

Decision-making controls for sustainability – National Disability Insurance Scheme access

CMHA would like to thank the Australian National Audit Office (ANAO) for the opportunity to contribute to the audit on Decision-making controls for sustainability - National Disability Insurance Scheme (NDIS) access.

CMHA is a coalition of the eight state and territory peak community mental health organisations. CMHA, through its state and territory bodies, has a direct link and contact to mental health organisations delivering services at the community level. CMHA provides a unified voice for approximately 800 community-based, non-government organisations who work with mental health consumers and carers across the nation and who are members of, or affiliated with, the various coalition members.

CMHA promotes the recovery of people living with a mental health condition so that they are contributing citizens and included in all of the economic and social aspects of their community. The organisation presents a united and representative voice for the community managed mental health sector who work every day on mental health issues and have the expertise through a specialised workforce, including a peer workforce and lived experience.

CMHA remains committed to the NDIS and the benefits that it can bring to the lives of people living with a mental health issues. However, it is vital to ensure that the recovery focus of community managed mental health services — which has come to inform the overall approach that is taken to addressing mental illness — is not lost. We also do not want to create a situation where some people receive a high level of support and others do not. People living with a mental health condition must have their psychosocial needs met regardless of whether they are eligible for the NDIS or not.

CMHA's contribution to the audit will address the objective of the ANAO audit in terms of examining NDIS access decisions being consistent with legislative and other requirements, and the audit criteria:

1. Suitable information, training and guidance is available to support effective decision-making about access to the NDIS;
2. Suitable administrative systems and processes are in place to support transparent, accurate, timely and consistent assessment of eligibility; and
3. Suitable quality and compliance arrangements have been established to mitigate the risk of incorrect NDIS access decisions.

Much of the information provided has been raised in other CMHA submissions to processes examining the NDIS, primarily the Productivity Commission NDIS Costs Issues Paper and the Joint Standing Committee on the NDIS inquiry into mental health.

Legislative and other requirements

A key issue that is impacting on choice and control for NDIS participants and access to the NDIS, and consequently sustainability, is the interpretation of the NDIS Act by the National Disability Insurance Agency (NDIA) in making decisions about participants plans.

Issues are occurring with requests for plan amendments triggering reviews of full plan, which are done centrally rather than regionally. Clients are typically not permitted to see a plan before it is finalised – although anecdotally this does not appear to be applied consistently - which anecdotally providers state is hindering clients understanding of their plan. The NDIA are stating verbally in meetings that the planning process is adhering to legislation.

The use or interpretation of the NDIS Act 2013 by the NDIA appears to be an area requiring examination. The December 2015 independent review of the NDIS legislation by Ernst and Young¹ stated as a key finding that while, at the time, the legislative framework was broadly enabling government to progress the NDIS Act, an important caveat was that the NDIS was at an early stage and evolving. That as the scheme moved into more locations and took on more people, a key recommendation was the government should conduct another review in 2 to 3 years to ensure the legislation was 'fit for purpose' for full scheme.

CMHA has recommended that a review of the legislation is required as its interpretation is leading to implementation problems and escalating administrative costs with the scheme.

Suitable information, training and guidance is available to support effective decision-making about access to the NDIS

NDIA engagement with participants

A central issue about information, training and guidance will be how the NDIA engages with participants or prospective participants and the level of skills of those assessing and developing plans in particular areas, such as mental health. It is important to note that there will be large variances in this area in terms of the skills of people assessing plans, which the current planning process has shown.

CMHA is concerned that the NDIA is moving away from face-to-face assessment and planning for people applying for the NDIS. This will have a significant impact on all people applying for the NDIS, but particularly people with any form of mental illness or cognitive impairment or disability. It creates significant difficulties for communicating or assessing level of need, and taking into account relevant factors such as non-verbal communication and issues, including body language. Further, for mental health, which is typically episodic, having non-face-to-face assessment and planning creates difficulties in adequately assessing need and the person's circumstances.

Some service providers have reported that conducting engagement and planning via the telephone limits the assessor's ability to get a true understanding of an individual and their situation, particularly given a large proportion of communication is non-verbal. Non-verbal communication is an essential part of building rapport with people with a psychosocial disability. This is especially true for people who experience symptoms such as depressive thoughts or paranoia. While using technology plays an important role in increasing access to services, a move away from face-to-face consultations will also mean a lack of rapport and an increase in the number of people who will disengage from services.

In order to complete a thorough accurate assessment, meeting face-to-face with a consumer is key, and this process can take several meetings as part of the process. A provider in Tasmania provided the example of dealing with a young person in the community with severe behavioural and mental health issues who was attempting to access the NDIS where access to internet and phone was limited. While there was access to a mobile (again limited), credit to use the device was not an option. The situation was also compounded by the individual's learning difficulties that made understanding and accessing the internet and completing any form connected to the NDIS difficult. It was important for this young person to have trust and rapport with the worker before any information could be shared or a plan created.

¹ Ernst and Young, Independent review of the NDIS Act, December 2015, https://www.dss.gov.au/sites/default/files/documents/04_2016/independent_review_of_the_ndis_act.pdf

NDIS assessment and planning process

Providers have suggested that having pre-planning assistance for consumers and allowing consumers to view their plan before it is finalised would be steps to address some of the problems occurring through the planning process. The pre-planning phase is viewed as vital, and it is important that people receive information to help in the pre-planning phase, as many people are going to planning sessions unprepared and individuals don't always know what they can ask for or how to articulate their disability. The required information would include:

- Documentation needed to support the assessment process
- Guidance on how people can be thinking about goals and how their needs may change in future.
- Guidance on the types of services that are available.
- Services people currently access as compared to what is actually available
- Longitudinal evidence (e.g. case notes) is vital as people may have difficulty defining their needs in a short term assessment. The wider the evidence network (psychiatrist, GP social worker, case worker social supports), the better the evidence.

The NDIA must play a role in ensuring such information is provided, but currently this is not occurring.

The following quote from a provider in the NT exemplifies the issues occurring with the planning process:

The main issue affecting the majority of our clients is their failure to participate fully in discussions regarding transition to the NDIS as many struggle to fully understand the scheme. It is challenging to communicate all the aspects of the NDIS and build the understanding of clients regarding the assessment process, how they will access services and how they may be affected if deemed ineligible. To overcome these issues there is continuous engagement with the client with the support of their family members, however this can be a long and resource intensive process. Another issue is that our clients are very transient and some, despite all efforts, cannot be contacted.

There needs to be an adaptive and flexible approach to the planning process, providing consumers with the opportunity to review plans prior to them being finalised by the NDIA. Plan errors and inconsistencies not only create confusion and frustration for consumers, their families and carers, they also place a heavy administrative burden on community mental health organisations and the NDIA.

There must be performance indicators that sit alongside the indicator of the number of people receiving plans - currently the main indicator for the NDIS - such as the number of reviews and appeals requested, and consumer satisfaction with and understanding of plans received.

Skills of assessors and planners

A further issue raised has been planners being adequately experienced in mental distress. In order to be effective, planners need to have an understanding of psychosocial disability and mental illness, and the impact these have on the entire planning process and future needs of consumers and participants. This includes adopting a recovery framework to developing a plan and assessing people's needs. A provider of an Aboriginal and Torres Strait Islander service in the NT has also made the point that many of their clients have elements of post-traumatic stress disorder (PTSD) due to their cultural background, therefore an understanding of not just mental health but culturally relevant factors needs to be a significant consideration.

The feedback from the sector has been that plan implementation has been difficult due to many people not understanding what are the types of services they can purchase and what is then in their final package. A central part of this occurring is the understanding of the planners as to what services are available. This does not mean these services won't be available, however, the community-managed sector needs to be supported to enable them to evolve and maintain services, and the planners need to be well linked into and aware of what supports that are currently available. This is particularly important in remote areas, including in Aboriginal and Torres Strait Islander communities, where services are often provided by a regional council.

If a planner understands the depths of a person's disability and what is needed to support the individual, the package developed will suit them over a longer term. This reduces the need for a plan to be amended in the future, thereby reducing administrative burden on the NDIA and building confidence in the process for the consumer.

Issues for people experiencing social and geographic isolation

There is concern about engagement with and access to the NDIS for people who experience social and geographic isolation in rural and remote regions. Feedback from community mental health organisations in Queensland is that these people are often hard to reach and generally not engaged with services due to lack of knowledge of the availability of services and supports. For many of these people experiencing mental health issues, access to appropriate and understandable information is challenging. In some rural and remote regions in Queensland, there are also concerns that there will not be adequate NDIS registered services available for people to purchase the supports and services that they need.

Input from a provider in Tasmania demonstrates the difficulties created by geographic isolation:

Geographical isolation (rural & remote areas) only amplifies the difficulties for the consumer to access the NDIS. In assisting a young person and their family in North West Tasmania, it was extremely difficult for them to meet with the planner and have more of an input regarding her needs.

It was also difficult for the family to understand what they could access as part of the plan and what was available in the area. It is all good and well that the plan states the consumer can access activities A, B & C – but if they are available in the local area (which in this case is what happened) then the plan becomes worthless. This leads to poor consumer confidence & frustration in the process and in turn a lack of engagement with the NDIS in the future.

Again, it comes back to the planning process – having a key planner working with the individual to not only understand the specific needs of the consumer but also linking these requirements with appropriate and available services in the area. If the planner does not understand the parameters of the local area that the consumer is living in, then it is impossible to deliver a supportive plan that will meet the needs of the individual.

Experiences of the NDIS rollout on Palm Island and in some other Aboriginal and Torres Strait Islander communities have uncovered the importance of working with a community to identify tailored ways in which to support the transition utilising an outreach model. Identifying activities appropriate to the community, ensuring appropriate methods for measuring outcomes are employed, appropriately resourcing and acknowledging the importance of family supports are all important aspects of outreach that should be considered for many communities. Further, issues have been raised in the NT about using culturally appropriate and safe tools, planning and assessment for Aboriginal and Torres Strait Islander people,

particularly addressing cultural and language differences so that people are not disadvantaged. Significant challenges exist in engaging Aboriginal people in disability services, particularly in remote areas, and there is a need for the NDIS to have a higher proportion of skilled Aboriginal workers. This also applies to culturally and linguistically diverse (CALD) communities.

The one size fits all approach to the delivery of NDIS information, has not been particularly effective in terms of assisting the NDIA to reach their targets. A more tailored, thoughtful and patient approach, working with each community and drawing on their own strengths could have proved to be more effective in supporting people to engage with the NDIS.

Suitable administrative systems and processes are in place to support transparent, accurate, timely and consistent assessment of eligibility

NDIS planning process

A significant area where CMHA believes there must be a focus is how the NDIS is being implemented, in particular the structure and administration of the NDIA and the overall structure and administration of the NDIS through the Federal Government. In all of the processes examining NDIA costs, there is an emphasis on providers and consequently consumers taking on the largest amount of risk. It needs to be recognised that the way governments and agencies implement the NDIS is also going to have a significant impact on the costs of the NDIS.

In terms of both the short and long-term impacts on cost, creating administrative processes that drive up the costs of delivering the NDIS, add considerably to the costs of the NDIS. Government has a significant influence on this, particularly in terms of how the governing legislation for the NDIS is implemented, monitored and evaluated.

As noted above in relation to legislative and other requirements, issues are occurring with requests for plan amendments triggering full reviews of plans, and participants are generally not permitted to see a plan before it is finalised, and the NDIA are stating the process is adhering to legislation. CMHA has recommended a review of the legislation is required as its interpretation is leading to implementation problems and escalating administrative costs.

Assessment for eligibility

An issue that has been raised by providers is that there should be a functional assessment tool for people living with a mental illness seeking NDIS eligibility. Diagnosis for mental illness will not in many instances provide an understanding of a person's functional capability and in situations where assessors and planners do not have specific mental health and cultural awareness training, this lack of understanding will have an impact.

CMHA understands that the NDIA is examining the potential use of a mental health functional assessment tool and would urge this work to be completed as a matter of importance. Input should also be sought from the community managed mental health sector to ensure the template developed is workable. While CMHA is pleased that the NDIA is undertaking this work, the concern is that this work was not undertaken prior to implementation and the potential impact this is having on people's eligibility and the level of support they receive through the NDIS.

Suitable quality and compliance arrangements have been established to mitigate the risk of incorrect NDIS access decisions

Existing administrative and governance arrangements and the NDIA measuring performance

The governance and administration of the NDIS is a significant issue and will be central to the success and sustainability of the NDIS. CMHA has raised these issues throughout this submission and reiterates the need for a review of the NDIS Act to assess the impact it may be having on the implementation and administration of the NDIS.

There must be indicators that sit alongside the indicator of the number of people receiving plans such as the number of reviews and appeals requested, and consumer satisfaction with and understanding of plans received.

Input from a provider in Tasmania exemplifies the need for indicators related to consumer experience of the NDIS:

It has been in my experience that the consumer, who is already struggling to fully understand the NDIS planning development, will not question the process or feel they even have a right to do so. In implementing performance indicators, it would assist the planning process to better meet the consumers' needs and by more thorough feedback empower the consumer to understand the plan that directly affects them. What seems to be forgotten is as part of the recovery process for consumers is empowerment to take control of their lives.

CMHA recently supported a call by the disability sector to include genuine engagement with consumers in their governance structures and that people with a disability are a central part of the overall decision-making structures, including representation on the NDIS Board. The involvement of consumers and participants in the governance, design, implementation and management of the NDIS will be vital to ensuring the NDIS is being informed by those who are actually experiencing its implementation, and therefore mitigating incorrect and uninformed decisions being made.

Quality assurance processes for mental health

CMHA's Federal Pre-Budget Submission 2017-18² called for the development of quality assurance processes specifically tailored for psychosocial support services as a part of the NDIS Quality and Safeguarding Framework.

The NDIS pricing structure and its relationship to qualified mental health staffing is having a significant impact, with there seeming to be a misunderstanding between what constitutes psychosocial disability support and what constitutes psychosocial rehabilitation. A model that includes community-based rehabilitation as a necessary part of a high functioning mental health system is essential. The skills and knowledge required are different with the NDIS pricing structure able to fund disability support, while being unclear about its reach into more complex supports.

² Community Mental Health Australia 2017-18 Federal Pre-Budget Submission, <http://www.treasury.gov.au/~media/Treasury/Consultations%20and%20Reviews/Consultations/2016/2017%20PreBudget%20submissions/Submissions/PDF/Community%20Mental%20Health%20Australia.ashx>

The NDIS pricing does not officially set mental health sector workers' wages, however, it does have a significant influence over wages that mental health organisations are able to pay their employees. Some stakeholders have noted that pricing was not sufficient to purchase a suitably skilled workforce that engaged in complex 'cognitive behavioural interventions' as well as direct personal care.³ The NDIS is based on the principle of people living with a disability accessing the supports they need to maintain a 'normal' life, and therefore generating economic activity in the community and paying for itself by generating extra consumer spending. Without adequately trained staff, these supports will be missed and the increase in activity will be less. An investment in trained staff is vital.

The Federal Government recently announced the Quality and Safeguard Framework for the NDIS. In order to maintain and support the community mental health sector workforce and ensure the current quality of service continues through the transition to the NDIS, it is vital that quality assurance processes specifically for psychosocial services are developed.

Case Studies

The following case study has been provided by the Mental Health Council of Tasmania, from a clubhouse provider in Tasmania of consumer's experience with the NDIS.

Fran's Personal Experience

Advice

My advice would be that even if you are well now that following through with the NDIS is worth going through. You have nothing to lose so you may as well go through with the process. Don't expect the process to go smoothly so be determined to see the process through till the end and follow up with each step to make sure the application keeps progressing.

Experience of NDIS

There has been a lot of talk around me at the Clubhouse about NDIS since late last year. I did not believe that it applied to me though as I have been well for nearly 2 years now. It was only when one of the staff members showed me a handout on 'Psychosocial disability, recovery and the NDIS' that I realised that the NDIS is something that could apply to me. My first step was to go in the Clubhouse Van to collect an Access Request Form and then made time with a staff member to fill out the form. The part that I had to fill out was pretty straightforward and only required name, address, phone number and my primary disability labelled. From there I made an appointment with my GP so that they could fill out his supporting information about my disability and the impact that it had on my life.

My experience with my GP was they were in a rush to get through this paperwork so that they could get back to seeing patients. They wrote my primary disability on the form as well as my medication and in all areas they signed me off as not requiring assistance. When I looked over the questions later I couldn't help but think that the questions were geared towards people with a physical or intellectual disability rather than people with a

³ Community Mental Health Australia (2015). *Developing the Workforce: Community Managed Mental Health Sector National Disability Insurance Scheme Workforce Development Scoping Paper Project*. Sydney: Mental Health Coordinating Council.

mental illness. Which makes me concerned that people with mental illness are going to be overlooked in the NDIS.

As my Dr did not do the original diagnosis I thought that my NDIS access request form may have more weight if I attached the original diagnosis which was done through community mental health. On contacting them they were unwilling to release the paperwork directly to me as I have not accessed their service for close to 2 years and advised me to contact my GP to get them to contact Mental Health to release the paperwork to them. This is where I am currently up to with my NDIS application.

Positives

The assistance that the Clubhouse has given me with the NDIS process has helped me immensely. I doubt I would have even commenced the process if it hadn't been for Clubhouse informing me of the NDIS, taking me to collect an Access Request Form, helping me fill out the paperwork and discussing any setbacks in the process and what making suggestions on what my next step should be.

Negatives

The NDIS process has not been straightforward. My GP was not overly keen to fill out the paperwork and the way it was filled out will more than likely lead to my Access Request Form not being processed. It has required me to be self-driven in this process and one that I am willing to see to the end, mainly because of my own involvement with the NDIS was face-to-face. If it was not for this face-to-face contact, I probably would have abandoned this process by now given that there is no guarantee that all this time and effort may not even justify what I serve to gain through the NDIS.

The following case study is taken from the submission by the Mental Health Community Coalition ACT to the Productivity Commission NDIS Costs Issues Paper.ⁱ It demonstrates the need to have effective information for both NDIA staff and consumers; NDIA staff who are skilled and qualified in psychosocial disability; appropriate compliance processes; and unambiguous administrative arrangements to ensure incorrect decisions are not made that affect people's access to the NDIS and the services they receive.

Second plan – participants needs reduced but more funding allocated

Participant #1 is a 52 year old woman who lives alone who had previously been homeless and sleeping in her car with a history of self-harm. Participant #1 had her first plan which budgeted for *Assistance with daily life at home in the community, education and at work (\$500.00)*; *Assistance with daily life at home in the community, education and at work (19,000+)*; *Improved life choices (\$13,000+)*. During the life of this plan her life improved markedly.

Her second plan, however, was perplexing. It increased in value and the funding was allocated in a nonsensical and irregular manner. She received two support budgets: \$39,000+ for *Core Supports* and \$26,000 for *support coordination*. In part this reflects a review process that gave no time to the participant to communicate the positive life changes she experienced during her first plan. The Support Coordinator considered it unethical to accept this plan as it was. They have other participants with greater need and a much smaller amount of Support Coordination allocated.

Kitchen adaptation funds allocated for participant with brand new serviceable kitchen

Participant #2 is a 38 year old woman who lives alone with mental health issues and stage 4 cancer. Her plan budgets for *assistance with decision making, daily planning and budgeting x 20* which she does not need as she is highly organised and has no issues with managing her finances. It also budgets for *diet consultation and diet plan development x 10* which the participant states she also has nil issues with. The third support budget is for *home modification – kitchen adaption.....so reasonable and necessary decision can be made regarding potential modifications to existing kitchen* Participant #2 lives in a brand new home with a modern serviceable kitchen with all necessary amenities.

Inappropriate plan – demonstrates fundamental lack of understanding of PSD

This example is of a plan that was reviewed prior to review date with no warning; over the phone with a participant who has problems communicating and had no support with her; and which resulted in reduced supports.

Participant #3 is a 43 year old woman who lives alone with a chronic mental health condition which she does not understand or manage without extensive supports and assistance. This woman was contacted by the NDIA two months' prior to her stated review date. She is very quiet and finds communication very challenging. She needs to attend a regular clozapine clinic; she does not drive and is unable to use public transport; she lives a long way from her clinic and does not have close access to health and shopping amenities; she is unable to maintain her home without regular domestic support and she frequently does not provide access to support services.

In spite of comprehensive evidence from her professional treatment team, her review plan included only \$3,000 for the year for support coordination and also included a budget for *finding and keeping a job!* This woman is unable to manage basic tasks of independence and has a significant untreated substance use issue; and her family are elderly and unable to provide consistent mainstream support. This participant is also at high risk of suicide as she regularly stockpiles medications and alcohol.

Inappropriate process – demonstrates fundamental lack of understanding of PSD

Participant #4 is 64 year old man who lives alone with a chronic mental health condition which he has little insight into or understanding of; he also has significant health issues – tardive dyskinesia – which means he has frequent burns to his hands when making hot drinks for himself. He has a very involved long-term carer who does not live with him and a very involved long-term clinical manager. This man also lives with significant thought disorder and frequent delusional thinking. This man was contacted by the NDIA for a plan review over the phone to which he consented. A new plan was made without any notification to mainstream supports and the participant does not know if he has received his plan in the mail or not.

Yes, you are eligible! No, you are not!

Participant #5 is a 27 year old man who lives with his mother and has mental health, a chronic health condition and cognitive impairment. His mother reported that she received two letters – both dated the same day with one stating that her son is ineligible to the scheme and the other letter stating that her son is eligible to the scheme. The mother phoned her son's service provider totally confused.

i Productivity Commission Report into NDIS Costs, MHCC ACT Submission, 24 March 2017.
http://www.pc.gov.au/__data/assets/pdf_file/0005/215771/sub0135-ndis-costs.pdf