

Submission to the National Disability Insurance Scheme (NDIS) Costs study  
Productivity Commission  
GPO Box 1428  
BARTON ACT 2600

**13<sup>th</sup> February 2017**

Dear Commissioners,

As a person living with HIV for over 16 years with 2 permanent health conditions, I wish to draw the following to the consideration of the Productivity Commission in regards to people living with HIV (PLHIV).

### **The NDIS and people living with HIV (PLHIV)**

PLHIV experience the impact of early onset of a range of co-morbidities years if not decades before 65 years of age. Examples of comorbid and permanent health conditions include cognitive impairments (ranging from mild to severe e.g. HIV-associated neurological disorder HAND), peripheral neuropathy, arthritis, osteoporosis and other degenerative bone diseases, and mental illness including significant episodic impairments.

**The ongoing need for reasonable and necessary support during our working life needs to be considered by the Commission to ensure PLHIV continue our economic participation in Australian society.**

PLHIV access a range of mainstream and community services and supports to maintain our independent and economic participation in society through a range of mainstream and specialised public and private healthcare services. Therefore it is **critical that the NDIS ensures the complexity of PLHIV need is maintained and integrated into the scheme**, especially in the current economic environment. A revised or reduced eligibility criterion, particularly for those PLHIV who live outside the inner Sydney area, and need to travel where most specialist services are located will have negative consequences on both PLHIV and the health care system.

**The Commission ought to ensure that PLHIV retain eligibility for the scheme based on functional impairment without obstacle and avoid the assumption that all the support needs of PLHIV should be met by the health system or the person's carer.**

The scheme's design, rules and application, and access needs to:

- ensure that **NDIS workforce training** addresses culturally appropriate care, sensitivity and understanding, non-discrimination and strong protections for client confidentiality in recognition of the diversity of Australia's population, and the scheme's assessors must be supported to create a culturally appropriate environment to be able to accurately assess PLHIV needs and provide them with supports that are best tailored to their individual need. Assessors must also be supported by the scheme to take into account the social and structural barriers that PLHIV experience, especially those related to stigma. PLHIV, especially those from sexually and gender diverse (GLBT) communities have experienced significant and pervasive discrimination historically, in society and from service providers and without dedicated policies and training,

the assessment process can result in PLHIV missing out on the supports they need, and/or discrimination within the NDIS system. Many supports associated with religious or church-based service providers alienate and stigmatise PLHIV around issues associated with HIV status, sexuality, ethnicity, gender identity, injecting drug use, culturally and linguistically diverse backgrounds including Aboriginal and Torres Strait Islander Peoples and the Productivity Commission must **ensure the scheme's assessment process and workforce** remains culturally appropriate and comprehensive, especially for this marginalised population;

- must ensure support for PLHIV **basic needs** is recognised. For example this can mean retaining secure accommodation which requires budgeting, planning, and income self-management and this is a significant need for them to remain independent and active in their community;
- retain a strong focus on **remaining complementary to the mainstream healthcare system** when providing supports to PLHIV who also access clinical care and make extra provision to ensure that PLHIV do not fall between the cracks between the NDIS, health, mental health, aged and palliative care sectors. The Commission needs to ensure that PLHIV have integrated access to NDIS supports especially when their medical clinical needs are addressed through the mainstream health system;
- consider including a provision for **independent advocacy support** for PLHIV, especially those with cognitive impairment to ensure they are supported in understanding and navigating the complex process of accessing the NDIS;
- provide for increased protections regarding **privacy issues** that affect PLHIV especially where their HIV status affects their assessment processes, records management and referrals to supports and services;

I understand that this submission could be placed on the Privacy Commission's website and that all personal details (e.g. home and email address, signatures, phone, mobile and fax numbers) will be removed from my submission before they are published on the Privacy Commission's website. Thank you for the opportunity to provide a submission.

Sincerely,

Richard Kennedy