

NSW DISABILITY NETWORK FORUM

Response to Productivity Commission Review of NDIS

Costs: Issues Paper

24 March 2017

About the NSW Disability Network Forum

The NSW Disability Network Forum comprises non-government, non-provider peak representative, advocacy and information groups whose primary purpose is to promote the interests of people with disability. The aim of the DNF is to build capacity so that the interests of people with disability are advanced through policy and systemic advocacy.

NSW Disability Network Forum Member Organisations:

- Being Mental Health and Wellbeing Consumer Advisory Group
- Blind Citizens NSW
- Deaf Australia NSW
- DeafBlind Association NSW
- Deafness Council (NSW)
- First Peoples Disability Network
- Information on Disability and Education Awareness Services (IDEAS) NSW
- Institute for Family Advocacy
- Intellectual Disability Rights Service
- Multicultural Disability Advocacy Association of NSW
- NSW Council for Intellectual Disability
- NSW Council of Social Service (NCOSS)
- NSW Disability Advocacy Network
- People with Disability Australia
- Physical Disability Council of NSW
- Positive Life NSW
- Side by Side Advocacy Incorporated
- Self Advocacy Sydney
- Synapse (Brain Injury Association NSW)

Introduction and Summary of Recommendations

The DNF welcomes the opportunity to contribute to this Issues Paper on National Disability Insurance Scheme (NDIS) costs. This submission focuses on areas of investments that will reduce long-term NDIS costs. The areas of investment we focus on are:

- systemic advocacy to assist all levels of Government to fulfill their responsibilities under the National Disability Strategy;
- the ILC;
- planning processes which encourage participants to develop self-direction; and
- community-based supports for people ineligible for the NDIS.

In summary, the DNF recommends:

1. That the Commonwealth ensure that all levels of government act in concert to fund representative and advocacy organisations to guarantee fulfilment of responsibilities under the National Disability Strategy.
2. That the level of resources allocated to the ILC is commensurate with demand.
3. That information and capacity building supports in the ILC be available to both NDIS participants and non-participants.
4. That the NDIA invest greater resources in early intervention for young people experiencing psychosis and other related disorders, to prevent or minimise a trajectory of long-term disability.
5. That the NDIS planning process resource participants to engage with an independent planner of their choice to develop a life plan exploring greater self-direction. This life plan

The NSW Disability Network Forum can be contacted through the NCOSS secretariat

could then be brought back to the NDIA for approval at the same time as the person's accompanying funding plan is finalised.

6. That the Commonwealth provide additional funds under the National Disability Advocacy Program to facilitate adequate pre-planning support.
7. That people with disability who are not eligible for the NDIS receive continuity of supports in respect of services such as PHaMs and PIR, and other Commonwealth, State or Territory funded services they currently receive.

All levels of Government act in concert to fund the National Disability Strategy

The way the NDIS interacts with mainstream services would be improved if mainstream services were more responsive to the needs of people with disability.

People with disability still encounter significant systemic barriers to full inclusion and participation. Whilst the Australian and NSW Governments have committed to the National Disability Strategy to address barriers and promote a more inclusive and accessible community, progress has been slow. Many mainstream and community services continue to have structural and cultural barriers that challenge people with disability, who need individual advocacy in order to use the services in the way others take for granted. Many mainstream systems continue to require systemic advocacy to demonstrate the barriers experienced by service-users with disability and to contribute to the redesign of systems to be more responsive.

In NSW, this work has been undertaken by a small number of advocacy organisations that face substantial uncertainty of funding. Under the Bilateral Agreement between NSW and the Commonwealth, all of NSW funding for disability services, including approximately \$25 million per year which funds disability advocacy and information organisations, will be transferred to the Commonwealth after 30 June 2018. As highlighted below, this shortfall is unlikely to be made up by increases to the National Disability Advocacy Program.

Currently, the Department of Ageing Disability and Home Care (ADHC) funds advocacy organisations to work across the whole of government to improve systems for people with disability in areas as diverse as health, education, transport, children's services, justice, housing and domestic violence. This work, critical to enabling people with disability to use mainstream services, will be lost unless ongoing funding is provided.

While NDIS Local Area Co-ordinators (LAC) assist individuals to link to mainstream services, it is individual advocacy that assists when things go wrong and systemic advocacy that improves the responsiveness of mainstream services to people with disability. For example, while a LAC can link a person with disability with local doctors, the NSW Council of Intellectual Disability works proactively with trainee doctors to improve communication between doctors and patients with intellectual disability. This leads to earlier diagnosis and more effective treatment, saving the costs to the NDIS that would arise if the person's impairment worsens as a result of a preventable sickness or disease.

In another example, Transport for NSW convenes a group of disability advocacy organisations to assist it in identifying and responding to current, emerging and potential accessibility issues or barriers for people with a disability in the transport system. The advocacy advice to the Department

on these matters has made systems and processes within Transport more accessible to people with disability. As the Commission would be aware, the more accessible the transport system, the less people with disability will need to rely on the NDIS to fund their transport needs.

After 2018, advocacy organisations will no longer be funded to engage in consultation activities for the NSW Government. With many receiving the majority of their funding from the NSW Government and having a focus on advocacy, rather than service provision, it is unclear whether they will be sustainable post June 2018. Making change towards inclusion relies on effective partnerships between Government, people with disability and their representatives. Without the expertise of these organisations, progress is likely to stall, putting greater pressure on the NDIS.

While the DNF acknowledges that the National Disability Advocacy Program (NDAP) funds some advocacy in NSW, this national funding also faces an uncertain future. Outcomes of a review are due in August 2017, but there is no certainty about when a new system will be in place or whether overall funding will be increased to maintain advocacy funding at pre-NDIS levels. More pertinently, it is unlikely that the NDAP will fund activities that fulfil responsibilities of the NSW Government.

Accordingly, the interaction of the NDIS and mainstream services would be improved if all levels of Government act in concert to fund the contribution of advocacy organisations to implementing the National Disability Strategy.

Recommendation 1

That the Commonwealth ensure that all levels of government act in concert to fund representative and advocacy organisations to guarantee fulfilment of responsibilities under the National Disability Strategy.

Greater resources to ILC will reduce cost pressures

The DNF believes that the level of resources allocated to the ILC is not commensurate with the demands on the ILC. Simultaneously, Local Area Coordinators are not fulfilling their community development functions due to the demands of planning work. As a result, many services critical to building the capacity of individuals and of mainstream systems will not be available equitably across Australia.

This approach will increase cost pressures on the NDIS as people who are unable to access information and capacity building in the ILC will need to include capacity building as part of reasonable and necessary support in their NDIS plan, thereby increasing package size. In addition, there is a concern that the lack of widely available capacity building support to those who are not NDIS participants may ultimately lead to an increase in the number of people eligible to become NDIS participants.

Recommendation 2

That the level of resources allocated to the ILC is commensurate with demand.

Recommendation 3

That information and capacity building supports in the ILC be available to both NDIS participants and non-participants.

Importance of early intervention programs for young people with psychosocial disability

In addition to the general Early Childhood Early Intervention (ECEI) approach, early intervention and prevention plays a crucial role for young people with psychosocial disability. Support and education programs can prevent or minimise long-term disability and could decrease the number of people requiring individual packages or decrease package size later on in life. This is a valuable opportunity to develop early intervention strategies to support young people experiencing psychosis or other illnesses or disorders that have a known trajectory of long-term disability without early intervention.

Recommendation 4

That the NDIA invest greater resources in early intervention for young people experiencing psychosis and other related disorders, to prevent or minimise a trajectory of long-term disability.

Planning processes should encourage participants to pre-plan and self-direct their supports

The DNF believes that when participants self-direct their support and self-manage their funds they are more likely to be able to achieve positive outcomes. This is because they will organise paid support to facilitate their desired lifestyle and compliment, rather than drive out, freely given support by family and friends.

In the main, participants who self-manage are less interested in traditional specialist disability services and want their reasonable and necessary support provided by mainstream services, which increases the cost effectiveness of their packages.

The DNF is concerned that in the “My First Plan” process, participants are not encouraged to think about how they might become more independent, more self-managing and more included. In the long term, this will increase costs of NDIS packages.

The pre-planning and advocacy work done by many DNF members assists people to build their capacity to direct their supports, and thus is an important investment in NDIS cost savings. To continue this investment, the DNF believes NDIS participants should have access to independent pre-planning support to develop a life plan exploring greater self-direction. This life plan could then be brought back to the NDIA for approval at the same time as the person’s accompanying funding plan is finalised.

An expansion of the National Disability Advocacy Program will be required to facilitate this pre-planning support.

Recommendation 5

That the NDIS planning process resource participants to engage with an independent planner of their choice to develop a life plan exploring greater self-direction. This life plan could then be brought back to the NDIA for approval at the same time as the person’s accompanying funding plan is finalised.

Recommendation 6

That the Commonwealth provide additional funds under the National Disability Advocacy Program to facilitate adequate pre-planning support.

Continuity of community-based services will reduce cost pressures on the NDIS

The DNF is concerned that the cessation of Commonwealth funded community-based supports for people with disability by 2019-20 will put greater pressure on the NDIS.

In particular, Partners in Recovery (PiR) and Personal Helpers and Mentors (PhaMs) are projected to be rolled into the NDIS. These programs provide practical, one on one, and ongoing support for people with severe mental illness, and assist people to navigate services and advocate for services that meet their needs. The number of people with mental illness receiving social support is far higher than the number of people with psychosocial disability projected to become NDIS participants¹, demonstrating that programs such as PiR and PhaMs are cost effective.

BEING² has received feedback about the personal costs that would occur if these services were not available. The strong care coordination and ongoing support provided through PiR and PhaMs means a person with severe mental illness, who does not meet the criteria for the NDIS, can live a full and contributing life without an NDIS individual support package. Without these supports, there is a risk a person could develop a psychosocial disability over time and therefore become an NDIS participant.

The maintenance of services, such as PiR and PhaMs, therefore represents a cost saving measure for NDIS. The closure of these programs would also put further pressure on the already stretched service system—including, emergency departments, clinical mental health services and other state funded community based supports.

¹ Australian Government Department of Health. (2015) [Australian Government Response to Contributing Lives, Thriving Communities – Review of Mental Health Programmes and Services](#), at 17.

² BEING is the peak body for people with a lived experience of mental illness in NSW.

Recommendation 7

That people with disability who are not eligible for the NDIS receive continuity of supports in respect of services such as PHaMs and PIR, and other Commonwealth, State or Territory funded services they currently receive.