

Disability Council NSW

Submission to

Joint Standing Committee on the NDIS: The Provision of Services under the NDIS for people with psychosocial disabilities related to mental health conditions

15 February 2017

Locked Bag 4028, Ashfield NSW 2131 Ph: (02) 8879 9100 www.disabilitycouncil.nsw.gov.au

Email: disabilitycouncil@facs.nsw.gov.au

Contents

Contents	2
Disability Council NSW	2
Introduction	
List of Recommendations	4
People with dual diagnosis or presumed dual diagnosis	5
The importance of housing	5
Transition from prison to the community	6
The episodic nature of mental illness	7
Support for people without an NDIS package	7
Family and other supports	8
Expertise of NDIS planners	8
References	9

Disability Council NSW

The Disability Council NSW (Council) was established under the *Community Welfare Act 1987* (NSW), and was re-constituted under the *Disability Inclusion Act 2014* (NSW) on 3 December 2014. Council's main responsibilities under the Act are to:

- Monitor the implementation of Government policy;
- Advise the Minister on emerging issues relating to people with disability, and about the content and implementation of the NSW State Disability Inclusion Plan and Disability Inclusion Action Plans;
- Advise public authorities about the content and implementation of Disability Inclusion Action Plans;
- Promote the inclusion of people with disability in the community and promote community awareness of matters concerning the interests of people with disability and their families;
- · Consult with similar councils and bodies, and people with disability; and
- · Conduct research about matters relating to people with disability.

The Council consists of a diverse group of 8 to 14 members (currently 12 members). Each member is appointed for up to four years by the Governor of NSW on the recommendation of the Minister for Disability Services. Members are selected to be on Council because:

- · They have lived experience of disability
- They have particular expertise on disability issues
- They want to improve the lives of people with disability

Council is funded by the NSW Government through the NSW Department of Family and Community Services (FACS) and is supported by a secretariat team within FACS.

Introduction

The Disability Council does not have long-standing experience in the field of mental illness. Only since the NDIS started has mental illness been considered part of the disability field. Historically, people with disability and those with mental illness were often lumped together in the same institutional settings, to the detriment of both groups. Disability advocates have long fought for the proper distinction to be made between the two groups, as part of the fight for proper treatment of people with disability, and to counter the widespread public perception that having one condition automatically meant having the other.

Only recently has there been recognition that the social consequences of mental illness constitute, in themselves, a disability. The NDIS has completed that circle, by recognising that we must offer support to those with a psychosocial disability on the same terms as we offer it to those with a physical impairment or an intellectual disability.

That recognition flows through to the membership of the Disability Council, which now includes people with psychosocial disability, as well as with a range of other disabilities types, including—vision impairment, hearing impairment, intellectual disability, cerebral palsy and acquired brain injury.

This submission is based on feedback received from Council members, and on their understanding of the issues that arise from the trial sites, and from their experience in the community.

List of Recommendations

Recommendation 1: That services, treatments and supports be decided on the needs of the person with a psychosocial disability, and not by the diagnosis and silo-ing of their needs into one category/system or another

Recommendation 2: That strong and continuing links be made between NDIA and local housing authorities, so that provision of housing is co-ordinated to complement the NDIS supports provided to a person with psychosocial disability

Recommendation 3: That NDIA considers retaining more traditional funding models (eg block funding) in exceptional circumstances, such as for transitioning ex-prisoners, with a view to improving individual outcomes.

Recommendation 4: That recognition of the episodic nature of mental illness will lead to models of support that allow for easy movement into and out of the support system

Recommendation 5: That ILC be allowed to directly fund specific mental health services that, through their minimal supports, can make the difference between continued life in the community, or relapse back into serious illness; this prevents people transitioning from needing minimal social supports within a community setting to needing a full NDIS package

Recommendation 6: That NDIA encourages, supports and funds long-term contingency planning by people with mental illness, and their families and support networks, as part of its acknowledging the episodic nature of mental illness

Recommendation 7: That the NDIA develops 'expert panels' on various disability types, including psychosocial disability, who can give advice to planners that reflects the best knowledge of that disability. Similarly, plans which request only minimal support compared to statistical norms could be referred to the panel to ascertain if a person has not been able to properly ask for the supports that they need. Panels should also have expertise in consulting with families/carers.

People with dual diagnosis or presumed dual diagnosis

The provision of services to people with mental illness is primarily the responsibility of the various health departments and health services across Australia. The NDIS is concerned with the social supports needed by people with psychosocial disability to enable a sustainable, dignified and productive life in the community.

But a person with psychosocial disability may also have another disability, just as a person with disability may also have a mental illness. The Disability Council – and the disability movement generally – has held a long-standing concern that the presence of both mental illness and other disability, particularly intellectual disability, has led to an abrogation of responsibility for treatment, with each system seeking to transfer responsibility to the other system.

Equally, within the health system, there have been instances of people with genuine medical needs not receiving treatment when their symptoms are ascribed to their mental state rather than their physiological status¹, and vice versa – the Council is aware of reports of overdiagnosis of mental illness based on a person's intellectual, physical or sensory disability.

Conversely, the Council is aware of people with mental illness but with no other disability who have been directed by the NDIS to supports for people with intellectual or other disabilities.

The Disability Council welcomes the NDIS for its ability to respond to the needs of the client, irrespective of their diagnosis. Our recommendation asks simply that co-ordination of services across all areas that respond to a person with mental illness be a continuing priority.

Recommendation 1: That services, treatments and supports be decided on the needs of the person with a psychosocial disability, and not by the diagnosis and silo-ing of their needs into one category/system or another

The importance of housing

The underfunding of supports for people with mental illness has been a longstanding feature since the closure of the large institutions under the Richmond report. It manifests in the increasing numbers of homeless people, the majority of whom have a mental illness². Similarly many reports have pointed to the large proportion of people incarcerated in the criminal justice system who have a mental illness.

Concern has been expressed about the delivery of service options to people whose illness has made them homeless, and out of contact with the normal routes to obtaining professional help. Although the NDIS is rightly founded on the principle of personal choice and control, this applies only to those who are participants. Prisoners, and those leaving prison, may not have access to the NDIS, or even be aware of it; further, there may not be suitable services available to them.

Experience in the USA has shown that provision of secure, safe housing to homeless people is the best precursor to them gaining enough stability to access appropriate mental health services, and subsequently, employment, physical health support and education – all the things that lead to a successful transition to a stable life in the community.

Recommendation 2: That strong and continuing links be made between the NDIA and local housing authorities, so that provision of housing is co-ordinated to complement the NDIS supports provided to a person with psychosocial disability

Transition from prison to the community

The Community Restorative Centre, in its recent report³, recognised the instability which characterises the transition of people with mental illness from the prison system to the community at the end of their sentence. This instability derives from the interaction of their illness with the loss of routine, their need to suddenly be self-reliant, and the likelihood of their being homeless and under-resourced financially. All too often, this leads to reoffending, including drug use, and rapid re-incarceration.

The instability itself militates against a recently released prisoner being able to engage with the measured process of planning inherent in accessing the NDIS, and using the supports that then become available. They miss appointments, they move frequently, they take drugs, and they get arrested again. The likelihood of receiving continuing, consistent treatment for their mental illness is very low, and the lack of that treatment makes re-incarceration almost certain. Our high recidivism rates attest to this ugly truth.

The Disability Council believes that a rethinking of the NDIS funding model – specifically for transitioning ex-prisoners – could enhance the stability of those with psychosocial disability leaving the prison system.

The current individualised funding model works against the sustainability of post-release services. Specifically, as clients move in and out of prison, and in and out of hospital, and in and out of their residence, cash-flow to services, particularly accommodation

services, is unreliable. If a service closes for lack of consistent funding, clients are left with few options to receive vital treatment, counselling and employment support.

The Disability Council remains committed to the NDIS model of individual choice and control. However, we strongly encourage NDIS to consider other funding models in these exceptional circumstances, with a view to improving outcomes for those with psychosocial disability transitioning into the community.

Recommendation 3: That the NDIA considers retaining more traditional funding models (eg block funding) in exceptional circumstances, such as for transitioning exprisoners, with a view to improving individual outcomes.

The episodic nature of mental illness

The trial sites for the NDIS have already illustrated the difficulties of dealing with the episodic nature of mental illness, and the matching need for supports. The Disability Council commends the work that has been done, and recommends only that continued effort be made to find models of support that meet these needs.

A person suffering a sudden relapse is, almost by definition, not in a position to go through a considered, time-consuming planning process to access needed supports through the NDIS. Those supports should be made available as soon as they are needed. It is perhaps better to err on the side of giving supports when they may not, in the end, be needed, than to withhold them when they are necessary for a person to be safe and supported.

Identifying the onset of an episode may also be an issue. Carers and family members of people with episodic conditions are often in a position to identify the needs for supports, and their input should be considered, in line with the *Carers (Recognition) Act 2010.*¹ (See also Recommendation 6.)

Recommendation 4: That recognition of the episodic nature of mental illness will lead to models of support that allow for smooth and appropriate movement into and out of the support system

Support for people without an NDIS package

It is of concern that there are likely to be people with psychosocial disability who do not qualify for an NDIS package, although their needs cannot be met by the ILC (with its focus on the delivery of generic community services to people with disability).

¹ http://www.austlii.edu.au/au/legis/nsw/consol act/ca2010197/

For example, having a support group to meet with is a regular part of addiction recovery, but this is not part of the community's normal provision of service. But a support group may be the key to keeping a person from lapsing in their medication regime, or provide enough social support for them not to lapse into depression again. Such services may not necessarily be seen by Health systems as 'treatment' and therefore not funded. In the absence of funding from Health systems, who will fund these 'low-key' social supports that marginalised people rely on, and the lack of which can be the trigger for more serious illness – leading to much greater strain on both Health systems and the NDIS?

Recommendation 5: That ILC be allowed to directly fund specific mental health services that, through their minimal supports, can make the difference between continued life in the community, or relapse back into serious illness; this prevents people transitioning from needing minimal social supports within a community setting to needing a full NDIS package.

Family and other supports

People with carers, family or other social supports do better in the treatment of their mental illness. However, family and individual conflict and distress can occur when a person is relapsing but because of their illness, cannot see the need for treatment to recommence, whilst it is obvious to their family and support networks that they need help.

One way through the dilemmas inherent in this situation is to ensure pre-planning takes place between episodes of illness, so that people are clear on their roles during the bad times, and even empowered by the person with a disability to act against their expressed wishes during an acute episode of illness, particularly in regard to entering treatment.

The Disability Council recognises that this issue should rightly be part of the Health system's continuing treatment, and so confine our recommendation to the areas of liaison and co-ordination.

Recommendation 6: That NDIA encourages, supports and funds long-term contingency planning by people with mental illness, and their families and support networks, as part of its acknowledging the episodic nature of mental illness.

Expertise of NDIS planners

The Disability Council has been made aware of the beliefs of many in the disability community about the lack of knowledge of planners about specific disabilities, and the

attendant needs of the participant. A truism common to all cognitive impairments — mental illness, brain injury, intellectual disability — is that the impairment makes it difficult for the person involved to ascertain, express, and sometimes fight for the supports they need. Many people are intimidated by the process of applying, as are many carers and family members present as a supporter. Others are overly compliant to suggestions, at the expense of their true needs. Others are simply not aware of their own internal process, or don't know the words to express them.

Recommendation 7: That the NDIA develops 'expert panels' on various disability types, including psychosocial disability, who can give advice to planners that reflects the best knowledge of that disability. Similarly, plans which request only minimal support compared to statistical norms could be referred to the panel to ascertain if a person has not been able to properly ask for the supports that they need. Panels should also have expertise in consulting with families/carers.

References

- 1. ABC TV. 7.30 Report 8/2/17
- 2. Mental Health and Homelessness Final Report: Mental Health Commission of NSW June 2013
- 3. Supporting people with Cognitive Impairment and criminal justice system involvement: A briefing paper overviewing key challenges and service gaps.
- Alison Churchill, Mindy Sotiri and Simone Rowe (Community Restorative Centre)