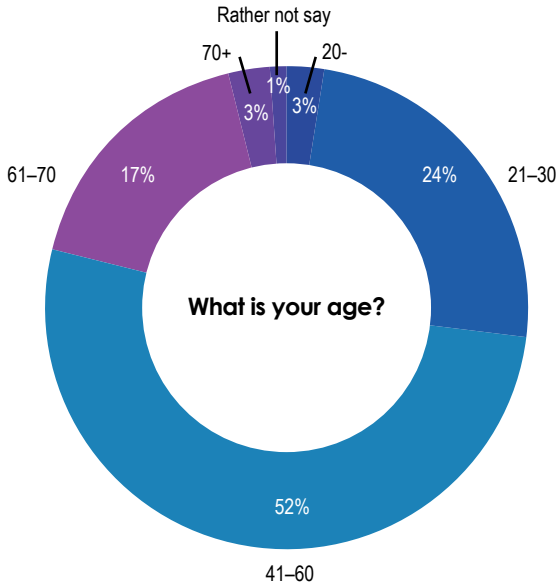
Overall the outcomes from the survey were consistent with the forum results noting the sample size for analysis at the forum level is very small and any differences in results between the forum and the survey in a purely statistical manner is not achievable. However, a series of consistent messages were seen across several of the measures and these are a very good indicator of a genuine similarity in the experiences or opinions of participants.

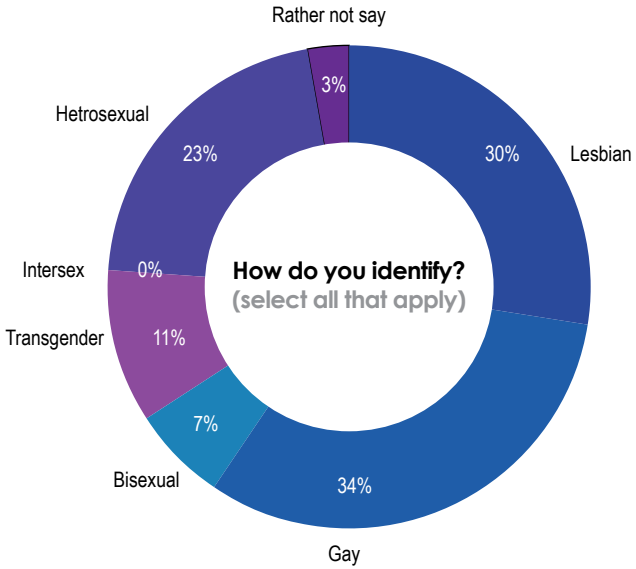
Response rates and demographics

Overall, the survey had a reasonably high response rate and the findings can be considered to be indicative of experiences within the ACT. There were a total of 218 respondents, with ages ranging from under twenty to over seventy years old. 51.8% of respondents were between the ages of forty-one and sixty. This indicates that the majority of responses were from the perspective of those who are not currently accessing aged care services, but would be looking to do so in the relatively near future.

With regard to sexuality, a combined 65.1% of respondents identified as gay or lesbian with 34.8% as gay and 30.2% as lesbian. A further 6.8% identified as bisexual. In addition, 3.6% indicated they would rather not say and over half of those who responded with 'other' identified as queer. Other identities included asexual, pansexual, polysexual/ polyamorous and family members.

With regard to sex and gender, a total of 24 respondents (11%) identified as transgender. It is important to note that over half of these respondents also identified as having sexuality other than heterosexual. There were more responses to this question than the number of respondents, as there was an option to tick all that apply. This indicates that 16.5% identified with more than one 'category'. Importantly, there were no respondents who identified themselves as intersex. For this reason, some existing Australian literature and research covering issues for intersex people has been considered in the development of this report.





The survey was open and by no means exclusive to the LGBTIQ and HIV+ communities. It was promoted broadly and sought responses from friends and family of people who are LGBTIQ and HIV+ as well as workers within aged care. A total of 23% of people identified as heterosexual, and although this included a few respondents who also identified as transgender, the high percentage clarifies that the results of this consultation include the views of not only LGBTIQ and HIV+ persons; it is inclusive of the views of those around them.

Most people considered that aged care services meant in-home help, social support, nursing homes, meals on wheels, transport and palliative care, in that order. When asked at what age they thought aged care services were needed, the majority of 174 respondents to this question thought that aged care services would be needed when they reached a level of ill health or incapacitation that warranted accessing care services. This was anticipated to be around age 70 by 78% of respondents. Sixteen percent thought it would be between the ages of 60 and 70, with the remaining 6% indicating they thought it would be between the ages of 40 – 60. Those who thought they would need aged care services earlier were respondents who had existing health and/or mental health issues.

Comments included:

> *I'm 49 and I am already experiencing health problems, so I suspect that I will need at least some aged care services in the next 15-20 years.*

> *At present my youngest child, in her teens, cares for me when I collapse and can't walk. In ten years time I hope I'll be back to full-fitness but as a former nurse I must be realistic. I have a strong family history of dementia and my inability to exercise (at times) due to my chronic fatigue syndrome means that I am squarely within the risk zone for developing coronary heart disease and dementia.*

> *None, prefer living in own home due to severe isolation as experienced in workplaces, felt ostracised, and will be lot worse if placed in nursing homes as there won't be like-peers of same disabilities as we are minute in numbers. Disabilities are profound Deafness with deep/ massive depression and isolation [sic].*

> *As a 65-year old, I can already find some things difficult to do and I certainly have a lot less stamina than when I was in my 20s.*

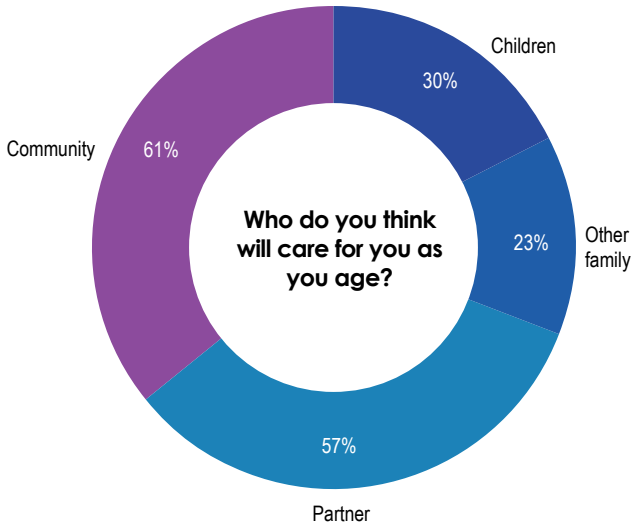
> *I cannot give a definite response to this but I would think that by age 65-70 I wouldn't be working in my current job, and may not even have a job, plus a few health issues will come to the fore by then.*

This last comment indicates that there are some concerns about financial capacity to access aged care services.

Overall, responses to this question indicate that the timing and type of aged care services that LGBTIQ and HIV+ people will require as they age is dependent on their health status. The experience of mental illness, disability and HIV status increase the likelihood that aged care services will be required.

Expected source of care

Respondents were given the answer choice of children/other family/ partner or community when asked who they thought would care for them as they aged. A substantial majority thought it would be community.



A significant number of people indicated in the open ended comments of the survey that they could not answer the question about who they thought would care for them as they age, because they did not know or were not sure who would actually care for them. A majority of the respondents (60%) who completed this question indicated that they expect to depend on the LGBTIQ community to care for them as they age. A further 57% said they would be dependent on their partner for care. 30% of people said that they would depend on their children for care, and 22% on other family.

Of significant note, there were comments which highlighted isolation issues.

> *No idea. I am single. My sister and brother are not in a position to assist me, maybe the community, but I would rather that be the gay community.*

> *No idea....my partner is not out to her kids so the future is pretty scary. Realistically I face homelessness.*

> *Good question, no kids, currently no other family or partner, and very aware that our society is slow on the uptake of the LGBTI community.*

Many LGBTIQ and HIV+ people are likely to be socially isolated and lack support in their later years due to reasons such as a lack of acceptance from family or friends and a lower likelihood to have biological children. Moreover, it may be more common for LGBTIQ people to have a 'family of choice', who may not be biological relatives, but rather, partners, friends and other people they trust (Barrett, 2008).

People who are gender diverse and/or intersex have an even higher chance of being socially isolated and/or of living alone than both the LGB communities and the wider population. The *Gender Diversity in the ACT* survey undertaken by A Gender Agenda indicated that the majority of transgender respondents also had little to no contact with their family (David, et al., 2011). This is consistent with other studies (Pitts, et al., 2006). The low levels of connection with family and other forms of social support create added difficulties for gender diverse and intersex individuals.

The project report on LGBTIQ undertaken by the Council of The Ageing (COTA) reported that intersex people are far less socially integrated than the general population (Childs, 2012). This combined with much less understanding of intersex issues generally poses increased challenges for people who are intersex as they age. The fact that there were no respondents who identified themselves as intersex in this survey is an example of the challenges of even reaching this group for assistance in understanding how to ensure inclusivity.

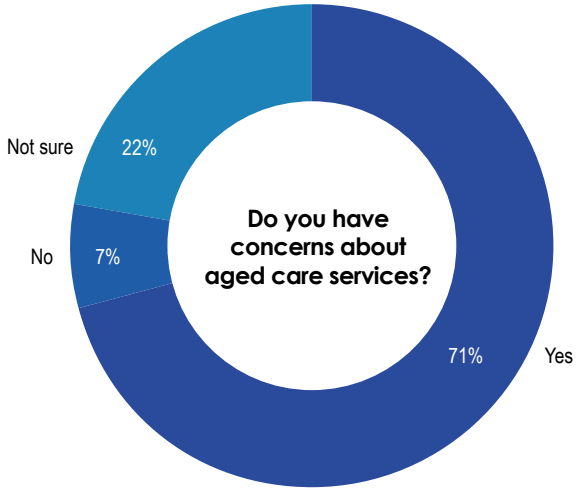
40% of transgender respondents to the survey indicated they would need to rely on government or the community for support as they aged, or they did not know how they would get support. In addition, a report on the experiences of LGBTIQ seniors in aged care services indicated that isolation is considered to be a primary risk factor for abuse and neglect within the ageing population (Barrett, C., 2008).

This has implications in terms of reliance on community and state funded care services which may be disproportionately required by LGBTIQ and HIV+ seniors. Relatively lower instances of natural supports, combined with financial access issues which were also highlighted in the survey, mean that there will be less dependence on their own superannuation, friends, or family for support as they age.

Concerns with care

An overwhelming majority of survey respondents (72%) stated that they had concerns about aged care services, as highlighted in the graph below.

The main concerns reported about aged care services broadly included access to care, fear of discrimination, recognition of partners, losing individuality, access to LGBTIQ-specific services and training of aged care workers and accreditation of aged care service providers. These issues will be explored further in turn.



Access to care

27% of respondents indicated they were very concerned that their sexual orientation might limit the type and quality of aged care services available to them. A further 38% reported that they were somewhat concerned, and 35% said that they were not concerned.

As discussed earlier in this report, concerns about access to care largely included the anticipated cost of services and worries about affordability. A number of people had concerns about being accommodated with their partners and were worried about being separated from them in the last years of their life if this was not an option.

Only a quarter of respondents who were HIV+ stated they were not concerned that their HIV+ status might limit the type and quality of aged care services available to them, while 46% indicated they were very concerned and 29% somewhat concerned.

> *I am worried about a lack of acceptance and understanding of the needs of HIV+ people. Even now when I have been in hospital, all medications are provided and administered to me except my HIV medication which I am left to provide and take myself.*

It has been documented in previous studies that people living with HIV are at risk of receiving substandard care. For instance, aged care staff who lack training and understanding of HIV and AIDS may withhold care due to misinformed beliefs about the transmission of the disease (Barrett, 2008).

40% of transgender respondents indicated they were very concerned that their gender identity would limit the type and quality of aged care that they would have access to. A further 27% indicated that they were somewhat concerned. These relatively higher levels of concern from this group are indicative of the levels of discrimination and mistreatment people who are transgender experience in all parts of society.

Fear of discrimination

Concerns about discrimination in the form of fair access to aged care services were a very common theme in both the survey findings and at the community forum. These concerns were associated with the belief that since a significant proportion of aged care service providers are faith based and that they may not provide appropriate services and be unwilling to compromise and acknowledge different sexuality and gender diverse lifestyles. There was a fear that some might use reparative therapy approaches in their pastoral care guidelines. For some, this perpetuated the belief that non-disclosure could be the only way to access services:

> *Religious persecution and bigotry.*

> *Most are run by churches. I used to be clergy. I am terrified about having to go back in the closet, to exercise care.*

> *As many services are run by religious affiliated organisations, I am concerned about acceptance and tolerance and the lack of understanding [of] my life.*

Once LGBTIQ older adults were accessing care, they worried about being understood and treated with empathy by care staff:

> *As most aged care facilities are now run by religious groups, the issue of being a lesbian is a massive concern.*

> *Lack of respect for my sexuality.*

> *The attitude of staff towards someone of a different sexual persuasion to themselves.*

> *I am hoping that aged care services are sympathetic and recognise the needs of gay/lesbian elderly. I would not want to be living in circumstances where my sexuality is a cause for discrimination.*

They were concerned about being able to express their sexuality and culture without discrimination, whether it be from staff or co-residents.

> *Living in a homophobic environment.*

> *Being able to express my sexuality.*

Sexual and cultural expression was identified as being able to freely have material such as books, DVDs or music, and having significant relationships recognised as such.

> *I've worked in aged services and they didn't cope with [the issue of] sexuality at all and this was largely heterosexual couples. There's a lot that needs to be done before nursing homes are equipped for any ongoing sexual relationships let alone same-sex ones.*

> *Lack of acknowledgement and understanding of [same-sex] relationships.*

Heteronormative assumptions by aged care workers and institutions, exacerbated by a lack of legal recognition of relationships, can contribute to a lack of inclusion and feelings of being discriminated against.

> *My aunt's long term partner of 47 years is referred to as her friend and even her daughter by one staff member.*

> *The loving partners/carers of young men dying of AIDS were prevented from visiting them in hospitals or hospices as they were not legally recognised as next of kin.*

Across the world, research into the experiences of gender diverse and, to a lesser extent, intersex people indicate alarmingly high rates of discrimination, harassment and violence on the basis of these attributes. The 2007 Tranznation report found that nearly 90% of respondents had experienced harassment or discrimination at least once (Couch, et al., 2007).

There has been a demonstrated correlation between high rates of social stigma and discrimination and associated high levels of depression, anxiety and other mental health concerns within these communities.

In regards to aged care, the fear of discrimination and mistreatment based on very real experiences is bound to cause high levels of anxiety and stress. One respondent noted:

> *I'm a trans-woman, I worry about everything, some people just hate us and it's scary to think of being dependant on a sadistic transphobe.*

Another stated

> *I am terrified of the potential lack of dignity or being mislabelled due to being trans, and my genitalia not matching with what people expect.*

These very real concerns of transgender people about accessing aged care highlight the need for the development of education for care providers to enable appropriate responses.

Although the research conducted for this report did not include the perspectives of intersex people, it is likely that similar concerns would arise. Intersex-specific needs and concerns are largely unknown or ignored, and thus their adequate provision in aged care is uncertain.

In addition, it is important to note the high levels of unemployment and financial constraints which limit the choices of many individuals. This is particularly relevant in regards to members of the gender diverse and intersex communities, who are significantly more likely to have histories with long periods of unemployment based on discrimination. In other words, while some services can be proven to be accepting and provide adequate care for members of the LGBTIQ communities, these may not be accessible to all who wish to access them due to financial constraints.

Skill and knowledge of carers

The findings from the ACT survey suggested there was low confidence in the current skills of aged care workers overall, let alone their ability to provide LGBTIQ-sensitive care. It was acknowledged by respondents that a lack of funding to the aged care sector was the cause of inadequate training of staff. It was also observed that aged care workers are believed to be:

> *underpaid and therefore not committed about the care that is given.*

And that there is a:

> *lack of skilled staff and fair remuneration for workers.*

It was suggested in both the survey responses and the forum that there is a need for greater training in LGBTIQ issues within aged care services and that education is part of the solution. It is important to note that the provision of this training needs to take into consideration the specific needs of people who are gender diverse and/or intersex, as the needs and concerns are different from those within the gay, lesbian and bisexual communities.

Disclosure

The fear of discrimination and mistreatment when accessing aged care leads to the decision of many lesbian, gay and bisexual people to not disclose their sexual identity within these settings. The choice not to disclose is indicative of anxiety and stress and a fear of discrimination, and should not be necessary. It is essential to note that for many gender diverse and intersex people in aged care settings, disclosure is not a choice at all.

It is important to understand that not all intersex people have bodily differences which are outwardly apparent, and some intersex people may still have the choice of disclosure. However, in many circumstances physical differences, either natural or caused by 'normalising' surgeries which result in scarring, may be present and thus the issue of disclosure will still be relevant.

For many gender diverse people, this lack of choice may be caused by incongruence between identity documentation and gender presentation, and/or physical bodily differences combined with the intimately physical nature of personal care services (Barrett, 2008).

One survey respondent expressed his concerns regarding the lack of choice in disclosing his transgender status:

> *I'm out as a gay man, and confident in that - and confident that it wouldn't be a big issue once I am older. But I am terrified of being out as trans, and in an aged care setting I would have no choice in the matter - my carer would know when I needed to be changed or bathed, have a catheter put in or any other number of necessary procedures or care. Being aged means being easily taken advantage of, and there isn't much stopping nursing staff or doctors from telling everyone else about my trans status if I were a patient, or seeing me as a freak.*

Many other respondents indicated they were highly concerned about mistreatment due to their identity.

> *Nothing would presently ease my concerns, I can't imagine being forced to be out to carers who bathe and change me.*

Fear of disclosure and the lack of choice in disclosure is a fundamental concern for many people who are gender diverse and/or intersex. This is compounded by the fact that many members of these communities will have limited choices when it comes to aged care services due to personal or financial constraints. In addition to the immediate assumption that people are heterosexual, or as often is the case in aged care - asexual, the general assumption is that people are cisgendered.

People who are gender diverse or intersex also usually have a sexual orientation, and therefore equally have a need for expression of this as well as other concerns related to gender and gender expression.

Understanding specific health needs

Australia's population, as in other developed countries, is rapidly ageing. The number of LGBTIQ Australians over the age of 65 has been projected to increase to 500 000 people by 2051 (National LGBTI Health Alliance, 2013).

All of the respondents to this survey endorsed the idea that their physical health needs would determine when and what form of aged care services they would be required to access. Most respondents indicated they would like to remain independent for as long as their health status allowed. They acknowledged the stepped process of access to aged care services, beginning with in-home community care and ending with permanent residential care.

Respondents who were HIV+ indicated their expectation of requiring aged care services earlier than their peers, due to the likelihood of early onset age-related health conditions associated with HIV. Thus, aged care services need to be equipped with knowledge of HIV and AIDS in order to provide appropriate care to clients who are HIV+.

For people who are gender diverse or intersex, accessing appropriate health care often has the added complicating factor of a strong history of negative interactions with health care providers. Experiences of discrimination and/or inadequate care are shown to be unacceptably high for these groups across virtually every study conducted. Over 25% of transgender respondents to the survey indicated misunderstanding or mistreatment in regards to healthcare provision as their primary concern when growing older. These findings are likely to be the same or higher for people of intersex status as misunderstanding and discrimination within healthcare is a central concern for these populations (OII Australia 2014).

Approximately 78% of respondents to the 2011 *Gender Diversity in the ACT* survey indicated they had personally experienced difficulties in accessing appropriate medical care (David, et al., 2011). These findings were consistent with the 2007 *Tranznation* report. As well as misunderstandings surrounding particular needs for people who are transgender, intersex, or gender diverse, many healthcare services are gendered and thus restrict access to many members of these communities (Couch, et al., 2007).

In addition, in many cases additional healthcare requirements exist for members of these communities. For example, one survey respondent noted that as a transgendered woman who had undergone surgery, she would require regular dilation. One of her key concerns with accessing aged care was the uncertainty around the provision of this care. Another potential issue may be the administration of hormone replacement, which becomes especially important for overall health as a person ages.

While some forms of intersex are associated with additional health concerns, in most cases intersex bodies are completely healthy bodies. However many intersex people have various additional physical or mental health concerns due to the effects of normalising surgeries or procedures, often undertaken without informed consent. For example hormone replacement is often needed as a result of medical intervention and this may not be understood by service providers. (OII Australia, 2014).

It is essential that the specific needs of people who are gender diverse or intersex are understood and catered for in the provision of aged care services.

Mental illness

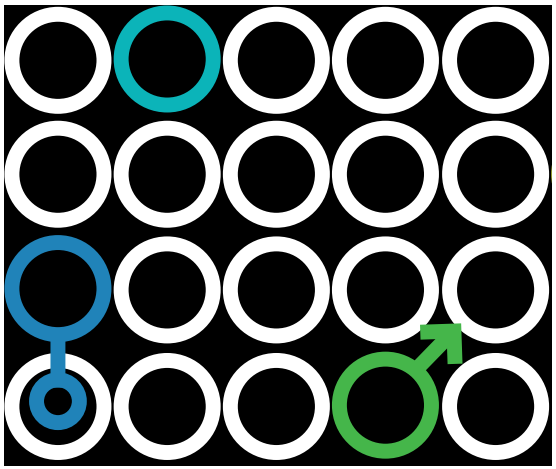
While the survey did not directly collect data on the incidence of mental illness, a small number of respondents made reference to their experience of mental illness within their responses. These respondents indicated their belief that having a mental illness would possibly impact upon their need to access aged care services in the future, particularly in times of mental ill health. Older persons' mental health was considered to be part of aged care services required by LGBTIQ and HIV+ people in later life.

Existing literature consistently shows that LGBTIQ and HIV+ Australians have significantly poorer mental health and higher rates of suicide compared to their heterosexual counterparts (Corboz, et al., 2008; Rosenstreich, 2013). It is important to note that it was not sexual orientation, gender identity or intersex status in themselves which predicted higher rates of mental illness, but the effects of stigma, discrimination and social exclusion so frequently experienced by these individuals at the hands of the broader community (Corboz, et al., 2008; Rosenstreich, 2013).

Keeping in mind the historical context within which older LGBTIQ people have lived much of their lives, it is reasonable to expect they are at greater risk of having a history of mental illness. Older people face unique challenges in the process of ageing which makes them susceptible to developing affective disorders in later life. Older LGBTIQ and HIV+ people thus have an added layer of risk as a result of experiences of discrimination and marginalisation throughout their lifetimes. (Rosenstreich, 2013). Health and aged care services therefore need to be equipped to support older LGBTIQ and HIV+ people in their experience of mental illness and to maintain their mental health overall.

In addition, rates of mental health concerns are shown to be significantly higher for members of the gender diverse and intersex communities. These findings are consistent across virtually every study of these communities (Childs, 2012; National LGBTI Health Alliance, 2013; Pitts, et al., 2006; Couch, et al., 2007) and need to be considered when providing care for these populations.

One respondent to the survey indicated experiencing dual disability of deafness and mental illness, and these conditions would affect their ability to access appropriate aged care services when necessary. *The Private Lives* 2 (2012) study of lesbian, gay, bisexual and transgender Australians found that 23% reported having a disability or long-term health condition, which were primarily either a physical or psychiatric disability. These additional health concerns prevalent in the LGBTIQ communities will have an impact on aged care services' capacity to provide adequate care and support and may increase the likelihood that aged care services will be required relatively earlier.



Dementia

The issue of dementia was mostly raised in this survey in the context of it being a condition that would hasten one's need to access aged care services. One respondent was a younger person who had worked in a residential aged care facility as a nurse, and shared this experience:

> *[I] have seen how damaging the stigma against LGBT residents can be, especially when it is held by the people who are supposed to care for them. I have seen a lady suffering from dementia snickered at, because her partner of 55 years would come visit every day, and they would simply hold hands and lay down together. What to me was a lovely act of devotion, became something to belittle, because the couple were women.*

Indeed, people who identify as lesbian, gay or bisexual may face unique challenges when they experience a neurodegenerative condition such as dementia. Cognitive impairment and problems with memory may lead to inadvertent revelation of a person's sexuality to others if this was previously carefully guarded (Birch, 2009). They may be more vulnerable to discrimination and abuse from co-residents or service providers if they are unable to assess whether it is safe to disclose their sexual orientation due to impaired cognition. (Barrett, 2008; Birch, 2009). Others who are comfortable disclosing their sexual orientation may lose the ability to do so as their dementia progresses, a concern shared by one respondent who completed the survey on behalf of a lesbian aunt who lived in an aged care facility:

> *[A concern is that] my aunt is referred to as 'Mrs' and that her partner is not recognised as her partner. [It is] often assumed that her 'husband' is her partner. [It is] distressing that as she is losing her memory, she will no longer be able to voice her relationship with the staff that get it wrong.*

Early stages of dementia and age-related illnesses are usually associated with the need to access aged care services in the home. The home for many older LGBTIQ people is a safe place for them to be themselves but they may feel compelled to put away photos, books, paintings or DVD or music collections if they are unsure about a service provider's acceptance of them (Birch, 2009).

It is well documented that many people with HIV, particularly those who have been using HIV medications for many years, are developing additional medical problems at relatively young ages. This includes a number of conditions commonly associated with ageing such as diabetes, hypertension, cardio vascular disease and dementia. Early onset dementia is a key issue for consideration for people living with HIV.

In the ACT survey, dementia was not raised in regards to the experiences of gender diverse and intersex people. There are, however, particular concerns in relation to the experience of dementia, as various studies have shown (Barrett, 2008; Barrett, 2012). For example, gender expression is often of high importance to people who are transgender and the lack of autonomy people with dementia are provided in many aged care settings is likely to restrict this.

In addition, complications surrounding identity documentation pose particular problems in regards to dementia. Without adequate advocacy on behalf of ageing gender diverse individuals — particularly in circumstances involving dementia — correct and respectful acknowledgement of a person's identity may be compromised.

Aged care service providers will encounter LGBTIQ and HIV+ older people with dementia and therefore will be required to provide a service that is sensitive to their needs. The particular needs of older LGBTIQ and HIV+ people living with dementia in the ACT are areas that would warrant further research.

Financial issues

The majority of respondents indicated that the cost and affordability of aged care services was a significant concern for them. 33.7% of people reported they could afford to pay for aged care services. The majority (56.4%) stated they could afford to make a contribution towards the cost of accessing services, but they could not afford to pay the full amount. A smaller proportion of respondents (15.1%) indicated they did not have the capacity to pay anything.

> *I doubt that I'll ever be able to afford a place in a hostel etc, so I guess I'll have to rely on family/ children to provide me with some help wherever they can. I don't wish to become a burden on them both time-wise nor financially.*

> *How will I ever pay for anything? I won't have any Super worth anything by that stage.*

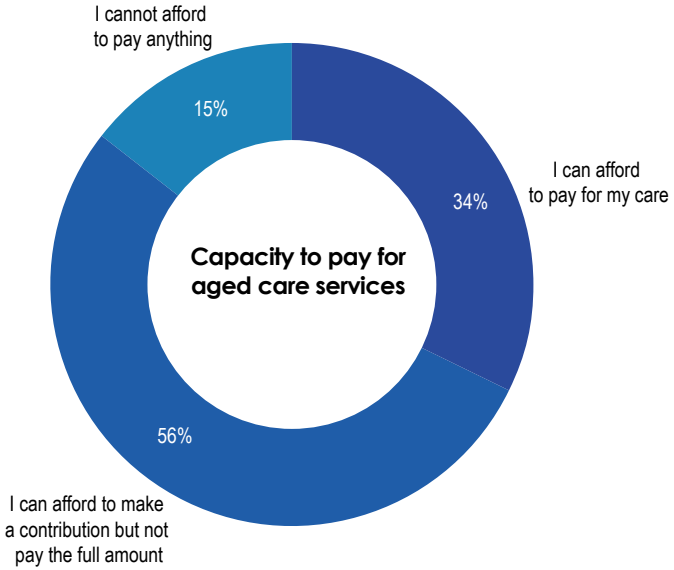
> *I am a very proactive person, I like to think that I would work actively with my community to establish an environment I felt happy, safe and cared for in my old age. In the event I cannot, my fears would be that I will not be able to afford services, and that I would not be with like-minded people.*

Numerous people commented on the unpredictability of projected costs because they could not foresee what specific services they may require, and their personal circumstances at the time. This was particularly applicable to younger respondents of the survey. Another common theme was the expectation that the government should be funding some part of the cost of aged care services for all older Australians.

A notable observation was the number of people who indicated they were on a disability support pension, and/or experienced a mental illness that affected their ability to work and therefore accumulate sufficient wealth and superannuation for their later life.

Consistent with the wider population, concerns surrounding the cost of aged care were emphasised within the survey responses of people who identified as transgender. Over 25% of these respondents listed it as a primary concern. 36% of transgender respondents indicated they would be unable to pay for care as they grew older, over twice that of the total response. An additional 25% indicated they were unsure, or would only be able to pay a portion of the expected cost.

The *Gender Diversity in the ACT* report estimated the rate of unemployment for people who are transgender in Canberra to be six times higher than that of the wider population, despite above average educational qualifications. Several respondents indicated they have had a history of unemployment due to their transgender identity and additional challenges they have had to face because of it. Due to this unemployment they were not confident they had accumulated enough superannuation to afford aged care.



Identification

Similar to the wider LGBTI population, transgender respondents placed a high value on independence. This desire is often related to experiences of discrimination and is more likely to occur amongst members of the gender diverse and intersex communities as rates of recorded discrimination for these communities are substantially higher than other demographics.

An additional concern faced by people who are gender diverse (and in some cases intersex), is that of identity documentation. Until March 2014 in the ACT, there was a requirement that a person must have undergone gender reassignment surgery in order to change their gender on their birth certificate. This is still the case everywhere in Australia outside of the ACT (Couch, et al., 2007).

The impact of this requirement includes the fact that a high proportion of gender diverse people do not have ID documentation that matches their gender presentation.

This was measured as high as 91% in an ACT survey in 2011 (David, et al., 2011), 85% of whom indicated they wanted to but were unable due to the current structure. This also meant that only 22% of respondents were able to produce 100 points of ID with matching gender markers.

The significance of this in regards to ageing populations has several aspects. Firstly it prevents the choice of disclosure of an individual's gender or intersex status. Secondly, it has the potential to prevent or at least complicate accessing care, government support or other services. Lastly, as previously mentioned in relation to dementia, in situations where a person's autonomy is compromised, a greater potential exists for that person's gender identity to be inadequately respected. This becomes even more likely in cases where identity documents are inaccurate.

LGBTIQ-specific vs. LGBTIQ-friendly mainstream services

The notion of having LGBTIQ-specific aged care services such as an LGBTIQ exclusive residential aged care facility or home care services was a very polarising issue in the survey. On the one hand, respondents who suggested having LGBTIQ-specific aged care services believed they would be better understood by like-minded carers and co-residents.

> *Being a tiny number – one or two – in a centre is an issue. Could centres 'niche' – like cultural specific ones? - not 'only.*

> *In an ideal world (All) - Dedicated facilities to alphabet soup community (just a wing would be a start).*

> *Health care suitable accommodation – women only.*

On the other hand, about the same proportion of respondents preferred that '*current services be genuinely inclusive of LGBT&I*'. The sense was that people wanted to be included in mainstream services that could be educated about their needs, rather than be segregated.

> *If an aged care organisation is working well and employing a range of staff, i.e. [culturally and linguistically diverse], LGBT&I etc, I see no reason to have a special organisation. I would like to be treated as part of society and not some 'special case.*

> *Rather, the existing providers should be reformed if necessary.*

> *I think accessible and inclusive mainstream services are the key. We fought for a long time for inclusion, not segregation.*

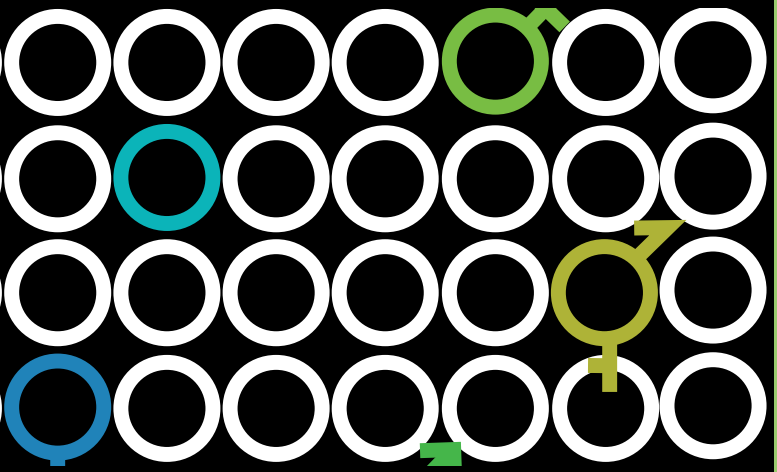
> *Having a facility that is for LGBT&I people or friendly.*

There were a significant number of comments about being able to identify which services are LGBTIQ and HIV+ friendly indicates the importance of aged care services having marketing strategies and promotional material that demonstrates inclusiveness.

> *More information from Aged Care Facilities willing to accept gay persons.*

> *1. Current services being genuinely inclusive of LGBT&I and demonstrate this by employing openly LGBTI workers, include in all written material and mission statements, posters etc, or*
>
> *2. Develop LGBT&I specific aged care services.*

KEY FINDINGS AND SPECIFIC ASPECTS



What is different about LGBTIQ ageing?

So what does all this mean?

Despite the unique considerations, older LGBTIQ people share many of the same issues and concerns as all older Australians. These include mental and physical health; being able to make informed choices about retirement and health care; concerns about living situations; need for both interpersonal and institutional support; the impact of chronic diseases and illnesses and issues surrounding bereavement and preparations for end of life. However, additional and significant concerns arise in these areas for LGBTIQ people, and people living with HIV, due to their shared experience of being part of minority populations and their likelihood to have been subjected to exclusion, discrimination and stigma.

Concerns about the capacity of aged care service providers to understand and accommodate LGBTIQ and HIV+ specific needs were a constant theme in both the outcomes of the forum and the survey responses. The complexities that exist for these populations include issues of disclosure — in different ways for LGB, TI and HIV+ people, fears about discrimination, lack of recognition or understanding of relationships, and the need to constantly challenge heteronormative assumptions.

The fear of disclosure and its consequences for LGBTIQ and HIV+ people in the current demographic of seeking or considering aged care is based on years of experience of discrimination.

Those who were born in the early twentieth century were coming of age in an era where homosexuality and gender diversity were criminalised and classified as a mental illness. In fact Gender Dysphoria is still considered a mental illness in the current *Diagnostic and Statistical Manual of Mental Disorders, 5th Edition* (DSM-5).

Socially, they were viewed as immoral, deviant, and may have been ostracised by religious groups, family and friends. They may have been subjected to enforced medical 'cures' which likely included aversion therapies and other harmful practices. People were at risk of losing their employment, harassed by police or jailed on the basis of their sexual orientation or gender identity. HIV+ people were openly discriminated against because of people's misconstrued understandings and ignorance. Within this context staying closeted to the rest of the world and being oneself with trusted friends only was a protective factor.

Advancement of recognition of gender diverse and intersex people has been slower and more recent. It was only in 2011 that it became possible for Australians to have an option other than 'Male' or 'Female' on a passport with the option of 'X' being introduced (Commonwealth of Australia, 2013). It was as recent as April 2014 that the High Court of Australia recognised a 'non-specific' gender category in the NSW Registrar of Births, Deaths and Marriages v. Norrie case and it was only in 2014 that legislative amendments to the *Births, Deaths and Marriages Registration Act* 1997 in the ACT were introduced which remove reassignment surgery as a prerequisite for a person to

change their legal sex and provide an alternate, non- surgical regime for change of sex on key identification documents. The ACT is the first, and currently the only, state or territory to make this change.

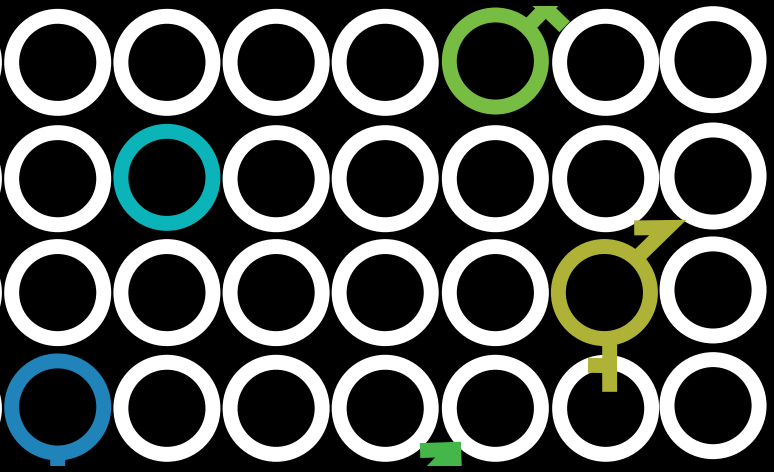
This generation of LGBTIQ seniors has witnessed a tremendous shift in laws and societal attitudes towards equality for people of diverse sexualities, sex and gender identities. A gay man aged 80 today would have been 39 by the time the American Psychiatric Association removed homosexuality from its list of psychiatric disorders in 1973. He would have been 44 when the first Gay and Lesbian Mardi Gras was held in Sydney in 1978 as a demonstration and protest. Depending on which state in Australia he lived in, male homosexuality would have been decriminalised at differing times, starting with South Australia in 1975, to Tasmania in 1997. If he lived in the ACT, he would no longer have feared criminal prosecution based on his sexual orientation in 1976. When he was in his 50s, he may have lost many of his friends to a new disease and in his 60s he may have feared ostracism or discrimination after watching the Grim Reaper advertisements aimed at preventing the spread of AIDS in 1987. If he lived in the ACT, he would have witnessed two events when he was nearly 80 which would have been unfathomable in his youth - same sex marriage equality being recognised in his state, albeit for a very short time, and the recognition of non-specific gender.

Ageing, as with any period of life transition, brings new issues and challenges. Many LGBTIQ seniors bring with them a background of discrimination and marginalisation, and very likely a belief that hiding their sexual orientation, gender identity or intersex status would keep them safe and allow them to have their needs met, as reflected by this poignant reflection in the ACT survey:

> *I fear a future where I have to go back in the closet so I can die with dignity.*

Aged care service providers must keep in mind the life history and experiences of their clients who may identify as LGBTIQ and/or HIV+ in order to create a safe and supportive environment within which to deliver care which is sensitive to their needs. This can be achieved in a range of ways as suggested in the following recommendations.

RECOMMENDATIONS



1. Addressing discrimination through education and awareness raising

The most effective way to address and understand issues concerning the unique aged care needs of LGBTIQ and HIV+ people, their fear and experience of discrimination and the impacts of disclosure, is through awareness raising, education and training at all levels. This includes service providers, staff and co-residents, training providers, policy makers and the broader community.

1.1 Aged care service providers and workers

Since there was a range of views about accessing specific LGBTIQ/HIV+ services or mainstream services, it is important that mainstream aged care services are LGBTIQ and HIV+ inclusive, appropriate and responsive, have quality assurance measures in place which include specific policies and procedures and ensure that workers uphold national standards and are accredited.

For service providers steps could include:

- undertaking audits and assessments of aged care human services for LGBTIQ inclusive practice and benchmarking existing aged care training and education requirements within organisations to determine opportunities for improvement;
- measuring existing practice against (national) standards with respect to awareness and support of the LGBTIQ and HIV+ communities, with a particular focus on anti-discrimination activities, and on respecting and valuing the relationships of LGBTIQ and HIV+ people receiving aged care;
- developing an education program for health and human services through providing LGBTIQ and HIV+ awareness training and education to aged care service providers which includes understanding different issues across these cohorts;
- developing organisational action plans which ensure all staff are provided opportunities to attend such training;
- developing and delivering programs for co-residents to ensure that discrimination is minimalised;
- participating in the Rainbow Tick program or similar in order to promote and market inclusive practice and ensure the community feels comfortable to access services;
- increasing employment of workers who identify as either lesbian, gay, bisexual, transgender, intersex or queer and consider having specific liaison positions;
- ensuring that selection criteria for new staff include questions about inclusivity;
- providing education and opportunities for all clients of aged care services to understand their legal rights and providing access to non-discriminatory grievance and appeal processes and procedures; and
- ensuring that organisational leadership is committed to inclusive practice.

1.1.1 An opportunity for the ACT

The AIDS Action Council in conjunction with A Gender Agenda and Northside Community Service are currently undertaking LGBTIQ training and education for aged care service providers in the ACT, as part of the Commonwealth-funded Living Longer, Living Better Aged Care reform package. It is anticipated that over the next three years, a number of residential aged care facilities and community services delivering aged care in the ACT will undergo this training.

A step further would be to have an accreditation process available for ACT aged care services to facilitate a shift to becoming LGBTIQ-sensitive. An LGBTIQ inclusive practice service accreditation process, the Rainbow Tick, exists in Victoria, but no such service is currently available in the ACT. Gay and Lesbian Health Victoria has developed national standards and accreditation programs and are currently working with Quality Innovation Performance (QIP) and partner LGBTI organisations in other states and territories to publicise the Rainbow Tick nationally and to assist organisations in preparing for LGBTI-inclusive service accreditation. Having such a process available in the ACT would provide accountability and guidance for aged care service providers, as highlighted by one respondent:

> “Ensure all community services are competent to offer services to the LGBT&I community-include this in their contracts and ensure that they report against it or risk losing their funding.

The main message from the survey respondents about training and accreditation processes is that state and federal governments need to be responsible for regulating aged care service providers and hold them accountable for providing an inclusive service to LGBTIQ seniors.

Additionally, in 2012, the Commonwealth Department of Health and Ageing recognises the specific needs of older LGBTIQ Australians accessing aged care services through the *National LGBTI Ageing and Aged Care Strategy* which clearly identified that people of diverse sexual orientation, sex or gender identity require ‘particular attention due to their experience of discrimination and the limited recognition of their needs by service providers and in policy frameworks and accreditation processes’.

In line with this strategy, the Commonwealth of Australia has allocated $2.5 million to facilitate the delivery of aged care services which are sensitive to the needs of LGBTIQ older people, under the *Living Longer, Living Better* — Aged Care Reform package. Organisations within the ACT should explore options to access portions of this funding.

1.2 Training providers:

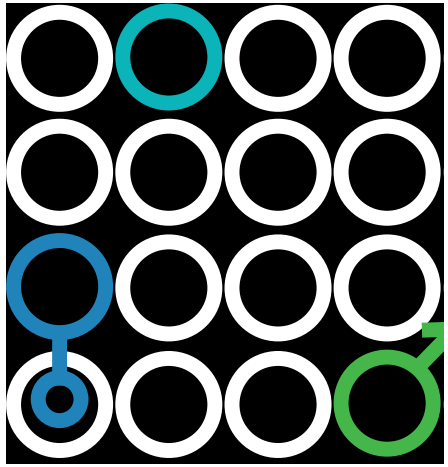
The role of training providers is pivotal to ensuring that information about ways to provide appropriate and respectful care and understanding of the specific issues affecting LGBTIQ and HIV+ communities is widely disseminated. This should be included in accredited training competencies. Suggestions for training providers include:

- adding specific modules onto existing accredited training courses (such as CIT) and having relevant guest speakers;
- ensuring that LGBTIQ and HIV+ people are involved with the development of training modules; and
- including information about the impact of stigma and marginalisation, HIV and AIDS related dementia and other associated health and mental health issues in training programs.

1.3 Community education activities

Strategies for increasing community awareness and working towards attitudinal change include:

- developing broader community education campaigns and programs based on attitudinal change around acceptance and non-judgment which highlight human rights discrimination awareness for lesbian, gays, bisexuals, transgender, intersex and HIV+ people;
- promoting legal reforms including marriage equality will have an effect on the attitudes of aged care workers and the community more broadly;
- developing Speakers' Bureaus can provide a list of knowledgeable specialists to present conference papers, provide guest presentations and fulfil public speaking requests; and
- promoting the use of social media to raise awareness of LGBTIQ and HIV+ communities can contribute to attitudinal and societal change.



2. Developing and maintaining advocacy services

Developing and maintaining both individual and systemic advocacy services which promote the legal rights of LGBTIQ and HIV+ people both within and external to the community will assist to uphold their human rights. Advocacy services should be specific for LGB, TI and HIV+ issues.

2.1 Individual Advocacy

A recurring theme arising from the survey was LGBTIQ older adults' fierce desire to retain their independence and individuality, including their sexual and gender identity in their later years. This can sometimes become challenging, particularly with the progression of a neurodegenerative disease such as dementia, which can compromise one's capacity for decision making. As summed up by one survey respondent,

> If I ever were to spend time in an aged facility, I would like to be treated as an individual and not as an 'Old Person' or someone's perception of a 'Gay Old Person'.

Another respondent reflected:

> It is important not to lose my identity as a gay man, or have to hide it [but I worry about] being unable to choose what I want for myself.

The need for and benefit of individual advocacy was identified as a safeguard. An advocate could be a friend, family member or an independent LGBTIQ organisation, which is there to speak out on their behalf. Having an advocate in aged care has been shown to result in positive experiences for LGBTIQ older people (Barrett, 2008). In fact, the majority of respondents (67%) in the ACT survey identified that having organisations to advocate for older LGBTIQ people in the ACT would be beneficial. Ideally, these would be LGB, TI and HIV+ specific:

> Later in life, LGBTIQ elders will need advocates-case managers who are strong and will stand up for us in talking to service providers.

> The presence of individuals or groups who could provide advocacy in the absence of immediate family members (such as children) would be reassuring.

> As one ages, to have an advocate who can assist in difficult conversations is important.

> If I were elderly and had someone to liaise with my carers on my behalf and have the awkward conversation about my being trans, it would take a lot of the stress out of situations and help me feel cared for.

2.2 Systemic Advocacy

Another role identified for LGBTIQ advocacy organisations is to investigate instances of discrimination, and handle complaints from the community.

> Intercede or support when dealing with stigmatising and discriminatory service providers.

> Provide legal advice regarding discrimination.

Providing information about LGBTIQ/HIV+ friendly aged care services, consumer's rights and responsibilities and assistance in navigating the minefield of processes in order to access aged care services was also identified as a possible role for an advocacy organisation.

On the other hand, 12% of respondents said that they would not find an LGBTIQ organisation helpful. One respondent had concerns that:

> Such an organisation may not particularly represent my views or situation. At the end of the day, all people are different regardless of sexuality and gender differences.

Advocacy organisations for older LGBTIQ and HIV+ people in the ACT could have multiple roles, as suggested by the survey responses. These roles could include communicating with aged care services on behalf of an LGBTIQ/HIV+ older person, addressing complaints or instances of discrimination within aged care services, providing information and assistance in navigating the process of accessing aged care, organising social activities to maintain a social network for isolated seniors and being a primary source of information for LGBTIQ/HIV+ friendly aged care service providers in the ACT.

One respondent reported that an LGBTIQ advocacy organisation in the ACT could;

> Be a resource for a full range of interests of senior LGBTI people, e.g. personal health and fitness, research into LGBTI ageing issues, connections and exchange of ideas, conferences with national and international senior LGBTI groups, living or lifestyle opportunities for seniors, training and study programs, travel, volunteering and activities to support younger or vulnerable LGBTI communities.

Such organisations could also provide assistance with the development of awareness campaigns both within and external to the LGBTIQ and HIV+ community which include information about legal recognition and legal rights and the development and management of a speakers bureau to enable key experts to be linked to requests for information and assistance.

There were suggestions to consider an official visitor style scheme, however noting that a significant proportion of aged care services are in the home. Nevertheless, an official visitor for aged care facilities with a specific mandate would reduce incidences of discrimination in residential care settings.

Additionally, aged care service providers must be aware of their legal responsibilities in relation to LGBTIQ/HIV+ older people. The *ACT Human Rights Commission* recognises the human rights of anyone in the ACT, established by the Human Rights Commission Act (2004), which allows for freedom of expression and protection from discrimination based on sex, sexuality, gender identity or HIV and AIDS status.

The *Same-Sex Relationships (Equal Treatment in Commonwealth Laws—General Law Reform) Act 2008* removed discrimination against same-sex couples and families from a range of Commonwealth laws and programs and afforded them the same rights as unmarried heterosexual couples in areas such as veteran's affairs, social security, taxation, access to the Pharmaceutical benefits Scheme, Medicare Safety Net, superannuation, citizenship *and* aged care.

Furthermore, the passing of the *Sex Discrimination Amendment (Sexual Orientation, Gender Identity and Intersex Status) Act 2013* means that it is unlawful to discriminate against a person on the basis of sexual orientation, gender identity and intersex status under federal law. Same-sex couples are now also protected from discrimination under the definition of 'marital or relationship status'. Several respondents indicated a lack of clarity around the implication of the amendments to the Discrimination Act and whether religious organisations would be exempt, indicating a need for education around discrimination and legal issues.

These laws apply to all Commonwealth-funded aged care services and there was a suggestion that there needed to be some type of enforcement system to ensure that they are being upheld.

3. Increasing efforts to reduce isolation

Developing peer support networking opportunities and community visitor schemes can promote community cohesiveness, reduce isolation and contribute to increasing natural supports. Improving mental health access and support for the LGBTIQ and HIV+ communities is an important contributor to increasing general health and wellbeing.

Providing social inclusion activities, particularly for isolated members of the LGBTIQ and HIV+ communities as they age was identified prominently in the responses. Some respondents highlighted the importance of linking younger LGBTIQ people with seniors, and suggested organising social activities, home visits or bringing meals to LGBTIQ older people living at home, and organising visits to older LGBTIQ and HIV+ people living in residential aged care facilities. There is also a role for aged care residential facilities to provide inclusive activities in their regular programs.

The ACT could participate in the Community Visitors Scheme (CVS) which is a national program that provides companionship to socially or culturally isolated people living in Australian Government-subsidised aged care homes. Specific LGBTIQ/HIV+ schemes should be considered. The Community Visitors Scheme arranges community volunteers to visit selected residents on a regular, one-to-one basis and is funded by the Australian Government and operates in every State and Territory. Any resident whose quality of life could be improved by the companionship of a regular community visitor can be referred to the Community Visitors Scheme.

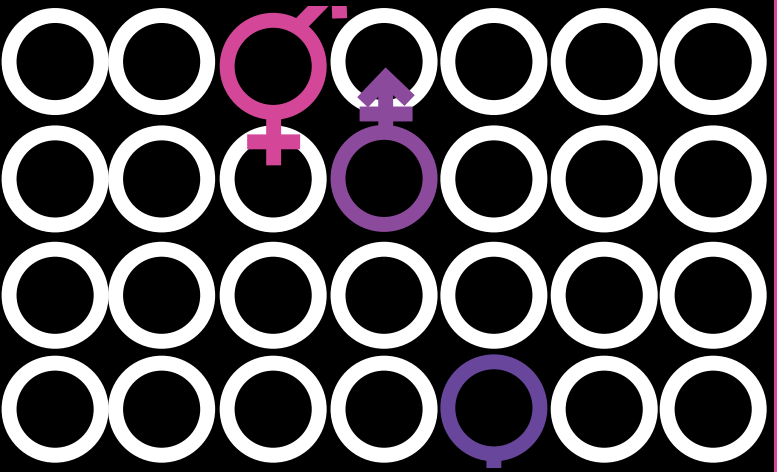
4. Ensuring appropriate health and mental health support services

In order to increase health and wellbeing and possibly delay the requirement to access aged care services, there needs to be adequate, accessible and specifically relevant health and mental health support services. Early intervention (before residential care) is a key component.

Initiatives may include:

- health care professionals following clients/ patients throughout the system to provide a continuum of care;
- developing an understanding of the specific needs of LGBTIQ/HIV+ people within health, mental health and aged care settings;
- updating medical practices to include the awareness of specific needs e.g. universal health precautions, hormonal treatments;
- providing specific LGBTIQ/HIV+ aged care facilities or dedicated programs which may contribute to enhanced mental health and wellbeing; and
- encouraging ongoing research in this area.

LIMITATIONS AND CONSIDERATIONS



Whilst the consultation undertaken provides insight into the issues and concerns surrounding ageing within the LGBTIQ and HIV+ communities in the ACT, there were some limitations.

As noted in the introduction, not all respondents identified as LGBTIQ and/or HIV+. This necessarily means that not all views expressed or responses provided were from within the community, but also included those with family, friendship or professional connections.

Only a small number of respondents identified as queer or bisexual and the little specific research done in Australia with these groups. This has resulted in this report not identifying explicit issues related to being bisexual or queer.

A challenge exists when conducting research within the LGBTIQ communities surrounding the notions of 'identity' and 'labels'. While members of the communities can be broadly categorised within the acronym LGBTIQ, the reality is that a far wider range of identities exist. In addition many people do not identify within the LGBTIQ spectrum for a range of reasons, and/or would prefer not to be labelled and considered as such.

This is particularly relevant for people who are gender diverse or intersex, as a range of identities other than 'transgender'. exist within this category. In addition, respondents may identify as 'male' or 'female' and not with any identity within the LGBTIQ spectrum despite the fact they may have done so at some stage in their lives, or have experiences in common with those who do.

Similarly, intersex people may or may not identify with the LGBTIQ spectrum or communities due to the fact that intersex status is determined by biological sex characteristics rather than sexuality or gender identity and thus the experiences and concerns are frequently likely to be different.

Due to these complexities surrounding identity it must be noted that research conducted in this area is unlikely to capture the true range of experiences with 100% accuracy. The survey provided a range of options (lesbian, gay, bisexual, transgender, intersex and heterosexual), and included the option to specify an identity not listed. A number of respondents did specify alternatives which have been incorporated into the findings the best way possible.

An area often misconstrued within research of the LGBTIQ communities is the differences in experiences and challenges faced by people along the LGBTIQ spectrum. In particular, it is essential to distinguish between sexuality, sex or gender diversity, and intersex status. While in some ways the issues and concerns are common across these communities, in many ways the experiences are vastly different.

In reality, most people who are transgender or otherwise sex or gender diverse also have a sexuality and are just as likely as anyone else to also identify as gay, lesbian, bisexual or queer. In the same way intersex people will also likely have a sexuality and a gender identity which is often not acknowledged. The importance of this distinction is highlighted within the survey as over half of participants who identified as transgender also identified as lesbian, gay, bisexual or queer.

The survey received no responses from people who identified as intersex. There are several possible reasons for this. As previously mentioned, intersex status is distinct from sexuality and gender identity, and it is often not considered an 'identity', as it was referred to within the survey. Intersex refers to biological and physical characteristics (OII Australia 2014), thus the wording of the question within the survey may have prevented participants who are intersex from responding.

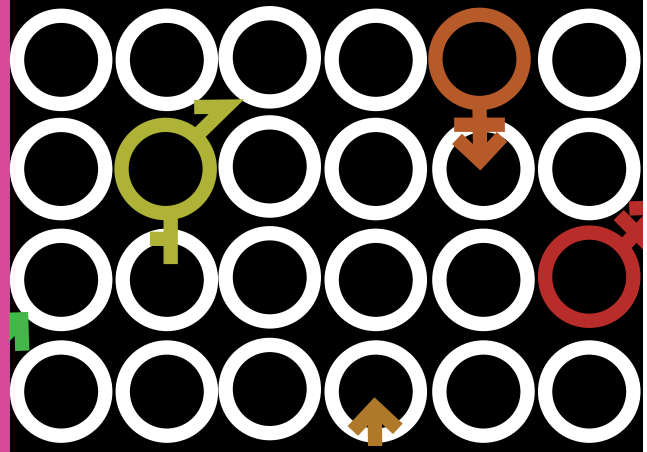
The low response rate is consistent with other studies conducted in Australia and it is clear that far more research is needed into the experiences and concerns of intersex people and that better ways to access these groups needs to be considered.

It must be acknowledged that intersex people will face various challenges in regard to ageing, many of which will not overlap with those experienced by other LGBTQ people. For example, there is a strong history of interference in the lives of intersex people and medical interventions made without informed consent (Childs, 2012).

Population estimates of intersex people vary, however they are likely to be around 1.7% (OII Australia, 2014). This is a small but significant proportion of the population. As such this report has only included reference to the experiences of intersex people in regards to aged care based upon secondary research.

Finally, the survey instrument and discussion at the forum did not include detailed considerations for specific issues experienced by other minority groups within the LGBTIQ and HIV+ community such as Aboriginal or Torres Strait Islanders, people from culturally diverse back grounds and those with disabilities.

RECOMMENDATIONS FOR FURTHER RESEARCH



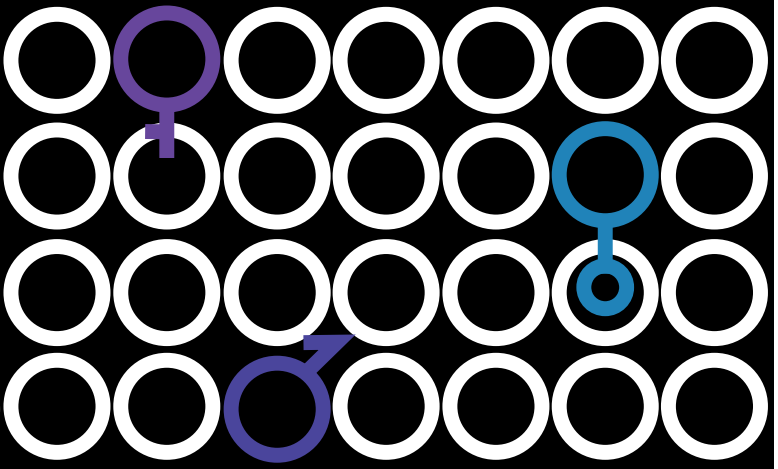
As indicated from the limitations discussed in the previous section, there is a real need to develop ways of eliciting information that assists to understand the distinct differences for each of the groups within the LGBTIQ spectrum. This includes identifying the needs of lesbians as different to gay men and bisexuals, the needs of gender diverse people as different again and understanding that people represented by the 'I' and 'Q' are all also unique groups in themselves in spite of crossover of similarities. Complexities exist within LGBTIQ classifications and personal identities vary widely. Sexuality, gender diversity, and intersex status are distinct categories, and people who identify within the LGBTIQ spectrum may possess more than one identity.

Within future research, it is recommended that the target population is seriously considered when constructing survey questions for clarity, and in order to obtain the most accurate responses.

Future research should actively engage with members of the intersex community in order to accurately represent an often overlooked portion of the population. Specifically this could include experiences of education and employment, financial status and access to superannuation funds, and understanding their distinct experiences in order to ensure appropriate care.

Specific research should be undertaken into understanding issues faced by specific sub groups within the LGBTIQ and/or HIV+ communities such as Aboriginal and Torres Straits Islander, those from culturally and linguistically diverse backgrounds - including refugees and humanitarian entrants who escape persecution, dementia and LGBTIQ/HIV+ seniors with non-age related disabilities.

CONCLUSION



Members of LGBTIQ and HIV+ communities possess particular needs in relation to ageing and accessing aged care services. In addition, distinct differences exist both on an individual basis but also between sexuality, gender diversity and intersex status. It is essential that policy makers, service providers and the wider community are aware of the similarities and differences in order to adequately cater for these cohorts as they age.

Both the survey and forum indicated that a high level of concern exists regarding ageing within the LGBTIQ and HIV+ communities in the ACT. These concerns surround both personal circumstances as well as the social and family situations of individuals. Concerns about respectful provision of care and individual needs being adequately catered for, were also high amongst respondents. Fear of mistreatment and discrimination was frequently expressed as a potential cause of anxiety contributing to the decision to not disclose one's identity in an aged care setting. It is important to note that for many people, especially many gender diverse and intersex people, the choice to disclose is not always an option. This, in conjunction with the likely lack of choice in care, was identified as a major problem within these communities. Both across and within the LGBTIQ and HIV+ communities, a high degree of variability in both experiences and needs has been shown to exist.

In regards to future direction, several approaches were identified within this report to provide overall improvement to the experiences of ageing for LGBTIQ and HIV+ communities.

Approaches such as the implementation and continuation of sensitivity training and accreditation for service providers, the identification of LGBTIQ friendly or exclusive services, and greater levels of advocacy for LGBTIQ and HIV+ people were all suggested as ways in which to improve the experience of ageing within these communities.

As one survey respondent concluded;

> *Acknowledge we are here; understand that we may be lacking in both financial, health and mental health resources due to the impact of homophobic attitudes and abuse over many years. Understand that we are a diverse group and make no assumptions.*

By respecting and understanding the particular needs of these communities, as well as the individuality of senior LGBTIQ and HIV+ people in the ACT, significant improvements can be made to their experience of ageing.

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GLOSSARY

Biological sex	Refers to physical and biological characteristics which are traditionally used to classify people as 'male' and 'female'. These characteristics include genitalia, reproductive organs, hormones and chromosomes.
Bisexual	A person who is attracted to both men and women. Although the 'bi' meaning 'two' is used, the term bisexual in some cases includes attraction to people who identify outside of the gender binary.
Cisgender	Individuals who have a match between the gender they were assigned at birth, their bodies, and their personal identity. As distinct from transgender.
Closet (in the closet) (closeted)	Undisclosed sexual orientation or gender identity—the opposite to being 'out'.
Dementia	A term used to describe the symptoms of a large group of illnesses associated with a progressive decline in a person's functioning which can include a loss of memory, intellect, rationality and social skills. Alzheimer's disease is the most common form of dementia. Other forms of dementia include vascular dementia and AIDS-related dementia.
Gay	A person who is primarily sexually/ emotionally attracted to people of the same gender. This term is usually used to refer to homosexual men although many women also identify as gay.

Gender diverse	A broad umbrella term used to describe individuals who do not identify with the gender they were assigned at birth. This includes a wide range of identities such as transgender, transsexual, gender fluid or gender queer. Gender diverse people may or may not have undergone surgical or hormonal treatments.
Gender identity	A person's inner sense of 'who they are' in gendered terms. A person may see themselves as male, female, both or neither.
Heteronormative	The tendency to assume people are heterosexual, live by traditional gender roles and generally conform to the nuclear family model. Heteronormative assumptions can be made at both an individual and an institutional level.
Heterosexism	When heteronormative ideals are biased against non-heterosexual people and lead to inadequate consideration of their needs. Heterosexism also refers to the mentality where the 'traditional' heterosexual lifestyle is seen as superior to all others.
Homo/ transphobia	The fear and hatred of LGBTIQ people. This can result in discriminatory attitudes, actions, and behaviours towards non-heterosexual people (homophobia) or transgender people (transphobia).
Homosexual	A person who is primarily sexually/ emotionally attracted to people of the same gender.
Heterosexual	A person who is primarily sexually/ emotionally attracted to people of the opposite gender

Intersex	A range of physical variations or traits which lie between the ideals of male and female. Intersex people can have physical, hormonal or genetic features which are not wholly female or male, are a combination of male and female, or are neither female nor male. There are many forms of intersex which can become apparent prenatally, at birth or later in life. Intersex should be seen as a spectrum rather than a single category due to the diversity of intersex variations (OII Australia, 2014).
Lesbian	A woman who is primarily sexually/ emotionally attracted to women.
LGBTIQ	An acronym for Lesbian, Gay, Bisexual, Transgender, Intersex and Queer. A wide range of other identities exist outside of these terms, however for the purposes of this report LGBTIQ is used as an umbrella term to encompass all non-heterosexual and/ or non-cisgendered identities.
Transgender	Individuals who do not identify with the gender they were assigned at birth. The term is often, but not exclusively, used to refer to people whose identity has changed from male-to-female or female-to-male. Transgender people may or may not have undergone surgical or hormonal treatments.
Queer	Often used as an umbrella term for people who have alternative sexual and/or gender identities. Its use is contested however and some people find it offensive while others prefer to use the term exclusively, the former more likely amongst older generations.

APPENDIX: BLANK SURVEY INSTRUMENT

Ageing and Issues Facing Older LGBTIQ People in the ACT

Introduction

Do you think about what life might look like as you grow older? Where you might live? Who might care for you if you're unable to care for yourself?

These types of questions are often particularly challenging for members of our Lesbian, Gay, Bisexual, Transgender, Intersex and Queer Community, complicated by uncertainty about whether our relationships, needs and choices will be recognised and respected as we grow older.

In December 2012, the Federal Department of Health and Ageing launched a 'National LGBTI Ageing and Aged Care Strategy'. The Strategy provides the first ever national framework to recognise and address the unique challenges faced by older LGBTIQ Australians.

The ACT LGBTIQ Ministerial Advisory Council has recently been established to provide strategic advice to the ACT Government on issues affecting the LGBTIQ communities in the ACT. Further information about the Council is available here:

http://www.communityservices.act.gov.au/wac/community/act-lesbian,-gay,-bisexual,-transgender-and-intersex-community-advisory-council

Council members recognise that aged care and related issues are increasingly important for many members of our community. At this stage, we are keen to hear from you about what Ageing and Aged care issues are important for you and your family. Your views will help us provide advice to Government and the Community Sector regarding the needs and views of the ACT LGBTIQ Communities.

Council members invite you to complete this brief survey.

Demographics

1. What is your age?

- ◯ 20 or Under
- ◯ 21- 40
- ◯ 41- 60
- ◯ 61-70
- ◯ Over 70
- ◯ Rather not say

Ageing and Issues Facing Older LGBTIQ People in the ACT

2. Do you identify as (select all that apply):

- ☐ Lesbian
- ☐ Gay
- ☐ Bisexual
- ☐ Transgender
- ☐ Intersex
- ☐ Heterosexual
- ☐ Rather not say

Other (please specify)

Aged Care Services

3. What do you consider aged care services to be?

- ☐ In-home help
- ☐ Nursing homes
- ☐ Transport
- ☐ Meals on Wheels
- ☐ Social support
- ☐ Palliative care

Other (please specify)

Ageing and Issues Facing Older LGBTIQ People in the ACT

4. At what age do you consider you will need aged care services and why?

- ◯ 40 - 50
- ◯ 50 - 60
- ◯ 60 - 70
- ◯ 70+

Why - please comment

5. Who do you think will care for you as you age?

- ☐ Children
- ☐ Other family
- ☐ Partner
- ☐ Community

Other (please specify)

6. Do you think you will have concerns about aged care services?

- ◯ Yes
- ◯ No
- ◯ Not sure

7. What issues are you most concerned about when you think about aged care services and growing older?

Ageing and Issues Facing Older LGBTIQ People in the ACT

8. Do you/will you have the capacity to pay for aged care services?

- ☐ I can afford to pay for my care
- ☐ I can afford to make a contribution but not pay the full amount
- ☐ I cannot afford to pay anything

Additional comments

Access to Aged Care Services

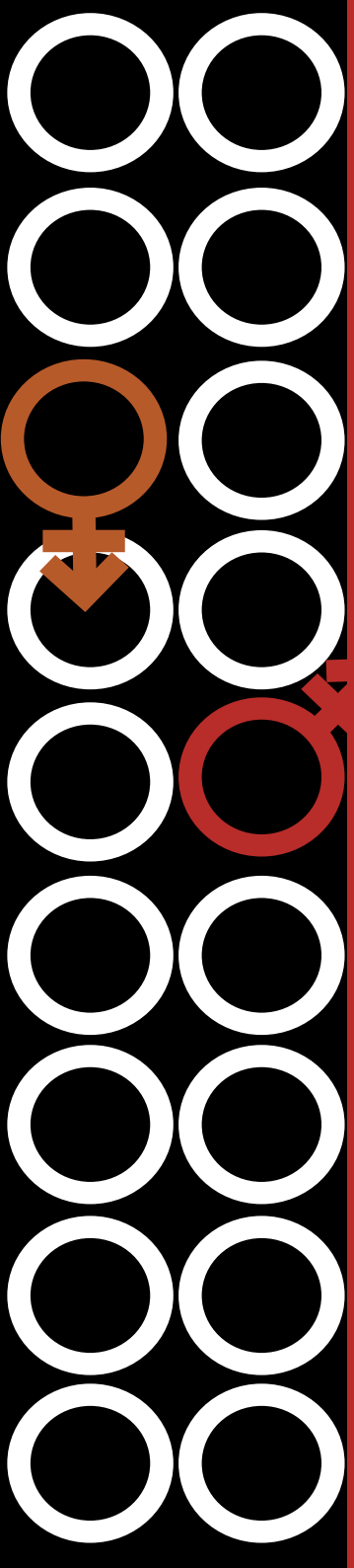
By 'Aged Care' we mean any services you may use, such as in-home help, transport, meals on wheels, hostel care or aged care services that you have received, or might receive, now or in the future.

9. Are you concerned that your sexuality might limit the type and quality of aged care services available to you?

- ☐ Very concerned
- ☐ Somewhat concerned
- ☐ Not concerned
- ☐ Not applicable

10. Are you concerned that your gender identity might limit the type and quality of aged care services available to you?

- ◯ Very concerned
- ◯ Somewhat concerned
- ◯ Not concerned
- ◯ Not applicable



Ageing and Issues Facing Older LGBTIQ People in the ACT

11. Are you concerned that your Intersex status might limit the type and quality of aged care services available to you?

- ◯ Very concerned
- ◯ Somewhat concerned
- ◯ Not concerned
- ◯ Not applicable

12. Are you concerned that your HIV positive status might limit the type and quality of aged care services available to you?

- ◯ Very concerned
- ◯ Somewhat concerned
- ◯ Not concerned
- ◯ Not applicable

Disclosing your sexuality, gender identity or intersex status

13. Are you currently, or do you think you would be, comfortable about being 'out' about your sexuality to your aged care provider?

- ◯ Yes, I currently am / or think I would be comfortable
- ◯ No, I am not / don't think I would be comfortable
- ◯ Not Sure
- ◯ Not applicable

14. Are you currently, or do you think you would be, comfortable about being 'out' about your gender identity to your aged care provider?

- ◯ Yes, I currently am / or think I would be comfortable
- ◯ No, I am not / don't think I would be comfortable
- ◯ Not Sure
- ◯ Not applicable

Ageing and Issues Facing Older LGBTIQ People in the ACT

15. Are you currently, or do you think you would be comfortable about being 'out' about your intersex status to your aged care provider?

- ◯ Yes, I currently am / or think I would be comfortable
- ◯ No, I am not / don't think I would be comfortable
- ◯ Not Sure
- ◯ Not Applicable

16. What may help to ease your concerns (if any) about ageing and aged-care related issues?
For example: more information about services; the opportunity to discuss issues with service providers; the chance to discuss these issues with other members of the LGBT&I community?

17. Would having a LGBT&I organisation focused on helping LGBT&I people as they age be helpful to you?

- ◯ Yes
- ◯ No
- ◯ Not sure

please comment

18. What (could) would you like to see an LGBT&I organisation with an aged care focus do?

- [ ] Organise social activities
- [ ] Assist with housing options
- [ ] Offer training to aged care organisations
- [ ] Provide direct support to LGBT&I community members
- [ ] Fundraising - I could donate time, I could donate money

Other - please comment

19. How could the LGBT&I community better support our LGBT&I elders?

20. How could the ACT Government better support our LGBT&I elders?

Wills and Enduring Powers of Attorney

21. Wills and Enduring Powers of Attorney

Do you have a will?

◯ Yes ◯ No ◯ Not Sure

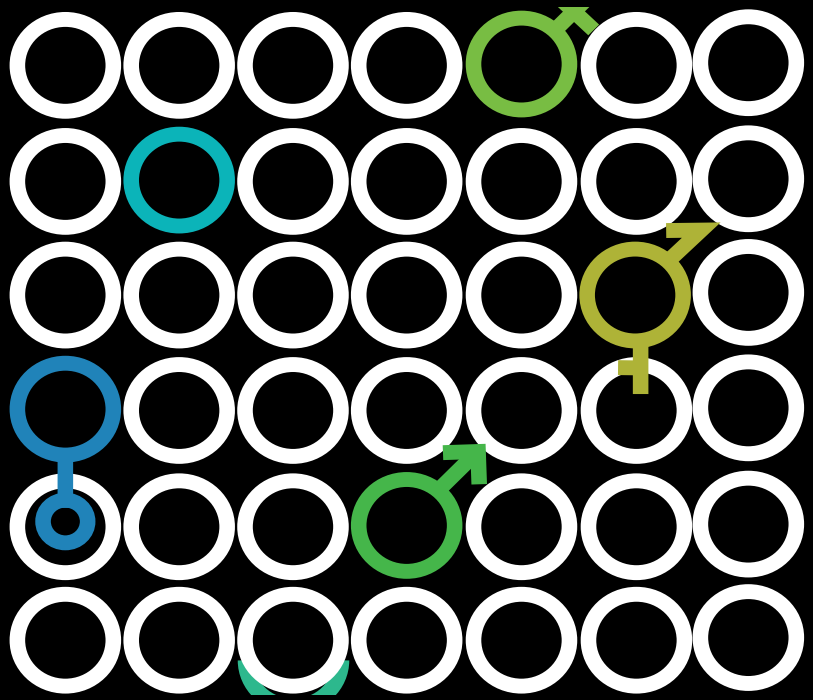
22. Do you have an enduring power of attorney?

◯ Yes ◯ No ◯ Not Sure

23. Do you have an advance care plan?

◯ Yes ◯ No ◯ Not Sure

24. Thank you for completing the survey - this is the last question - Is there anything else you would like to tell us?



Acknowledgement and thanks

The LGBTIQ Ministerial Advisory Council is grateful for the opportunity to collaborate with the community organisations and community members who have made significant contributions to this report. The Council would like to thank:

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CONSULTATION REPORT 2014

Aged care issues raised by Lesbian, Gay, Bisexual, Transgender, Intersex, Queer and HIV+ people in the ACT