Submission to the Productivity Commission Position Paper on NDIS Costs

19 July 2017

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Introduction

The Aboriginal Medical Services Alliance of the Northern Territory (AMSANT) would like to thank the Productivity Commission for the opportunity to comment on the Position Paper on NDIS costs.

As the Commission is aware, AMSANT is the peak body for the Aboriginal community-controlled health service (ACCHSs) sector in the Northern Territory which has played a pivotal role in addressing the burden of ill health carried by Aboriginal people. It is from the perspective of our sector's long history of representing the health and wellbeing needs of Aboriginal communities, and working alongside government to meet those needs, that we provide the following comments on the Commission's Position Paper on NDIS costs.

Key recommendations

AMSANT highlights the following key recommendations to the Productivity Commission and requests that these are implemented in reforming the Scheme:

1. That the NDIA ensures the cultural safety of the Scheme and its effectiveness for Aboriginal people, including through brokerage/coordination of positions in ACCHSs, and developing appropriate cultural safety standards and practices, in consultation with the ACCHSs sector and Aboriginal organisations.

2. That in remote Aboriginal communities, the APO NT Partnership Principles be incorporated into NDIS service delivery in preference to competitive market mechanisms.

3. That changes are made to the criteria for NDIS provider and selection processes so that it is more feasible for ACCHSs and other Aboriginal organisations to become providers.

4. That an Aboriginal workforce strategy is developed by the NDIA in consultation with Aboriginal organisations and the ACCHSs sector.

5. That the NDIA ensures that strong accountability mechanisms are in place for current and future care plans, including to ensure quality and cultural appropriateness of the plans.

6. That the NDIA carries out an independent review of the Scheme with respect to its current impacts on Aboriginal participants, communities and organisations to ensure the Scheme properly provides for the needs of Aboriginal people with disabilities.

7. That the further rollout of the Scheme to Aboriginal communities be modified in line with the outcomes of the independent review.

How is the scheme tracking?

The vision of the National Disability Insurance Scheme (NDIS) is compelling. Choice and control for people with disability and their families, double the funding for disability support to respond to the high need for services and equipment, an insurance approach that invests in early intervention and increased equity and life opportunities for people with disability across Australia.

AMSANT supports concerns that the scale and pace of NDIS is 'highly ambitious' and risks poor implementation and poses risks to financial sustainability of the Scheme. AMSANT acknowledges the Commission's concerns about scheme costs and the interests of the Commonwealth in managing cost pressures to ensure sustainability of the Scheme. However, without further investment to ensure equitable access by Aboriginal people with disability, the existing investment will not be effective and will continue to fail the needs of this group.

The release of 2016 Census data has shown just how prevalent the issue of disability is for Aboriginal and Torres Strait Islander communities, being at least twice the rate of other Australians. In 2014-15, 6% of disability service users were Aboriginal and Torres Strait Islander people, with most aged under 50 (84%). For this reason, the NDIS should incorporate strategies and accountability mechanisms to ensure that existing funding commitments to the Scheme are equitably apportioned to Aboriginal and Torres Strait Islander disability as supported by NACCHO in the *Redfern Statement*.

There are at least 60,000 Aboriginal and Torres Strait Islanders across Australia who live with a severe or profound disability, with an estimated total of 6,545 participants entering NDIS in the Northern Territory. AMSANT acknowledges and supports significant concerns of under-reporting of impairment and disability for Aboriginal and Torres Strait Islanders and the impact this has on modelling projects to determine how the Scheme is tracking.

Other key considerations highlighted by our Member services include the omission of travel and transport in planning and the significant implications this adds to modelling costing for remote service delivery within the Scheme currently.

Disability is often compounded by other challenges in Aboriginal communities, such as a lack of cultural competence of mainstream services, poverty, comorbidities, and for remote people, a pervasive lack of access to services.

Member services have reported significant cost shifting to the Primary Health Care ACCHS Sector in providing additional services for participants of NDIS who are not receiving care within their specified plans or within the processes of planning with participants to ensure quality, cultural safety and advocacy for Aboriginal people and families. Whilst not funded under the Scheme, our sector understands the risks for Aboriginal people living with a disability, and the imperative need for immediate high-level advocacy and effective Aboriginal consultation/evaluation approaches.

Clear recognition must be given that not all people with disability will be eligible for the NDIS and assurances must be made that appropriate companion schemes and services are available and accessible for Aboriginal and Torres Strait Islander people over the long term.

AMSANT challenges the Productivity Commission's suggestion in Finding 2.4 that 'the NDIS is improving the lives of many participants and their families and carers through greater choice and control over the supports they receive and an increase in the amount of support provided.' AMSANT proposes the evidence base supporting positive outcomes for Aboriginal and Torres Strait Islanders living with a disability under the Scheme remains preliminary and inconclusive nationally, and in particular within the Northern Territory, where in-depth trial site qualitative analysis and evaluation is currently underway. Furthermore, there are a number of research projects that reinforce poorer outcomes for our most vulnerable groups living in remote communities, including those described within the position document (NPY Women's Council 2015, Sanders & Venn 2017).

Additionally, reports from AMSANT's member services participating in the NDIS roll-out support this conclusion, showing that significant service gaps currently remain for Aboriginal

and Torres Strait Islander peoples living with disabilities, their families and communities. Examples provided include clients who were receiving services by external providers previously now being significantly disadvantaged by waiting extended periods to receive the same service or not receiving essential services by providers, such as, physiotherapy, speech therapy and medical aids. Alarmingly, some essential disability services critical for supporting wellbeing have been completely omitted in the planning process.

Also of particular concern are the reports we are receiving of the lack of cultural competence embedded in NDIS systems and NDIA planning staff who are simply unaware of culturally-respectful ways of engaging with Aboriginal people. These concerns will be explored in some detail throughout our submission as these intersect with all aspects for the Scheme and are of primary importance to our Member services.

Furthermore, Aboriginal and Torres Strait Islanders with disability do not always receive appropriate supports and opportunities, even in circumstances where these supports would be readily available. They are at higher risk of experiencing family violence, removal from families and contact with the criminal justice system.

The particular vulnerabilities in relation to the health and wellbeing of Aboriginal people and communities in Australia requires special consideration and response by the NDIA, which to date has been insufficient. A recently published ABS issues paper, completed in collaboration with FPDN, identified that 45% of the Aboriginal and Torres Strait Islander population reported some kind of disability in 2014-15 (ABS 2017).

As outlined in the submission made by the First People's Disability Network (FPDN) to this review, the issue of intersectionality for Aboriginal people with a disability is often overlooked, despite the unique situation of disadvantage that is experienced by individuals who are Aboriginal *and* have a disability. It is therefore essential that the NDIS has systems and policies in place to ensure that the particular challenges and barriers faced by Aboriginal people in accessing services through the NDIS are fully understood and can be responded to.

Scheme Supports

AMSANT supports the Commission's overall finding of 'focusing too much on meeting participant intake estimates and not enough on planning processes, supporting infrastructure and market development' and the resultant poor outcomes for participants.

AMSANT supports Draft Recommendations 4.1 and 4.2 and argues the resolution of our concerns regarding cultural safety for Aboriginal and Torres Strait Islander people extends beyond the measure of delegating approval functions to Local Area Coordinators to improve outcomes for NDIS participants.

AMSANT argues that significant concerns remain with the quality and cultural appropriateness of care planning, consultation and interactions with Aboriginal and Torres Strait Islander people living with a disability, their families and our communities, with remote clients the most disadvantaged in the assessment process and delivery of disability services. Local Area Coordinators are often 'unskilled and outsourced to external providers' and do not

understand working with Aboriginal and Torres Strait Islander people. In particular NDIA-employed LACs have proved to be 'culturally unsafe' at times, with limited understanding of culturally respectful ways to engage with Aboriginal communities.

Concerns have also been raised about the disordered nature of NDIA's communication, both internally and with service providers. It has been reported to AMSANT that while discussion is being facilitated by NDIA directors to improve ways of working in response to concerns raised, such as the lack of cultural competency, there is a lack of follow-up process to ensure that practice is altered in response to these discussions. Adding to these concerns are issues voiced by the ACCHS sector regarding breaches of confidentiality from within the NDIA and other agencies' communication.

Poor communication has also been reported during the demobilisation of an NDIS Pilot project, where questions raised by the service provider in regards to unmet outcomes were never responded to. This member service also noted disappointment that the collaboration, goodwill and support provided by them was never acknowledged by the NDIA.

Any delegation of additional responsibilities would address the short-term need for timely approval processes within the Scheme without consideration of the broader implications of quality appropriate planning and meeting the cultural needs for Aboriginal and Torres Strait Islander people and communities.

AMSANT member services have reported negative impacts on families' social and emotional wellbeing due to inappropriate cultural interactions across all levels of external workforce outside of the ACCHS sector in their dealings with the NDIS roll out.

Critically, some NDIS participants are reported to be receiving no services at all with plans in place within remote Aboriginal communities raising real concerns regarding the 'quality of life' for individuals with profound disabilities and/or limited life expectancy. In such instances the ACCHS sector has provided and funded these additional services to support these Aboriginal people and families in their communities. Where they are available, ACCHSs are best positioned to achieve strong outcomes for Aboriginal people. With strong networks into the communities they serve, the range of services they offer means that many Aboriginal people with disability will already be accessing them, even if not seeking support for their disability needs.

AMSANT challenges Draft Recommendation 4.1 and requests NDIA develop and implement specific processes/standards regarding interactions and engagement with Aboriginal and Torres Strait Islander people that respect their cultural practices and ways of doing business, and that these be developed in consultation with the ACCHO sector and Aboriginal organisations.

Whilst AMSANT acknowledges the development of the Aboriginal and Torres Strait Islander Engagement Strategy, there is increasing concern that the involvement in decision-making by Aboriginal people and organisations has departed from the original intent of a partnership with NDIA in developing workforce strategies, building the research and evidence base to support decision-making and quality assurance processes. Our position is strongly supported

by the First Peoples Disability Network (FPDN) and arguably many Aboriginal organisations in their responses to the Commission.

While AMSANT supports the sentiments outlined in the NDIS's Aboriginal and Torres Strait Islander Engagement Strategy, in particular, the desire to be underpinned by a community approach involving 'building community capability and capacity to develop local solutions and a deliberate focus on options to grow the number of Indigenous registered providers of support', we are disappointed that this does not seem to be occurring in practice.

We are concerned that the current application of market principles through the NDIS is not sufficiently considering the unique cultural, social and health needs of Aboriginal people, nor the advantages of awarding preferred provider status through the direct commissioning of funds to ACCHSs and other Aboriginal service providers, who are able to provide a unique and culturally safe service model.

Member services indicate the significant advantage of a dedicated project officer position in advocating and coordinating the complexities of the NDIS for clients of the service and community connector positions funded under NDIA to sit within the Sector, supporting community based engagement approaches. However, these positions must be dedicated within the ACCHO sector and funded on an ongoing basis to have real long-term benefits. It also needs to be noted that while essential, this will be insufficient to meet the cultural safety needs of all Aboriginal and Torres Strait Islander people living with a disability.

AMSANT supports mechanisms for plan approvals, responsive timely reviews and accountability that sit within Aboriginal organisations and that can provide advocacy beyond what the current Scheme allows. This will extend the capacity for engagement in governance and accountability to Aboriginal people.

ACCHSs understand the need for an intensive whole-of-family/whole-of-community response to healing, good health and wellbeing and have existing quality systems and standards in place that can support culturally safe disability service delivery. Our approach is to ensure all Indigenous people are able to determine their own priorities, and have more meaningful control over their own lives and cultural well-being. This approach is set out in the principles of Aboriginal community controlled primary health care (AMSANT 2017).

Aboriginal Community Controlled Organisations (ACCOs) in the Northern Territory, including the health services represented by AMSANT, have a well-established history of strong relationships with the communities in which they operate, a commitment to building community capacity and development, strong cultural competence, and a permanent presence in Aboriginal communities.

AMSANT would argue there are real risks for Aboriginal and Torres Strait Islander participants within the current rollout timetable and any continuation must be considered in light of incorporating fundamental cultural safety standards and practices, developing an Aboriginal workforce and quality assurances processes.

Provider Readiness

In response to Information Request 6.1 of the Productivity Commission's position paper AMSANT notes that significant service gaps exist for many of our member services, in particular those who operate in remote areas, which leads to significant uncertainty and challenges related to 'market size' and potential revenue for these service providers. For these services, becoming an NDIS service provider is a high-risk venture.

From the experience of our sector, and from a large and growing evidence base, it is clear that increased competition is not the answer to improved outcomes in remote communities in Aboriginal Australia. In fact, past experience has shown that increased competition in remote Aboriginal communities can lead to *worse* outcomes by undermining the effectiveness and potential development of existing Aboriginal service providers through the introduction of new external non-Indigenous providers that will increase service fragmentation, provide less culturally-safe service delivery, and compromise the ability for service integration at a local and regional level (AMSANT 2016).

The reality for many service providers in Aboriginal communities is that they have limited existing facilities and assets that can be used to provide NDIS services. Overcoming this requires significant upfront investments for capital expenditures that will likely put undue financial stress on these providers.

A persistent challenge for Aboriginal health services operating throughout the Northern Territory, and in remote areas particularly, is the ability to find and retain staff for core operations. In light of this, and the Commission's own acknowledgement that 'it is unlikely that the disability care workforce will be sufficient to deliver the supports expected to be allocated by the NDIA by 2020', AMSANT would recommend that the NDIA develop an Aboriginal workforce strategy [refer to 'workforce' below for more detail].

Despite these significant challenges, the sector reports strong advocacy for services that are not currently being delivered by the NDIS to be in place, and report that they are often picking up these services for clients when they are not provided through the scheme.

Of primary concern to AMSANT is that the current competitive private market mentality means that smaller ACCHSs and other Aboriginal organisations in the NT are unable to compete with the economies of scale of larger mainstream providers, including those who operate for profit.

At the same time, there are currently few if any incentives within the NDIS for service providers to actively work to build community capacity or show that they are able respond to the unique cultural, social and health needs of Aboriginal people.

A possible solution for remote regions where markets are 'thin' or fragmented, with few or no private sector providers, is the development of regional service hubs for outreach provision. Such a framework would allow smaller services throughout that region to spread both the costs and corresponding risks of NDIS service provision. However, encouraging

cooperation among services within these hubs would still be difficult within the current competitive market model.

In light of the unique circumstances of service delivery for Aboriginal people in the Northern Territory, particularly in remote areas, and the particular strengths and advantages that ACCHSs provide in the delivery of these services, AMSANT recommends that the APO NT Partnership Principles (see attached) should apply to the implementation of the NDIS in Aboriginal communities in the NT. These principles should be considered in conjunction with the NDIS Aboriginal and Torres Strait Islander Engagement Strategy in informing a framework for the commissioning of services within the NDIS in Aboriginal communities moving forward.

In response to Information Request 6.2 of the Productivity Commission's position paper AMSANT would again point to the absolute centrality of improving the current standards of cultural competency within NDIA systems and planning processes through the development of cultural standards as already discussed in this submission.

From the evidence received by AMSANT from our member services it would appear that providers are extremely concerned about the lack of sufficient support from the NDIA, which is resulting in providers taking on an extreme burden of work and financial investment to ensure that their clients' needs are met.

AMSANT has received feedback from our member services that in many cases clinics feel it is necessary to complete client access forms and plans ahead of engagement with the NDIA to ensure that clients fully understand the process and ensure quality in their plans. This work is extremely labour and resource intensive, with one service having conducted 'between 450-500 separate interviews in total for approximately 170 clients', with no reimbursement received for this extensive work.

Despite this, AMSANT member services feel that this kind of intervention is necessary to ensure that their communities are properly represented and resourced through the scheme. This is largely a result of serious concerns which have been raised about the quality of client interviews and plans when completed by NDIA staff.

Similarly, reports have been received to suggest that NDIS funding intended to secure the employment of a Project Officer for an NDIS pilot project was insufficient. This particular service was placed in the position of meeting all additional costs (e.g. recruitment, contract term, relocation) at its own expenses to attract an appropriately qualified applicant. This was in addition to covering all other additional program expenses internally.

Concerns have been raised about the rigid assessments process for quality and safety standards set by the Office of Disability in registering as a Provider of services and the lack of cultural safety requirements in these standards and the external assessors. AMSANT takes seriously the issue of quality and safety and have protocols in place to ensure that these standards are upheld. However, we remind the Commission of the need for these standards to be contextually relevant and enforced in a respectful manner. This again speaks to the

cultural competency of the NDIA and its staff, and their ability to comprehend how dominant mainstream structures and institutions have impacted Aboriginal people, and respond to this reality in way that is respectful and avoids re-traumatisation.

AMSANT has also identified that there is considerable need for increased knowledge within the Office of Disability of the existing capabilities of the Aboriginal Community Controlled sector to provide services as part of the NDIS. It is vital that the Office is aware of the invaluable cultural and community knowledge that these organisations bring with them, and particularly the role of the Aboriginal community controlled health sector as the largest provider of primary health care to Aboriginal people in the NT, providing over half of all episodes of care (56%) and contacts (59%) (NTAHKPI Report 2015/16).

Workforce

In response to Information Request 7.1 of the Productivity Commission's Position Paper, AMSANT recommends the development of an Aboriginal workforce strategy. Such a strategy should be developed through a process which engages in a direct and meaningful way with Aboriginal organisations, and ACCHSs in particular, with consideration given for the unique situation in each jurisdiction.

It is AMSANT's view that increasing the size of the Aboriginal and Torres Strait Islander health workforce is fundamental to closing the gap in Indigenous life expectancy. Furthermore, evidence shows that Aboriginal health professionals can better ensure culturally appropriate and improved health care to other Aboriginal Australians (Anderson et al 2009).

As acknowledged in the Position Paper, the disability workforce is not currently growing quickly enough to meet demand within the NDIS. Given the existing difficulties in remote Aboriginal communities to find and retain appropriately skilled staff, it is likely that workforce issues will be particularly acute in these areas. Our organisation and member services have serious concerns that the NDIS roll-out does not allow sufficient time for necessary workforce training and development.

In spite of the challenges that are present in remote areas, ACCHSs employ Aboriginal people at a significantly higher rate than other health services do. Data from 2014-15 reveals that ACCHSs employed 3,265 Aboriginal people nationally, and that even amongst services focusing solely on Aboriginal health, they employ over five times as many Aboriginal people as non-ACCHOs, with almost 60% of their staff being Aboriginal (AIHW 2016).

AMSANT would encourage the NDIA to draw on the extensive experience within our sector in the development of an Aboriginal Workforce Strategy. It is absolutely essential that the development of such a strategy includes measures that facilitate Aboriginal health services to 'grow our own' as a priority. If careful consideration and consultation is allowed to take place there is a real opportunity for the NDIS to expand employment in Aboriginal communities through the training of local Community Based Workers, Support Coordinators, and Interpreters to gain disability support qualifications, and potentially through options such as the introduction of Aboriginal Cultural Support as a funded Support Category in the NDIS. AMSANT recognises the urgency to meet our Allied Health workforce shortfalls with the

recent development of the Aboriginal Allied Health Academy in three secondary schools within Darwin in partnership with the Indigenous Allied Health Association. Such innovative models require immediate priority and investment to meet long-term workforce needs.

We also recommend to the Commission that the development of any workforce strategy must consider the need for trauma-informed service delivery to Aboriginal communities. AMSANT would like to emphasise that the most complex health, mental health and substance use issues within Aboriginal communities throughout Australia can be better understood in the context of historical and transgenerational trauma.

There have been significant recent developments in our scientific understanding of how experiences of trauma impact neurobiology, developing minds and bodies and how these impacts are passed on from generation to generation. Health systems which are developed to deliver services to Aboriginal people, without the integration of Aboriginal perspectives and ways of being, are far more likely to contribute to the very issues that they have been funded to prevent or manage. AMSANT therefore proposes that the NDIS commits to necessary reforms to achieve culturally and trauma informed systems. Central to such a system is the development of a trauma-informed workforce who understand and are able to respond to the causes and impacts of trauma.

Workforce and systems reform should occur within a Social and Emotional Wellbeing framework that encompasses domains of connection to culture, body, mind and emotions, land, family and kinship, spirituality and community (Gee et al. 2014). Understanding the implications of disruption and connection in relation to these domains is central to developing the capacity of staff, services and organisations to create a culturally-informed environment in which healing and wellbeing can be nurtured.

AMSANT has developed 8 core principles that capture the broader concepts of being Trauma Informed. These are:

1. Understand trauma and its impacts;
2. Create environments in which families and social groups feel physically, emotionally and spiritually safe
3. Provide culturally competent staff – staff need to respect specific cultural backgrounds including reflection of self as a cultural bearer;
4. Empower and support clients' control;
5. Share power and governance including individuals and families in the design and delivery of programs;
6. Integrate and coordinate care to holistically meet the needs of individuals;
7. Support relationship building as a means of promoting healing; and
8. Enable recovery.

Participant readiness

In response to Information Request 8.1 and 8.2 regarding the delivery of support coordination, AMSANT member services remain concerned that the lack of cultural

competency within NDIS is a major barrier to participant engagement with the scheme and non-Indigenous organisations who deliver support coordination services.

AMSANT considers the coordination of support for Aboriginal and Torres Strait Islander participants includes a high-level advocacy role ensuring the quality provision of all services, communication and interactions are provided to a culturally acceptable standard.

Our member services support the investment in culturally appropriate community engagement and awareness strategies with participants and communities which ensure Aboriginal people understand their rights and entitlements, and which support addressing issues of 'shame' and are in the participant's preferred language. In our view, this can only be addressed by strengthening the scope and investment for ACCHSs and other Aboriginal organisations and advocacy groups in the NDIS.

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