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SUBMISSION TO THE ROYAL COMMISSION

Questions about you

Submitted By: HIV Institute of WA
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State: WA

Do you live in a remote, rural or regional area? : I do not live in a remote, rural or regional area
Previous submission:
This submission is on behalf of : Other
Name of service provider or other person : HIV Institute of WA , a peer base organisation

About your submission

Which of the Royal Commission s terms of reference is your submission about?: Substandard or unsafe aged care services delivered (including mistreatment, all forms of abuse and systemic failures); Challenges and how to best deliver aged care services to people over 65 with disability; Challenges and how to best deliver care for younger people (under 65) with disability; Challenges and how to ensure aged care services are person-centred (including by allowing people to exercise choice, control and independence of care and improving engagement with family and carers); Challenges about understanding what care is available, the assessment process, how to get care, and at the level of care needed; Challenges about the availability of post-hospital care and rehabilitation services or other support services that might assist living at home; Challenges and how to best deliver aged care services in a sustainable way (including through innovative models of care, use of technology and investment in the aged care workforce and infrastructure); Challenges and how to ensure high quality and safe end of life care; Challenges associated with providing high quality, safe and affordable aged care services generally; Interface between aged care services and primary health services, acute care and disability services and regulatory systems (including how people transition from other care environments or between aged care settings); Staff challenges in operating in the aged care system, and what might be changed in order to deliver better quality and safer services; Examples of good practice and innovative models in delivering aged care services

What, if any, specific concern/s does your submission relate to? Physical abuse or assault; Emotional abuse; Discrimination of any kind; Staffing issues including ratios; Neglect; Dignity; Independence, choice and control over care; Clinical care; Medication management; Mental health; Loneliness, disengagement, disconnection and/or boredom; Nutrition (including malnourishment); Restrictive practices; Governance arrangements and management support systems; End of life care

What type of aged care services does your submission address? Care in an aged care home (nursing home); Care to a person with a disability living in an aged care home (nursing home) under the age of 65

Your Submission

What would you like to tell the Royal Commission?

HIV Institute of WA Submission to Aged Care Royal Commission

This submission is written with the help of the HIV Institute of WA.

The HIV Institute is an independent voice for HIV people and families in Western Australia.

HIV people who are now aging have been following the debate about Aged Care. We are acutely aware that there has been some work done surrounding HIV and Aged Care - but as consumers, who are looking to go into Residential Aged Care Facilities (RACF), or, to continue to receive community based services delivered to our homes, there is a lack of information in regards to the placement and location of the safest places for us to make plans for our needs towards the end of our life.

Specifically in regards to RACF locations, as the potential new homes for HIV people, we believe that there should a duty of care to ensure Aged Care settings are safe, without stigma, or, discrimination which is detrimental to our health wellbeing and journey, as people with living with HIV.

HIV Long-term Survivors have a history of being discriminated against in health settings, including Hospitals and Nursing Homes.

Long-term survivors will again be the pathfinders for HIV in residential care and it does need to be noted that this group of people come with a history of being both stigmatized and discriminated against.

As people who will be the forerunners yet again there is a lot of fear and apprehension about the negative circumstances that this will present.

The Public Fear and resulting discrimination that we faced when the pandemic first occurred from the ill-advised Grim Reaper scenario and misinformation, has done more harm than good. These sorts of things should not be inflicted on HIV+ People again, especially this group of pathfinders.

The key concerns that we would please like to ask The Royal Commission to address for the HIV community looking at residential Care are:

1 – Consultation with Consumers about Choice

There has been a lack of consultation with Consumers to underpin decisions that are being made by HIV Leaders and Authorities that directly affect people who are looking or going into residential care and receiving care in their homes.

The lack of information is directly preventing our consumer's right to be informed and make proper consent in relation to the selection of our placement in residential homes.

It is a known fact that People become isolated in Residential Care settings and are at the mercy of medical staff. This is why both the right to choose the best fit for yourself and properly trained medical staff are so important.

The HIV Training Programs for staff, that is currently is being rolled out by HIV Organisations are in High-End Private Providers only, within Western Australia. These high-end facilities are not accessible to people on low incomes, and currently, these training programs not being implemented in public residential care homes.

A barrier preventing universal training is that the government-funded training programs are being copyrighted by HIV Organisations so that they can only be implemented on a fee for profit basis at high-end nursing Homes.

Copyright and restricted access to government Funded developed Training programs should never be allowed to occur and curriculums should be available as open source so that volunteer organizations can undertake the training free of charge in Residences Care Facilities.

When the number of HIV people requiring placements increases with an aging HIV population and all the current beds at high-end homes are filled, public homes will all need to be HIV friendly and ready in order to prevent more stigmatization and harm to HIV People.

2 - Entrenched Poverty

Entrenched poverty is an issue for HIV long-term survivors. This entrenched poverty will make public placement as the only available option for most of us.

Entrenched Economic Privilege is a huge issue for consumers who are impacted by treatment prices, the cost of medical access and the inability to pay for upmarket residential care settings or those which have private fees to see doctors. This is something that Governments, NGOs and Advocates must factor into their decision-making processes on behalf of consumers.

The future will see an increased number of HIV+ people going into residential care, so it is time to quickly address this issue. We cannot wait for another foreseen preventable crisis to arrive involving harm to people who have already experienced the trauma of this type of discrimination and fear over and over again.

3 - Stigmatisation

As HIV people we believe that reducing the stigma in the wider community will have a trickle-down effect into the residential aged care area and workforce.

We ask this Royal Commission to call for a U=U Undetectable = Uninfectious campaign to be rolled out in all state and Territories.

There is a need for the HIV funding organizations to support a U=U campaign as an essential component of

HIV strategies aimed at both addressing prevention of infection with HIV and reducing stigmatization of those already infected with HIV.

There have been no effective U=U campaigns to reduce Stigma despite the medical evidence having been established for the past two years. Nationally and within Western Australia, these campaigns need to be sourced out to a professional organization that could develop a campaign which would have beneficial traction and impact within the wider community, in addition to the normal target LGBTI communities.

We are concerned that currently some of the overseas trained RACF staff that are bring employed bring with them to this country values surrounding HIV & LGBTI Rights that do not match Australian values.

All overseas staff needs to undergo cultural training to ensure their attitudes are not leading to harm for people in residential care.

The Kerryn Phelps Email in the Wentworth By-election demonstrates proof of the Entrenched Stigma and discrimination. It is clear that Grim Reaper style myths are still being perpetuated by the silence surrounding and lack of education about new developments about HIV today.

4 - Legal Rights of Consumers & Consumer Organisations

There needs to be an increased legal role for Consumer Organisations, along with funding provided to develop trained Advocates to fill the role of Visitor. These are people that are able to make unannounced visits with the power to enter and protect the needs of vulnerable clients in Residential Care settings.

It is best for the long term that advocates be placed within Consumer Organisations due to the increasingly fragile status of traditional HIV Organisations. This fragile status is real and stemming from the many calls by the HIV community, medical professionals & LGBT lobby groups to merge the Blood Borne Viruses (BBV) and Sexually Transmitted Infections (STI) sectors to increase their capacity and eliminate the stigmatisation by normalising HIV, along with the excessive duplication of services that currently exists within the sector.

As HIV is becoming classified as just another STI it is important for each jurisdiction to have properly resourced and empowered Health Consumer Councils who are the future of advocacy so that consumers are not reliant on organizations that are not viewed as having a long term future in HIV care and prevention.

Our Key Recommendations to the Royal Commission are

1 – Information to be Freely Available:

Information surrounding accreditation programs should be freely available and placed online for HIV people and their carers to plan our future needs.

2 – Address Legislative Issues & Barriers:

National legislation should be in place to sort out the conflict between state and federal responsibilities for HIV people when they go into residential care. As it stands when HIV+ people go into residential care, their status as clients of state-based HIV organizations ceases and HIV people then come under the care of the Federal Government system. This loses a vital support network from local organizations that does make access to community-based medical care possible. This is something that we believe the Royal Commission should address.

3 – Strategies to Protect Against Discrimination & Stigma

That there be a legal framework and strategies put in place to protect HIV people from harmful care, caused by Fear, discrimination and the ignorance, especially when their Viral Load count might increase in the latter stage go life. We believe there is a duty of care to ensure that HIV+ people in Residential Care settings are not isolated, or, shamed in their home by staff, or, other residents at this time in their life.

Information in training programs needs to include the trauma associated with HIV and what happens to people as we do approach the end of Life to ensure we are cared for in a respectful and dignified way.

End of life data is an unknown quantity as people aging with HIV has not been well documented or researched. This is a very real fear that people have. What will happen to me at the end of my life?

4 – Structured Consumer Consultation Framework

In Western Australia, there has been a lack of consultation directly with the HIV community on HIV aging and residential care issues.

There needs to be a better process put in place that will address consumer's concerns and fears.

Supporting Documentation Accompanying this Submission

The HIV Institute has endorsed the recommendations from the Submission that was made to the Senate inquiry on Aged care by The Western Australian HIV Forum which we have attached for your consideration.

Supporting material provided:

Submission o Senate Community Affairs References Committee On HIV Aged Care April 2016 (5) (1) (1).pdf

Can this submission be made public I agree to my submission being made public under my name