

Submission by the Commonwealth Ombudsman

JOINT STANDING COMMITTEE ON THE NDIS

THE PROVISION OF SERVICES UNDER THE NDIS FOR PEOPLE WITH PSYCHOSOCIAL DISABILITIES RELATED TO A MENTAL HEALTH CONDITION

Submission by the Acting Commonwealth Ombudsman, Richard Glenn February 2017

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BACKGROUND

The Commonwealth Ombudsman safeguards the community in its dealings with Australian Government agencies by:

- correcting administrative deficiencies through independent review of complaints about Australian Government administrative action
- fostering good public administration that is accountable, lawful, fair, transparent and responsive
- assisting people to resolve complaints about government administrative action
- developing policies and principles for accountability, and
- reviewing statutory compliance by law enforcement agencies with record keeping requirements applying to telephone interception, electronic surveillance and like powers.

The Commonwealth Ombudsman's unique position in the Australian administrative law landscape provides this office with an understanding of the individual experiences of members of the public, who are dissatisfied with the way that government has dealt with their concerns. The Commonwealth Parliament has given the Ombudsman's office the power to investigate those complaints by obtaining records and information from the agency that would not ordinarily be available to a person acting on their own behalf. Over time, through investigating complaints about the actions of a particular Commonwealth department or agency, the Ombudsman's office is able to build up a detailed picture of an agency's operations.

The office also engages with peak bodies and community representatives that have direct access to stakeholders affected by government policies and programs. This engagement provides an opportunity for the office to develop a more holistic understanding of the public's experience of those programs, and is of particular value when the affected parties may be disinclined to make individual complaints.

THE OMBUDSMAN'S ROLE

The Commonwealth Ombudsman has jurisdiction to consider complaints about the administrative actions and decisions of Australian Government departments and agencies, as well as the delivery of services by contracted service providers for and on behalf of the Australian Government.

Within its Commonwealth jurisdiction, the Ombudsman's office can receive and consider complaints about the National Disability Insurance Agency (NDIA) and its administration of the National Disability Insurance Scheme (NDIS) (the Scheme). Since the NDIS commenced on 1 July 2013 (initially in trial form) the Ombudsman's office has received 255¹ complaints about the NDIA, with 154 of those being received in 2016-17 alone. We expect this number to continue to grow steadily each financial year as more people enter the Scheme.

Currently, the complaints arrangements for the NDIS are somewhat fragmented. While the Commonwealth Ombudsman has jurisdiction to handle complaints about the NDIA, state

¹ At 2 February 2017

and territory disability complaints bodies remain responsible for handling complaints about providers of NDIS-funded services in their state. This arrangement will continue until the Australian Government implements a national quality and safeguarding framework for the NDIS.

When necessary, our office engages with the relevant state or territory body to investigate cross jurisdictional complaints. For example, many complaints raise concerns about the NDIA's planning process (which falls within the Commonwealth Ombudsman's jurisdiction) as well as a matter of service provision which is a state or territory responsibility. To date the Commonwealth Ombudsman has worked on a number of cross jurisdictional complaints. While the growth in the number of complaints is promising, we are mindful that people with disability often do not complain readily. In turn, for the past eighteen months the Ombudsman's office has focused heavily on building a broader understanding of the NDIS, as well as the experience of people accessing the Scheme. This has included visits to each of the original trial and early launch locations to meet with the NDIA, participants, families, carers, support people, advocates, peak bodies and service providers.

Using our complaints and the intelligence gained from engagement we routinely provide feedback to the NDIA, both locally and nationally. We have also made submissions to a number of inquiries relating to the NDIS including the Review of the Operation of the *National Disability Insurance Scheme Act 2013* conducted by Ernst & Young (October 2015), the DSS reviews of the National Disability Advocacy Framework (July 2015) and the National Disability Advocacy Program (June 2016), and the government's consultation on the draft NDIS Quality and Safeguarding Framework (May 2015).

RESPONSE TO TERMS OF REFERENCE

The Ombudsman's office welcomes the opportunity to contribute to the Committee's Inquiry into the provision of services under the NDIS for people with psychosocial disabilities related to a mental health condition. We provide the following comments based on the individual complaints and engagement work we have completed to date.

Complaints

Our office has received a number of complaints about the NDIA from people who identified as having a mental health condition. The bulk of these complaints reflected similar issues as those complaints received from people with other disabilities including delays, poor communication, dissatisfaction with plans and planning staff, and difficulties with the review process. However, what was different, and particularly concerning about the complaints we received from people with mental health conditions were the reports of those people feeling alienated from the access and planning processes, and being more inclined to disengage from the Scheme when they experienced problems.

Eligibility criteria

We have received feedback that suggests a barrier to accessing the Scheme, especially for young people with psychosocial disability, is that medical professionals may be reluctant to assess the person's condition as permanent or likely to be permanent. This tends to be either because of the difficulties with early diagnosis or for fear of 'labelling' a young person with a condition that has associated stigma. Stakeholders also indicated that some health

professionals believe making a diagnosis of 'permanent' may impede recovery for some people.

Access to the Scheme requires the prospective participant to arrange and fund the necessary assessments or reports and provide these to the NDIA. There is no provision for the NDIS to reimburse these costs, unless the NDIA specifically requests the assessments.² Feedback to our office is that the expense of obtaining specialist reports can be significant barrier to accessing the NDIS, particularly as many people with a mental health condition are often already financially disadvantaged. Sometimes this can lead to a diagnosis of one disability (the one already or more easily diagnosed, such as a physical disability) but not another that is not as easily assessed (such as a learning disorder or mental health condition). In turn, the person's NDIS plan may reflect only part of their support needs.

However, even providing appropriate evidence of a severe functional impairment can be difficult for a person with a mental health condition. Stakeholders told us that, when a person with a mental health condition is not functioning, they often cancel their medical appointments and only attend when the episode has eased, thus appearing in better health than they actually are. Stakeholders reported that this approach applies equally to NDIS planning meetings, where the participant only attends on a "good" day.

We recently met with staff working on a NSW project aimed at assisting people with transition from the state system to the NDIS. They confirmed there is often difficulty for prospective participants in obtaining evidence of their disability because some people who have been accessing state services don't have clear or recent evidence of a diagnosis. Indeed, many of these prospective participants have an inherent mistrust of government and the medical profession and are deciding to opt out of the Scheme rather than obtain necessary evidence. The project also found that some of these people have complex needs and comorbidities (especially related to ageing), while at the same time caring for children with disabilities. These people often do not have the time, energy or capacity to engage with the process of seeking scheme access. Further, many of these people also have a diagnosis of mental illness, or it is suspected they would have if properly assessed.

Another barrier to access (and broader participation in the Scheme) is the need for participants to have a MyGov account and use the internet to engage in the NDIS, including to book services once their plan is approved. Peak bodies told us that many people with psychosocial disability do not access the internet for a variety of reasons including lack of access to a computer, cost of services and mistrust of technology. During outreach an advocacy body told us they had been assisting people with psychosocial disability who were living in a boarding house to make access requests to the NDIA by sitting with them and sending an access request via email. This had initially been accepted by the NDIA but the practice was then discontinued and all prospective participants are now required to fill out a paper form, which can only be obtained by requesting it from the NDIA. The advocacy body was particularly concerned about this shift as it had previously been able to coach, peer support and capacity build with these people while assisting them with access. Without this assistance it was unlikely these people would be able to make an access request to the NDIA at all.

A further barrier can be as simple as the person being homeless and not having a stable address to which the access request form can be posted. Further, it is understandable that

² Section 6, National Disability Insurance Scheme Act 2013

people living in a car or in a park with even their most basic needs not being met will often have difficulty focusing on anything as time-consuming or complex as the access process.

Transition to NDIS

Many peak and community organisations have told us that, based on Australian Bureau of Statistics data, they believe the actuarial projections for people with a mental health condition who are or will be eligible for NDIS funding are likely to be grossly underestimated. In turn, these organisations have queried how well resourced the NDIA and the Scheme will be to adequately address the needs of people with mental health conditions.

On the other hand, stakeholders and even the media³ have talked about the risks that many people who are currently receiving Commonwealth or state/territory funded mental health services – many of which will be phased out once the NDIS is fully implemented - will not meet the eligibility criteria for the NDIS and, in turn, may receive little or no services. Further, many have indicated the data collected by the state and Australian governments do not factor in those people who need, but are not currently receiving mental health assistance, meaning that the size of the at-risk group is even greater than already acknowledged.

We are aware that governments have committed to providing continuity of existing supports for those people with mental health conditions who will not be eligible for the NDIS. However we are also aware there are many changes occurring in mental health 'systems' occurring as the NDIS is rolled out nationally. Stakeholders have expressed concern that these changes (in particular the withdrawal of block funding for most services and the focus on individual agency and choice) may mean the people who are the most vulnerable but the least likely to complain or seek support – including people with little or no informal support, such as Indigenous people and people from culturally and linguistically diverse backgrounds – are at the greatest risk of falling between the cracks.

The media⁴ has also recently reported on significant decreases in the workforce for mental health service providers in light of the uncertainty about future funding and demand for services in the absence of block funding. This may prove to be problematic if people are eligible for the NDIS but then unable to access a suitable service as a result of under-supply.

Information, Linkages and Capacity (ILC) Building framework

The ILC Framework aims to provide information and coordination around disability support to those who are not eligible for the NDIS, as well to the broader community. The ILC Framework includes Local Area Coordinators (LACs).

Participants with mental health conditions, along with peak bodies and advocates, have spoken to us about the difficulties they have encountered in engaging (or not engaging) with LACs in their local area. In particular:

• some LACs do not have even a basic understanding of the impact of a mental health condition on a person's life or on their family / community

³ *100,000 mentally ill lose NDIS cover,* **The Australian**, 19 December 2016

⁴ NDIS funding changes lead to mental health case worker job cuts in northern Tasmania, **ABC Online**, 20 January 2017

- many LACs seemed ill-prepared to respond appropriately to the issues raised by participants with mental health conditions and/or their families and carers, perhaps due to a lack of experience and training
- where an LAC was unable to assist with an issue, they appeared to lack awareness of appropriate referral channels for people with mental health conditions.

The lack of referrals in foundational areas such as housing assistance left participants in a situation where even if they had plans and funding, they may not be able to access services because their basic day to day requirements were not being addressed. For example, if a participant had insecure housing they could not engage home delivered support services, or if a participant has insufficient funds to pay the entrance fee to a swimming pool, the support to attend the pool can't be utilised.

Plans and planning

The NDIA fact sheet⁵ *Psychosocial disability, recovery and the NDIS* acknowledges the often episodic nature of psychosocial disability and the focus on recovery, with the provision for flexible supports when needed. It also emphasises the need to work with existing government, community and informal support systems and clearly states the NDIS does not fund health related services.

The experience of some scheme participants with psychosocial disability is that there is a lack of clarity around the distinction between 'disability' (funded by the NDIS) and 'health'. For many people with psychosocial disability, their disability and their health issues are inextricably linked and are difficult, if not impossible, to delineate. The question of health versus disability has been argued on appeal at the Administrative Appeals Tribunal (AAT) a number of times to date and will almost certainly be a point of continued appeal into the future, especially as a greater number of people with psychosocial disabilities access (or attempt to access) the NDIS. It can be onerous to expect participants to go through an internal and external appeal process on this point especially if they are unwell. Legal and advocacy bodies emphasised the strain experienced by participants who had either appealed an NDIA decision or complained about the NDIA's processes.

We have heard from stakeholders about prospective participants who have been contacted by phone by the NDIA for a discussion, but not understood it was a planning meeting until they then receive a plan in the mail. We understand the NDIA has subsequently adjusted the messages given to participants about these phone planning discussions, but there remain some concerns about how well equipped some participants – particularly those who may lack capacity or who have a guardian or nominee – are to participate in these planning discussions without support.

In situations where families or support people were involved in planning discussions, some reported feeling that the planner dictated what the participant needed, and ignored the lived experience of the person with disability. A number of participants reported being told they "should be further along the way to recovery" which discounted their own feelings and belief. Peak bodies have pointed out to our office that recovery is an individual process, not easily able to be defined or compared.

⁵ <u>https://www.ndis.gov.au/medias/documents/heb/h21/8799160959006/Fact-Sheet-Psychosocial-disability-recovery-and-the-NDIS-PDF-774KB-.pdf</u> accessed 23/12/16