



LEGISLATIVE ASSEMBLY
FOR THE AUSTRALIAN CAPITAL TERRITORY

STANDING COMMITTEE ON EDUCATION AND COMMUNITY INCLUSION
Mr Michael Pettersson MLA (Chair), Miss Laura Nuttall MLA (Deputy Chair),
Ms Nicole Lawder MLA (Member)

Submission Cover Sheet

Inquiry into Loneliness and Social Isolation in the ACT

Submission Number: 13

Date Authorised for Publication: 05 March 2024



Inquiry into Loneliness and Social Isolation in the ACT

LCommitteeECI@parliament.act.gov.au

Standing Committee on Education and Community Inclusion
ACT Legislative Assembly,
GPO Box 1020,
Canberra ACT 2601

The following submission has been drafted by Meridian staff with valuable insight and case studies from our service users.

Meridian is a peer led, community controlled organisation and at the heart of our mission lies a commitment to building a community that thrives on inclusivity, support, and genuine connections. Today, we share our insights and experiences with a deep concern for the prevailing issues of loneliness and social isolation within our beloved community.

Introduction

The Australian psychosocial landscape is vast and diverse, and within it, social isolation and loneliness affect various populations. When examining the intersection with people living with HIV and LGBTQIA+ communities, unique challenges and vulnerabilities emerge. Individuals within these communities often face heightened risks of loneliness, exacerbated by factors such as discrimination, stigma, and limited access to supportive networks. Tackling loneliness and isolation aligns seamlessly with our mission at Meridian, where we prioritize bringing our diverse community together to celebrate, nurture, and strengthen collective resilience. Recognising the adverse effects of stigma, discrimination, and marginalisation, we understand that fostering connection is essential for the health and wellbeing of our community members.

Our commitment to the legacy of peer-led initiatives, initially responding to the HIV epidemic, remains steadfast. By valuing our communities, volunteers, members, and allies, we not only acknowledge our history but also affirm that unity and support are central to our work. In our holistic approach to health, we prioritize safety, security, and connection as crucial elements contributing to individual fulfillment.

At Meridian, we appreciate the diversity of our communities, understanding that health needs vary. Through person-centred programs and services, we ensure an inclusive and tailored approach to improving the health and wellbeing of our clients. As fierce advocates, we stand up against discrimination and injustice, taking proactive action to meet the needs of our communities, thereby addressing the loneliness and isolation that may arise from systemic challenges.

In placing this inquiry as a top priority for our organisation we came to realise how difficult it is to capture the extent, unique challenges faced, and experiences of loneliness and isolation for LGBTQIA+ and HIV impacted community members. So, we asked ourselves: How can we provide a voice to the voiceless when the issues are so nebulous, insidious, and unique to every individual that experiences it here in the ACT?

We believe that the iceberg analogy is the most apt to understand the difficulty we face; that those people who reach out to us and those people that we support are a tiny fraction of these most vulnerable and isolated people in the ACT. So, with such a colossal task, we have decided to keep this submission personal, and provide the Assembly with the core thoughts, feelings, and experiences which introduce the story of loneliness and social isolation for our communities in the ACT, from our staff, volunteers, members, and clients.

Below we have attempted to focus in on the experiences of some of the community members we support, including the most unique and profound barriers to connection. These experiences are only a few of the many that we see as being of paramount importance when the government is considering the state of loneliness and social isolation in the ACT.

People living with HIV+ and HIV Impacted Community Members

Loneliness and social isolation is particularly pronounced when considering the impact on individuals living with HIV. The stigma surrounding HIV/AIDS has, unfortunately, endured over the years, contributing to heightened isolation for those diagnosed. The profound effects of social isolation on HIV+ individuals extend beyond emotional well-being to impact physical health outcomes. Research consistently demonstrates that social isolation can compromise immune function, potentially exacerbating health challenges faced by those living with HIV.

Ms J.'s Experience of Loneliness as a 70-Year-Old Trans Woman living with HIV+

Background:

This case study explores the life of Ms. J, a 70-year-old transgender woman living with HIV, who has been grappling with profound loneliness and isolation since the passing of her spouse two years ago. Ms. J's journey is characterized by the struggle to suppress her feminine identity during her marriage and her current challenges in establishing meaningful social connections in the aftermath of her spouse's death.

Ms. J grew up in an era when societal attitudes towards gender identity and sexual orientation were significantly more conservative than today. Despite recognising herself as a bi-sexual woman from an early age, she felt societal pressure to conform to conventional expectations and present as a man, married to a woman. During her marriage, Ms. J found it challenging to express her feminine identity and sexuality openly, fearing the strain it would put on her relationship.

Ms. J's wife had been a source of emotional support, but with her gone, Ms. J faced the daunting task of rediscovering and expressing her true self and overcoming feelings of guilt, grief, and shame.

Current Needs:

Ms. J's main struggle lies in the profound loneliness she experiences. The loss of her wife has left a void in her life, and the isolation is exacerbated by the limited social connections she has. Although Ms J was already connected with Meridian and was receiving social support prior to her wife dying, her social needs have changed. This was difficult for her to accept as it is also deeply connected to a denial of the impacts of aging, both physically and cognitively. Ms J has attended counselling on and off for over two years with us and is now beginning to accept who she is and what she needs. Her mental health journey has been focused on processing grief due to the loss of her late wife and grief at the loss of her youth and middle age due to living a life incongruent with her identity. Affordable and inclusive counselling has been available to her due to her HIV status, however, the feelings and struggles she presents with are common for older transgender people.

Ms. J has had to deal with the loss of her social groups, hobbies, and activities due to her changing needs and how her identity is perceived by her existing network. Ms. J, who now feels able to express her true self, faces challenges in finding acceptance and understanding from others. The societal stigma surrounding transgender individuals, especially those in their later years, adds an additional layer of complexity. Ms. J has found it challenging to establish meaningful connections with others who appreciate her for who she is. The limited social interaction she experiences often revolves around men seeking casual relationships rather than genuine companionship. Ms J. has had to rely on her support worker who she obtained through our care finders, for social engagement, amounting to one and a half hours a fortnight.

Conclusion:

Ms. J's case illustrates the intricate challenges faced by individuals in our communities with complex barriers to navigating loneliness and social isolation. A holistic approach that addresses mental health, community engagement, and societal awareness is crucial to supporting individuals like Ms. J in their journey towards healthy ageing with HIV, coping with grief, and rediscovering and expressing their authentic selves. Ms. J. is lucky to have a positive and trusting relationship with her GP throughout her transition as this is an often-overlooked element of loneliness (i.e. being able to discuss identity, medical needs, and medical interventions connected to gender).

Aged LGBTQIA+ Community Members

Within the intricate tapestry of our community, we find a segment that demands special attention—our aging LGBTQIA+ members. As our community members age, they encounter unique challenges related to isolation. Historical discrimination, coupled with the complex needs experienced during later years, can result in barriers to aged-care services, contributing to a sense of disconnection. Meridian's commitment to inclusivity extends to our seniors, ensuring that their later years are marked by support, camaraderie, and a sense of belonging. Becoming a care finder provider has been our most recent project to engage and support aging LGBTQIA+ and HIV impacted community members. We also developed gender and sexuality diversity training videos in multiple languages for Aged Care Workers.

Dr A's Urgent Needs for Personal Care Support

Background:

Dr A, a 76-year-old man with heart disease residing in North Canberra, faces severe isolation compounded by medical frailty and urgent personal care needs. He has a culturally and linguistically diverse (CALD) background and is the sole carer of his older partner who is living with dementia. Due to his sexual orientation Dr A has been disconnected from his family and ostracised from his cultural community. He is living with COPD (Chronic obstructive pulmonary disease) which impacts on his physical wellbeing and neither himself nor his partner can drive or take public transport.

Dr A is feeling isolated and is unable to leave the house due to his partner's dementia. He has lost friends and contacts over COVID and is also extremely cautious about going out due to his compromised immune system. Dr A has a strong desire to connect with folk from his cultural background and engage in social activities outside their home. Dr A reports that he rarely leaves the house and feels lonely and isolated which causes great shame and distress for him as he still lives with his partner.

Current Needs:

Dr A is suffering from carer stress which is exacerbated by his struggle to self-advocate. With no close family or friends and limited community connections he feels unable to find help. The physical limitations he is experiencing include difficulty with walking, and his house is becoming increasingly more inaccessible.

While the Care Finder was able to support Dr A with immediate financial assistance through Secured Age Pension, connecting him with Care Financial, and home-based support (personal care, cleaning, and shopping), the options for community engagement were limited. Connections with local services and food pantries were the most that Care Finder could facilitate at the time.

Conclusion:

After engaging with Care Finder, survival is now something that Dr A can have confidence in and within three months, Dr A reported improvement in well-being, financial stability, and community engagement, thanks to the effectiveness of tailored support interventions. For him and his partner to thrive, connectedness and community is vital. With their advanced age, this would provide a degree of suicide protection and support positive outcomes if moving into assisted living or if grief were to impact this couple. Unfortunately, without accessible community groups and activities which are co-ordinated with carer respite support, LGBTQIA+ inclusive, and targeted at bridging cultural connectivity, Dr. A's loneliness and social isolation will be difficult to overcome.

Trans and Gender Diverse Community Members in the ACT

Community members living with Disability in the ACT

The intersection of disability and LGBTQIA+ identity creates a multitude of complex experiences, introducing unique challenges that can significantly contribute to feelings of loneliness and social isolation. This intricate interplay of marginalized identities often intensifies the struggle for connection, with profound implications for mental health and well-being. Our wellbeing staff regularly discuss their concerns that while loneliness and social isolation is the predominant reason this group reach out for counselling and psychology, it is often difficult for this to be identified in therapy and case management. Among other factors this is due to the internalised societal belief that one must be self-sufficient. This can mean that meaningful change for these clients deems them inappropriate referrals for a brief intervention program. The result of this is the need for referral to less LGBTQIA+ inclusive support programs and further detachment from the community they identify with.

The LGBTQIA+ community have a greater risk of suicidality and self-harm as we discuss below, and this vulnerability is compounded when intersecting with disability. These individuals grapple not only with societal biases surrounding sexual orientation and gender identity but also contend with the physical, cognitive, and/or sensory challenges that

accompany their disabilities. Meridian is steadfast in its advocacy that people with disabilities require nuanced interventions that address the multifaceted nature of isolation.

In response to this imperative, Meridian has launched The Roundabout Project, an initiative designed to provide disabled LGBTQIA+ and HIV+ community members with dedicated peer volunteer community members. These volunteers serve as more than companions; they are beacons of support, with their unique understanding of the specific challenges faced by those navigating the intersection of disability and LGBTQIA+ identity.

The Roundabout Project represents a pivotal step toward fostering genuine connections, offering a lifeline to those who may feel marginalized by societal norms. By pairing vulnerable community members with compassionate and knowledgeable volunteers, Meridian aims to break the cycle of isolation, creating spaces where individuals can share experiences, find solace, and build lasting connections within a community that fully embraces and celebrates their diverse identities. Addressing these aspects is vital for the government's efforts to enhance support systems for individuals in the ACT facing isolation, but the capacity for the sector to provide more of this for all minorities is urgently needed.

Tackling Loneliness and Social Isolation as Suicide Prevention

A theme that has emerged through our findings while gathering and selecting our case studies which cannot be overstated is the role that loneliness and isolation play in a person's risk of suicidal thoughts and these developing into suicidal behaviours and death.

Within the LGBTQIA+ community, the risk of suicide and self-harm remains alarmingly high, reflecting the impact of societal discrimination, stigma, and the struggle for acceptance. The absence of meaningful connections intensifies feelings of despair, fostering an environment where individuals contemplate or act upon suicidal thoughts. This underscores the imperative to address loneliness as a cornerstone in comprehensive suicide prevention efforts.

Loneliness and social isolation are pivotal determinants of mental and physical health, profoundly impacting the holistic wellbeing of individuals. In both Australia and the ACT, these issues command immediate attention, reflecting a critical juncture where the nexus between loneliness and rising suicide rates necessitates concerted and nuanced strategies.

Meridian recognises the urgency of addressing loneliness as a significant contributor to suicide, especially within the LGBTQIA+ and HIV impacted communities, and have two of our counselling and psychology clinicians attending the Suicide Prevention Capacity Building Program. Through strategic interventions, collaborative efforts, and advocacy, our organization remains unwaveringly committed to cultivating a more connected and supportive society, ultimately reducing the risk of suicide associated with loneliness. We see this as an overdue, territory-wide, and ongoing project that requires urgent investment from both the Government and the ACT community.

Opportunities

Collaboration and Increased Networking

Tackling suicide prevention and loneliness mandates a collaborative approach. Meridian diligently collaborates with government bodies, health organizations, and community stakeholders to support individuals as they transition between services and to ensure that our expertise is available to other orgs and departments and that the ACT community are benefiting from the wealth of expertise available here and in Australia as a whole. This collaborative spirit extends to advocating for inclusive policies and creating environments and inter-organisational programs that effectively reduce loneliness and associated risks.

Expertise and peer community knowledge is required for a system which ensures greater collaboration between NGOs and Government organisations, particularly those LGBTQIA+ and neurodivergent-focused organizations for suitable group social and support programs. The value of peer support is becoming increasingly accepted and proven as risk reduction resources, which we have demonstrated through our collaboration with Safe Haven and other peer led organisations.

Our final collaboration opportunity is best described in the outcomes of the 2021 Queensland Government inquiry into Loneliness and Social Isolation known as Social Prescribing where GP's and other primary health professionals are aware of and connect patients with local NGO's and government social groups and support programs. This is much needed in the bid to ensure individuals in minority communities and experiencing social isolation are exposed to others who experience similar barriers and that the wealth of community organisations in the ACT are valued and utilised for the services they provide.

Policy

While many of the opportunities discussed in this submission require significant financial investment, some is already available to those with social capital, and in theory, to those without. There is a devastating barrier to financial support for folks with a disability and dealing with aging when their capacity to understand, administrate and advocate through the application and review process for My Aged Care, National Disability Insurance Scheme and Disability Pensions is diminished. Meridian has recently set up Copilot, a program aimed at providing free support for anyone requiring help with these processes in our community as the existing systems are perceived to be discriminatory, have a lack of awareness of the needs of our community and are not focused on supporting the applicant in understanding what they are entitled to. This is a new program being trialled at the moment however we predict a huge response as a number of members and clients are certainly eligible for financial aid for social support, but have become disenfranchised by the process and don't have the administrative skills or support to manage and pay for the wealth of appointments and professionals they would need to navigate to complete applications and reviews.

Awareness Raising

Many of those who are experiencing loneliness and social isolation may require more than a few hours of rapport building to identify the impacts that isolation is having on them. Given the urgency of this matter Meridian believes that the public require a wake-up call to the prevalence of loneliness in the ACT and are provided with strategies for talking about loneliness with family and friends and particularly with at risk people in their community. In addition, heightened awareness campaigns to destigmatize seeking help and bring the very real dangers of loneliness to the collective consciousness of the greater ACT community.

Social campaigns are important to promote the visibility, presence and care for older transgender, gender and sexuality diverse and people with intersex variations among other at-risk members in of our community whose presence and needs are often invisible and overlooked.

Community Support

Clinical and Therapeutic Services

Meridian recommends increased funding for mental health programs including targeted initiatives for all the at-risk community member discussed here, to be designed much like Meridian's programs for providing free counselling and peer case workers for HIV+ folks. Affordable and sustainable counselling and social groups for trans, gender and sexually diverse and intersex people is required to support their forming of a confident and resilient identity and ultimately provide them with the foundation and networks for seeking supportive and appropriate social capital.

Improving Access to Inclusive Healthcare, Living and Service Providers

While reaching those with minimal or no social capital or family is a monumental task, where we are most concerned about the currently isolated, disconnected, and unseen individuals whom we are struggling to reach through conventional means due to the depth of isolation experienced. For some, Health and Allied Health Professionals are the only other souls they will encounter.

Thus, all social, healthcare and community services have a huge role to play in identifying, discussing, and supporting lonely and isolated community members. Trusted professionals must have a keen eye, be curious but respectful and knowledgeable about the needs of the most vulnerable. We believe that much like in our training modules for aged care and disability workers, this must be provided by community peers who can empower through engaging discussion, provide tangible strategies, and facilitate a safe environment for workers and organisation leaders to ask questions, discuss cases and role play positive interactions.

Workshops we currently provide can be targeted towards aged care workers, staff and leadership team of retirement and aged care residences, health professionals, family support workers, and service providers. Training should be available in multiple languages to

facilitate a better and deeper understanding of gender and sexuality diversity, particularly for workers who are culturally and linguistically diverse.

Improved education on intersex awareness for medical professionals not only supports our community members with intersex variations in feeling accepted within medical environments but also enhances competency among healthcare providers. This increased competency enables medical professionals to better support individuals with intersex variations, promoting improved health and wellbeing outcomes for them.

At Meridian we recognise the wide-ranging reasons for the link between our communities and disability. This ranges from the growing research on the link between long term trauma and stress and auto-immune disorders later in life, to the prevalence of sexual and gender diversity in those who identify as being neurodivergent, many of whom have disabilities. We have focused on making our current premises sensory safe and physically accessible and our services and programs as affordable as possible, however, our current home does not allow for the modifications needed and funding is currently unreliable. Our new Executive Manager of Sector Development, Aging and Development is tasked to increase capacity in our programs which promote social engagement and develop greatly needed supports for individuals who need advocacy and support to access funding. However, we find ourselves having to cut popular and much needed programs to support some of the most vulnerable and valuable members of the rich ACT community.

For many individuals with psychosocial disabilities to find connection and belonging they would require developing skills in co-operation, emotional regulation, and social communication. Others would benefit from therapeutic supports to develop motivation to build social capital however social anxiety and a lack of awareness of the value that social networks provide, means that these resources are often not sought until they are urgently needed. Programs focused on these vulnerable members of our community would have to be sensory safe and be LGBTQIA+ inclusive and neurodiversity affirming.

Conclusion

As we engage in this inquiry, we bring to the forefront not just the statistics but the lived experiences of individuals navigating the intersections of HIV, LGBTQIA+ identity, and social isolation—across generations. We invite the Legislative Assembly to engage with community organisations and service users (co-design) including Meridian in crafting policies, design community programs, events, education, and services that dismantle stigma, foster inclusivity, and address the systemic issues contributing to the loneliness experienced by our diverse community members.

Meridian Incorporated

www.meridianact.org.au

(02) 6257 2855

