

**NSW
HACC
Issues
Forum**

**Submission
on the**

**Draft *National Disability
Insurance Scheme Bill 2012***

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About the NSW HACC Issues Forum

The NSW HACC Issues Forum brings together a range of stakeholder representatives in the Home and Community Care (HACC) program across NSW, including regional HACC Development Officers, other statewide policy and development officers, statewide local government organisations, non-government provider peak bodies, and statewide consumer peaks. The HACC Issues Forum meets six times per year to consider program-wide policy, planning, access issues, and developments.

Consultation on the draft *National Disability Insurance Scheme Bill 2012* (the Bill) also occurred with the NSW Aboriginal Community Care Gathering Committee. The Gathering Committee is the state-wide peak body for Aboriginal and Torres Strait Islander community and non-government organisations involved in providing services and supports to NSW Aboriginal and Torres Strait Islander older people, people with disability, their carers and families. The Gathering has developed a set of policies to address and improve service delivery of community care and related services for Aboriginal and Torres Strait Islander people in NSW and meets four times per year.

The Council of Social Service of NSW (NCOSS) provides secretariat support to the NSW HACC Issues Forum and the NSW Aboriginal Community Care Gathering Committee (the Gathering).

Introduction

The NSW HACC Issues Forum (NSW HACC Issues Forum) is pleased to be able to provide feedback to the Committee on the draft *National Disability Insurance Scheme Bill 2012* (the Bill). NSW HACC Issues Forum supports a number of aspects of this draft Bill, and notes that they have considerable prospects for successfully supporting people living with disabilities to live well. NSW HACC Issues Forum particularly supports the person centred approach embedded in many aspects of the draft Bill, and the provision for considerable choice and control by people living with disabilities in support of a good life.

NSW HACC Issues Forum particularly supports:

- General Principles (section 4)
- General principles guiding actions of people who may do things or act on behalf of others (section 5)
- Provision of notice under the Act (section 7)
- Inclusion of a simplified outline in section 8
- Principles relating to plans (section 31)
- That funds can be provided to a person to directly manage services to meet their needs
- The participant can nominate a registered plan management provider to manage the plan alongside the participant

In considering the Bill, NSW HACC Issues Forum has had the opportunity to consider the views of the Disability Network Forum and its submission to this Inquiry. NSW HACC Issues Forum would generally support the recommendations made by the Disability Network Forum unless otherwise noted in this submission.

About this submission

The HACCC Program

The NSW HACCC Issues Forum is primarily concerned with the former Home and Community Care (HACCC) Program. The target population for the former HACCC Program included: frail older people over the age of 65 and younger people with disability. In July 2012 the HACCC Program was divided between the Commonwealth and State and Territory governments (excluding Victoria and Western Australia), according to the terms of the *National Health Reform Agreement 2011*. The Commonwealth component, for non-Aboriginal people over the age of 65, and Aboriginal people over the age of 50, is now known as the Commonwealth HACCC Program. In NSW, the remainder of the Program (funded by the NSW State Government for non-Aboriginal people with disability under the age of 65 and Aboriginal people with disability under 50), is now named the Community Care Supports Program (CCSP).

The Commonwealth HACCC Program and CCSP provide the following range of supports to people with disability and older people:

- allied health services (including dietetics, occupational therapy, physiotherapy, podiatry and speech pathology)
- assessment
- case management
- centre based day care
- care coordination
- counselling, support information and advocacy
- domestic assistance
- goods and equipment
- home maintenance
- home modification
- linen services
- meals and other food services
- nursing care
- personal care
- respite
- social support
- transport

Previous guidelines for the former HACCC Program defined the target population for the Program as:

persons living in the community who, in the absence of basic maintenance and support services provided or to be provided within the scope of the Program, are at risk of premature or inappropriate long term residential care, including:

- *older and frail persons aged over 65 years with moderate, severe or profound disabilities;*
- *younger persons with moderate, severe or profound disabilities.*¹

Nationwide, over 200,000 younger people with disability were using HACCC services, around 50,000 of whom reside in NSW.² Data supplied by the NSW Department of

¹ NSW Ageing, Disability and Home Care (2009) *NSW Guidelines for Home and Community Care (HACCC) funded services*, Sydney.

Family and Community Services, Division of Ageing, Disability and Home Care indicate the variety of circumstances that people under 65 using former HACC/CCSP services are in.

With the emphasis on providing basic maintenance and support, Commonwealth HACC/CCSP services historically worked with people with a variety of support needs, with varying levels of functional capacity – some people using HACC/CCSP services have very high support needs, for more than 35 hours per week, while others require less than 1 hour of service per week.

The NSW HACC Issues Forum is concerned with how this target group will relate to the NDIS, and whether high quality, person centred support will be available for this group of people once funding arrangements and eligibility criteria for access to the NDIS are established. However, the Gathering is concerned about Aboriginal people living with disability who may be unintentionally excluded from enjoying the full benefits of a “high quality person centred approach” due to the lack of access to the relevant services and supports. This submission will primarily focus on how the draft Bill is likely to affect people with disability who have lower support needs who, at present, are accessing support through the CCSP in NSW.

Summary of Recommendations

1. That any further consultation in relation to the NDIS be conducted in the months February-November and be in accordance with the National Compact with the not-for-profit sector.
2. That the Act make reference to the specific Articles of the Convention on the Rights of Persons with Disabilities that it aims to fulfil, and make specific reference to obligations under Article 28 of the Convention, which outlines the right of people with disability to an adequate standard of living.
3. That the Act allow specific funding for independent advocacy and independent information for people with disability, including legal advocacy, in relation to obligations or actions under the Act.
4. That the Home and Community Care Program and the NSW Community Care Supports Program are included in the list of prescribed programs in the rules, as noted in subsection 21(2)(b)(iii) of the draft Bill.
5. That section 22 (1) of the draft Bill be amended to read:

22 Age requirements

- (1) A person **meets the age requirements** if:
 - (a) the person was aged under the age of eligibility for the Age Pension when the access request in relation to the person was made; or
 - (b) the person is aged over the age of eligibility for the Age Pension, they meet all other access requirements, and the CEO is satisfied that the person's support needs are not met by other systems including aged care, health and/or palliative care.
 - (c) if the National Disability Insurance Scheme rules for the purposes of this paragraph prescribe that on a prescribed date or a date in a prescribed

² Australian Government Department of Health and Ageing (2011) *Home and Community Care Program Minimum Data Set 2009-10 Annual Bulletin*, Australian Government Department of Health and Ageing, Canberra, Table A3.

period the person must be a prescribed age—the person is that age on that date.

6. That Subsection 22 (1) states that Aboriginal and Torres Strait Islander people who were under the age of 65 when the access request was made meet the age requirements.
7. That subsection 23 (1) of the draft Bill be amended to read:
23 Residence requirements
 - (1) A person meets the residence requirements if the person:
 - (a) resides in Australia; and
 - (b) is one of the following:
 - (i) an Australian citizen;
 - (ii) the holder of a permanent visa;
 - (iii) a special category visa holder who is a protected SCV holder;
 - (iv) the holder of a temporary visa who has access to Medicare and meets the disability requirements or the early intervention requirements; or
 - (v) the holder of a temporary visa who meets the early intervention requirements; and
 - (c) satisfies the other requirements in relation to residence that are prescribed by the National Disability Insurance Scheme rules.
8. That subsection 24 (1) (a) be deleted from the Bill.
9. That the Australian Government and other State and Territory Governments take into account the benefits of basic and low level support for people with disability in any rules relating to section 24 (1) (c) of the NDIS Act.
10. That the NDIS rules specify that only upon commencing services through a program specified in the *Aged Care Act 1997* does a person cease to be a participant of the NDIS.
11. That the NDIS Act specifies that a participant's supports will continue, in terms of funding and management, as previously after the participant turns 65.
12. That the Australian Government consult extensively about provision of support to people living with a disability who do not meet access requirements to become a participant of NDIS.
13. That section 34 (e) be amended to read:
 - (e) the funding or provision of the support takes account of support that a participant accepts families, carers, informal networks and the community to provide, and what they are able to provide;
14. That subsection 33 (6) in the draft Bill be deleted.
15. That criteria in relation to a grace period for a temporary absence from a plan require the CEO to have regard to:
 - (a) the personal and/or family circumstances of the participant; and
 - (b) any correspondence relating to their absence from Australia that the participant sends to the CEO, including verbal correspondence.
16. That section 104 include a subsection preventing the CEO from requiring a person to take action to obtain compensation, if in so doing the person would experience suffering and/or hardship.

17. That subsections 105 (2) and (3) are deleted from the draft Bill, and/or that a subsection is added to section 105 stating:

If a participant or prospective participant does not take the required action, the CEO may decide to continue the preparations for a prospective participant's plan, or to continue a participant's plan that is already in progress.

General comments

National Disability Insurance Scheme Rules

NSW HACC Issues Forum is concerned about the numerous mentions of the National Disability Insurance Scheme rules which will qualify the operation of the Bill. At the time of making this submission the rules have not been detailed which makes it difficult to provide specific feedback on particular aspects of the proposals.

Lack of an independent complaint and appeal mechanism

The Bill has no provisions for a rigorous complaints and appeals mechanism. The NSW HACC Issues Forum understands that during the Launch sites period, existing complaints and appeals mechanisms will continue to operate within states and territories. However, this being National legislation, the Bill must provide comprehensive assurance to the participant and all parties of a quality complaints and appeals mechanism that covers the provision of quality supports, general supports by the Agency, complaints handling by the Agency and any other necessary matters. These must be dealt with by a third party, not by the Agency itself.

Limited list of reviewable decisions – all decisions should be reviewable.

The NSW HACC Issues Forum recommends that all decisions should be reviewable and that creating a list (section 99) will necessarily and possibly inadvertently overlook or omit an important reviewable decision now or in the future. Consequently, the NSW HACC Issues Forum recommends that all decisions should be reviewable and that the list is deleted.

Independent advocacy and independent information

NSW HACC Issues Forum supports the NSW Disability Network Forum recommendations in relation to advocacy & independent information functions. The Gathering also endorses these recommendations, expressing the need for culturally-appropriate Aboriginal advocacy and independent information. There are a number of functions in relation to the NDIS Bill with which advocates and providers of independent information could assist.

Consultation process

The NSW HACC Issues Forum is concerned that the consultation period for this draft Bill was set for the December-January summer holiday period, where many stakeholders would have limited capacity to comment. It would be preferable for all further consultation to be conducted in accordance with the Shared Principles in the National Compact with the not-for-profit sector, which state:

- We aspire to a relationship between the Government and the sector based on mutual respect and trust.

- We agree that authentic consultation, constructive advocacy and genuine collaboration between the sector and the Government will lead to better policies, programs and services for our communities.³

Recommendation 1.

That any further consultation in relation to the NDIS be conducted in the months February-November and be in accordance with the National Compact with the not-for-profit sector.

Chapter 1

Part 2 – Objects and Principles

The NSW HACC Issues Forum supports the Objects of the Act (Section 3), and the general principles guiding actions under the Act (Sections 4 and 5). These are consistent with providing person centred support for people with disability to live independently in the community, and achieve their aspirations and goals. These objects are clear and consistent with Australia's international human rights obligations.

With regard to subparagraph 3 (h), the NSW HACC Issues Forum recommends that the Act specify the obligations under the Convention on the Rights of Persons with Disabilities (the Convention) which the Act aims to fulfil, with reference to specific Articles of the Convention. The NSW HACC Issues Forum recommends making reference specifically to Article 28 of the Convention, which outlines the right of people with disability to an adequate standard of living.

Recommendation 2.

That the Act make reference to the specific Articles of the Convention on the Rights of Persons with Disabilities that it aims to fulfil, and make specific reference to obligations under Article 28 of the Convention, which outlines the right of people with disability to an adequate standard of living.

Support in meeting obligations under the Act

The NSW HACC Issues Forum strongly supports Section 6 in the draft Bill, enabling the Agency to support participants and prospective participants in order to meet obligations or doing things under the Act. Costs of obtaining supporting documentation, diagnosis, undertaking medical assessment or diagnostic testing can be significant. Costs can include transport, accommodation, and other expenses (such as those relating to ensuring the person's carer can support the person to undertake these tasks) can escalate. Supporting people with disability to meet these costs is likely to ensure better outcomes by enabling support to be in place earlier and reducing the escalation of a person's support needs.

However, the NSW HACC Issues Forum is concerned about the lack of reference to independent advocacy and independent information within the draft Bill. Supporting a person with disability to meet statutory obligations is a key task of independent advocacy and independent information provision. The further exclusion of funding

³ Australian Government (2012) *National Compact: working together*, Canberra.

legal assistance for people with disability to meet obligations under this Act is concerning. The obligations of individuals under the Act would not be immediately obvious to a lay person, and many people with disability do not have carers or other support persons who have the capacity to provide them with this type of support.

The NSW HACC Issues Forum supports the recommendations of the NSW Disability Network Forum in relation to provision of independent advocacy and independent information and recommends that the Bill extends this section to enable the development of Disability Support Organisations, to provide independent advocacy and independent information, language interpreting services and other such support services that should not incur expenses from an individual's funding budget.

Recommendation 3.

That the Act allow specific funding for independent advocacy and independent information for people with disability, including legal advocacy, in relation to obligations or actions under the Act.

Chapter 3 – Participants and their plans

Access requirements

Continuity of support

The NSW HACC Issues Forum is pleased to note that subsection 21(2) in the draft Bill appears to guarantee the continuity of support for people presently accessing support from one of a number of programs identified in the rules. This provision is likely to be significant for people with disability using CCSP-funded services who are not assessed as meeting the other access criteria for the NDIS.

The NSW HACC Issues Forum also notes that, under the *Intergovernmental Agreement for the National Disability Insurance Scheme (NDIS) Launch*, signed by the Council of Australian Governments (COAG) on 7th December 2012 that payments made under the National Partnership Agreement for Transitioning Responsibilities for Aged Care and Disability Services, and the Home and Community Care Agreement can be sourced for host jurisdictions' contribution to the cost of the NDIS in launch sites commencing on 1 July 2013 (section 58).

Furthermore, the *Heads of Agreement between the Commonwealth and NSW Governments on the National Disability Insurance Scheme*, signed on 6 December 2012, specifies that the NSW Government will cease to provide basic community care services after the full implementation of the NDIS (section 33).

These agreements strongly suggest that the CCSP will no longer be available after the implementation of the NDIS, and that funds currently allocated for the CCSP will be transferred to the NDIS.

The NSW HACC Issues Forum is concerned about the inclusion of Home and Community Care funding in the potential pool for host jurisdictions' contribution to the NDIS, due to the fact that it is not clear if many people who use Home and Community Care services, and services funded under the National Partnership Agreement for Transitioning Responsibilities for Aged Care and Disability Services, will meet the access requirements for the NDIS.

Without subsection 21 (2), this decision would amount to removing access to support for people with disability, currently accessing supports through the CCSP. The HACC Issues Forum therefore recommends that the Home and Community Care Program and the NSW Community Care Supports Program are included in the specified programs in the rules as per subsection 21(2)(b)(iii) of the draft Bill.

Recommendation 4.

That the Home and Community Care Program and the NSW Community Care Supports Program are included in the list of prescribed programs in the rules, as noted in subsection 21(2)(b)(iii) of the draft Bill.

The NSW HACC Issues Forum particularly supports that a person will not have to meet age requirements for the NDIS in order to avail themselves of this provision. There are a number of people with long-term disability who, at present, are reliant on the support of HACC/CCSP and specialist disability services, and are aged under 65. However, many will turn 65 before the commencement of the NDIS in their area. It would be inequitable for people in these circumstances to be required to find other support due to the funding for disability programs being transferred to the NDIS.

However, the NSW HACC Issues Forum is concerned that the continuity provisions in subsection 21 (2) only apply to people who meet the residency requirements set out in section 23 of the draft Bill. At present, the CCSP does not specify that a person must meet any residency requirements in order to access support, nor do many other disability programs. There are no residency requirements specified for the target group outlined in the *Disability Services Act 1986 (Commonwealth)* or the *Disability Services Act 1993 (NSW)*. Removing access to support for people who currently require it is inequitable. See the section on *Residence requirements*, pages 11-13 of this submission, for details.

Age requirements

The NSW HACC Issues Forum is concerned about the age requirements for access to the NDIS for a number of reasons. Due to the former HACC Program supporting people both under and over age 65, the HACC sector has considerable experience with working with people with long-term disability who are ageing, and with people who acquire non-age related disabilities after they turn 65.

The NSW HACC Issues Forum supports subsections 29 (1) (a) and (d) of the draft Bill, which allows a participant over the age of 65 to remain in the NDIS for the person's lifetime, or as long as they choose. This submission is primarily concerned with people who meet the other access requirements for the NDIS but acquire their disability after the age of 65, and that disability is not well supported by aged care, health or palliative care services.

The NSW HACC Issues Forum supports the aim of section 22 of the draft Bill to limit disability funding to people with disability who require support, and that the aged care system is available to frail older people. The NSW HACC Issues Forum agrees that, where alternative support is available through aged care services, it is inequitable for an older person who experiences age-related frailty and disability to be able to access both aged care and disability support, where a younger person would not be able to.

However, the aged care sector is not well equipped to work with people with certain disabilities, is not resourced to provide appropriate support, and people who acquire non-age related disability over the age of 65 frequently experience serious hardship in attempting to secure adequate support.

For instance, in NSW the High Need Pool operated as part of the former HACCC Program to support people with high support needs of 15-35 hours per week. Applications by individuals aged 65 years and over are not processed by NSW Ageing, Disability and Home Care due to the demand for support. This has meant that people who have acquired Motor Neurone Disease, Multiple Sclerosis, and other conditions which lead to high needs for support, after the age of 65 have not been able to access appropriate support. Due to the rapid degenerative nature of these conditions, circumstances for people with these types of conditions have tended to reach crisis point quickly, with people being unable to remain independent where, with timely and appropriate support, they were otherwise likely to.

Assessment for most aged care programs other than the Commonwealth HACCC Program also tends to be limited to people aged over 70 years, due to planning ratios using population data for the number of people aged 70 years and over. The NSW HACCC Issues Forum has heard a number of reports from members that it is difficult for a younger person to access an Aged Care Assessment.

Disability services and aged care services are also funded at quite different levels, with differing guidelines for allowable use of resources. Residential and in-home aged care services tend to have lower levels of funding than comparable disability services. For instance, the highest level of Home Care Package (Level 4) will be \$45,000 (with an additional Dementia Supplement of up to \$4,500), however it is estimated that the funded component of an individual plan under the NDIS could be considerably higher than this and would be directly related to the participant's support needs and their plan.

The aged care sector also has quite different aims from the NDIS. Unlike the draft NDIS Bill, the *Aged Care Act 1997* does not make reference to the human rights of the older people using aged care services. Aged care services do not reflect a person centred approach that is built on the goals and aspirations of the person, and are not focused on the social participation of older people. Funding guidelines for both Home Care Packages and residential aged care services exclude certain types of support – for instance, motorised wheelchairs and any home modifications other than minor modifications⁴. No elements in the *Living Longer. Living Better* aged care reforms address these issues. For people living with a disability who meet all other access requirements, restricting them to a more limited source of support on the basis of age would be inequitable.

The NSW HACCC Issues Forum also notes that the Productivity Commission recommendation 3.6 specified that the upper age limit for accessing the NDIS should be the Age Pension age, and not 65.⁵ As the age of eligibility for the Age Pension is increasing from July 2017, aligning with this age of eligibility will reflect that people with disability are likely to experience a variety of circumstances after age 65, such as needing to maintain employment or other responsibilities.

⁴ Department of Health and Ageing (2011) *Community Packaged Care Guidelines*, Australian Government Department of Health and Ageing, p.64, 82.

⁵ Productivity Commission (2011) *Disability Care and Support*, Report no. 54, Canberra, p. 198.

The NSW HACC Issues Forum proposes that a minor amendment could be made to section 22, allowing that a person could meet age requirements if the CEO of the Agency is satisfied that the person's support needs are not met by other support mechanisms, including aged care, health, and/or palliative care. The rules could furthermore include provisions to state that support provided to a person through the NDIS over the Age Pension age could be limited to those types of support not provided through other services the person is receiving, or, if the NDIS funds support similar to that in another program, that it does so on a full cost recovery basis. This provision is common in aged care services to avoid duplicate services being provided to a person eligible for more than one program.⁶ Including such a provision would ensure that people who acquire non-ageing related disability, whose needs would not be met by the aged care sector, would be able to access appropriate support, while also ensuring that frail older people who acquire ageing-related disability would not have access to support through both the aged care system and the NDIS.

Recommendation 5.

That section 22 (1) of the draft Bill be amended to read:

22 Age requirements

(2) A person **meets the age requirements** if:

- (a) the person was aged under the age of eligibility for the Age Pension when the access request in relation to the person was made; or
- (b) the person is aged over the age of eligibility for the Age Pension, they meet all other access requirements, and the CEO is satisfied that the person's support needs are not met by other systems including aged care, health and/or palliative care.
- (c) if the National Disability Insurance Scheme rules for the purposes of this paragraph prescribe that on a prescribed date or a date in a prescribed period the person must be a prescribed age—the person is that age on that date.

Age requirements for Aboriginal people

The Gathering would like to see provision made in Subsection 22 (1) that Aboriginal and Torres Strait Islander people with disability under 65 meet the age requirements.

Recommendation 6.

That Subsection 22 (1) states that Aboriginal and Torres Strait Islander people who were under the age of 65 when the access request was made meet the age requirements.

Residence requirements

The NSW HACC Issues Forum queries the inclusion of residence requirements for access to the NDIS in section 23 of the draft Bill. A range of similar schemes and programs do not have residence requirements, or, if they do, do not have as exclusionary residence requirements as the draft NDIS Bill specifies. Inclusion of such residency requirements is inequitable and may increase NDIS costs in future due to a person who does not meet residence requirements missing out on early intervention supports which may have the effect of reducing later support needs.

The Statement of Compatibility with Human Rights accompanying the draft Bill states that "these are the same requirements that apply to the broader social security

⁶ E.g. see the DoHA (2011) *Community Packaged Care Guidelines*, Australian Government Department of Health and Ageing, pp.79-83.

system” (p.10). However, this is not true. The NDIS is not a social security scheme. There are a number of social security payments and types of government assistance that certain non-permanent visa holders in Australia are able to access. Medicare is available to holders of a range of temporary visas, and anyone holding a bridging visa who has applied for a permanent visa and is awaiting processing.⁷

Target groups specified in the *Home and Community Care Act 1985*, the *Disability Services Act 1986 (Commonwealth)* and the *Disability Services Act 1993 (NSW)* do not specify residence requirements for access to support, and community aged care programs specifically do not have any residence restrictions.⁸ The CCSP also does not specify that a person must meet any residency requirements in order to access support. As discussed earlier, the interaction of section 23 and subsection 21 (2) of the draft Bill would act to deprive people who are, presently, legitimately using necessary support from continuing to access support, as well as creating inequitable outcomes for permanent and non-permanent visa holders.

A number of people holding temporary visas have been in Australia for several years studying, working and/or awaiting processing of an application for a permanent visa. According to Australia’s citizenship requirements, a child born in Australia is not a citizen of Australia unless at least one parent is a citizen at the time of birth. Thus, children of temporary residents, who were born or have resided in Australia for considerable lengths of time and who have no other source of support, would not meet the residence requirements for the NDIS.

Children who are born with disability, to temporary visa holders, and adults holding temporary visas who acquire disability before their application for a permanent visa is processed, would experience significant hardship and disadvantage due to these residence requirements. Current visa processing times for certain subclasses range from 14 days to a number of years, depending on the date an application was lodged, and the priority given to the subclass. Thus, hardship associated with disability costs can be ongoing for a number of years for migrants holding temporary visas. The NSW HACC Issues Forum is concerned that, in this interim period, a person’s support needs could escalate significantly. Upon being granted a permanent visa, thereby meeting the residence requirements for the NDIS, it is likely that many of the benefits of early intervention would not be available to the person, and thus they would experience a reduced quality of life, ongoing for their lifetime, compared with others in similar circumstances. The NSW HACC Issues Forum considers this inequitable and contrary to the Objects of the Act.

Recommendation 7.

That subsection 23 (1) of the draft Bill be amended to read:

23 Residence requirements

- (1) A person meets the residence requirements if the person:
 - (a) resides in Australia; and
 - (b) is one of the following:
 - (i) an Australian citizen;
 - (ii) the holder of a permanent visa;

⁷ Australian Government Department of Immigration and Citizenship (2012) *Sharing Client Information for Medicare Purposes*, Department of Immigration and Citizenship, Canberra, November 2012, available at: <http://www.immi.gov.au/living-in-australia/settle-in-australia/to-do-first/medicare-client-share.pdf> (last accessed: 18/01/2013).

⁸ DoHA (2011) *Community Packaged Care Guidelines*, Australian Government Department of Health and Ageing, pp.103, 114, 126.

- (iii) a special category visa holder who is a protected SCV holder;
 - (iv) the holder of a temporary visa who has access to Medicare and meets the disability requirements or the early intervention requirements; or
 - (v) the holder of a temporary visa who meets the early intervention requirements; and
- (c) satisfies the other requirements in relation to residence that are prescribed by the National Disability Insurance Scheme rules.

Disability requirements

The NSW HACC Issues Forum is concerned about the way disability requirements for access to the NDIS are set out in the draft Bill. As discussed in the Introduction to this submission, the CCSP supports numerous people with varying levels of functional capacity. HACC Issues Forum is concerned about people in the target group for the CCSP, whether or not they are presently using CCSP-funded services, and whether the disability criteria specified in the draft Bill may exclude a significant number of people currently accessing or eligible for support. The HACC Program/CCSP has provided support to numerous people with lower support needs whose needs would likely escalate rapidly without the support of basic community care services. Continuity of support to people with disability in these situations is vitally important to ensure their quality of life, independence and capacity to achieve their aspirations is maintained.

The former HACC Program and the CCSP, unlike the NDIS, have not been schemes where all persons have an entitlement to support if they are assessed as eligible. Service providers are also required to prioritise provision of support based on a range of conditions, resulting in many people being placed on a waiting list, sometimes for considerable periods, or in being referred elsewhere for support. Funding for the Program is finite, and service providers have had to use the available funds according to guidelines for prioritisation. This has meant that some HACC/CCSP services have not provided support at an early stage for a person with lower support needs. Members of the NSW HACC Issues Forum are aware of many cases of a person with low support needs experiencing a rapid deterioration of their functional capacity due to the failure of timely intervention, resulting in much higher support costs as their needs have escalated.

The CCSP also supports people with a variety of types of disability. Due to eligibility criteria for access to support being based on functional capacity only, people with disability who find that access to other programs is limited by disability type have often been able to access support through the former HACC Program/CCSP. People with mental health conditions, HIV/AIDS, brain injury, people recovering from stroke, degenerative neurological conditions, and disability arising from a chronic health condition include some of the people who access support from the CCSP, and who are often unable to access support through other means.

Disability requirements in the draft Bill differ significantly from those recommended by the Productivity Commission's Final *Disability Care and Support* Inquiry Report. Recommendation 3.2 in the Report outlines the proposed eligibility criteria for a person to access the NDIS:

Individuals receiving individually tailored funded supports through the NDIS:

- *should have a disability that is, or is likely to be, permanent, and*
- *would meet one of the following conditions:*

- have significantly reduced functioning in self-care, communication, mobility or self-management and require significant ongoing support
- be in an early intervention group, comprising individuals for whom there is good evidence that the intervention is safe, significantly improves outcomes and is cost effective

In exceptional cases, the scheme should also include people who would receive large identifiable benefits from support that would otherwise not be realised, and that are not covered by the groups above. Guidelines should be developed to inform the scope of this criterion and there should be rigorous monitoring of its effects on scheme costs.⁹

The NSW HACC Issues Forum supports the focus of these recommended criteria on the functional capacity of the person rather than attributing their disability to a type of impairment. Attributing the disability to a broad category of ‘impairment types’ will tend to exclude some people who find it difficult to obtain a diagnosis. This situation affects a number of people with acquired brain injury, as discussed in Brain Injury Australia’s *National NDIS Consultation Report: June-September 2012*, which outlines a number of recommendations about appropriate eligibility screening processes.¹⁰

With the possibility that CCSP funding will be transferred to the NDIS, the HACC Issues Forum is concerned that people currently eligible for support may be excluded according to the disability criteria outlined in the draft Bill. A number of people with HIV/AIDS, especially those who develop other chronic health conditions, are likely to have significant deterioration of their functional capacity. The joint submission by Positive Life NSW and ACON to the Productivity Commission *Disability Care and Support Inquiry* outlines how disability can affect a person living with HIV/AIDS due to both co-morbidities and the long-term effects of anti-retroviral therapy.¹¹ A person with disability arising from HIV/AIDS, however, would not meet the disability criteria, despite the significant gains for the person and society from the option for these individuals to access support. Where others with similar support needs, but who have a different ‘impairment type’ can access support through the NDIS, it is not equitable to exclude a person on the basis of their impairment type.

The NSW HACC Issues Forum is also concerned that people with a number of other conditions which are difficult to diagnose medically, such as chronic pain conditions, Chronic Fatigue Immune Dysfunction Syndrome/Myalgic Encephalomyelitis, and which may not meet the disability requirements in the draft Bill. People living with these types of conditions experience similar levels of limitation in their social participation, may have similar support needs, to those who have a disability which meet the definitions in subsection 24 (1) (a) of the draft Bill.

The HACC Issues Forum does not consider that subsection 24 (1) (a) of the draft Bill increases the precision or effectiveness of the disability requirements, and the

⁹ Productivity Commission (2011) *Disability Care and Support*, Report no. 54, Canberra, p. 198.

¹⁰ Brookes, Derek (2012) *National NDIS Consultation Report: June-September 2012*, Brain Injury Australia, available at: http://biansw.org.au/images/stories/PDFs/brain_injury_australia_-_national_ndis_consultation_report_2012.pdf (last accessed: 18/01/2013).

¹¹ Positive Life NSW & ACON (2011) *Joint submission to the Productivity Commission Disability Care and Support: Draft Inquiry Report*, April 2011, Sydney, available at: <http://www.acon.org.au/sites/default/files/PC%20Disability%20whole%20submission.PDF> (last accessed: 18/01/2013).

exclusionary effect of the requirement for a person's disability to be attributable to one of a list of impairment types outweighs the benefit of this subsection.

Recommendation 8.

That subsection 24 (1) (a) be deleted from the Bill.

The HACC Issues Forum is also concerned that the requirement that the "impairment or impairments result in substantially reduced functional capacity" in subsection 24 (1) (c) is ambiguous, and that a definition of "substantially reduced functional capacity" may only be available in the NDIS rules.

As discussed above, the former HACC Program/CCSP provides support to people with a range of functional capacities. Depending upon the specific definition used in the rules, there may be substantial numbers of people using HACC/CCSP services who will no longer be eligible for any type of support.

Setting the threshold for demonstrating "substantially reduced functional capacity" at a very severe level is likely to compromise the effectiveness of the scheme. Many people living with a disability who would be able to make successful contributions to the community and society would, instead, be subject to a great deal of hardship and poverty. Health costs are also likely to increase, as, without support both people living with a disability and their carers would be likely to have deteriorating mental and physical health. People with disabilities would be more likely to be in crisis before they meet the NDIS disability requirements, and thus would result in higher costs, without necessarily delivering greater benefits to the person.

Recommendation 9.

That the Australian Government and other State and Territory Governments take into account the benefits of basic and low level support for people with disability in any rules relating to section 24 (1) (c) of the NDIS Act.

The NSW HACC Issues Forum is also concerned about how Aboriginal people with disability will relate to these disability requirements. The NSW Aboriginal Community Care Gathering Committee policy position is that disability is often not "distinguished" in Aboriginal communities in the same way as non-Aboriginal communities which may result in "very low referral and for disability treatment and disability development and services". With Aboriginal people experiencing disability at 2.4 times the rate of non-Aboriginal people,¹² the Australian Government must work with Aboriginal communities to ensure that access criteria are culturally appropriate for Aboriginal people. The NSW Aboriginal Community Care Gathering Committee is concerned that the number of disability requirements for the NDIS will create barriers that may prevent Aboriginal people with disability becoming participants and impact on their families and carers and communities.¹³

HACC Issues Forum supports the inclusion of people with conditions whose support needs increase intermittently or episodically under subsection 24 (2) of the draft Bill. Former HACC Program/CCSP supports a number of people who have permanent disability, but whose support needs and functional capacity change over time. HACC

¹² Australian Institute of Health and Welfare (2011) *Aboriginal and Torres Strait Islander people with disability: wellbeing, participation and support*, IHW 45, Canberra: AIHW.

¹³ Workshop with NCOSS, 14/12/2012.

Issues Forum commends the Government for recognising the needs of people who have variable functional capacity, and ensuring that they can benefit from the NDIS.

When a person ceases to be a participant

In accordance with the above comments on the age requirements for the Scheme, HACC Issues Forum is concerned about the potential meaning of subsection 29 (1) (b). The aged care system does not include an entitlement for any person assessed as meeting eligibility criteria to access support. Places in aged care services are limited, and allocated according to a planning ratio. Growth in places does not necessarily match the rate of growth in the target population.

In the experience of the NSW HACC Issues Forum, aged care places often involve significant waiting times after a person is assessed and approved for a residential aged care place, or a community care package.¹⁴ NSW HACC Issues Forum seeks clarification that subsection 29 (1) (c) does not mean that a person who is approved for an aged care place then immediately ceases to be a participant of the NDIS, before they are successful in securing a place.

Recommendation 10.

That the NDIS rules specify that only upon commencing services through a program specified in the *Aged Care Act 1997* does a person cease to be a participant of the NDIS.

The National Health Reform Agreement also specifies that full funding responsibility for non-Aboriginal persons over the age of 65, and Aboriginal people over 50, transfers to the Commonwealth Government. NSW HACC Issues Forum assumes this to mean that a participant, should they elect to remain in the NDIS after the relevant age, will continue to have the same support arrangements, funded at the same levels and managed through the same processes, as prior to their 65th/50th birthday. NSW HACC Issues Forum recommends that this be clarified in the Act.

Recommendation 11.

That the NDIS Act specifies that a participant's supports will continue, in terms of funding and management, as previously after the participant turns 65.

NSW HACC Issues Forum also advises that the *Aged Care Act 1997* is currently in the process of being amended to remove all reference to "community care". "Community care" will instead become "Home Care Packages". NSW HACC Issues Forum suggests the Bill be amended to reflect these changes.

People with disability who do not meet access requirements

NSW HACC Issues Forum notes that the draft Bill refers to the only beneficiaries of the NDIS as participants who have met the access requirements, and have a funded plan in accordance with Part 2 of Chapter 3 of the draft Bill. However, other documents relating to the establishment of the NDIS, such as the Productivity Commission *Disability Care and Support* Final Inquiry Report and the Heads of Agreement between the Commonwealth and the NSW Government on the NDIS refer to a class of persons who can seek support from the NDIS but who would not

¹⁴ See Productivity Commission 2011, *Caring for Older Australians*, Report No. 53, Final Inquiry Report, Canberra, Ch. 3.

necessarily receive a funded individual support package, who would be in “Tier 2” of the NDIS.

NSW HACC Issues Forum have been advised by the NSW Government Department of Family and Community Services that it is intended that the Agency will have the power to fund support for people who do not meet the access requirements. NSW HACC Issues Forum proposes that a consultation process relating to these proposed supports be initiated before they are funded.

NSW HACC Issues Forum notes that NDIS is being established partly to address fragmentation of current support resources & programs. Establishing tiers within the NDIS or funding other programs may have the effect of continuing fragmentation. NSW HACC Issues Forum advises that people with a disability would prefer simplified arrangements that are likely to be comprehensive, rather than further confusing proliferation of programs, funding streams, and sources of support.

Recommendation 12.

That the Australian Government consult extensively about provision of support to people living with a disability who do not meet access requirements to become a participant of NDIS.

Participants’ plans

Reasonable and necessary supports

NSW HACC Issues Forum supports the general principles relating to plans in section 31 of the draft Bill, and the focus of plans on the goals and aspirations of the participant. Building supports from the participant’s aspirations reflects a person centred approach, which is strongly supported by NSW HACC Issues Forum members. This approach is likely to result in very good outcomes for participants.

However, NSW HACC Issues Forum has some concerns about what can be defined as “reasonable and necessary supports” under section 34 of the draft Bill. NSW HACC Issues Forum is concerned that section 34 (e) states that funding provision must take into account “what it is reasonable to expect families, carers, informal networks and the community to provide” without reference to what a person wants their family, carer/s, community and informal networks to provide, and what those groups are actually capable of providing.

In the experience of the NSW HACC Issues Forum, reasonable expectations of families, communities and carers vary considerably according to the circumstances of a person. They can vary regionally, for example by socio-economic status, age, gender, and cultural factors. The combination of each person’s individual circumstances contributes to the quantity and quality of support available to them, and whether they can reasonably avail themselves of that support. For instance, there are a number of socially isolated people accessing HACC/CCSP services who have family who are unwilling and/or unable to provide support for them. In these circumstances, it would be onerous to expect the person to source a level of informal and community support that is simply not available.

The NSW Aboriginal Community Care Gathering Committee has also expressed considerable concern about this provision. Gathering members have stated that there are Aboriginal families providing informal and unpaid care to a family member with disability and often an Aboriginal person with disability may have more than one

carer who carries out different aspects of support, and all may work together when required to participate in the person's care and planning. There are also Aboriginal families that have multiple individuals who are both carers and recipients of care, who have their own support needs arising from health conditions, socio-economic status and other complex circumstances. Each family situation is unique and there can be no uniform reasonable assumption that can be formed about families, communities, carers or informal support.

Recommendation 13.

That section 34 (e) be amended to read:

- (f) the funding or provision of the support takes account of support that a participant accepts families, carers, informal networks and the community to provide, and what they are able to provide;

Role of the National Disability Launch Transition Agency and the CEO

The NSW HACC Issues Forum notes that under sections 42 and 43, and Chapter 6 of the draft Bill, the NDIS Launch Transition Agency (the Agency) and the CEO of the Agency will have considerable powers and functions with regard to participants, their plans, in addition to determining whether a person meets the access criteria, and approving the funded portion of the *statement of participant supports* (specified in section 33 of the draft Bill), the Agency will be able to manage the plan and the funds for the participant, and the CEO will be able to appoint a plan nominee (section 86) to manage the plan on behalf of the participant, and will monitor acquittal of the funds paid under a plan.

The NSW HACC Issues Forum is concerned about the ubiquity of the Agency in this process. There is potential for the Agency to have total management of a person's supports, and to monitor its own performance in conducting these functions. NSW HACC Issues Forum considers that the functions of allocating funds, and managing and purchasing supports on behalf of a person, are conflicting functions. Where the Agency will need to have regard to value for money and risk management overall (section 118), preparation, management, and review of participants' plans are likely to conflict with these broader public interest goals and may not comply with the General Principles guiding actions of people who may do acts or things on behalf of others in section 5 of the draft Bill.

The Gathering is also concerned about this issue and would like to see a clear separation of duties and a more balanced process to ensure transparency and accountability and to avoid any potential or perceived conflicts. There is potential that this narrow decision making process may be at odds with the admirable concept of a person centred approach and the provision for considerable choice and control by people living with disabilities in support of a good life.

The NSW HACC Issues Forum is also concerned that the requirement under subsection 33 (6) of the draft Bill is overly restrictive, limiting supports purchased by the Agency in managing a participant's plan to those provided by registered providers of support, and the possibility that the rules may contain further restrictions.

Many socially isolated people who do not have strong support networks, or who have not had good information provided to them about the NDIS, are likely to take up the option of nominating the Agency as the manager of their plan. This is likely to be the case for many people with disabilities who are ageing, as in these circumstances

they are less likely to have a carer or other support networks who have the capacity to act as a strong advocate.

The likely consequences of these provisions in the draft Bill, taken together, will be serious restrictions on the possibilities for a person with disability who is likely to be more vulnerable, resulting in poorer outcomes and a poorer quality of life.

Recommendation 14.

That subsection 33 (6) in the draft Bill be deleted.

Suspension of plans and crisis situations

Provisions under section 47 for review of a participant's plan outline a comprehensive process involving specific timeframes. These timeframes are appropriate for plans which need to be reviewed comprehensively, however, NSW HACC Issues Forum is concerned that crisis situations and sudden changes in a participant's circumstances are not taken into account anywhere in the draft Bill.

A variety of crisis situations may occur which require considerable changes to a plan, or the use of funds outside the plan. Some examples are:

- Hospitalisation of the participant, or a family member/friend
- needing to attend a funeral
- natural disasters and other emergencies

NDIS needs to be responsive in such situations, especially emergencies which may affect the health and safety of the participant.

For many people with relatives overseas, these occurrences are likely to require overseas travel. Although a plan may include overseas travel, where a plan does not include travel, a crisis situation may prompt the requirement to do so. NSW HACC Issues Forum considers that the grace period of 6 weeks, as specified in subsection 40 (2) may be too brief in some cases

Recommendation 15.

That criteria in relation to a grace period for a temporary absence from a plan require the CEO to have regard to:

- (c) the personal and/or family circumstances of the participant; and
- (d) any correspondence relating to their absence from Australia that the participant sends to the CEO, including verbal correspondence.

Chapter 5 – Compensation payments

The NSW HACC Issues Forum has experience of people either using or seeking support under the former HACC Program/CCSP who were eligible for a compensation payment having considerable difficulty with the interaction of compensation claims with eligibility for government funded support. People have had supports disrupted or have been required to seek alternative support after a compensation claim was successful, where they have been able to make a compensation claim. HACC Issues Forum is therefore concerned that the

requirement of a participant to take action to obtain compensation may be counter to the Objects of the Act, and jeopardise the continuity of a person's supports.

The NSW HACC Issues Forum is concerned that subsection 104 (3), noting the factors which the CEO of the Agency must take into account in deciding whether it is reasonable to require a person to take an action, is limited, and would not prevent the CEO or a delegated officer from making a decision which would result in hardship or suffering on the part of the person. NSW HACC Issues Forum considers that the CEO must be prohibited from making a decision to require an action that would cause suffering or hardship to the person and/or their family.

Recommendation 16.

That section 104 include a subsection preventing the CEO from requiring a person to take action to obtain compensation, if in so doing the person would experience suffering and/or hardship.

The HACC Issues Forum is also concerned that section 105 requires a participant's plan to be suspended if they do not take the required action to obtain compensation within a specified period, and that the suspension of the participant's plan is not subject to the discretion of the CEO. This provision is unnecessarily punitive, and likely to result in considerable hardship for people in circumstances which may limit their ability to take the required action. There is also no scope within section 105 for a person to make a claim about why they cannot take the action, or why taking the action may be unreasonable.

Recommendation 17.

That subsections 105 (2) and (3) are deleted from the draft Bill, and/or that a subsection is added to section 105 stating:

If a participant or prospective participant does not take the required action, the CEO may decide to continue the preparations for a prospective participant's plan, or to continue a participant's plan that is already in progress.