



Public Health Association
AUSTRALIA

**Public Health Association of Australia submission on the
National Disability Insurance Scheme (NDIS) Costs –
Issues Paper**

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Introduction

The Public Health Association of Australia

The Public Health Association of Australia Incorporated (PHAA) is recognised as the principal non-government organisation for public health in Australia and works to promote the health and well-being of all Australians. The Association seeks better population health outcomes based on prevention, the social determinants of health and equity principles. PHAA is a national organisation comprising around 1900 individual members and representing over 40 professional groups.

The PHAA has Branches in every State and Territory and a wide range of Special Interest Groups. The Branches work with the National Office in providing policy advice, in organising seminars and public events and in mentoring public health professionals. This work is based on the agreed policies of the PHAA. Our Special Interest Groups provide specific expertise, peer review and professionalism in assisting the National Organisation to respond to issues and challenges as well as a close involvement in the development of policies. In addition to these groups the Australian and New Zealand Journal of Public Health (ANZJPH) draws on individuals from within PHAA who provide editorial advice, and review and edit the Journal.

In recent years PHAA has further developed its role in advocacy to achieve the best possible health outcomes for the community, both through working with all levels of Government and agencies, and promoting key policies and advocacy goals through the media, public events and other means.

Vision for a healthy population

The PHAA has a vision for a healthy region, a healthy nation, healthy people: living in an equitable society underpinned by a well-functioning ecosystem and healthy environment, improving and promoting health for all.

Mission for the Public Health Association of Australia

As the leading national peak body for public health representation and advocacy, to drive better health outcomes through increased knowledge, better access and equity, evidence informed policy and effective population-based practice in public health.

Priorities for 2017 and beyond

Key roles of the organisation include capacity building, advocacy and the development of policy. Core to our work is an evidence base drawn from a wide range of members working in public health practice, research, administration and related fields who volunteer their time to inform policy, support advocacy and assist in capacity building within the sector. The aims of the PHAA include a commitment to:

- Advancing a caring, generous and equitable Australian society with particular respect for Aboriginal and Torres Strait Islanders as the first peoples of the nation;
- Promote and strengthen public health research, knowledge, training and practice;
- Promote a healthy and ecologically sustaining human society across Australia, including tackling global warming, environmental change and a sustainable population;
- Promote universally accessible people centered and health promoting primary health care and hospital services that are complemented by health and community workforce training and development;
- Promote universal health literacy as part of comprehensive health care;
- Support health promoting settings, including the home, as the norm;
- Assist other countries in our region to protect the health of their populations, and to advocate for trade policies that enable them to do so;
- Promote the PHAA as a vibrant living model of its vision and aims.

Preamble

PHAA welcomes the opportunity to provide input to the Productivity Commission’s consultation on the National Disability Insurance Scheme (NDIS) costs issues paper. The reduction of social and health inequities should be an over-arching goal of national policy and recognised as a key measure of our progress as a society. The Australian Government, in collaboration with the States/Territories, should outline a comprehensive national cross-government framework on reducing health inequities. All public health activities and related government policy should be directed towards reducing social and health inequity nationally and, where possible, internationally.

Health Equity

As outlined in the Public Health Association of Australia’s objectives:

Health is a human right, a vital resource for everyday life, and a key factor in sustainability. Health equity and inequity do not exist in isolation from the conditions of society that underpin people’s health. The health status of all people is impacted by the social, political, and environmental and economic determinants of health. Specific focus on these determinants is necessary to reduce the unfair and unjust effects of conditions of living that cause poor health and disease.

The PHAA notes that:

- Health inequity differs from health inequality. A health inequality arises when two or more groups are compared on some aspect of health and found to differ. Whether this inequality (disparity) is inequitable, however, requires a judgement (based on a concept of social justice) that the inequality is unfair and/or unjust and/or avoidable. Inequity is a political concept while inequality refers to measurable differences between (or among, or within) groups.¹
- Health inequity occurs as a result of unfair, unjust social treatment – by governments, organisations and people,² resulting in macro politico-economic structures and policies that create living and working conditions that are harmful to health, distribute essential health and other public services unequally and unfairly, preventing some communities and people from participating fully in the cultural, social or community life of society.

Social Determinants of Health

The social determinants of health are the conditions in which people are born, grow, live, work and age, including the health system. These circumstances are shaped by the distribution of money, power and resources at global, national and local levels, which are themselves influenced by policy choices. The social determinants of health are mostly responsible for health inequities – the unfair and avoidable differences in health status seen within and between countries. This is particularly pertinent when considering issues such as disability policy.

The determinants of health inequities are largely outside the health system and relate to the inequitable distribution of social, economic and cultural resources and opportunities. Health inequities are the result of the interaction of a range of factors including: macro politico-economic structures and policy; living and working conditions; cultural, social and community influences; and individual lifestyle factors.

PHAA comments on NDIS costs – Issues paper

Cost pressures

Why is there a mismatch between benchmark package costs and actual package costs

The provision of services to support people with disabilities covers two different levels of complexity - the health condition and the social determinants of health. Firstly, within the disability itself and the myriad number and type of conditions which can lead to limitations on daily activities and participation in work and education. Disabilities are usually not experienced in isolation from other health issues. Australians with a disability are more likely than others to also have mental health issues, preventable chronic conditions such as diabetes, to be smokers, and to be overweight or obese.³ Secondly, within the socio-demographic circumstances of the individual requiring support. NDIS packages are packages because the provision of services to support these individuals requires multiple service types, in packages tailored to suit individual circumstances and needs. These will be affected by factors such as age, sex, cultural background, education, employment, location, availability of services, waiting times, and individual choice.

With this dual complexity, a mismatch between pre-determined packages and actual packages is unsurprising. This may be interpreted as an indication of an area in which the NDIS is working well – recognising individual needs and tailoring packages of care accordingly.

Early childhood early intervention approach

Is the ECEI approach an effective way to ensure that those children with the highest need enter into the NDIS, while still providing appropriate information and referral services to families with children who have lesser needs?

With early intervention proven to be successful in reducing the need for long-term support and improving the health and wellbeing of people with disabilities, the PHAA is concerned to ensure that the ECEI approach is used to facilitate early intervention services rather than to reduce the numbers of children participating in the NDIS. The issues paper notes that a higher than expected number of children participated in the NDIS trials. However, there is no clear evidence presented in the paper that these were inappropriate referrals of children not in need of support services for a disability.

The ECEI approach involves having an early childhood intervention service provider discuss the needs the child and identify appropriate supports and whether the supports should be provided through the NDIS or mainstream services. Such an approach has the potential to be an effective and efficient way to streamline the process of accessing support services. However, this will require that the early intervention service provider in the ECEI meeting is able to directly link the child and family to the appropriate support services, seamlessly liaising between the NDIS and mainstream services.

If the ECEI approach is not an interface between the systems, it may instead simply lengthen the time and energy spent in one system before having to begin the process again in the other. This would effectively decrease access to services overall, particularly for those for whom issues such as language, literacy and transport mean that equality of access to services generally is already difficult. The ECEI approach must assist in the navigation of the process for accessing services rather than adding another layer of complexity to it.

Intersection with mainstream services:¹

Is the current split between the services agreed to be provided by the NDIS and those provided by mainstream services efficient and sufficiently clear? If not, how can arrangements be improved?

Is there any evidence of cost-shifting, duplication of services or service gaps between the NDIS and mainstream services or scope creep in relation to services provided within the NDIS? If so, how should these be resolved?

How has the interface between the NDIS and mainstream services been working? Can the way the NDIS interacts with mainstream services be improved?

Correctional settings - Implications of NDIS exclusions for people with a disability

In no other domain is the transition to the National Disability Insurance Scheme (NDIS) more unclear than with respect to how it will interact with the criminal justice system for people with a disability in custodial settings. ⁴The Council of Australian Government defines custodial settings to include any person who resides in prison, youth detention facilities, secure mental health or disability facilities. ⁵Therefore, the challenges raised here are generalisable to all of these settings.

For people with a disability in custody, Paragraph 7.25(a) of the NDIS (Supports for Participants) Rules state that the NDIS will not be responsible for “the day-to-day care and support needs of a person in custody, including supervision, personal care and general supports”. ⁶This is problematic because increasing evidence from Australia and internationally indicates that the continuity of disability-specific services and day-to-day care through the criminal justice system experience is crucial for improving the health and justice outcomes for people with a disability in custody. ^{4,7} In other jurisdictions positive policy changes in custodial settings have achieved considerable success and cost-effectiveness, by shifting the model of social service and healthcare provision from a siloed, custodial-centric framework to complete throughcare case management, eliminating most of the traditional barriers to these services for people in custody. ⁸ Recently in Australia, this case management throughcare model has been asserted as fundamental to reduce inequity and improve the social, health and justice outcomes for people with cognitive disability in the criminal justice system. ^{9,10}

At times the principles to determine responsibility between NDIS and other services for this group are unclear and almost contradictory. For example, these principles state that the NDIS will provide “training for staff in custodial settings where this relates to an individual participant needs”, however the NDIS will not be responsible for “assisting prison staff to understand individual clients’ needs and human rights...” nor “...implementing practical disability training available to Corrections Officers and other criminal justice staff...”. ⁵ This lack of clarity will likely lead to ambiguity as to who is ultimately responsible for the disability-specific care for people with a disability in custody and promote a reactive service model, implemented only on a last resort, ‘ad-hoc’ basis. Additionally, the NDIS (Supports for Participants) rule 7.25(b) states that the NDIS will not be responsible for ensuring access to justice for people in custody. ⁶ If neither State-based prison providers nor the NDIS assumes this responsibility, it cannot be considered anything but a direct contravention of the human rights obligations as outlined by the UNCRPD. ¹¹

¹ The PHAA gratefully acknowledges the contribution of Young, JT, Research Fellow, Melbourne School of Population and Global Health, The University of Melbourne, in drafting this section of the submission.

Why is the NDIS important for people with a disability in custody?

Nearly all forms of disability are overrepresented among people with criminal justice system involvement.

The overrepresentation of disability in the criminal justice system has been observed in juvenile detention,^{12,13} pre-trial detention^{14,15} and adult correctional facilities.¹⁶⁻¹⁹ Furthermore, although physical disability is more prevalent among people in the criminal justice system,²⁰ it is likely just the ‘tip of the iceberg’. Every expression of cognitive disability is substantially over-represented in the criminal justice system including developmental disabilities such as Autism Spectrum Disorder (ASD)²¹ and foetal alcohol spectrum disorder;^{22,23} cognitive impairment from acquired brain injury;²⁴ and intellectual disability.¹⁸ Despite increasing efforts to develop diversionary sentencing and trial options to divert individuals with significant cognitive impairment away from prison into appropriate care, it is estimated that 1 in 10 prisoners in Australia has an intellectual disability.¹⁸ Inclusion of psychiatric and cognitive impairment increases the proportion of people in the criminal justice system with disability substantially.²⁵

Current evidence suggests that people with a disability in custody may face substantial challenges in accessing the NDIS.

People with cognitive disability in the criminal justice often have multiple and complex needs.²⁶ These substantial needs include physical/cognitive disability and chronic physical health conditions, mental illness, and substance use; entrenched disadvantage, victimisation and trauma, social isolation, stigma and barriers to health and social service access.^{18, 27-29} This interaction can lead to substantial difficulties in exercising choice and decision-making which are particularly important in individual support planning.³⁰ Effectively, this suggests that without an informal carer in place, most individuals with cognitive disability are unlikely to have the skills and/or adaptive capacity required to advocate for, and successfully initiate, the process of having their NDIS eligibility assessed.⁴

Unless the NDIS includes eligibility for active in-reach to identify disability among people in custody, a substantial proportion will remain unidentified and therefore ineligible for NDIS support upon release.

Because of the way it is expressed, physical disability is often more overt and thus identifiable than cognitive disability. Accordingly, people with unidentified cognitive disability in the criminal justice system have often been referred to as the ‘hidden’ majority. There are also inconsistencies in the requirement for identification of cognitive disability. In practice, people with intellectual disability are more likely to meet eligibility requirements for disability-based support in custody, than persons with other cognitive disabilities (ie. those who may acquire a brain injury after the age of 18).²⁶ Although the majority of support requirements are the same or similar for people with intellectual disability and those with significant cognitive impairment from other causes, in many jurisdictions the applied definition of intellectual disability tends to prohibit eligibility for anyone who is deemed to have acquired significant cognitive impairment after the age of 18.

This is problematic because research has highlighted that a substantial proportion of individuals with cognitive/intellectual disability are not diagnosed prior to contact with the criminal justice system.³¹⁻³³ Compounding this issue, a recent report highlighted that there is “no consistent process to identify, assess or support this group of vulnerable prisoners” in some jurisdictions.^{p.7; 9} Without an identification of cognitive disability, these individuals do not qualify for disability-specific services, either while in prison or after release to the community. Recent research has observed that approximately two out of three people with intellectual disability remain unidentified and unsupported upon release from custody.³¹ Without a systematic and NDIS-integrated approach to the identification of intellectual/cognitive disability in the criminal justice system, a substantial proportion of vulnerable individuals will be precluded from assessment of their eligibility and thus it is likely their needs will remain unmet. These arbitrary distinctions

are exactly the issues that can be addressed by the NDIS eligibility requirements and the principles to determine responsibilities of the NDIS and other service systems.

A lack of disability-service capacity and defined benchmarks for evaluation within correctional settings likely will increase public expenditure.

The NDIS exclusions for people with disability in correctional settings necessarily shift the responsibility of diagnosing cognitive disability to the correctional service providers. Recent research has highlighted the limited disability-specific training, education and service capacity among criminal justice service providers.³² Furthermore, in a criminal justice and prison health service setting, the focus is often on the risk of committing further crimes rather than service provision focused on disability-related functional impairments, social and/or economic participation; all of which are core principles of the NDIS Act.³⁴ A survey of service providers from two jurisdictions has indicated that current service models are implementing an informal or ‘ad hoc’ approach to the identification of cognitive disability in correctional settings.³² The existing evidence suggests that considerable expenditure will be required to increase this disability service capacity placing increased budgetary stress on an already overburdened system. Therefore, it is unlikely that a criminal justice-led disability service model will achieve value for money without considerable in-reach and integration with the NDIS.

Without the continuous provision of NDIS support and care during the transitional period, people released from custody are at increased risk of poor health and justice outcomes.

Upon release from the criminal justice system, individuals with cognitive disability must quickly adapt to a new physical, social and service environment with a host of new rules, priorities and barriers. If adequate support is not provided, significant impairments in social interaction, learning, adaptive functioning self-care and communication often impedes understanding and adherence to the new sets of abstract rules. A recent report by the Victorian Ombudsman on the rehabilitation and reintegration of prisoners, specifically acknowledged that prisoners with cognitive/intellectual disability are particularly vulnerable.⁹

Successful navigation of, and interaction with, a complex service environment at a time of rapid change and stress, such as release from prison, is likely beyond the capacity of most individuals with cognitive disability without support. Any gaps in the support and care from the lack of integration between the criminal justice system and disability systems will likely magnify the disadvantage for this vulnerable population. Recently, substantial gaps in the continuity of disability-specific and health services during the transitional period from prison to the community have been observed.³² These gaps increase the risk of poor health and justice outcomes for people with a disability. Without adequate, continuous support, cognitive disability can increase the risk of incarceration and return to custody, risky substance use behaviours such as injecting drug use and needle-sharing, and premature death from preventable causes.^{27,35}

NDIS exclusions for people with a disability in custody will lead to service gaps necessitating costly acute health service use, unidentified morbidity, delayed access to care and return to custody.

Incarceration necessitates considerable public expenditure estimated at over 4 billion dollars per annum; the daily cost per prisoner exceeds the average daily wage in Australia by a factor of 2.^{36,37} As noted in the Issues paper, the average annualised NDIS package costs are estimated at \$36,049 which is approximately one-third of the annual cost per prisoner in custody. This suggests that delaying return to custody for people with a disability is a legitimate priority for reducing public expenditure.

Considerable evidence suggests that meeting the health and social service needs of people in the criminal justice system will decrease public expenditure both directly through acute health service use and return to custody; and indirectly through other costs such as unemployment and policing.³⁸ Research in Australia has established that health-related factors predict return to custody in ex-prisoners.³⁹ Growing evidence

suggests that policy reform aimed at increasing the integration of the NDIS for people with disability at every stage of the criminal justice system will have positive impact on both public expenditure and public safety.

Intersection with mainstream mental health services

How will the full rollout of the NDIS affect how mental health services are provided, both for those who qualify for support under the scheme and those who do not?

What, if anything, needs to be done to ensure the intersection between the NDIS and mental health services outside the scheme remains effective?

Mental health disability has a devastating effect on individuals and it should be a priority that there are no gaps in service provision during this process. People living with a mental disability are currently dependent on services and any gap in services may have adverse impacts. This will present a challenge for the implementation and transfer of services from the current models to the new funding models. Service providers will need to prepare for provision of care under the NDIS and this may challenge resources if they are redirected towards funding models rather than care delivery.

Services will face the challenge of structuring and delivering care. Current service delivery has worked under a recovery based approach. This has been supported by the National Mental Health Commission and state mental health commissions, and will need to be clarified with the provision of services under NDIS. The NDIS is funding people with a permanent psychological disability. Clarity will be needed to determine if the recovery based approach will be a part of this new NDIS service delivery and if, not where these types of services will be available if they are not available through the NDIS.

Funding for alternative mental health services will need to remain for people living with a mental disability who are not eligible for NDIS. This population will require ongoing access to mental health services and provision must be made to ensure that targeted and appropriate services remain available. NDIS funding should be independent of services that are provided for vulnerable populations such as Aboriginal and Torres Strait Islanders, Culturally and Linguistically Diverse, former defence personal, GBLTIQ, farmers, women affected by DV and people living in rural areas, fly in fly out workers and youth and adolescent services. Funding should also be independent from services providing alcohol and other drug support.

There should be national, state and local strategies implemented towards promotion and prevention of mental health to stem the increasing rates of mental health issues within Australia. These should be coordinated and be targeted at all populations across Australia.

The capacity of people with psychiatric disabilities to manage their own care options should be considered. It is recognised that some people with a psychiatric disability may lack insight into their condition or may lack the skills to negotiate their own care packages. Due to the nature of mental health conditions, they may also lack family members or friends who would be willing to act as substitute decision makers. Due to the episodic nature of mental illness, substitute decision makers may also need to be short term. These issues should be taken into account when considering access to psychiatric disability support services.

Clear and defined standards of care provision should be established so that service providers are able to provide optimum support for people living with a psychological disability. It is essential that these targets and standards address areas such as physical health care and mental health, work provision and support for meaningful activity, safety of accommodation and engaging isolated populations such as the homeless, people living with a psychological disability who are incarcerated and any other populations who have difficulty engaging with support services. This will also need to include people with cognitive issues that affect personality, behaviour and decision making.

In the area of psychiatric disability in particular, there needs to be a very close relationship between clinical mental health services, disability support services and other important services such as housing, in order to achieve stable mental health and stability in other life areas. Assessment of the NDIS services should thus consider 'social inclusion' outcomes for people with psychiatric disability (housing, employment, social support).

Conclusion

PHAA supports the broad directions of ensuring that the NDIS is sustainable. However, we are keen to ensure equity of access to services and the elimination of gaps between the systems, in line with this submission. We are particularly keen that the following points are highlighted:

- Packages need to be tailored to suit the individual needs of clients, taking into account their health needs and circumstances;
- The ECEI approach must be an effective interface between NDIS and mainstream services;
- Particular care must be taken in regards to people with disability who are in the correctional system
- Eligibility criteria and alternative services must be clearly defined to ensure there are no gaps in the systems
- There needs to be clear coordination between clinical mental health services, disability support services and other important services such as housing.

The PHAA appreciates the opportunity to make this submission and the opportunity to contribute to ensuring the sustainability of the NDIS.

Please do not hesitate to contact me should you require additional information or have any queries in relation to this submission.

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