
SUBMISSION

National Disability Insurance Scheme

Parliamentary Joint Standing Committee

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Lived Experience
A U S T R A L I A

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Contents

Introduction	3
A. The impact of boundaries of NDIS and non-NDIS service provision on the demand for NDIS funding, including:	3
i. the availability of support outside the NDIS for people with disability (e.g. community-based or ‘Tier 2’ supports),.....	3
ii. the future of the Information, Linkages and Capacity Building grants program;	3
B. The interfaces of NDIS service provision with other non-NDIS services provided by the States, Territories and the Commonwealth, particularly aged care, health, education and justice services;	3
C. The reasons for variations in plan funding between NDIS participants with similar needs, including:.....	4
i. the drivers of inequity between NDIS participants living in different parts of Australia,	4
ii. whether inconsistent decision-making by the NDIA is leading to inequitable variations in plan funding, and	4
iii.measures that could address any inequitable variation in plan funding;	5
D. How the NDIS is funded, including:.....	5
i. the current and future funding sources for the NDIS,	5
ii.the division of funding between the Commonwealth, States and Territories, and	5
iii.the need for a pool of reserve funding;	5
F. The measures intended to ensure the financial sustainability of the NDIS (e.g. governance, oversight and administrative measures), including:	6
i. the role of state and territory governments, and the Disability Reform Ministers Meetings,	6
iii the way data, modelling, and forecasting is presented in public documents about the NDIS, (e.g. NDIS Quarterly Reports and Reports by the Scheme Actuary), and	6
measures to ensure transparency of data and information about the NDIS;.....	6
G. The ongoing measures to reform the scheme including:.....	6
i. the new early childhood approach, including whether or how early intervention and other supports intended to improve a participant’s functional capacity could reduce their need for NDIS funding, and	6
ii.planning policy for personalised budgets and plan flexibility; and	7
H. Any other related matters.....	7
Contact.....	7

Introduction

Lived Experience Australia (hereafter LEA) is a national representative organisation for Australian mental health consumers and carers, formed in 2002 with a focus on the private sector. Our core business is to advocate for systemic change, empowerment of consumers in their own care, promoting engagement and inclusion of consumers and carers within system design, planning and evaluation and most importantly, advocating for consumer choice and family and carer inclusion.

LEA is pleased to provide this Submission to the Joint Standing Committee on the National Disability Insurance Scheme (NDIS) for your consideration.

LEA has made comment to the relevant parts of the Terms of Reference that are crucial to the mental health sector's people with lived experience as either consumers or families and carers.

A. The impact of boundaries of NDIS and non-NDIS service provision on the demand for NDIS funding, including:

i. the availability of support outside the NDIS for people with disability (e.g. community-based or 'Tier 2' supports),

This is a very contentious issue. Since the introduction of the NDIS, many of the Commonwealth funded mental health services (Partners in Recovery [PiR] and the Personal Helpers and Mentors [PHaMs] program, for example) were closed with our understanding that the funding of those services were rolled into the NDIS. The states and territories were tasked with continuing to fund support services for these and other people who were not accepted into the NDIS, with many of these funded services also closed.

This has left a huge gap in services for those consumers with psychosocial disability with many falling through the gaps. The transition across to NDIS by many people with significant psychosocial disability has not been a smooth process for all who were previously receiving this support through these programs.

LEA and other organisations are currently progressing this issue as a consortium, given the large number still stuck between systems, and the great concern for these people.

ii. the future of the Information, Linkages and Capacity Building grants program;

LEA has made 2 applications for funding under this grants program which we strongly believed were very worthwhile, but unfortunately, neither were accepted. LEA is of the view that this is a very important program to keep in place. We are aware of some of the grants that are successful, and wonder about their value which not always seems to be beneficial to consumers. Perhaps a more rigorous and transparent process of selecting the recipients of grants could be adopted, to ensure that funds are used more directly focus in measuring benefit and outcomes for NDIS recipients and those who are seeking NDIS support.

B. The interfaces of NDIS service provision with other non-NDIS services provided by the States, Territories and the Commonwealth, particularly aged care, health, education and justice services;

The interface depends a lot upon the NDIS support person; their knowledge, skills, energy and commitment . There are a lot of services offered in the community sector such as cooking, ten pin

bowling, music, walking etc but the inclusion of people on the NDIS is dependent upon the knowledge of their support worker to refer or take them to that service.

In terms of States/Territory/Commonwealth service provisions, the supported employment services looking at placements for people with a disability also varies from excellent to poor. An individual can experience both depending upon which service they engage. A current police clearance is required as well as working with 'vulnerable people', and some NDIS participants have, because of their mental illness, been charged with offences relating to violent outbursts etc. This precludes them from accessing the supported employment service's potential placements.

Educational opportunities are also available, but people with severe psychosocial disability find it extremely hard to concentrate, or study. This again often precludes them, based on their mental health capacity.

Aged care is a different issue as the NDIS stops when a person reaches 64 years of age.

Many people with psychosocial disability are subject to Community Treatment Orders, and/or are patients of public community mental health services. Many don't have the time or opportunity to talk about personal issues, goals, fears, hopes etc because much of the interaction is around the management of their medications. A predominance of a more coercive approach that focuses on risk rather than building collaborative relationships and supported decision-making with the person can also mean that people on CTOs lose trust and then don't engage well with these services.

A strong step forward would be for NDIS participants to have access to a psychologist as part of their plan where these issues can be discussed. Some accept a private psychologist via their funding, but not a lot of participants are aware of this provision. The Recovery Coach role could also be more attuned to this particular group who may be more disempowered due to the dual systems in which they find themselves.

C. The reasons for variations in plan funding between NDIS participants with similar needs, including:

- i. the drivers of inequity between NDIS participants living in different parts of Australia,

It is fair to say that metropolitan-based NDIS participants have access to more services than regional, rural or remote, but this is also so with health and mental health support generally.

Given the use and uptake of telehealth, LEA believes that more flexible funding should be made available to access these services within their plans.

- ii. whether inconsistent decision-making by the NDIA is leading to inequitable variations in plan funding, and

LEA has been contacted over time by NDIS participants and/or their families and carers and also those who applied but were not accepted onto the scheme.

The whole application process, criteria and application of that criteria by NDIA personnel is having a detrimental effect on people. The appeal process is equally difficult to navigate and unless someone has an advocate, lawyer etc, we have heard that the process is certainly inequitable.

Additionally, having the understanding of the process, outlining and articulating requirements and goals, can be very hard for a potential participant, especially one who because of their mental illness, has little insight into their issues and needs.

LEA is of the view that there is inconsistent decision-making and it is leading to sometimes large variation in plan funding, and potential inequity of access to psychosocial support.

iii. measures that could address any inequitable variation in plan funding;

For many with psychosocial disability, the core funding line items consist mostly of:

- Assistance with daily life (1)
- Consumables (3)
- Assistance with social and community participation (4)
- Increased social and community participation (9)
- Improved life choices (14)
- Improved daily living skills (150)

An amount is attributed to all these individually to complete the funding for the participant.

Currently, there is very little ability to manoeuvre between these line items, so it is not unheard of to have an underspend in some, and then having to stop support in others because the funding for this item has met its limit.

There certainly is a strong case to be less prescriptive with more availability to move between funded items.

In relating to the previous question, this also is a challenge for NDIA staff to negotiate the needs of the potential participant who may require a lot of assistance, for example in social and community participation when they are completely isolated.

Having a flexible funding package is required and some of the items should be rolled together.

D. How the NDIS is funded, including:

i. the current and future funding sources for the NDIS,

LEA is of the understanding that the NDIS contemplates having 60,000 participants with psychosocial disability on the NDIS. This and other disabilities means that people can have the necessary assistance to live a fulfilling life, despite their issues.

LEA is also of the understanding that the NDIS funding has blown out extensively over time to an amount far exceeding expectations.

LEA believes that people should be treated in a respectful, dignified and compassionate manner and the NDIS can offer this. What costs can Australia put on this approach.

ii. the division of funding between the Commonwealth, States and Territories, and

LEA has already commented on this issue previously in this Submission.

iii. the need for a pool of reserve funding;

This is a difficult question for LEA to respond to as we are a mental health consumer and carer organisation and do not feel adequately skilled to provide commentary of this question other than to say the NDIS has been a clear game changer for people with a disability and especially their family and carers. We hear comments all the time from families and carers saying that they can now be

parents or partners, rather than carers. LEA believes a sufficient funding pool is necessary to accommodate the needs of those with a disability.

F. The measures intended to ensure the financial sustainability of the NDIS (e.g. governance, oversight and administrative measures), including:

- i. the role of state and territory governments, and the Disability Reform Ministers Meetings,

LEA believes that the NDIS is the responsibility of all governments working together to achieve the best possible outcomes for people with a disability. This includes measure that need to be taken to ensure the ongoing sustainability of the NDIS in a shared funding capacity.

- lii the way data, modelling, and forecasting is presented in public documents about the NDIS, (e.g. NDIS Quarterly Reports and Reports by the Scheme Actuary), and

measures to ensure transparency of data and information about the NDIS;

LEA believes that public reporting is critical in keeping Australians including participant and family and carer organisations such as ours up to date with costs, outcomes, accountability etc.

G. The ongoing measures to reform the scheme including:

- i. the new early childhood approach, including whether or how early intervention and other supports intended to improve a participant's functional capacity could reduce their need for NDIS funding, and

NDIS participants, their families and carers are of the understanding that the funding of their plan is for life. This gives certainty as people strive for a more fulfilling life, despite their disability.

However, psychosocial disability can also be episodic in that within the chronic and life altering disability, there are crises or episodes which require hospitalisation (often involuntary) community treatment orders under mental health legislation etc

Full recovery in the absence of symptoms etc is not possible for many people however LEA does support a more wholistic approach which could increase their functional capacity.

LEA has heard from many NDIS participants, reference to recovery is frightening as they are very fearful they will lose their NDIS funding. This is a real concern and can be seen as a barrier to obtaining their best possible life experiences, despite their mental illness.

LEA strongly supports early identification of an imminent crisis, and intervention strategies, but we see the Australian mental health system is unable to accommodate this approach (admit people early in their episode) because it is crisis driven, beds seem inadequate to accommodate early intervention strategies, and is broadly speaking, uncoordinated.

The Australian Government has announced a number of key interventions targeting children 0-12 years old and also heavily funds the Headspace initiative for young people. LEA strongly supports these measures and hopefully this will bring about identifying children and young people at risk, and support their mental health and wellbeing to a point where they may never require the NDIS.

ii. planning policy for personalised budgets and plan flexibility; and
LEA has covered this issue in C (iii) above.

H. Any other related matters.

LEA believes the success and sustainability of the NDIS depends very much on the organisations tasked with providing NDIS support services/providers to the participants.

We are concerned that for some support providers there seems to be little understanding of boundaries, mental health issues, awareness of the lack of insight of the participant, or organisational oversight of what and how effective their support providers are handling their interactions and tasks with participants.

Psychosocial disability is far less tangible than other physical disabilities, where participants abilities can be seen and addressed.

LEA is of the view that education in the mental health sector, oversight of service providers, and a registration and certification process for service providers is required including the same personal development, training, supervision offered to other health providers is critical to the ongoing success of meeting the needs of people with psychosocial disability across Australia.

Contact

We would be very keen to provide further clarification or opportunity to further discuss or concerns, my details are below.

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