Table of Contents

1. Tell us about you ........................................................................................................................................... 2
   1.1 What is your full name? ......................................................................................................................... 2
   1.2 What stakeholder category do you most identify with? ................................................................. 2
   1.3 Are you providing a submission as an individual or on behalf of an organisation? ............. 2
   1.4 Do you identify with any special needs groups? ............................................................................. 2
   1.5 What is your organisation’s name? ................................................................................................. 2
   1.6 Which category does your organisation most identify with? ..................................................... 2
   1.7 Do we have your permission to publish parts of your response that are not personally identifiable? ........................................................................................................................................... 2

2. Response to Criteria in the Legislation ................................................................................................................. 3
   2.1 Whether unmet demand for residential and home care places has been reduced..... 3
   2.2 Whether the number and mix of places for residential care and home care should continue to be controlled ........................................................................................................................................... 4
   2.3 Whether further steps could be taken to change key aged care services from a supply driven model to a consumer demand driven model ........................................................................................................... 5
   2.4 The effectiveness of means testing arrangements for aged care services, including an assessment of the alignment of charges across residential care and home care services ................. 6
   2.5 The effectiveness of arrangements for regulating prices for aged care accommodation 6
   2.6 The effectiveness of arrangements for protecting equity of access to aged care services for different population groups ........................................................................................................... 7
   2.7 The effectiveness of workforce strategies in aged care services, including strategies for the education, recruitment, retention and funding of aged care workers .............................. 7
   2.8 The effectiveness of arrangements for protecting refundable deposits and accommodation bonds ........................................................................................................................................... 8
   2.9 The effectiveness of arrangements for facilitating access to aged care services ........ 8

3. Other comments ....................................................................................................................................................... 9
1. Tell us about you

1.1 What is your full name?

1.2 What stakeholder category do you most identify with?
Peak body - consumer

1.3 Are you providing a submission as an individual or on behalf of an organisation?
Organisation

1.4 Do you identify with any special needs groups?
Nil

1.5 What is your organisation’s name?
National Association of People Living with HIV Australia

1.6 Which category does your organisation most identify with?
Consumer Peak Body

1.7 Do we have your permission to publish parts of your response that are not personally identifiable?
Yes, publish all parts of my response if desired

Founded in 1989, The National Association of People with HIV Australia (NAPWHA) is Australia’s peak non-government organisation representing community-based groups of people living with HIV (PLHIV). NAPWHA’s membership of national networks and state-based organisations reflects the diverse make-up of the HIV-positive community and enables NAPWHA to confidently represent the positive voice in Australia. NAPWHA’s vision is of a world where people with HIV live their lives to their full potential, in good health and free from discrimination. NAPWHA’s mission is to provide national advocacy, leadership and representation across the diverse needs of all people living with HIV in Australia.
2. Response to Criteria in the Legislation

2.1 Whether unmet demand for residential and home care places has been reduced

<table>
<thead>
<tr>
<th>Refers to Section 4(2)(a) in the Act</th>
</tr>
</thead>
<tbody>
<tr>
<td>In this context, unmet demand means:</td>
</tr>
<tr>
<td>• a person who needs aged care services is unable to access the service they are eligible for</td>
</tr>
<tr>
<td>e.g. a person with an Aged Care Assessment Team / Service (ACAT or ACAS) approval for residential care is</td>
</tr>
<tr>
<td>unable to find an available place; or</td>
</tr>
<tr>
<td>• a person who needs home care services is able to access care, but not the level of care they need</td>
</tr>
<tr>
<td>e.g. the person is eligible for a level 4 package but can only access a level 2 package.</td>
</tr>
</tbody>
</table>

Response provided:

There are a number of different elements that NAPWHIA responds to under this heading and we will use a system of dot points as below in response to this question.

- The first problem encountered by anyone entering the system is that the use of the 1800 number and website has not been very helpful for individuals trying to enter into the system. Usually they need a person to negotiate on their behalf as the process of finding out options is often occurring in a crisis situation. Where major health crisis is being experienced a centralised web is not enough. In this context, because ageing people living with HIV can be socially isolated from the general community and dealing with a few to several comorbidities by the time they reach this stage they really need help. They turn to HIV Positive organisations that they know for support to negotiate the process. Organisations such as Living Positive Victoria and Queensland Positive People have noted that it is to these organisations that People Living with HIV (PLHIV) often turn to for support as a first step.

- Another major problem is that a persons living with HIV often experience an ‘accelerated aging process’, this is backed by international research (see Deeks, S.G., 2011. HIV Infection, Inflammation, Immunosenescence, and Ageing. Annual review of medicine, 62, p.141.). Along with emergent number of comorbidities many people who require ‘aged care’ services, don’t fit the criteria (in terms of age) as specified in the legislation. Caveats should be included within the legislation for those people suffering from a chronic condition such as HIV who are under 65 yrs old but are still ‘aged’.

- Greater flexibility is needed when accessing eligibility criteria and directs attention towards a special need for PLHIV and that the eligibility should more directly be assessed on medical conditions per se rather than just concentration on age 65. To spell this out more directly PLHIV who are 45 years and older may be experiencing ageing health related issues which are normally experienced by 65 – 75 year olds.

- Whether unmet demand has been reduced often depends on location. For example in the immediate vicinity of Perth there seems to be little difficulty accessing home care places and in instances where there has been any difficulty ACAT and local organisations have managed to find an interim arrangement, in other states this is not always the case and difficulties in terms of access have occurred.

- In Victoria, for example, most places are attached to regional and rural hospitals and the vast bulk are private operators in Melbourne - the experience is that there is access available but only if you can afford it. Clients have experienced a real “run around” in the assessment and placement process and geographic area and access is not uniform throughout the state.

- For example Queensland Positive People report that many PLHIV under 65 there have been many challenges in obtaining home care support. And the problematic staging process is outlined as:

  1) Apply to Disability Services for determination of eligibility for services (approx. 3-4-month wait is not uncommon).

  2) Disability Services determine a person is eligible; however, there are no packages of support available.

  3) Next step is to seek a package of support through an ACAT assessment (depending on need; further delays of 1+ month).
4) After ACAT assessment; referrals are then approved at levels determined by ACAT assessment of need.

5) Contact is then made with service providers to determine if they have packages available at the level of support required.

6) There may be several service providers that have to be contacted to find someone with packages available at the level of support required. For Under 65’s there may not be any packages available or not at the level of support required.

- A number of jurisdictions report challenges as above but also that for PLHIV over 65 - once a package is granted; most service providers do not provide all areas of care/support a person may need – so there are further steps involved in sourcing all of the services needed to deliver outcomes of support to the HIV positive client.

- Once a service provider is able to offer support – they then have to visit and assess for delivery of service and explain costs payable by the client (complicated charging calculations for people who are unwell and in need of support to ‘digest’ and agree to) with an outcome that clients sometimes find the process overwhelming in time/delay/process and withdraw; struggling on without support and living a life of surviving rather than living as well as possible (with some basic support).

- Additional challenges/barriers are people’s expectation of services being free or a very low cost as part of Government initiatives to assist people to stay in their homes and therefore reduce the need for Residential Care places versus the reality of costs starting from $9.85 per day (Level 1-2 package, costs increase for those who can afford) x days in the month regardless of the hours of support provided.)

- The increasing number of PLHIV living with HIV and experiencing Multi-morbidity issues has been identified in a recent report published by Positive Life NSW (see especially P. 12 of this report, available at http://www.positivelife.org.au/images/PDF/2016/PLHIV-Access-to-healthcare-NSW-Report-2015.pdf), this provides further evidence that responding to unmet demand means also responding to a range of complicated issues faced by PLHIV. This in turns supports an argument that this population i.e. PLHIV, need special consideration within the overall structure of aged care service provision and should be included in the ‘different population’ groups in terms of the Aged Care Legislative Review.

- Further challenges for people who identify as LGBTI are fears about judgement from home care workers connected to services auspiced by some religious organisations. Additionally people living heterosexually with HIV have fears about stereotyping and stigma that they may also experience in aged care settings.

2.2 Whether the number and mix of places for residential care and home care should continue to be controlled

Refer to Section 4(2)(b) in the Act

In this context:

- the number and mix of packages and places refers to the number and location of residential aged care places and the number and level of home care packages allocated by Government; and
- controlled means the process by which the government sets the number of residential care places or home care packages available.

Response provided:

Some places get more funding because of high level needs. There needs to be systematic mapping and longitudinal studies and evidence based research commissioned and analysed to predict future trends. Fortunately in Australia there is evidence available that there is expected to be an increasing number of PLHIV who will require aged care support services (see Jansson, J., Wilson, D. and Watson, J., 2010. Mapping HIV outcomes: Geographical and clinical forecasts of numbers of people living with HIV in Australia). The trends indicate that there will be more PLHIV requiring aged care services. For example in Victoria alone it is estimated the PLHIV over the age of 55 has increased from 3% in 1985 to 25% in 2010 and in this case government does have a role in predicting future needs because the information is available. Government must play some role in control over number of places and
home care packages so that it doesn’t become skewed to only private interests and that vulnerable groups do not miss out – PLHIV are one of those special needs and vulnerable groups. Because government is in the position to collate data they can assist in predicting future demands. However NAPWHA points out that government allocations must be based on evidence and again in this case there is evidence pointing toward a special position for PLHIV in respect to accessing residential and home care packages and places and that this should by based on well understood and anticipated need. Access should be determined by need, backed by research and prediction for the future. The assessment criteria requires a review, to include people under 65 years suffering from chronic health conditions, including HIV. Many people living with HIV in the next 15 to 20 years will be in their 50’s and 60’s and many will lose the ability to adequately care for themselves and their partners. Services could have the capacity to decide how many packages they can offer at the levels needed based on client need. For example, as argued by Queensland Positive People, government might allocate 10,000 level 4 packages while current assessment is showing 15,000 level 4 packages are and this is leaving people vulnerable due to lack of full service availability to them. This is also a problem when you have under 65’s being referred for ACAT assessments as they have been deemed suitable and been awarded a Disability Package however there are no funds for these packages. This is resulting in more ACAT packages being taken up by the under 65’s leaving a deficit for the elderly. **Forecasting and prediction needs to be built into the system in a more direct way than it currently is. In the context of what is needed by PLHIV this needs to include the increasing numbers of comorbid conditions which aging PLHIV are experiencing and this increasing level of comorbidities implies that greater flexibility is required so that access is available as required.**

### 2.3 Whether further steps could be taken to change key aged care services from a supply driven model to a consumer demand driven model

**Refers to Section 4(2)(c) in the Act**

In this context:

- a supply driven model refers to the current system where the government controls the number, funding level and location of residential aged care places and the number and level of home care packages;
- a consumer demand driven model refers to a model where once a consumer is assessed as needing care, they will receive appropriate funding, and can choose services from a provider of their choice and also choose how, where and what services will be delivered.

**Response provided:**

NAPWHA suggests that this either/or proposition is itself problematic. Both aspects - a combination approach is necessary. There needs to be supply driven by government for people who aren’t engaged in the processes or don’t have the advocacy access. Supply driven by government at least guarantees that those without financial resources will have places available. Aged care is a matter for government direction and interventions and cannot be abrogated to private providers to work out all the details. Consumer driven interests should also be the priority in delivery – consumers (clients) deciding the support they require rather than services dictating what they can provide. E.g. if a person decides their priority is to have their gutters cleaned out and therefore improve their tank water supply; this outcome should be provided rather than a service stating the consumer (client) can only be assisted with domestic or laundry assistance. Another example might be a client wants dishes washed and cupboards cleaned out but can only be provided with benches wiped down and floors cleaned (floors cleaned without moving any furniture/items). NAPWHA would frame it this way:

1. There should be a sufficient number of places guaranteed for all those who require it
2. There is a lack of clarity, currently in terms of how those numbers are decided and especially access for special needs groups like PLHIV
3. There needs to be some guarantee that consumers will get their needs met according to their needs – especially at the level of service provision
4) Aging PLHIV do need special attention due to the complexities of living long term with HIV and possibly with a number of comorbid conditions emerging well before the age of 65.

Government has a role to play in ensuring (1) - (4) above and with advice gathered from consumers through agencies like the state-based PLHIV organisations and through the peak national organisation, NAPWHA.

2.4 The effectiveness of means testing arrangements for aged care services, including an assessment of the alignment of charges across residential care and home care services

<table>
<thead>
<tr>
<th>Refers to Section 4(2)(d) in the Act</th>
</tr>
</thead>
<tbody>
<tr>
<td>In this context:</td>
</tr>
<tr>
<td>• means testing arrangements means the assessment process where:</td>
</tr>
<tr>
<td>o the capacity of a person to contribute to their care or accommodation is assessed (their assessable income and assets are determined); and</td>
</tr>
<tr>
<td>o the contribution that they should make to their care or accommodation is decided (their means or income tested care fee, and any accommodation payment or contribution is determined).</td>
</tr>
</tbody>
</table>

Response provided:

In the experience of NAPWHA member organisations and their constituents the difference between government provided or home based care is not clear, and the arrangement by which a person gets to that decision are complicated and often done in a crisis situation – the latter is not at all helpful. Those who are income tested care are shocked to find that they have to make contribution. NAPWHA also notes that is is important to protect the rights of the partner who may not need to access residential care and those individuals who don’t have assets and or private pensions. Means testing is valuable however people are living without quality of life. For people who have worked hard, saved and are not entitled to Aged Care pension – there can be challenges in outlaying their hard earned savings for home care assistance as they fear not having adequate money for paying essential living expenses. An outcome is clients (PLHIV) struggle on without assistance or needed repairs.

Client example: Means testing needs to take into account the costings for a client’s medications etc...the example given is of a client receiving income protection of over $6,000 per month, however the costs of his enormous list of medications takes a large amount out of his monthly income. He cannot get a health care card because of his income. He is struggling to get an ACAT assessment completed (under 65) and is paying for a private provider to shower him once a week and for one-hour social time. He has had to purchase a wheelchair (electric/motorised as he has no use of his left side), have his floors covered with suitable coverings, have his pavement fixed outside, he is isolated to the lower level of his house with no intercom that he is saving for now. He has purchased a 2nd hand car that carries a wheelchair so his elderly parents can get him around. He is paying his mortgage now that the income protection has come through but has to continue to get specialists to complete the paperwork for this to continue. So yes means testing works to a degree but not enough is considered.

2.5 The effectiveness of arrangements for regulating prices for aged care accommodation

<table>
<thead>
<tr>
<th>Refers to Section 4(2)(e) in the Act</th>
</tr>
</thead>
<tbody>
<tr>
<td>In this context:</td>
</tr>
<tr>
<td>• regulating prices for aged care accommodation means the legislation that controls how a residential aged care provider advertises their accommodation prices.</td>
</tr>
</tbody>
</table>

Response provided:

Regulating prices is imperative. A market led response will mean that many aged care providers are finding that they cannot compete in the market and many individuals will find they do not have access to aged care arrangements. It is essential that price regulation is controlled through legislation to prevent exploitation. Provision should be made for those who are economically disadvantaged, and equity of access should be guaranteed in the legislation, with government subsidising when necessary.
2.6 The effectiveness of arrangements for protecting equity of access to aged care services for different population groups

Refer to Section 4(2)(f) in the Act

In this context equity of access means that regardless of cultural or linguistic background, sexuality, life circumstance or location, consumers can access the care and support they need.

In this context different population groups could include:

- people from Aboriginal and/or Torres Strait Islander communities;
- people from culturally and linguistically diverse (CALD) backgrounds;
- people who live in rural or remote areas;
- people who are financially or socially disadvantaged;
- people who are veterans of the Australian Defence Force or an allied defence force including the spouse, widow or widower of a veteran;
- people who are homeless, or at risk of becoming homeless;
- people who are care leavers (which includes Forgotten Australians, Former Child Migrants and Stolen Generations);
- parents separated from their children by forced adoption or removal; and/or
- people from lesbian, gay, bisexual, trans/transgender and intersex (LGBTI) communities.

Response provided:

There are sometimes specific aged care facilities that do provide for cultural groups and “Inclusive Practice” is a framework that NAPWHA supports. Provision of places should be based on needs. Which means especially the ACAT teams have to be part of an “Inclusive Practice” – and thereby ensuring equity across a broad diversity of needs. HIV has to be understood as a chronic manageable illness and de-stigmatised. NAPWHA argues that the different population groups should include people living with HIV. This population group is vulnerable and subject to stigma and discrimination and it is appropriate that aged care services receive training in working with this population group to ensure equity of access to services and that PLHIV not discriminated against due to lack of educational training of staff. Studies demonstrate that aged care facilities will be caring for HIV positive patients if appropriate supports are in place. It is critical that preparation and provision be made for this population of PLHIV as a matter of urgency because they are a new group now entering the aged care system with particular experience e.g. early aging and as research has shown - more than likely with a range of co-morbid health conditions then experienced by the general population.

2.7 The effectiveness of workforce strategies in aged care services, including strategies for the education, recruitment, retention and funding of aged care workers

Refer to Section 4(2)(g) in the Act

In this context aged care workers could include:

- paid direct-care workers including nurses personal care or community care workers, and allied health professionals such as physiotherapists and occupational therapists; and
- paid non-direct care workers including: managers who work in administration or ancillary workers who provide catering, cleaning, laundry, maintenance and gardening.

Response provided:

Workforce development is essential. The Australasian Society of HIV is considering developing a national curriculum around HIV which might be adopted and fit for purpose in the context of workforce strategies in aged care services – so far this is in a pilot phase but follow up in the context of this review might be important to do. Training within aged care facilities who have never really engaged in HIV training is essential and there should be some form of HIV core competencies in any pre-service training. Training of the aged care work force is essential to ensure residents receive the best care. Screening staff at recruitment is critical to protect and safe guard the
resident’s against harm and discrimination. Training in HIV 101 should be mandatory for all aged care and in-home care support. One problem identified is that structurally the aged care sector lowly paid and often casual and general knowledge about HIV is extremely low and we know that religious or faith based beliefs have impacted on some worker behaviour in some aged care facilities. There is a National LGBTI Ageing and Aged Care Strategy signed off in 2012 some goals of that strategy are relevant but it is not completely relevant because not all people living with HIV are from LGBTI community. There is an increasing growing number of people living heterosexually with HIV in Australia and their needs also need to be accommodated. In reference to this issue a Mapping Study on Services for People Ageing with HIV in Victoria was carried out in 2013 by the Department of Infectious Diseases, Alfred Hospital and Monash University (authors Jeff Roberts, Karalyn McDonald and Julian Elliott). NAPWHA suggests that this study should be replicated on a national basis to provide evidence for future work in this area. NAPWHA looks forward to engaging further with the Department of Health and Ageing about developing a national mapping exercise similar to that carried out in Victoria.

### 2.8 The effectiveness of arrangements for protecting refundable deposits and accommodation bonds

<table>
<thead>
<tr>
<th>Refer to Section 4(2)(h) in the Act</th>
</tr>
</thead>
<tbody>
<tr>
<td>In this context:</td>
</tr>
<tr>
<td>• arrangements for protecting refundable deposits and accommodation bonds means the operation of the Aged Care Accommodation Bond Guarantee Scheme.</td>
</tr>
</tbody>
</table>

Response provided:

Nil

### 2.9 The effectiveness of arrangements for facilitating access to aged care services

<table>
<thead>
<tr>
<th>Refer to Section 4(2)(i) in the Act</th>
</tr>
</thead>
<tbody>
<tr>
<td>In this context access to aged care services means:</td>
</tr>
<tr>
<td>• how aged care information is accessed; and</td>
</tr>
<tr>
<td>• how consumers access aged care services through the aged care assessment process.</td>
</tr>
</tbody>
</table>

Response provided:

A survey has shown that only about 30% were satisfied with the My Aged Care website, the site is not user friendly. The 1800 was more popular but information was not always consistent. Health literacy needs to be developed but this cannot be done by the work of volunteer organisations alone or without investment by government in assisting the process. The Senior Voices Project in Victoria (see http://www.livingpositivevictoria.org.au/speakers/senior-voices-project) is exemplary in the way that it has developed a profile within its jurisdiction about the needs of people ageing with HIV. Some excellent work has been carried out in NSW on a project with the Uniting Church and their facilities. NAPWHA suggests that model projects like this could value add to developing health literacy nationally but this requires dedicated effort and government support if it is to happen nationally and across all jurisdictions. Government needs to raise community awareness, to ensure better understanding of consumer rights and how the process for accessing services works.
3. Other comments

Response provided:

The NAPWHA submission represents input from organisations all around Australia. Contributions to this document have been made by NAPWHA member organisations including Queensland Positive People, Positive Life New South Wales and Positive Living Victoria. Other input in preparing this document has been received from the Western Australian Aids Council and the South Australia Mobilisation and Empowerment for Sexual Health. NAPWHA looks forward to ongoing dialogue with government about this issues raised in this submission.