

NSW DISABILITY NETWORK FORUM

NSW Disability Network Forum Submission to NDIS Select Council on Disability Reform *An approach to Eligibility and Support under an NDIS*

The NSW Disability Network Forum is pleased to provide feedback on the Discussion Paper on Eligibility & Reasonable and Necessary Support to the NDIS Select Council on Disability Reform as part of its second forum. Member organisations of the NSW Disability Network Forum have contributed to this submission from their areas of expertise as well as including jointly agreed positions shared within the Forum.

If you require any further information or clarification, please contact the NCOSS secretariat, contact details listed at the foot of the page.

About the NSW Disability Network Forum

Initiated in June 2011, the **NSW Disability Network Forum** comprises non-government, non-provider peak representative groups whose primary aim is to promote the interests of people with disability. The aim of the NSW Disability Network Forum (DNF) is to provide a new avenue to build capacity within and across all organisations and groups so that the interests of people with disability are advanced through policy and systemic advocacy. The Council of Social Service of NSW (NCOSS) provides secretariat support to the Forum as part of funding from Department of Family and Community Services, Ageing, Disability and Home Care.

More information and current reports from the NSW Disability Network Forum are available at http://www.ncoss.org.au/component/option,com_docman/task,cat_view/gid,367/Itemid,78/

NSW Disability Network Forum Member Organisations:

Aboriginal Disability Network NSW	NSW Consumer Advisory Group - Mental Health
Association of Blind Citizens of NSW	NSW Council for Intellectual Disability
Brain Injury Association NSW	NSW Disability Advocacy Network
Deaf Society of NSW	People with Disability Australia
DeafBlind Association NSW	Physical Disability Council of NSW
Deafness Council (NSW)	Positive Life NSW
Institute For Family Advocacy	Self Advocacy Sydney
Intellectual Disability Rights Service	Side By Side Advocacy Incorporated
Multicultural Disability Advocacy Association of NSW	Council of Social Service of NSW NCOSS

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Eligibility FROM THE DISCUSSION PAPER

1. Does this description of eligibility cover all the things that you think a National Disability Insurance Scheme would need to know about you to determine whether you should be eligible to receive support under an NDIS?
 2. Are there additional questions that an NDIS should ask people before deciding if they are eligible to receive support?
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People with hearing impairments

All former child clients of Australian Hearing (AH) should be assessed as eligible for hearing services and devices. At the moment all services of AH cease at 26 years of age.

The acquired deaf who are partial to moderately deaf should be assessed on the extent the deafness impinges on their lives e.g. communication, education, employment, family and community life. All severe and profound hearing losses should automatically be eligible.

Early Intervention

The eligibility criteria must clearly include children, young people and adults who would benefit from early intervention. Currently all descriptors of impairment in section 4 focus on the long term nature of the impairment. Additional criteria on the value of early intervention which may diminish the long term nature of impairment are necessary. This may be achieved by adding a new 4(a) *“The impairment(s) is likely to be reduced through early intervention”*

Others optimally supported

The eligibility criteria must capture Group 3(c) as identified by the Productivity Commission i.e. “Others optimally supported” described as “people who have large identifiable benefits from support that would otherwise not be realised”.

Self-management and planning

There are grave concerns about the focus on undefined Activities of Daily Living and the omission of ‘self-management and planning’ as referred to by the Productivity Commission. There are no examples in the discussion paper that relate to the needs of people with intellectual or chronic psychiatric disability. The examples provided of Activities of Daily living relate mainly to people with physical and sensory disability. Please refer to further comments under *Reasonable and necessary support*.

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Draft Eligibility Statement

In the draft eligibility statement 4 b

It is impossible to judge the criteria without a definition of all the terms in 'substantially reduced functional capacity of the individual to undertake activities of daily living'. The 'and' between b and c should be changed to 'or'

In the draft eligibility statement 4 c

While participation in the community is mentioned in this point, employment has been specifically identified when no other specific examples of community involvement have been described. This suggests that employment may be more highly valued than e.g. recreation, informal education, skills building. The particular mention of employment occurs again in the criteria of reasonable and necessary supports.

Aboriginal and Torres Strait Islander people with disability

The eligibility criteria do not acknowledge that the Aboriginal and Torres Strait Islander community does not identify disability, or may identify disability differently. Consequently, engagement and promotion needs a strong focus with these communities.

For the assessment and eligibility process, the NDIS will need to utilise local Aboriginal resources and networks, including the employment of Aboriginal workers to assist and advocate within the process, thus ensuring that the cultural needs of the different Aboriginal clan groups are recognised and respected.

Non Aboriginal service providers need to build their cultural awareness and competence capacity within their local areas, both to assist Aboriginal people to engage with the NDIS and to build the capacity of Aboriginal people to engage more independently with the NDIS process into the future.

There needs to be more of an outreach approach for Aboriginal communities with the existing nominated launch sites, including multiple access points for engagement, especially for those in remote areas, with transport being a primary issue.

The NSW Aboriginal and Torres Strait Islander Community Care Gathering Committee has released its most recent Policy Position *Challenge Change and Choice*. The Chapter on Aboriginal and Torres Strait Islander people with disability contains guiding principles and recommendations in the areas of cultural approaches to disability, working from strengths, multiple carers, back to country-going home, individualised approaches and self-directed funding, disability supported accommodation, disability equipment and supports. Available here: <http://ncoss.org.au/resources/120704-challenge-change-choice.pdf>

Deafblind people

Deafblind people (people who have a combined vision and hearing loss to the extent that it causes problems with learning, access to information, access to the community and other mobility) must be eligible for funding as this is a profound disability, known throughout the world as the most isolating of all disabilities.

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Assessment of Deafblind people will not be able to be performed by for example Ability Links in NSW because of lack of knowledge of communication methods. Some Deafblind people use Auslan and can communicate with an interpreter, but there are many different methods used by others and many can only be assisted by someone familiar with their communication.

A person with congenital deafblindness may have current funding as a person with an intellectual disability (though not strictly true), and may be inappropriately accommodated in a group home with others who can communicate with staff and co-residents. This is completely inappropriate and a human rights abuse, and if not monitored by people who understand deafblindness will continue to be assessed as such, when they should be accommodated in specific houses for Deafblind people with staff who can communicate.

Because there has been no funding in the past for people with acquired deafblindness, assessment of needs would be difficult unless people with knowledge of this disability are involved. There is a great need for interpreter/guides for just a few hours per week, to assist each Deafblind person to access the community, which is currently denied. Deafblind people are mostly able to manage within their homes, but are isolated there, leading to endemic depression.

Assessment of technology which would help a Deafblind person to live a more fulfilling and active life could be assessed by technology experts.

The permanence of the disability

Who and what tool will be used to assess the permanence of the disability? The severity and frequency of injury symptoms can be episodic. What arrangements are being proposed to cater for these needs?

People with Intellectual Disability

Unless the expression “activities of daily living” is defined broadly, it could exclude a very high proportion of people with intellectual disability who will experience unacceptable, unreasonable and avoidable hardship and crisis unless provided with the appropriate supports.

The Productivity Commission recommended eligibility available to an individual with “significantly reduced functioning in self-care, communication, mobility or self-management and require significant ongoing support”. The term self-management was included in response to the above challenges facing people with intellectual disability. Self-management includes being in control of one’s behaviour, insight, memory and decision-making.

It is critically important that NDIS eligibility remains open to people who have significantly reduced functioning in self-care, communication, mobility or self-management and require significant ongoing support, not limited to the activities of daily living, defined in a narrow sense.

The Productivity Commission acknowledged that people with intellectual disability have a reduced capacity to participate in society. However, the Commission also identified that around 40% of individuals with intellectual disability and lifelong care and support needs do not face a “core activity limitation” (a limitation in self-care, mobility or communication).

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“People with intellectual disability face special challenges in learning and applying knowledge and in decision-making. This included identifying and choosing options at key life transition points and adjusting to changed circumstances and unfamiliar environments. It was important to consider supports people need in areas such as maintaining relationships and interacting with others.”

NSW Council for Intellectual Disability

It is very important that the NDIS funding be available for the needs of people with intellectual disability who may be independent in many respects but need support in areas like healthy lifestyles, dealing with life transition and personal crises, financial management, avoiding and responding to exploitation, and maintaining tenancies. Many people may need support to move from homelessness, to lead a lawful lifestyle, to deal with the criminal justice system and/or to care for and bring up children.

Reasonable and Necessary Support FROM THE DISCUSSION PAPER

The Productivity Commission approach to describing what would be ‘reasonable and necessary’ included consideration of the following factors:

- The benefit to the participant;
- The appropriateness of the support or service request;
- The appropriateness of the provider;
- Cost effectiveness considerations; and
- Whether the support or service would be most appropriately provided through an NDIS.

Reasonable and necessary supports:

- are designed to support the individual to achieve their goals and maximise their independence;*
- support the individual’s capacity to undertake activities of daily living to enable them to participate in the community and/or employment;*
- are effective, and evidence informed;*
- are value for money;*
- reflect community expectations, including what is realistic to expect from the individual, families and carers; and*
- are best provided through an NDIS and are not more appropriately provided through other systems of service delivery and support, including services that are offered by mainstream agencies as a part of its universal service obligation to all citizens.*

Questions:

1. Are there supports that you think are important to include in an NDIS that would be excluded by this description?
 2. Are there additional points that are needed to make sure that the support provided under an NDIS meets the reasonable and necessary support needs of people with disability?
 3. Does this description of reasonable and necessary supports, combined with the eligibility statement, help you to understand who will be supported in an NDIS and what supports might be provided to them? If not, how do you suggest that the description be made clearer?
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Significantly reduced functioning and self-management

Several DNF members again raised the danger of the possible narrow interpretation of *activities of daily living* instead of a more inclusive and preferred “significantly reduced functioning in self-care, communication, mobility or self-management and require significant ongoing support” as recommended by the Productivity Commission.

The wider interpretation will improve the eligibility to people with a range of cognitive and degenerative disabilities especially where participation can be enhanced through support with decisions and self-management. Overlooking supports to people in these groups could lead to more expensive interventions with less effective outcomes all round. This was clearly demonstrated in the Productivity Commission Report.

Reasonable and necessary supports page 6 of 8 of the discussion paper:

- The inclusion of “*develop and maintain relationships*’ in part (b)
- The inclusion of “life stages” in part (e) i.e. reflect community expectations related to life stages, including what is realistic...”

What supports will be provided?

Criteria for operationalising ‘reasonable and necessary’ should enable people to discern whether the NDIS would include, for example:

- the purchase of a sports wheelchair for a person whose goal is to be a paralympian?
- the payment of rent for a house sharer who provides informal support in lieu of rent?
- the costs of house and car modification?
- the additional cost of taxi transport that exceeds that met by state taxi transport subsidy schemes for people unable to use public transport?
- opportunities for co-funding e.g. for a computer that may be used in school and out of school

The person’s individual plan

The value of an individualised portable funding arrangement under an NDIS to a person with disability and their family/ carer is that they can shape their supports around the person with disability instead of the person having to fit into a service system that may not suit them or respond to their needs. Flexibility is key for the person and their family. There is very strong international and Australian evidence that person centred approaches and individualised funding arrangements result in more effective and efficient supports for people with disability, who will clearly make funding dollars work harder. While the Productivity Commission approach to describing what would be ‘reasonable and necessary’ did include consideration of a range of factors, the critical issue is that the person would determine their individual plan for how and (broadly) on what their allocated funding should be spent in order to achieve the best outcomes for the person. The identified factors are real considerations but an outcomes approach is the critical and overriding feature of a successful and true person-centred NDIS, one that meets the needs and goals of the individual. Neither the eligibility nor the assessment processes should be so burdensome as to stifle or restrict the possibilities and opportunities for a better deal for the person with disability.

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Additions for reasonable and necessary supports

Regional/rural/remote support funding.

It is not uncommon in regional rural and remote areas that the cost to travel to the client is more than the cost of the actual service delivery. Will the funding formula take into account these challenges?

Interpreting: non-English languages, including Auslan/sign language interpreting and additional deafblind supports. Costs for these services must not consume the funding of a person's support package. In most cases, there will need to be additional services provided and these must be additional to the individual funding provided.

Independent Advocacy and independent Information.

The NSW Disability Network Forum has been working on the role and function of independent advocacy and independent information at the state and national levels. The Forum argues that a separate block investment in Independent Advocacy and independent Information will enable people with disability and their families to utilise the proposed support pathways (NSW) and NDIS in a more effective way at relatively early stages in a cost effective manner. The use of Independent Advocacy and independent Information must not come from a person's individual funding. The DNF acknowledges that most people with disability and their families and carers will be affective advocates in their own right but may from time to time require non-aligned information and advice. The DNF has collated a series of real stories to illuminate the role of independent advocacy and independent information as well as describing how these can enhance the person-centred initiatives at state level and ultimately the NDIS at national level. A copy of the early version of this position paper is attached and also available at <http://www.ncoss.org.au/resources/DNF/forum/120903-NSW-DNF-Submission-to-the-Ability-Links-NSW-Taskforce.pdf>

Advocacy to enable access to available supports:

Some people with intellectual disability require a personal funding package even to be able to bridge the gap to existing assistance and supports that may be available. This arises from the effect of their disability on self-management and planning. Many people cannot get help to make choices, fill out forms, attend appointments, prove their eligibility, deal with difficult intake procedures and then be model service consumers. Some people with intellectual disability need a personal helper provided by a funding package to assist with the complexities that arise in finding essential assistance.

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This real story from the NSW Intellectual Disability Rights Service (IDRS) happened last week:

“Chris is a woman with intellectual disability in her early 20s, who has no family, is homeless, with not enough money to eat. Chris was referred to NSW Ageing, Disability & Home Care (ADHC) for support services so that she could be given a diversionary order by the court where she was facing criminal charges. She was accepted by ADHC but due to being homeless, and having limited travel skills and poor organizational skills, she failed to keep her appointments. ADHC then advised they could not assist until she had a home base. She had been to Housing NSW but couldn’t get her message through. IDRS contacted Housing NSW with her – she needed two forms of identification and was required to fill out an application form to get emergency housing. Chris had no identification and she can’t fill out forms. IDRS assisted her to get the two forms of identification and took her to Housing NSW and helped her complete the application forms. She was offered some three days of emergency housing. Meanwhile she had no money. She is on Newstart rather than the Disability Support Pension for which she would be eligible. She constantly fails to meet the job application and reporting requirements because she cannot comply, so she does not get her benefits (repeatedly). She has been prostituting herself to get money to eat. IDRS took her to Centrelink to sort out her benefit but had to deal with a difficult Centrelink staff person. IDRS reports the need to be quite assertive to get any assistance and will now try to get Chris on to the more appropriate disability pension”. NSW Intellectual Disability Rights Service

People with disability lowest priority in other systems

There were serious concerns that NDIS funding could not be used on the supports or services provided by other systems e.g. the aged care system, the clinical mental health system, the education system, the general health system.

The NSW Disability Network Forum understands that these and other systems must be expected to be as responsive to people with disability as to any other of their clients, customers, patients, students etc. NDIS should complement existing support systems and not replicate what is already available and functioning well. Further, the NDIS must not be seen by other general systems as an alternative funding source or a way of diverting their demand or workload. This is why the National Disability Strategy is so important.

However, if the intent of the NDIS is to address people’s support needs, then it must be acknowledged that many support systems will continue to deliver support in “the present arbitrarily rationed amount” (p6 of the Discussion Paper), whereby people’s support needs are not being properly met. The lived reality for many is that the person with disability, while still eligible, may often be amongst the lowest priority, with the longest wait, with the least adequate allocation or with few reasonable accommodations. The tactic from a systems viewpoint is to maintain pressure on the generalist systems to improve their responsiveness but the real consequence is for the person with disability for whom the NDIS was a hope for better inclusion and participation.

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Consequently, a balance must be struck to prioritise the needs of the person with disability while maintaining systemic pressure and not absorbing precious NDIS funding into other systems.

Physiotherapy for older people with physical disability

The Productivity Commission further proposed that people who acquire their disability after age 65 will not be able to enter the scheme, but will instead be assisted by the aged care system. However, the current aged care system is neither resourced nor tooled up to handle disability support provision i.e. under the HACC program access to funded physiotherapy is extremely poor. How and to whom in particular will these clients be referred? Will the HACC sector receive increased funding to cater for clients who are missing out?

Clinical mental health support

NSW Consumer Advisory Group Mental Health is concerned the NDIS will not cover clinical mental health support needs. Aside from crisis clinical intervention and the limited sessions available through Better Access, people have very limited access to clinical mental health services if they are unable to afford private services. The greater emphasis on non-clinical support in the NDIS is imperative but mental health consumers consistently report that proper access to clinical support can be just as important.

The following experience was shared by a mental health consumer at a NSW CAG consultation in the Western NSW Local Health District.

“Mrs. A lives in a rural area in NSW. She received non-clinical support from the local Personal Helpers and Mentors (PHaMs) program, and clinical support from the local community mental health service.

When we met her, Mrs. A had been without clinical support for months. She said she found the community mental health service unhelpful. They are always hectic, they never have time to properly talk to her, and they often cancelled or changed her appointment to prioritise someone deemed as having a higher need. A few times, she didn't find out her appointment had been cancelled until she was on her way to the clinic.

She said she needs more consistent clinical support which is not available through the community mental health service. She also said having been let down so many times, she no longer trusts the community mental health service and would rather not go there.

She takes comfort in having access to the PHaMs program, but they don't provide clinical support. She has also used up the sessions provided through Better Access, and she can't afford a private psychologist.” NSW Consumer Advisory Group - Mental Health

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To ensure the needs of the individual are addressed in a person-centred and need-based approach, the NDIS should not withdraw connections to specific systems, and it should work to ensure the gaps left by existing systems are addressed. For example, if a person requires additional clinical support to what is available in other systems, then the NDIS should ensure the person can access such additional support when they have exhausted the options in other systems. Using Mrs. A's experience as an example, it would have been very useful and much more effective if she could continue accessing a private clinical psychologist through the NDIS, after she used up the limited sessions available through Better Access.

Conclusion

The NSW Disability Network Forum appreciates the opportunity to provide input on the Discussion Paper on Eligibility & Reasonable and Necessary Support to the NDIS Select Council on Disability Reform as part of its second forum.

If you require any further information or clarification, please contact the NCOSS secretariat, Christine Regan at chris@ncoss.org.au ph. 02 92112599 ext. 117