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AMA submission to the Joint Standing Committee on the National Disability Insurance Scheme Inquiry into the Transitional arrangements for the National Disability Insurance Scheme

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As part of the committee's inquiry into the implementation, performance and governance of the National Disability Insurance Scheme (NDIS), the committee will inquire into and report on the transitional arrangements for the NDIS, with particular reference to:

(a) the boundaries and interface of NDIS service provision, and other non-NDIS service provision, with particular reference to health, education and transport services;
(b) the consistency of NDIS plans and delivery of NDIS and other services for people with disabilities across Australia;
(c) the rollout of the Information, Linkages and Capacity Building Program; and
(d) any other related matters.

In considering these issues, the committee will have regard to:

i. the Bilateral Agreements between the Commonwealth and State and Territory Governments;
ii. the Operational Plans between the Commonwealth and State and Territory Governments;
iii. the risks borne by the Commonwealth and State and Territory Governments in the rollout of the NDIS nationally;
iv. NDIS decision-making processes, particularly in relation to the Disability Reform Council and COAG; and
v. the impact on rural and remote areas, with particular reference to indigenous communities.

As the peak professional organisation representing medical practitioners in Australia, the Australian Medical Association (AMA) welcomes the opportunity to provide a submission to the inquiry into Transitional arrangements for the National Disability Insurance Scheme. This submission has particular reference to ToR (a), (b) and (d).

In this submission, the AMA notes:

1. Although there is $80 million promised in the Budget for psychosocial services for those with mental illness who do not qualify for the NDIS, there is still workforce insecurity and uncertainty, and a paucity of information about what future funding guarantees are in place.

2. Feedback from AMA members indicates that the boundaries and interface between NDIS service provision and other non-NDIS service provision is problematic, and the right balance between traditional medical mental health treatment and psychosocial supports for both those eligible for NDIS and those not eligible must be addressed as a priority.

3. Transport for people with mobility problems is vital. For people on NDIS packages living in regional and remote areas, alternative transport measures should be provided above and beyond the assessed NDIS package as the NDIS funding does not cover the full cost of accessing transport. As transport costs can be prohibitive, it acts as both a barrier and disincentive to participation and interaction with the wider community.

4. The AMA has previously called on Government to extend the MBS video consultation items to GP consultations for people with mobility problems, remote Indigenous Australians, aged care residents, and rural people who live some distance from GPs. This will considerably improve access to medical care for these groups and improve health outcomes

5. Transition arrangements to the NDIS must address the social determinants that affect Aboriginal and Torres Strait Islander people, especially housing. Unless these are included in the transition to the NDIS, then the chronic health problems will continue and the 'gap' in health outcomes will not close.

(a) The boundaries and interface of NDIS service provision, and other non-NDIS service provision, with particular reference to health, education and transport services.

The 2017-18 Federal Budget has particular relevance to the provision of non-NDIS services. The Government allocated $80 million of additional funding to maintain community psychosocial services for people with mental illness who do not qualify for the NDIS. The AMA has previously raised concerns with the Government about people falling through the cracks that exist between the NDIS and State and Territory community services. The Parliament of Australia Budget Review Index[1] explained the Budget measure in this way:

> "'Psychosocial disability' describes the 'disability experience of people with impairments and participation restrictions related to mental health conditions'. State and territory governments have primary responsibility for funding psychosocial support services (community mental health services), but the Australian Government also provides funding. Some government funding is transferring to the National Disability Insurance Scheme (NDIS) as it is gradually implemented across Australia. However, not all people with psychosocial disabilities have conditions that fulfil the severity and permanency criteria for accessing NDIS Individually Funded Packages (an impairment condition may be considered permanent even if it varies in intensity or is episodic). In 2019–20 approximately 64,000 NDIS participants are expected to have a significant and enduring primary psychosocial disability, fewer than the estimated '230,000 Australians with severe mental illness [who] have a need for some form of social support'. Australian governments have committed to providing continuity of support for people who currently receive services and who will be ineligible for the NDIS. Nevertheless, stakeholders expressed concern at a lack of clarity about these arrangements.

> To address these concerns, the 2017–18 Budget allocates $80.0 million over four years from 2017–18 to fund psychosocial support services for people 'with severe mental illness resulting in psychosocial disability' who are not eligible for the NDIS but are 'existing clients of Commonwealth-funded psychosocial services', such as the Partners in Recovery, Day to Day Living Program and Personal Helpers and Mentors programs. The funding is to be delivered through regional Primary Health Networks (PHNs), which have previously been barred from commissioning psychosocial support services. [NOTE: The AMA is not aware that this has been officially confirmed]. The Department of Health states that 'Commonwealth investment will be delivered once an agreement has been reached' with state and territory governments confirming their 'appropriate' contributions. Arrangements for the transition period are unclear, as is what will happen if state and territory governments do not agree to provide this funding."

There are many unanswered questions about how non-NDIS service provision for people with mental illness, but who are not assessed as eligible for an NDIS package, will operate. The AMA is not clear on how the allotted $80 million will be allocated to maintain consistent and continuous services across Australia. Our specific concern is that some states and/or territories have stopped funding their psychosocial services as they transition to the NDIS. It has been put to the AMA that some of these psychosocial services may have already ceased supporting mental health consumers and carers, and some service providers may have ceased their services, as part of the NDIS transition.

Although there is $80 million promised in the Budget, how, when and where these monies will be allocated has led to continued workforce insecurity and uncertainty, a loss of services and a paucity of information about what future funding guarantees are in place.

The AMA believes that the promised $80 million to maintain community psychosocial services for people with mental illness who do not qualify for the NDIS must be allocated as soon as possible and in an equitable way that does not penalise or disenfranchise mental health consumers and carers because of their location.

AMA feedback on access to services for patients requiring mental health care, but who are not eligible for NDIS packages

The AMA recently surveyed its members in regard to aspects of Primary Health Networks, including questions on the NDIS. This material has not been released, however we can advise this Committee that the findings showed that the majority of GPs surveyed believe that their PHN had failed to effectively facilitate mental health care for patients who are not eligible for NDIS packages. The survey findings also suggest the majority of GPs surveyed were of the view that their PHN has been ineffective in ensuring timely psycho-social supports for patients with mental health problems.

The boundaries and interface of NDIS service provision, and other non-NDIS service provision is clearly a major problem and the failure to provide the right balance between traditional medical mental health treatment and psychosocial supports for both those eligible for NDIS and those not eligible must be addressed as a priority.

Transport services

The provision of appropriate transport infrastructure, planning and design is vital to the long-term success of the NDIS. Currently in Australia there exists a range of physical, social and systemic barriers to the provision of health care, disability and mental health services. Too many Australians cannot access the health and allied health services they need – and this is not just a consequence of out-of-pocket costs and/or an inability to locate the appropriate medical care or psychosocial supports. For people with disability (with or without NDIS packages), the lack of transport to services results in poorer health outcomes, less full and effective participation and inclusion in society, and a reduction in dignity, autonomy and the ability to be independent.

Some people with a disability are unable to conduct routine activities, such as shopping, visiting health and allied health services, participating in physical activities, and attending social events, because there is not appropriate and sufficient transportation available. Access to transport is especially critical for those people on the NDIS. For people with mobility problems, appropriate and available transport is vital. It is therefore recommended that, where possible, housing and accommodation be situated within easy access of appropriate public transport services, including transport that caters for people who are immobile.

For people on NDIS packages in regional and remote areas, alternative transport measures should be provided, possibly above and beyond the assessed NDIS package. This is a problem for people in rural areas where public transport is not always an option, because the NDIS funding does not cover the full cost of accessing transport. As transport costs can be prohibitive, it acts as both a barrier and disincentive to participation and interaction with the wider community.

The AMA is concerned that the growth of the ridesharing platforms, such as Uber, may threaten the ongoing viability of mobility taxis and further restrict the availability of transport options for people with disabilities. In San Francisco, for example, the introduction of private ridesharing initiatives saw the number of wheelchair accessible vehicles in the city drop from 100 in 2013 to just 64 in 2015.[2] Accessibility provisions must be secured through the regulation and ongoing management of all existing and emerging ridesharing schemes.

Along with physical transport needs, it is essential that NDIS participants are provided with appropriate education; including telecommunications infrastructure such as high-speed broadband. The AMA position statement *Better Access to High Speed Broadband for Rural and Remote Health Care – 2016* outlines the AMA's concerns about access, and this applies in particular to people on the NDIS. Approximately 30 per cent of Australia's population lives outside the major metropolitan areas, and regional, rural and remote Australians often struggle to access health services that urban Australians would see as a basic right. These inequalities mean that they have lower life expectancy, worse outcomes on leading indicators of health, and poorer access to care compared to people in major cities. For people with disability, this struggle can exacerbate existing health problems.

The AMA Rural Health Issues Survey, which sought input from rural doctors across Australia to identify key solutions to improving regional, rural and remote health care, identified access to high-speed broadband for medical practices as a key priority. This result reflects not only the increasing reliance by medical practices on the internet for their day to day operations, but also the increasing opportunities for the provision of healthcare services, including NDIS information and services, to rural and remote communities via eHealth and telemedicine. For the full potential of these opportunities to be realised, good quality, affordable, and reliable high-speed internet access is essential. Technology-based patient consultations and other telehealth initiatives can improve access to care and can enhance efficiency in medical practice, but the need for better access to high speed broadband goes beyond supporting rural and remote health. In today's world, it is a critical factor to support communities in their daily activities, education, and business, and has the potential to drive innovation and boost the rural economy.

Rates of disability will increase as the population ages, and the effect of this is likely to be more pronounced in rural areas, given the high concentration of residents aged 65 years and over in regional Australia. It is becoming increasingly important that rural centres are able to adapt to the evolving needs of their residents. For this reason, the AMA urges the Committee to pay particular attention to the needs of NDIS recipients in regional and remote Australia. Their housing, transport and communications needs are likely to be more complex and expensive than their metropolitan counterparts, and the NDIS' physical 'design' should be sufficiently flexible to cater for specific requirements. It is also of the utmost importance that people with disability, and in particular people who are immobile, have access to high speed broadband that connects them to medical practices, other healthcare providers and institutions.

As an aside, the AMA has previously called on governments to extend the MBS video consultation items to GP consultations for people with mobility problems, remote Indigenous Australians, aged care residents, and rural people who live some distance from GPs. This will considerably improve access to medical care for these groups and improve health outcomes.

(b) The consistency of NDIS plans and delivery of NDIS and other services for people with disabilities across Australia.

According to *The Australian*, unpublished modelling commissioned by some state governments for the National Mental Health Service Planning Framework, reveals about 100,000 people who once received individual funding support through other federal, state and territory mental health programs, such as Day to Day Lining (D2DL) and Partners in Recovery (PiR), will no longer be covered when those federal and state programs end. These programs will transition to help fund the NDIS, however the issue is that the NDIS is not seen as able to fund the number of people experiencing mental illness.

D2DL is a structured activity program that provides funding to improve the quality of life for individuals with severe and persistent mental illness. D2DL is designed to recognise that meaningful activity and social connectedness are important factors that can contribute to people's recovery. D2DL is transitioning to the NDIS, however the programme has been extended for three years to support the transition of program funding to the NDIS. This extension is supposed to ensure service continuity for program clients until the NDIS rollout is completed in each jurisdiction. PiR provides support to people with severe and persistent mental illness with complex needs as well as their carers and families, by getting multiple sectors, services and supports they may come into contact with (and could benefit from) to work in a more collaborative, coordinated and integrated way. It too is transitioning to the NDIS over three years.

There is controversy about whether mental health should be included in the NDIS. What is crucial is that people with mental illness should not be disadvantaged in any transitional arrangements and that they should continue to receive support through programs such as D2DL or PiR irrespective of the funding model. As the Government is transitioning PiR, Personal Helpers and Mentors (PHaMS) and D2DL monies across to the NDIS, it is not clear if advocates for removing mental illness from the NDIS would be expecting these program funds to be clawed back from the Department of Social Services to support people with mental health needs, or whether they are championing for new money for those no longer in the NDIS.

The point of raising this is to highlight that some in the mental health sector are very concerned about the consistency of delivery (and National Disability Insurance Agency (NDIA) assessment) to the extent that there is a view that people with mental illness might be better off outside the NDIS.

In terms of this consistency of NDIS plans and delivery for people with mental illness, the AMA believes that there are other issues impacting on the transitional arrangements. We recognise that some of these may be addressed at the transition roll out across Australia, however the Committee should note the following concerns:

- the removal of the gatekeeper role of doctors to coordinate provision of heath care;
- the need to ensure and maintain the proper balance between psychosocial rehabilitation, medical and dental care; and
- the need to ensure the qualifications of those employed to look after and support people with mental illness meet appropriate standards.

Autism Spectrum Disorder

Autism Spectrum Disorder (ASD) is an example of where the transition to the NDIS is not clear. In late 2016, the AMA released a position statement on Autism Spectrum Disorder (ASD). The AMA Position Statement made specific recommendations, including:

> That the Government make a strong, ongoing commitment, that people who are affected by ASD will have ongoing access to support through the NDIS.

In a previous submission to the Productivity Commission Inquiry Issues Paper on National Disability Insurance Scheme (NDIS) Costs[3] the AMA noted its concerns about early intervention approaches and whether the NDIS is part of the health care system that is providing early intervention therapies to give children with ASD the best outcomes possible. In regard to ASD, and indeed other mental health and intellectual disabilities, the AMA does not believe the criteria for participant supports has been clear and effective. There is insufficient guidance for families of children with ASD. Improvements need to be made in recognising that in some conditions, such as ASD, there is no specific medical (or biomedical test) that can be used for diagnosis. A definitive diagnosis is made via screening tools and observation. Current research suggests that ASD can be reliably diagnosed at two years; a recent international review found that diagnosis often occurs at three years of age. An analysis of Medicare data found that the most frequent age for diagnosis was 5.9 years. In a survey of parents and carers of children with Autism, 34 per cent reported waiting over a year for a diagnosis, and close to 20 per cent reported waiting for more than two years.

The data suggests that children in Australia are not being identified as early as they should be. Early identification and diagnosis of ASD can make a significant difference in outcomes. During the process of diagnosis areas of deficits are likely to be identified. Following diagnosis, children can be referred on to a range of early intervention services which can be tailored to their needs. The fundamental goal of early intervention is to reduce the impact of the disability, which also tends to lowers the costs for families and the wider community associated with the disability. It is likely that because of unclear criteria and guidelines, some Australian children are experiencing significant delays in diagnosis, and access to appropriate early intervention, which reduces the effectiveness of some interventions.

As the NDIS transition occurs, eligibility guidelines must be broad enough to capture early diagnosis, as the ASD example illustrates. To ensure consistency, the NDIS must us objective tools that confirm diagnosis, ascertain severity, identify personal strengths and weaknesses and guide fair and targeted package allocations.

(d) Other related matters

Aboriginal and Torres Strait Islander People

Indigenous Australians are significantly more likely to report a disability or long-term health condition than the non-Indigenous population. The high prevalence of disability within Indigenous communities is due, in part, to poor health care and nutrition, and increased exposure to violence and psychological trauma. Disability in Indigenous communities is further compounded by a decreased propensity to seek a formal diagnosis or access established disability support services.

As it currently operates, the NDIS is designed to function on the basis that NDIS participants request the supports they need and make informed choices about the manner in which these supports are utilised. Whilst this allows for a greater degree of autonomy, it can have an obstructive impact on the ability of people within communities who do not acknowledge, or identify with, the term “disability” to access the appropriate support. It has been raised with the AMA that for some people, navigating the NDIS is itself a barrier and obstacle. Navigating what services and supports can be accessed may be an additional barrier for Aboriginal and Torres Strait Islander people in remote and regional Australia.

Housing is arguably the number one issue in terms of the social determinants of health for Aboriginal and Torres Strait Islander people. In the AMA’s annual Report Card on Indigenous Health, housing shortages, overcrowding, and lack of access to basic services such as potable water, electricity and sanitation, all contribute to poorer health outcomes. It is of paramount importance that the NDIS address Indigenous housing as a priority. This must be done in close consultation with NDIS recipients and their communities as the ‘one size fits all’ approach has been a well-documented failure in many aspects of Indigenous health and service provision over many decades. The AMA strongly supports calls for services to be embedded within local communities, and, where possible, the upskilling of community members to allow them to contribute to the care and support of their community.

Transition arrangements to the NDIS cannot ignore or not address the social determinants that affect Aboriginal and Torres Strait Islander people. Unless these are included in the transition to the NDIS, then the chronic health problems will continue and the ‘gap’ in health outcomes will not close.

The AMA draws the Committee’s attention to anecdotal reports provided to the AMA about inconsistent and unacceptable NDIS and NDIA assessments of Aboriginal and Torres Strait Islander people. We have drawn this to the attention of previous NDIS inquiries. The AMA has been told of instances where Indigenous people have been ‘assessed’ from a car parked outside a residence. We have heard of a person with otitis media whose forms were ‘lost’ and the young man and his family forced to travel 500 kilometres to a specialist to provide the correct medical paperwork. This is deeply concerning and raises the real risk that Indigenous people with a disability will not be properly assessed by the NDIA. In short, the anecdotal material from regional and remote Indigenous communities paints a worrying picture of how the NDIS is transitioning to meet the needs of some people with complex disabilities.

NDIS Independent Advisory Council (IAC)

In July 2017, the AMA wrote to the Minister for Human Services expressing its concerns about the recently announced expansion and new appointment of representatives to the NDIS Independent Advisory Council (IAC), starting from July this year.

It is our understanding that the IAC brings together the views of participants, carers and sector experts to provide the NDIA Board with independent advice on matters relating to the delivery of the Scheme.

While the AMA supports having a broader representation of people with a disability on the advisory panel during this critical period of implementation, the AMA is concerned that there are no Aboriginal and Torres Strait Islander representatives present. The prevalence of disability amongst Aboriginal and/or Torres Strait Islander people is significantly higher than the general population, and nearly half of all Indigenous people have experienced a disability during their lifetime.

This is deeply concerning and raises the real risk that Indigenous people with a disability will not be properly assessed by the NDIA. This highlights the need to have an Aboriginal and/or Torres Strait Islander person appointed to the IAC. As the peak organisation representing Aboriginal and Torres Strait Islander people with a disability, the AMA considers that the First Peoples Disability Network would make a suitable representative on the IAC.

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[1] http://www.aph.gov.au/About_Parliament/Parliamentary_Departments/Parliamentary_Library/pubs/rp/BudgetReview201718/MentalHealth

[2] District of Columbia Taxicab Commission Accessibility Advisory Committee, 2015. Annual Report on Accessible Vehicle for Hire Service. Available at: http://dctaxi.dc.gov/sites/default/files/dc/sites/dc%20taxi/page_content/attachments/DCTC%20Accessibility%20Advisory%20Committee%202015%20Annual%20Report%20100515%20FINAL%20update.pdf

[3] https://ama.com.au/submission/ama-submission-productivity-commissions-issue-paper-national-disability-insurance-scheme