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INQUIRY INTO IMPLEMENTATION OF THE NATIONAL DISABILITY INSURANCE SCHEME AND THE PROVISION OF DISABILITY SERVICES IN NEW SOUTH WALES

Organisation: Centre for Disability Research and Policy

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Centre for Disability Research and Policy

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Introduction

We have read the Terms of Reference for the Parliamentary Inquiry into the Implementation of the National Disability Insurance Scheme and the provision of disability services in New South Wales and offer the following response.

This submission comments only on those parts of the consultation for which we can make a meaningful contribution based on our knowledge. We therefore do not respond to each point.

The content relating to Aboriginal and Torres Strait Islander people has been collated by Dr John Gilroy. John is a Koori man from the Yuin Nation and is a doctor of sociology in Indigenous health, specialising in disability studies. He leads Indigenous health and disability research in our Centre and within the Faculty of Health Sciences more broadly.

The psychosocial disability-related content largely builds upon follow up conversations from the consultation that was carried out for the production of the report *Mind the Gap: the National Disability Insurance Scheme and psychosocial disability* (Smith-Merry et al, 2018). This submission should be read in conjunction with that report. The full report can be found here: **http://sydney.edu.au/health-sciences/cdrp/publications/technical-reports.shtml**

The responses related to services largely come from a PhD project by Ivy Yen whose PhD is examining the changing mission of for-profit and non-profit community service providers in the market based care environment created by the implementation of the NDIS. Her work focuses on Western Sydney and her comments in this submission mostly relate to Culturally and Linguistically Diverse (CALD) populations.

Overarching comments

The issues raised below in our response to the Parliamentary Inquiry, and elsewhere in individual commentaries and reports such as the *Mind the Gap* report show that these issues are complex and they are shared. They do not all sit in the lap of the NDIA or the NSW Government or the Federal Government. However, because they are issues that are all occurring in NSW there needs to be oversight of them by the NSW Government. We therefore strongly believe that NSW must continue to have a Minister for Disability, to advocate within the Government and with the Commonwealth on issues regarding people with disabilities. NSW mainstream services must respond to the needs of people with disabilities without offset due to the NDIS.

Responses to individual questions

The experience of people with complex care and support needs in developing, enacting and reviewing NDIS plans.

Psychosocial disability

Our consultations found that people with psychosocial disability often had considerable difficulty in developing, enacting and reviewing NDIS plans. This was caused by a lack of support during planning, poor understanding of psychosocial disability and complex needs by planners, and a lack of support for enactment of plans. Three main solutions were posed in response to this:

- Increased mental health literacy amongst NDIS planners and workers. This would allow planners to understand the context of psychosocial disability and enable appropriate supports to be included in plans. This would need to be funded and coordinated through the NDIS. This is a facet of the NDIS psychosocial disability pathway that is being introduced. However there is no data available from which to judge the success of the pathway implementation so far.
- Inclusion of carers and family members by default in planning meetings.
- Inclusion of service coordination as standard in plans where people have significant complexity of need. Service coordination is an approved item under the NDIS, however it is not included widely in plans. This means that for some people parts of their plans (or in some cases entire plans) are not activated. Respectful, recovery-oriented service coordination would help to facilitate an individual's choice and control by coordinating the services in their plan. Service coordination has been a significant part of service provision for programs for people with severe and complex mental illness (e.g. Partners in Recovery, whose funding is folding into the NDIS funding pool) because of the difficulties individuals have with the fragmented system that they must negotiate to meet their needs. This has shown to be successful in allowing for needs to be met (Hancock et al 2018) and should therefore be supported either within plans or as an adjunct to facilitate people's engagement with the NDIS model.

Culturally and Linguistically Diverse (CALD) communities

The PhD study by Ivy Yen has found that service providers working in Western Sydney with CALD communities had experiences of clients not activating their plans because of poor understanding of their cultural contexts from case managers. For example one provider related an example where a case manager arrived at a client's home with an interpreter – but it was an interpreter for the wrong language. They did not understand that the South Sudanese Arabic language is very different from normal Arabic. The case manager had only bought an Arabic interpreter. So the client did not open the door and chose not to engage.

These issues relate to cultural competency and poor understanding of different cultural contexts, including basic information about language, but also more subtle issues related to cultural norms. This is also spoken about below.

The solution to this is:

- to provide funding and support to providers already working with CALD communities to support people through their NDIS journey. That way they are already working with people who trust and understand their cultural contexts.

- funded training for the NDIS workforce in cultural competency, particularly for those working in areas of high cultural diversity. The NDIS pricing model does not allow for training of the workforce in this way so it is unlikely that this will happen unless it is funded externally.

The accessibility of early intervention supports for children.

Service providers reported that there were cultural barriers which limited people accessing the scheme. One respondent in Ivy Yen's PhD study spoke about stigma in particular Culturally and Linguistically Diverse (CALD) communities. They reported the experience of one woman who cared for three of her children who had intellectual disabilities. She feared the stigma of being labelled as the mother of children with disability and therefore did not like to go out with the children and access services. The solutions to this were:

- targeted support for dealing with this type of stigma in particular communities or they would become further marginalised because they were not accessing early intervention services.
- linking existing services that were being accessed (e.g. education services) with the NDIS to draw in people via their existing support networks.

The effectiveness and impact of privatising government-run disability services.

Aboriginal and Torres Strait Islander people.

The privatisation of government run organisations did not consider the need for more Aboriginal community controlled organisations (ACCO). This process favoured the large, powerful mainstream organisations. In effect, creating more competition that disadvantages ACCO disability and HACC organisations.

The NDIA prides itself in the NDIS giving people choice. The fact is a person can only have choice if opportunity is available to them in their communities. If we use a simple comparison, a local Koori family owns an XD Ford Falcon that requires new spark plugs and the gearbox throwout (thrust) bearings and engages with all mechanics. All but two mechanics have the knowledge and parts to fix the car. One mechanic charges $100 per hour is 150 km away and the local mechanic (knowing he has the monopoly) is charging $250 per hour to fix it. The family cannot afford to move the car to the cheaper mechanic. As such, the family has limited choice. Let's compare this to an actual scenario relating to the NDIS business model. A man living in Alice Springs requires parts for his electric wheelchair. The closet person is in Adelaide or Darwin! What does he do? The fact is, choice is dependent on opportunity in the local region. As such, the NDIS business model is based on reducing costs but disadvantages those people in remote and regional areas who need specialised services in their own communities. This happens because of the following:

1) East coast metro centrism: limited acknowledgement that rushing for-profit business models within a traditional NFP realm cannot work.

2) Whitefella values: a large proportion of remote communities have large percentage of Indigenous people.
3) A business model of 'for profit market capitalism': the NFP sector was developed and designed to address the weaknesses of capitalism and government systems. The NDIS is an encroachment on the Third Sector of the for-profit sector

The provision of support services, including accommodation services, for people with disability regardless of whether they are eligible or ineligible to participate in the National Disability Insurance Scheme.

Psychosocial disability

The origins of the Mind the Gap report were in a concern for what would happen to people who are ineligible for the NDIS or are otherwise not involved. While there was significant concern about this group we found that few solutions were put forward. The main concern was about the large numbers from existing programs whose funding was being transferred to the NDIS who would not actually be eligible for the NDIS. We derived the following figures for people with serious mental illness via publicly available data from the Federal Government and the NDIA's own reporting:

> "The National Mental Health Commission Report *Contributing lives, Thriving Communities* estimates that of the 3.7 million Australians who experience mental illness, 690,000 Australians live with severe mental illness. The federal government has estimated that one third, or 230,000 people, need ongoing support, although it is unclear how this figure was derived (Commonwealth of Australia, 2015). However, the National Insurance Disability Agency (NDIA) estimates that at full roll out (2019-20) only 460,000 will be participants in the Scheme, with 13.9% or 64,000 people expected to have a primary psychosocial disability requiring support (NDIA, 2017). This means a significant gap of up to 91% of people with severe mental illness, or 166,000 - 626,000 people (depending on the figures used), will have to rely on non-NDIS community mental health services to meet their needs." (Smith-Merry et al 2018)

Since our report has been released the federal government has provided further advice about the continuation of existing programs because the numbers of people ineligible from existing programs was much higher than expected (e.g. for PHaMS the original estimate was 5-6% and the real number is over 20%). For this reason money is being returned from the NDIS to some existing programs to provide 'Continuity of Support'. However it is unclear for how long this will continue and what will happen to existing clients when the programs eventually close.

Workforce issues impacting on the delivery of disability services.

There are concerns in the community sector about service viability given the pricing model used by the NDIS which focuses on items of care. Services that we consulted with stated that while the pricing usually would cover the cost of that instance of care it did not cover other important aspects of service provision, including:

- training,
- management,
- career progression

If these are not being funded through the funding model then the funds to develop the workforce in these important ways needs to come from outside of the NDIS.

There are also concerns about the NDIS funding model leading to the loss of a more highly qualified workforce because the pricing model will not support more qualified staff working at higher levels. In the *Mind the Gap* study service providers were concerned that the pricing levels did not meet the National employment Social, Community, Home Care and Disability Services Industry Award (SCHACDS) which meant that staff with long-term specialised experience, knowledge and skills in working with people with psychosocial disability. There are concerns that unless services have providers who have this type of experience in helping people with serious mental illness then those people who need support for these needs will miss out. There are reports of services refusing to work with people with complex needs and difficult behaviours caused by their mental illness. These people therefore need staff with higher levels of training and experience.

The pricing of these requirements must be matched to unit costs as defined by the NDIA. This was reviewed in the McKinsey and Co Pricing Review which added a 10% for people with 'very complex' needs. It is unclear how this will be actioned. The adequacy of this pricing should be part of ongoing pricing reviews. If this is not forthcoming then this will need to be funded by the NSW Government.

Challenges facing disability service providers and their sustainability.

CALD communities

It was felt that under the NDIS clients are provided with more 'choice' with providers but there are extensive gaps which are partially being met by new and emerging providers. One for-profit organisation spoke about clients coming to them, asking if they were an approved NDIS provider because of their cultural knowledge and the fact that they were ethno-specific and targeted a specific, marginalised, CALD community. They therefore made the decision to become an NDIS provider: "We felt that we had the cultural knowledge of the CALD community. We felt that since we had the cultural knowledge we should form an organisation to assist these clients". But there were problems with a lack of support and understanding during the start-up period. At the time of their interview the provider had only been operating for 3 months and was experiencing many challenges at meeting the expectations from the community and doing lots of in-kind work which they were concerned was not sustainable. There was an organisational struggle where they chose to either refuse a client because they didn't have enough money in their NDIS package, vs an expectation that they meet the needs of their own community.

Psychosocial disability

This provision of 'free' services which were essential for supporting an individual but were not included in their plans and there were no other providers to provide the support, was felt more broadly by providers working in psychosocial disability also. Service providers reported offering and providing unfunded services to many clients because they were not in the NDIS Scheme and no other funded services were available. This was most common in the pre-planning and application phases due to many having no support allocated at this time. It was also a problem where support needs changed very quickly due to a worsening of mental illness but the review process within the NDIS was unable to quickly adapt to this situation. It was also a problem within those programs (such as Partners in Recovery, Day to Day living and PHaMS) transitioning to the NDIS, having insufficient hours of support provided. To address this there are a couple of solutions:

- A contingency fund is developed within the plans of people eligible for the scheme whose mental illness fluctuates, which can be drawn on to increase funding for supports temporarily while they are more acutely unwell.
- The development of short-term state-based services operating on a care-coordination model which can step in to meet needs where people are temporarily not eligible for necessary services.

Fundamentally these 'gaps' need to be measured so that they are understood and appropriate service and system approaches can be developed. Currently we have no real understanding of the extent of the gaps except from the experience of diverse services. This is important evidence, but it is difficult to build sustainable, cost-effective solutions based on this evidence.

<u>Policies, regulation or oversight mechanisms that could improve the provision and accessibility of disability services across New South Wales.</u>

Data about the scheme.

Oversight of the scheme and the ability of the system and policy framework more broadly depends on an ability to gather data about the program and its operation. What we lack is data about the program performance including sophisticated data about:

- The numbers of people who are being denied access to the scheme and why.
- The needs being met with plans and the supports that are used to meet these needs.
- Plans that are not activated or parts of plans which are left unutilised and the reasons why.
- The numbers of plans that include supports for carers and support coordination.
- The figures above in relation to indigeneity, level of severity of disability, other complexities such as homelessness, drug and alcohol use and comorbid health conditions, and the rural and remote status.

This data should be coming from the NDIA but is not. In their response to the *Mind the Gap* report the NDIA critiqued the figures that we used which were publicly available with figures that they had not released. It is not possible for us to have a good understanding of the scheme if they do not release figures and only do so if we get those figures wrong. If a wider release of data is not forthcoming then the NSW state government needs to work out a way of collecting meaningful data. As a starting point the NSW Government should lobby the NDIA to release figures.

Aboriginal and Torres Strait Islander people.

There was not planned approach to ensure that the cultural needs of Aboriginal people were considered in the planned roll-out of the NDIS. We were treated as an after-thought. The NDIA staff attended many Aboriginal events and did not provide support or listen to Aboriginal peoples' concerns. In fact, the RAP and the NDIA and DSS policies about Aboriginal access and equity took many years to be released.

Any other related matter.

All of the issues discussed here are made more acute in rural and regional areas where there is often no market to provide services to meet needs.

Aboriginal and Torres Strait Islander people

This scheme was rolled out too fast. There was no preparation for the NDIA to ensure that Aboriginal people’s needs were considered before the trials were decided and launched. This was the same mistake the government made when the DSA was passed and rolled out (see Gilroy 2010). There needs to be acknowledgement of this and a state-wide strategy developed to address it.

About the Centre for Disability Research and Policy:

The Centre for Disability Research and Policy (CDRP) at the Faculty of Health Sciences of the University of Sydney aims to change the disadvantage that occurs for people with disabilities. We do this through addressing their social and economic participation in society, and their health and wellbeing. By focusing on data that demonstrates disadvantage, we can develop models of policy and practice to better enable support and opportunity for people with disabilities.

For more information about the Centre and links to our other NDIS-relevant reports you should visit the Centre website: **http://sydney.edu.au/health-sciences/cdrp/**

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