

29 April 2011

Disability Care and Support Inquiry
Productivity Commission
GPO Box 1428
Canberra City ACT 2601

(Via email to disability-support@pc.gov.au)

Dear Commissioner Scott

Please find attached a joint submission from ACON and Positive Life NSW on the *Disability Care and Support – Draft Report*.

The important issue of disability care and support has significant impacts on the lives of many people with HIV, and their ability to participate in social, economic and community life.

Our submission focuses on the intersection of HIV and disability, and explores the complementary relationship between disability and health services.

ACON and Positive Life NSW also endorse the submission from the Australian Federation of AIDS Organisations to this inquiry.

If you or the Productivity Commission would like to further discuss issues raised in this submission, please feel free to contact Rob Lake, Chief Executive Officer, Positive Life NSW on 02 9361 6011 or Alan Brotherton, Director, Policy, Strategy & Research, ACON on 02 9206 2048.

Kind Regards



Rob Lake
Executive Officer



Nicolas Parkhill
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PositiveLifeNSW
the voice of people with HIV since 1988



Submission to:

The Productivity Commission on
*Disability Care and Support: Draft
Inquiry Report*

April 2011

About ACON

ACON (formerly, the AIDS Council of NSW) was formed in 1985 as part of the community response to the impact of the HIV/AIDS epidemic in Australia. Today, ACON is Australia's largest community-based gay, lesbian, bisexual and transgender (GLBT) health and HIV/AIDS organisation. ACON works to improve the health and wellbeing of the GLBT community and people with HIV, and reduce HIV transmission.

ACON is home to the Community Support Network (CSN), the Positive Living Centre (PLC), the Luncheon Club, the Lesbian and Gay Anti-Violence Project (AVP) and the Sex Workers Outreach Project (SWOP). ACON has its head office in Sydney as well as branches in the Illawarra, Northern Rivers, the Hunter region and the Mid North Coast.

About Positive Life NSW

Positive Life NSW is a community based NGO that has represented the interests of people living with HIV in New South Wales since 1988. Positive Life NSW provide advocacy, peer support, HIV prevention and health education campaigns and resources that focus on the experiences of people with and affected by HIV. Positive Life NSW works to promote a positive image of people affected by HIV with the aim of eliminating prejudice, isolation, stigmatisation and discrimination.

General Comments

ACON and Positive Life NSW welcome this very important draft report from the Productivity Commission on Disability Care and Support (*Draft Report*).

People with HIV who experience physical, mental or social impairments to participate fully in community and economic life will significantly benefit from the proposals outlined in the *Draft Report* to double funding, expand of services and increase choice for people with disability.

ACON and Positive Life NSW supports the development of a National Disability Insurance Scheme (NDIS) that will provide community supports and services to people with disability across Australia. We also support an objective assessment of individual clients based on need, including the assessments of impairments or barriers that the individual client experiences.

For some people with HIV, the level of supports or services required will be minimal, whilst for others, a range of disabilities, functional impairments and social barriers as a result of HIV will require significant supports. ACON and Positive Life NSW applauds the Productivity Commission for proposing an NDIS that takes a client centred approach, with the flexibility to recognise the diversity of experiences for people with disability, even the same disability.

The focus of this submission is to provide further information to the Productivity Commission on the intersection of HIV and disability, and on the inclusion of people with HIV who have a disability.

Social Model of disability

The National Disability Insurance Scheme (NDIS) aims among other things to “cost-effectively minimise the impacts of disability, maximise the social and economic participation of people with a disability, and create community awareness of issues that affect people with disabilities.”¹

In achieving this aim, ACON and Positive Life NSW support the call from People with Disability Australia, Australian Federation of Disability Organisations and others to develop and implement the NDIS using the framework of the social model of disability. Through viewing disability from a social model, barriers, including structural social barriers, can be identified and addressed to minimise negative impacts on people with disability and enable them to live and participate more fully in the community and the economy.

The social model of disability also underpins the United Nations *Convention on the Rights of Persons with Disabilities* (CRPD), which Australia played a leadership role in developing. Australia has also signed and ratified the CRPD, committing to promote and realise the human rights of people with disability, a key component of which is the removal of barriers to participating fully in social, economic and political spheres of life.

The NDIS, in providing care and support services to people with disability and information and education to the broader population will be instrumental in lowering the discrimination and barriers to participation that people with disability currently experience. The NDIS aims to improve the ability of people with disability to participate fully in all aspects of Australian life, and to fulfil Australia’s obligations under the CRPD. To achieve this, the NDIS should adopt the social model of disability, and thus aim to address not only physical barriers, but also social and structural barriers, such as discrimination and stigma against people with disability. For people with HIV, the barriers with the most significant impacts often stem from stigma and discrimination.

Recommendation

1. That the National Disability Insurance Scheme is grounded in a social model of disability and addresses physical, structural and social barriers to people with disability living and participating fully in the community.

¹ Recommendation 3.1

Disability and HIV

HIV in Australia, with the wide availability of highly active anti-retroviral therapies, is no longer a terminal illness. Most people with HIV live healthy, productive and independent lives. However, it is also the case that over the long-term, many people with HIV will experience co-morbidities and episodic disability² as a result of long term HIV infection and anti-retroviral therapy.

Many co-morbidities that are experienced by people with HIV are also experienced by people without HIV as a result of ageing. However, for people with HIV, the early onset and impact of a range of co-morbidities are experienced many years if not decades before the age of 65, and the combination of factors will necessitate the need for disability supports during their working life.

Common disabling HIV related conditions include:³

- arthritis
- osteoporosis and other degenerative bone diseases
- cognitive impairments (ranging from mild to severe e.g. HIV-related dementia)
- mental illness

These above mentioned co-morbidities require different interventions from the healthcare system and the NDIS. The NDIS has a role when a person with HIV acquires a disability that limits their ability to live and participate independently in the community. An illustration of this can be seen in Case Studies A, B, and C, attached to this submission.

In addition to physical barriers that are experienced by some people with HIV, many also experience social barriers, such as stigma, discrimination and vilification. This reality was recognised in the *Disability Discrimination Act 1992* (Cth), defining "**disability**" in relation to a person as:

- (a) "total or partial loss of the person's bodily or mental [functions](#); or
- (b) total or partial loss of a part of the body; or
- (c) **the presence in the body of organisms causing disease or illness**; or
- (d) **the presence in the body of organisms capable of causing disease or illness**;
or
- (e) the malfunction, malformation or disfigurement of a part of the person's body; or
- (f) a disorder or malfunction that results in the person learning differently from a person without the disorder or malfunction; or

² O'Brien, K.K., Bayoumi, A.M., Strike C., *et. al.* Exploring disability from the perspective of adults living with HIV/AIDS: Development of a conceptual framework. *Health and Quality of Life Outcomes* 2008, vol 6(1), pp. 76-90.

³ Petoumenos, K., Law, M.G. (2006). Risk factors and causes of death in the Australian HIV Observational Database. *Sexual Health* 2006, vol 3(2), pp. 103-112.

- (g) a disorder, illness or disease that affects a person's thought processes, perception of reality, emotions or judgment or that results in disturbed behaviour;⁴

Since the *Disability Discrimination Act* coming into force, HIV has unambiguously been considered a disability. However, like other people with disability, there are diverse experiences and care needs. For the group of people with HIV that require support due to functional impairments relating to HIV, they should be included in the NDIS, and their care needs appropriately assessed and delivered.

Recommendation

2. That the eligibility criteria for NDIS be developed and implemented according to functional need, rather than disability type. Whether a disability is congenital or is acquired through illness or chronic illness, eligibility and assessment should be based on need.

Current context in NSW

The inclusion of people with HIV is particularly important as the experience in NSW has been that many people with HIV have had difficulty being considered eligible to access support services (such as Home and Community Care (HACC) services), even in cases where functional need has been established. Conversely, where HACC and similar services have recognised and met these needs, there have been examples of very positive outcomes in terms of support services and living independently.

The failure of many disability services to see past HIV as merely a medical condition resulted in the need for parallel services, many established in the early 1990's. These parallel services provide many community care services and supports that other disability services offer but at the time, access for people with HIV was limited, often on the basis of fears about HIV and a belief that all the support needs of people with HIV should be met by the health system.

ACON and Positive Life NSW support the inclusion of people with HIV who require supports in the NDIS to avoid unnecessary duplication and the creation of parallel frameworks to address similar needs.

The client centred and flexible approach to community services provided by some HACC services have benefited people with HIV, especially those living outside of inner Sydney, where most specialist services are located. The tailoring, packaging and brokering of care based on the needs and preferences of individuals have allowed many people to access services that are most appropriate to them and, when appropriate, to their partner or carer.

⁴ *Disability Discrimination Act 1992* (Cth), s4(1),
http://www.austlii.edu.au/au/legis/cth/consol_act/dda1992264/s4.html

For many people living outside of inner Sydney, this has meant that rather than needing to travel to inner Sydney to access specialised services, they are able to access other services available in their area. ACON and Positive Life NSW therefore endorse the client centred approach of support services outlined in the *Draft Report*.

Apart from the importance of services provided in the home or in the community, the NSW Government have also recognised the importance of providing supported accommodation for people with especially complex care needs, for example The Bridge, Sydney, a residential facility for people with AIDS related dementia. Supported accommodation, separate from hospitals or aged care facilities are important as some people with disabilities will require high levels of care and supervision, but would not be appropriately housed in hospitals or aged care residential facilities.

The *Draft Report* noted the different philosophy and approach of disability services and aged care. This important distinction is shared by ACON and Positive Life NSW and we call for the funding of appropriate models of supported accommodation facilities to meet the needs of people with complex or high care needs operating within the philosophy of the NDIS.

Recommendation

3. That the NDIS fund a range of service models based on the need of people with disability, including community and appropriate supported accommodation.

Eligibility criteria

ACON and Positive Life NSW support the broad approach outlined in the *Draft Report* where eligibility to different NDIS services are based on three tiers. In this section, the submission will focus on tier three, where the NDIS will provide funding for supports and services. ACON and Positive Life NSW also support a focus on functional impairments as a basis for eligibility.

As discussed in the earlier section **Disability and HIV**, working age people with HIV may experience disability episodically due to the impacts of HIV⁵ while some may experience permanent and severe functional impairments. In such circumstances, people who do experience disability will benefit from the support services developed, funded and implemented through the NDIS. ACON and Positive Life NSW anticipate that people with HIV could fall into any of the four categories under tier three.

As mentioned above, and demonstrated in Case Studies A and B, people with HIV may develop co-morbidities that meets the definitions under 3a (have significant

⁵ O'Brien, K.K., Bayoumi, A.M., Strike C., *et. al.* Exploring disability from the perspective of adults living with HIV/AIDS: Development of a conceptual framework. *Health and Quality of Life Outcomes* 2008, vol 6(1), pp. 76-90.

limitations in communication, mobility or self care) and 3b (have an intellectual disability). In such circumstances, people with HIV would be eligible for funded supports under the NDIS.

HIV for many people (particularly older people and those with long-term HIV infection) is a degenerative disease and will increasingly impact on functionality, as demonstrated in Case Study C. In these circumstances, it is important that people with HIV are included under 3c to minimise future negative impacts and enable access to early intervention or rehabilitation measures that support independence and social participation.

Assessment

ACON and Positive Life NSW support the implementation of an objective assessment based on the *International Classification on Functioning, Disability and Health* (ICF). This framework developed by the World Health Organisation is grounded in the social model of health and encompasses impairments, activity limitations and participation restrictions. It serves as an important mechanism to provide appropriate and proportionate services to individuals based on their needs.

In order to implement a fair and objective assessment based on the ICF, staff involved in the assessment process will require training not only on the assessment criteria, but also an understanding of how disability interacts with other aspects of the person's life and be sensitive to social and structural barriers that the people experience as barriers.

In recognition of the diversity of Australia's population, assessors will also need to create a culturally appropriate environment to be able to accurately assess the client's needs and provide the client with services that are best tailored to their individual need. This would include sensitivity and understanding of the gay, lesbian, bisexual and transgender (GLBT) community, non-discrimination and strong protections for client confidentiality.

People with HIV (of which around 80% come from the GLBT community⁶), and GLBT people have experienced significant and pervasive discrimination historically, in society and from service providers. There still exists a level of stigma and discrimination against people with HIV and the GLBT community. Without appropriate policies and training, the assessment process may result in people with HIV or GLBT people not receiving the care and support that they need, and/or discrimination within the NDIS system.

Recommendation

4. That the NDIS ensures the assessment process is appropriate and comprehensive, especially for the care and cultural needs of marginalised

⁶ National Centre in HIV Epidemiology and Clinical Research, *HIV, viral hepatitis and sexually transmissible infections in Australia: Annual Surveillance Report*, (2010), p. 35.

populations such as people with HIV and the gay, lesbian, bisexual and transgender community.

Interactions with the Healthcare System

All people with disabilities will access both the NDIS and the healthcare system, for different services. The NDIS should be complementary to the healthcare system, with the NDIS mainly providing community care and support packages, while the healthcare system focusing on clinical services.

Under current arrangements, the health system funds and provides the clinical care needs of people with HIV, through primary care, and, when necessary, secondary, tertiary or palliative care. Community support services, such as the Home and Community Care (HACC) programs do, and have the potential to, provide services to enable people with HIV to live independently in the community.

We welcome *Draft Recommendation 3.4* to ensure that individuals do not fall between the cracks between the NDIS, health, mental health, aged and palliative care sectors. In our view, regardless of the cause of the disability or additional care that is required from other sectors, the NDIS would be the best system to cater for the community support needs of people with disability.

ACON and Positive Life NSW recommends that the *Draft Report* amend *Draft Recommendation 3.3* so that “people” are not excluded from the NDIS if some aspects of their support needs are more appropriately met by the healthcare system. Language can be amended to recognise that people will access clinical care through the health system and support through the NDIS, and that both systems should be complementary, rather than mutually exclusive.

Recommendation

5. That the Productivity Commission amends *Draft Recommendation 3.3* so that it will not exclude people with HIV from receiving community supports from the NDIS while their clinical needs are addressed through the health system.

Interactions with the Mental Health system

ACON and Positive Life NSW support the broad approach taken in the *Draft Report* where service provision between the NDIS and the mental health system should be based on need.

Similar to the interactions with the health system, people with mental illness that require non-clinical supports in the community should be included under the NDIS.

Aged Care

ACON and Positive Life NSW supports the first (and preferred proposal by the Productivity Commission) where people have the option of entering into the aged care system, carrying their funding entitlements into the aged care system, or remain in the NDIS.

Culturally Appropriate Care

The workforce that assess, refers or services clients under the NDIS will need to provide culturally appropriate care so that all Australians with disabilities can enjoy equal access to NDIS regardless of their HIV status, sexual orientation, gender identity, cultural background or Aboriginal and Torres Strait Islander status.

To achieve this, clear and well understood non-discrimination and confidentiality policies are needed. To ensure that policies are embodied in day to day practices by staff members, the diversity of Australians with disability needs to be recognised.

For people with HIV in particular, some are homosexual, some are heterosexual; some are male, some are female, a significant number are from culturally and linguistically diverse backgrounds and some are Aboriginal and/or Torres Strait Islander.

Training for staff that engages with clients will be necessary and should be incorporated into workforce planning.

Recommendation:

6. That the Productivity Commission includes the cultural needs of people with HIV and GLBT communities as part of ongoing workforce development.

List of Recommendations

1. That the National Disability Insurance Scheme is grounded in a social model of disability and addresses physical, structural and social barriers to people with disability living and participating fully in the community.
2. That the eligibility criteria for NDIS be developed and implemented according to functional need, rather than disability type. Whether a disability is congenital or is acquired through illness or chronic illness, eligibility and assessment should be based on need.
3. That the NDIS fund a range of service models based on the need of people with disability, including community and appropriate supported accommodation.
4. That the NDIS ensures the assessment process is appropriate and comprehensive, especially for the care and cultural needs of marginalised populations such as people with HIV and the gay, lesbian, bisexual and transgender community.
5. That the Productivity Commission amends Draft Recommendation 3.3 so that it will not exclude people with HIV from receiving community supports from the NDIS while their clinical needs are addressed through the health system.
6. That the Productivity Commission includes the cultural needs of people with HIV and GLBT communities as part of ongoing workforce development.

For further information regarding this submission, please contact Alan Brotherton, Director, Policy, Strategy and Research on 02 9206 2048 or via email at abrotherton@acon.org.au.

Case Study A

An adult with severe disability resulting from HIV associated dementia

Michael is a 53 year old single gay man. He was diagnosed with HIV associated dementia about 10 years ago and lives at a specialised residential facility. His dementia is severe.

Michael was diagnosed with HIV in the 1980s. HIV anti-retroviral therapy was introduced in 1996. Michael refused to take therapy and instead used complementary therapies. He has two sisters, one of whom has schizophrenia. His mother has dementia and lives in a nursing home. His family has been unable to provide practical care and support and he receives infrequent visits from one family member.

Michael's exhibits behaviour that is both sexually and socially inappropriate. He has no understanding of social or sexual boundaries. His short-term memory loss and high levels of anxiety require 24 hour supervision and support. Michael can also become physically aggressive to staff, residents and members of the public. Short-term memory loss and anxiety cause him to exhibit repetitive behaviors, for example he will repeatedly ask the time (50 - 100 times in 15 minutes). Michael's inappropriate behaviour and poor interpersonal skills cause other residents to respond badly to his behaviour and he has become socially isolated.

Unable to perform basic day to day self care, he requires assistance with toileting, teeth cleaning, washing, dressing, grooming and to eating. His compulsive behaviors necessitate dietary supervision to maintain basic nutrition. He has no concept of personal safety and requires constant supervision to prevent serious injuries from burning/scalding, falling or placing himself at risk (waking out onto the road etc). His dementia is unlikely to improve and may deteriorate over time.

Case Study B

A transgender female with disabilities resulting from HIV infection and multiple co-morbid conditions

Carol is a 53 year old transgender female who lives alone in Department of Housing flat in a Sydney suburb. She was diagnosed with HIV in 1994. Stigma and discrimination resulting from HIV and her transgender status have contributed to her social isolation. She has no contact with her family. Carol has been taking HIV antiretroviral therapy since 1996 and she is also receiving treatment for depression, hypertension and dislipidemia.

In 2010, she was hospitalized after a mild stroke and her memory and concentration and verbal skills have been impaired. She has hairline fractures in her feet which are from degenerative bone disease. This makes walking difficult. Carol was granted a Disability Support Pension in 2010.

After discussion with her doctor and social worker, Carol contacts the National Disability Insurance Agency for information about what support she can obtain through the Scheme. Carol is contacted by the NDIA and an appointment is made for a formal assessment. The assessor from the National Disability Insurance Agency visits Carol at home and determines a package of supports to help her meet her needs for personal care, domestic, transport and social needs. The assessor also arranges an appointment with a service that provides wheelchairs and mobility aids.

Carol chooses a community support organisation in her local area to assist her to manage her support package and to put her in contact with the service providers that can meet her needs. A case manager from the National Disability Insurance Agency remains in contact with Carol to monitor the delivery of the support package and to check in with Carol that she is receiving the support that she needs.

Case Study C

A person living with HIV currently without disability but would benefit from early intervention.

John is a single 48 year old man, who was diagnosed HIV positive 15 years ago. John has been living well without any significant health issues and lives independently in rented accommodation, drives his car and works full-time as an accountant.

John tends to rely on take away/restaurant meals due to his limited cooking skills and reduced energy tolerance. John's daily smoking has increased, which he considers to be a relaxation technique. John has been on anti-retroviral medication for his HIV for 12 years. His T-cell count is healthy and his viral load is undetectable. However as a side effect of his medication John has developed facial lipodystrophy⁷ which affects his self esteem and results in occasional bouts of reactive depression. John is developing early signs of osteopenia⁸ and has reduced liver function due to long term HIV infection.

John would benefit from assistance with smoking cessation, exercise, stress management, energy conservation strategies and dietary advice to reduce his risk of various cancers, cardiovascular disease, osteoporosis and early onset diabetes, which are all associated with 'premature ageing' as a result of HIV disease process. He also requires support to address his mental health issues.

John contacts the National Disability insurance Scheme for information on smoking cessation, counseling, physiotherapy, dietetics and occupational therapy.

⁷ Facial lipodystrophies are characterized by a progressive atrophy of the subcutaneous fat of the face. Downloaded 21/04/11. [http://www.eclips.consult.com/eclips/article/Plastic-and-Aesthetic-Surgery/S1535-1513\(09\)79272-0](http://www.eclips.consult.com/eclips/article/Plastic-and-Aesthetic-Surgery/S1535-1513(09)79272-0)

⁸ A condition of bone in which there is a generalised reduction in bone mass that is less severe than that in osteoporosis, caused by the resorption of bone at a rate that exceeds bone synthesis. Downloaded 21/04/11. <http://medical-dictionary.thefreedictionary.com/osteopenia>