



Melbourne Disability Institute

SUBMISSION TO THE PRODUCTIVITY COMMISSION STUDY OF THE NATIONAL DISABILITY AGREEMENT

This submission is in response to the Productivity Commission Issues Paper on the National Disability Agreement (NDA).

The primary focus of this submission is on the architecture of the new NDA, and its relationship to the other Intergovernmental Agreements on Federal Financial Relations, rather than its very detailed contents and performance indicators.

Recommendations

It is recommended the NDA:

- should be retained but totally rethought, restructured and refocused, so that it complements the NDIS, aligns fully with the National Disability Strategy and supports Australia meeting our obligations under the UNCPRD;
- should be partially implemented through the other Intergovernmental Agreements on Federal Financial Relations through data collections and linkage, key performance targets, action plans and, potentially, earmarked funding, so that the needs of people with disability, are specifically measured and met under each of these Agreements;
- prioritise adequate specialist and mainstream supports for people with disability, who are not eligible for the NDIS, because responsibility for this group is shared between the NDIA, the Commonwealth and the States and territories and so best governed through the NDA. This will require a collaborative and coordinated effort;
- identify universal service systems which are not covered by Intergovernmental Agreements on Federal Financial Relations, especially in relation to justice, transport and residential building regulations, and set up monitoring systems, so that urgent equity and access issues are addressed;
- ensure a guaranteed adequate long-term funding formula for advocacy, because individual and systemic advocacy is essential for people with disability to be full citizens and, currently, there is no such arrangement;
- commit all governments to the collection of key national data essential for evidence-based disability policy and practice improvements and make it available for research, under the “5 Safes”; and
- should be governed through the Disability Reform Council and COAG, based on an annual report prepared by senior officers of the Commonwealth, States, territories and the NDIA supported by an Independent Advisory Committee, comprising a majority of people with lived experience of disability. The report should include agreed performance metrics, action plans, responsibilities and timelines, when agreed performance benchmarks are not met.

Overview

The NDA should be radically changed because of the total restructuring of disability funding arrangements between the Commonwealth and States and territories which will be complete once the National Disability Insurance Scheme (NDIS) is fully rolled out.

The NDA is essential and changes to its structure should be designed to ensure optimal alignment with other government policies and commitments and, above all, ensure that the NDA best serves the needs of people with disability, their families and carers.

In the absence of a major restructuring and refocusing, the NDA will not be fit for purpose, once the NDIS is fully operational.

However, it is not recommended that the other Intergovernmental Agreements should necessarily undergo a major change at this time, because there are no major structural funding shifts occurring in the other areas covered by Intergovernmental Agreements on Federal Financial Relations, at this time. Rather, it is recommended that the other Intergovernmental Agreements should be aligned with a repurposed NDA.

The current NDA and the other Intergovernmental Agreements on Federal Financial Relations are all structured to reflect the fact that, until now, they have covered areas of inter-action and cooperation between the Commonwealth and the States and territories in which three conditions have applied:

- First, the Commonwealth and the States and territories have agreed the areas are high priority,
- Second, the States and territories have been primarily responsible for service delivery, and
- Third, because of vertical fiscal imbalances, the States and territories have been reliant on the Commonwealth for funding to supplement State and territory funding.

The financial contributions from the Commonwealth have put the Commonwealth in the strongest position in the negotiations over Intergovernmental Agreements. As a result, the Commonwealth has generally had a disproportional effect on the agreements, as the Commonwealth has set national benchmarks and performance objectives, as a condition of funding.

Commonwealth priorities have also changed quite often, with at times little objective evidence. This has then forced the States and territories to change priorities, while also undermining a more collaborative and long-term approach.

Government relationships, both within and between governments, are also generally very hierarchical, rather than based on equality or at least a recognition of complementarity and symbiosis.

There is therefore a major opportunity to develop a more collaborative and effective approach in relation to all Intergovernmental Agreements, based on true partnerships.

To date, the Intergovernmental Agreements on Federal Financial Relations have covered funding, performance benchmarks and reporting with respect to:

- Disability (National Disability Agreement)
- Indigenous Reform (National Indigenous Reform Agreement)
- Schools and Workforce Development (National Agreement for Schools and Workforce Development)
- Public and Social Housing (National Affordable Housing Agreement)
- Education (National Education Agreement), and
- Health and Hospitals (National Health Care Agreement).

All of these agreements are very significant for people with disability, their families and carers, not just the NDA, as they cover mainstream services which people with disability need to access. For example, many

people with disability need access to affordable housing and good education for students with disability is essential for them to maximise lifetime opportunities.

However, it should also be noted that these agreements have not been comprehensive from the perspective of ensuring that people with disability are treated as full citizens. For example, they do not cover all of the universal services which have profound effects on people with disability. The justice and transport systems and residential building codes are examples of very significant omissions.

The current review of the NDA, therefore provides an opportunity to ensure that all mainstream services are inclusive of people with disability, as set out in the National Disability Strategy and the UN Convention on the Rights of Persons with Disability (UNCPRD) and the Optional Protocol, to which Australia has been signatories since 2008 and 2009, respectively.

Therefore, this study of the NDA provides a major opportunity to better align policies and practices with Australia's international disability obligations, as well as key domestic disability policies and frameworks.

With the introduction of the NDIS, the Commonwealth and States and territories have all reaffirmed and boosted their commitments to support people with disability, through very substantial additional funding.

However, the National Disability Insurance Agency (NDIA) is a Commonwealth authority and the States and territories are contributing their disability funding to the Commonwealth, under an agreed formula as set out in Bilateral Agreements. As a result, the direction of disability funding, from the Commonwealth to the States and territories, which has underpinned the NDA to date, is being reversed.

Second, the Commonwealth is not contributing any disability funding to the States and territories except for the proposed payments from the Disability Care Australia Fund, all of which are earmarked to assist States and territories with their NDIS funding contributions. This funding represents the States and territories' shares of the 0.5 per cent increase in the Medicare levy in 2013 to fund the NDIS.

Third, NDIS funding contributions are being managed through the NDIS Act and Bilateral Agreements between the Commonwealth and States and territories and the NDIA has to report on its performance to the States and territories.

These three changes are all very significant and mean that the structure of the current NDA is no longer appropriate.

Going forward, to complement the NDIS, align fully with the National Disability Strategy and achieve Australia's obligations under the UNCPRD, the NDA should prioritise adequate support for people with disability not eligible for the NDIS and create mechanisms to ensure that all people with disability have access to universal services.

The Productivity Commission in its Report on Disability Care and Support in 2011 identified three groups: Tier 1 (the Australian population); Tier 2 (all people with disability); and, Tier 3 (people with significant and permanent disabilities under the age of 65, who would be eligible for the NDIS).

It was expected that around one-half of NDIS participants would be existing clients of State and territory governments and one-half would be new clients who had previously not received supports. It was also envisaged that some of the NDIS funding should be available for Tier 2, to assist those who might need occasional supports but not need an individualised package.

Some of the funding within the NDIS was therefore earmarked for Tier 2 and it was expected that the Commonwealth and, especially, the States and territories would continue to provide support to people with disability not eligible for the NDIS. However, in implementing the NDIS, some funding which was

better aligned with Tier 2 has been allocated to the NDIS and there is now very little funding and in some jurisdictions no funding being allocated to non-NDIS participants.

As a result, there is a real danger now of a “cliff” at the edge of the NDIS, which will lead people with disabilities to exaggerate their needs, in order to become eligible for the NDIS, or who will become more disabled and eventually become NDIS participants at much higher cost. Either way, the vision and financial sustainability of the NDIS are at risk. We are seeing clear signs of this with the larger than expected numbers of children seeking access requests to the NDIS. In older age groups the absence of sufficient supports for those not eligible for the NDIS is being masked by continuity of support arrangements.

It is essential that the NDIS is built on strong foundations, through the provision of adequate disability supports for those not eligible for the NDIS. This needs to be more than “information”, “linkages” and mainstream “capacity building” as now reflected in the structure of the ILC. These disability supports should be bulk purchased and available on a needs basis. Otherwise, the NDIS will become “an oasis in the desert”.

Therefore, the NDA needs to provide effective mechanisms for specialist support for people with disability not eligible for the NDIS. In addition, people with disability must have full access, as citizens, to mainstream services.

The National Disability Strategy is aimed at making all mainstream services accessible and inclusive. It is a highly aspirational document, covering: inclusive and accessible communities; rights protection, justice and legislation; economic security; personal and community supports; learning and skills; and, health and well-being.

The National Disability Strategy sets “areas for future action”, but because the Strategy does not include any funding, adequate monitoring, clear accountability or action plans with timeframes and deliverables, it is failing to meet its very desirable objectives.

Therefore, a second key priority for this review of the NDA should be the development of mechanisms designed to ensure the fulfilment of the National Disability Strategy.

In seeking to achieve the goals in the National Disability Strategy and setting the purpose of the NDA, it should be recognised that this should be based on joint accountability and shared purpose, between the Commonwealth and States and territories.

High collaboration across the Federation, is essential for Australia to meet many of the challenges of the 21st century. The NDA therefore provides a major opportunity for all governments to build robust and transparent processes requiring shared governance, long term solutions and innovative problem solving to meet the needs of Australian citizens.

However, given that most interactions between the Commonwealth and States and territories to date are characterised by point scoring and often shifting of costs, the collaboration needed to deliver the NDA is also very challenging.

It is therefore essential that the new NDA includes mechanisms which align interests around a shared vision for supporting all people with disabilities as full citizens.

However, these mechanisms will not be effective without comprehensive data collections data linkage and clear reporting mechanisms, accountabilities and action plans, responsibilities and timelines, when agreed performance benchmarks are not met.

Therefore, it is recommended that the NDA should:

1. Identify funding and key performance targets in the other Intergovernmental Agreements on Federal Financial Relations, so that the needs of people with disability, are specifically measured and met.
2. Recognise that responsibility for the provision of specialist and mainstream supports for people with disability, who are not eligible for the NDIS, is a shared responsibility between the Commonwealth NDIA and the States and territories, which will require a coordinated collaborative effort, including shared funding.
3. Identify universal service systems which are not covered by Intergovernmental Agreements on Federal Financial Relations and set up monitoring systems and research in these areas.
4. Provide a mechanism so that advocacy is properly funded, because advocacy is essential to promote and protect people with disability.
5. Agree to the collection of key national data essential for evidence-based public policy improvements and make it available for research, under the “5 Safes”.
6. Require a comprehensive report to be prepared annually by senior officers of the Commonwealth, States, territories and the NDIA for the Disability Reform Council and, then, COAG, which should report on agreed performance metrics and include action plans, responsibilities and timelines, when agreed performance benchmarks are not.

Finally, in setting out a new NDA it is recognised that no funding currently attaches to this Study and that governments are already committing more funding to disability, through the NDIS, than at any time in Australia’s history. Therefore, the focus of the recommendations in this submission are not primarily aimed at additional funding.

Rather, the focus is on the development of shared objectives and then aligning agreements and existing funding optimally to best meet the needs of people with disability and then using rich data collections and analysis to drive reform under a very different NDA with clear responsibilities for action when performance targets are not achieved.

Other Intergovernmental Agreements on Federal Financial Relations

All Intergovernmental Agreements on Federal Financial Relations impact on the lives of people with disability, their families and carers. Each Intergovernmental Agreement should therefore include key performance targets designed to improve the lives of people with disability, their families and carers.

The focus should be on equity of access, adequacy of support, meeting the objectives of the National Disability Strategy and Australia’s obligations under the UN Convention on the Rights of Persons with Disability, as follows:

National Indigenous Reform Agreement

Australian Bureau of Statistics modelling, based on the 2016 census, identifies that after allowance for the age differences in the population, Indigenous Australians are almost twice as likely (8.5 per cent) to have a disability than non-Indigenous Australians (4.7 per cent). The raw number of Indigenous people requiring support in 2016 was 6.7 per cent, compared with 5.3 per cent of their non-Indigenous peers.

These figures demonstrate that Indigenous policy reform must go hand-in-hand with disability reform.

There is also a major opportunity to increase job opportunities for Indigenous Australians, as a result of the introduction of the NDIS, especially in remote communities.

It would be a lost opportunity and unaffordable to rely on fly in/fly out or drive in/drive out disability support workers in remote communities. The NDIS should therefore be integrated into indigenous job development and training programs, such as the Community Development Programme.

Within the National Indigenous Reform Agreement, performance targets and funding should be set aside to:

- prioritise reducing the incidence of disability amongst Indigenous Australians,
- support Indigenous Australians with disability who are not eligible for the NDIS, and
- increase development, training and employment programs and opportunities for Indigenous Australians, as a direct result of the implementation of the NDIS.

National Agreement for Schools and Workforce Development

The need to train and grow the disability workforce to support the delivery of the NDIS is a major opportunity and challenge, as disability spending doubles.

It is estimated that the NDIS will contribute about 20 per cent of all new jobs in Australia during the transition to full scheme. In rural and regional areas, it is likely to be 40 per cent of jobs and more than 80 per cent in remote areas. The demands for disability sector workers are also competing with the health and aged care sectors, which are also growing rapidly.

At the same time, the NDIS is leading reform across all of human services, because it is embedding disability policy in a long-term insurance product framework, giving participants control, choice and rights and seeking to build community capacity. There is therefore an added opportunity, as the workforce training needs of the NDIS are identified, to widely disseminate the lessons, in order to prepare the workforce of the future for the health and aged care sectors and other human services.

A second major opportunity is the training of people with disability, to boost employment of people with disability. Labour force participation rates amongst people with disability are well below the national average. In 2012 it was 52.8 per cent compared with 82.5 per cent for people without disabilities. Australia also ranks in the bottom one-third of OECD nations in terms of employment of people with disability.

Employment amongst people with disability must rise for the NDIS to deliver its potential as an economic reform. In 2011 the Productivity Commission estimated that if Australia could reach the OECD average in terms of employment of people with disability, the NDIS could add nearly 1 per cent to Australia's GDP by 2050.

Therefore, employment opportunities and pathways for people with disability should be separately identified within the National Agreement for Schools and Workforce Development. This work should extend to working with employers and social enterprises and include strategies such as customised employment for people with disability. Peer-worker models, which have been very successful in mental health, should now be extended to the disability sector more broadly.

There are therefore several important opportunities to use the framework provided through the National Agreement for Schools and Workforce Development to optimise all human services workforce development strategies and provide much greater opportunities for employment of people with disability, as well as build and train the disability workforce of the future.

National Affordable Housing Agreement

There is a major and growing lack of affordable housing for all people, including people with disability, as the stock of public and affordable housing is declining.

Looking ahead, a reduction in affordable housing supply is going to collide with rapid growth in demand, due to the NDIS.

When the NDIS is fully operational in 2010/21, it is expected that approximately 110,000 NDIS participants, who will not be eligible for Specialist Disability Accommodation (SDA), will be looking for housing as they will have support from the NDIS to live independently, but not necessarily suitable accommodation.

Therefore, it is essential that as more innovative approaches are developed to solve the current major housing affordability challenges, the housing needs of people with disability, who are not eligible for SDA, are specifically identified and then met through the National Affordable Housing Agreement.

National Education Agreement

The NDIS will not achieve its potential if students with disability do not have access to education which maximises their learning and lifetime opportunities. Sadly, it is well known that our education system is not meeting the needs of students with disability.

ABS data from 2009 demonstrates school life can be very challenging for many children with disability, with 61.4 per cent reporting they experienced difficulties. The most commonly reported problems were learning difficulties (45.1 per cent), communication difficulties (26.5 per cent) and fitting in socially (26.5 per cent).

Children attending special classes in mainstream schools were more likely to report experiencing difficulty (83.7 per cent) than children attending special schools (65.4 per cent) or those attending mainstream classes only (52.5 per cent).

In 2009 around one-fifth (22 per cent) of all 20 to 24-year-olds had a disability or were restricted by a long-term health condition (for example, asthma or a mental health condition). Of these around three-fifths (62 per cent) had attained year 12 compared with almost four-fifths (78 per cent) of those who did not have a disability or restrictive long-term health condition. Those who had a profound and severe disability were far less likely to have attained Year 12 (46 per cent) than those who had a moderate or mild disability (73 per cent).

The education of children with disability at schools is not being improved through the collection of the so-called Nationally Consistent Collection of Data on School Students with Disability (NCCD). Unfortunately, the NCCD, which is based on individual teacher assessments is not consistent and mixes up the education needs of students with disability with those students with learning, emotional and socialisation difficulties. It therefore highlights the need for not just data, but accurate data.

There are also major opportunity to innovate in education to improve outcomes for students with disability. For example, technology has enormous potential to enable children with disabilities to engage with the curriculum and learn in highly innovative ways.

Through the National Education Agreement there is therefore a major opportunity to collect and link accurate data, identify and action appropriate education targets for students with disability and, over time, improved education will lead to approved employment outcomes for people with disability.

National Health Care Agreement

Ensuring equitable access to health services for people with disability should be a key performance indicator within the National Health Care Agreement.

To achieve this goal, there are two key issues which need to be addressed.

First, there needs to be a clear boundary drawn between the disability sector and the health sector, to ensure clear accountabilities and minimise risks of cost shifting. Work is underway to address this issue as a result of the introduction of the NDIS. At the same time, however, there is a need to remain person centred and the ideal arrangement would be to support people with disability who need to access the health system in ways which put their needs first and the funding follows them, rather than the other way around.

For example, some people with disability need to be with people they know, because of their highly specialised support needs, very limited communication skills and/or a mental health condition. Therefore, to be supported by complete strangers in a hospital may be a highly risky or disturbing and the health and disability systems need to be sensitive to these special situations.

Second, we need much better data on people with disability and their experiences in the medical and health systems. This points to the need to collect consistent data which is also linked across the health disability systems and which includes other important information such as whether or not the person with a disability was being supported by family or other advocates.

Analysis of health and disability data will then allow a comprehensive set of performance measures to be developed and then, over time there is the potential to significantly improve access to health and medical services for people with disability. It will also mean that the medical and health outcomes for people with disability can then be compared with the population as a whole.

In summary, all of the Intergovernmental Agreements on Federal Financial Arrangements should include a section on people with disability, and potentially specific funding, with a commitment to data collection and linkage, performance metrics, targets for inclusion and access and clear accountability for action when targets are not met and all of these agreements should be formally linked to the National Disability Agreement with annual reports to the Disability Reform Council and COAG.

Support for People with Disability who are Ineligible for the NDIS

As noted earlier, the absence of adequate support for people with disability, not eligible for the NDIS represents a major risk to Scheme sustainability. It is also inequitable and is leaving many people with disability at risk of becoming more disabled.

A key focus should be on the group of people with disability who are “at risk” of becoming NDIS participants, in order to create a “smooth slope” rather than a “cliff” around the NDIS.

There are two key challenges.

First, only \$132 million (excluding LAC support) has been allocated to Information, Linkages and Capacity Building (ILC) from within the NDIS funding of \$22 billion. With an expected number of NDIS participants of 460,000 and approximately 5 million people (20 per cent of a total population of 25 million) in Tier 2, it is self-evident that allocating such a small amount of money to all people with disability who are not eligible for the NDIS is inadequate (\$26 per person compared with an average package size of nearly \$40,000 per person for NDIS participants) and will ultimately be self-defeating from the perspective of ensuring that the NDIS is sustainable.

Second, the States and territories, especially, are not stepping forward sufficiently to support people with disability who are not eligible for the NDIS. The most extreme example is NSW, which is arguing that people with disability will either be eligible for the NDIS or will be able to receive all the supports they will need from mainstream services. This is a disaster waiting to happen, which will lead to many people with disability falling through the social security safety net and, totally unnecessarily, becoming more disabled.

An immediate priority is to undertake more analysis of Tier 2, in order to identify the sub-group with the potential to have significant and permanent disabilities, and so become eligible for the NDIS, if they do not receive the essential supports they need.

The “at risk” group within Tier 2 should then be the primary target for bulk purchased, ILC-funded direct disability supports. The key reason why this group should be supported through the ILC is that under the risk sharing arrangements, the Commonwealth must meet the cost of over-runs and so this arrangement would align best with financial risks. The NDIA would then need to report on this aspect of its operations under the NDA, providing clear accountability.

The costs of supporting other people with disability in Tier 2 should be met by States and territories and there should be reports on the actions and outcomes in all jurisdictions, as a key component of the NDA.

Finally, in the Review of NDIS Costs, last year, the Productivity Commission recommended increased funding for ILC, as has the Joint Standing Committee this year. However, to date, the Commonwealth and the NDIA have not accepted these recommendations. This is very short-sighted.

The NDA therefore provides an important opportunity to put in place the essential medium to long term framework to identify and fund the support needs of people with disability not eligible for the NDIS and ensure that the NDIS is sustainable.

In summary, there should be two priorities within the new NDA to meet the direct disability support needs of those people with disability who are not eligible for the NDIA:

- 1. Increased ILC funding from within the existing funding NDIS funding envelope to meet the needs of the “at risk” group, and*
- 2. Sufficient State and territory block funded supports for other people with disability whose support needs exceed the capacities of mainstream services.*

Advocacy

Independent advocacy is essential for people with disability, because many cannot advocate for themselves.

Many people with disability, especially those with intellectual and psychosocial disabilities, are very vulnerable. They often have poor informal networks of family and friends and experience above-average risks of abuse, especially amongst women and girls.

It is also clear that while markets can serve people with disability and enable them to exercise control and choice, there are often significant information asymmetries and high transaction costs, which make people with disability vulnerable to exploitation.

As part of the consultations on the Quality and Safeguards Framework for the NDIS, Disability Complaints Commissioners, Ombudsmen, Public Advocates and Guardians all agreed that they could not undertake their work effectively without independent advocates.

It is therefore essential that independent advocacy is resourced adequately.

When the original work on the NDIS was undertaken by the Productivity Commission in 2011, independent advocates argued that it would be a conflict of interest for the NDIA to fund independent advocacy and that funding should therefore be directly from government.

However, governments also generally do not like funding independent groups who will then potentially be amongst their strongest critics. As a result, advocacy funding is often highly uncertain and this can at times lead advocacy organisations to feel conflicted, fearing that if they advocate too effectively, they may

compromise their future funding and, hence, their future existence. Many advocacy organisations are now being forced to undertake consulting work from governments to survive, but which can compromise their independence.

In NSW, advocacy funding has been extended until mid-2020, after the NSW Government threatened to discontinue all advocacy funding at 30 June this year. This sort of hand-to-mouth existence for advocacy services cannot be allowed to continue.

It is time to recognise that independent disability advocacy is essential and needs both sufficient funding and a new framework for allocating the funding, which appropriately manages conflicts of interest.

Currently, about \$40 million per annum is allocated by governments to fund independent advocacy with about one half from the Commonwealth and the balance from States and territories. However, this funding is uneven with, for example, SA providing zero advocacy funding.

The feedback from advocacy bodies is that they are currently overwhelmed. In many cases, systemic advocacy has had to be abandoned, in order to undertake an urgent individual advocacy in relation to the NDIS. In other cases, the need to prioritise NDIS-related individual advocacy is leaving people with disability not eligible for the NDIS very vulnerable.

Given the very significant benefits from strong independent advocacy, the total funding should be doubled to \$80 million, for individual and systemic advocacy and this amount should be indexed annually by average weekly earnings (AWE), as the costs of advocacy are almost 100 per cent wages. This would be a good investment as a report commissioned by the Disability Advocacy Network in 2017 suggested that the benefit – cost ratio of advocacy is 3.5:1.

The funding for independent advocates would only be available to organisations which are truly independent. They could not be a subsidiary or affiliated with any other organisation.

There are five potential sources of funding:

1. The Independent Advocacy Program funded by the Department of Social Services (DSS)
2. The new Quality and Safeguard Framework Commission
3. Allocation of a fixed proportion of package costs to the bulk-purchase of advocacy services, in recognition of the fact that many NDIS participants will need advocacy before or after they receive NDIS packages
4. Allocation of funding by the NDIA through the ILC, and
5. States and territories through their funding of advocacy services.

The simplest approach would be to fund advocacy equally from these sources. Responsibility for allocating the funding to individual advocacy organisations should be the responsibility of an independent committee, so as to ensure that advocacy is independent and to manage any perceived conflicts of interest.

The independent committee should be required to establish transparent criteria for allocating funding to individual organisations and formally consult with Disability Complaints Commissioners, Ombudsmen, Public Advocates and Guardians before allocating funding to individual organisations.

The criteria should include measures of effectiveness, including building capacity of people to self-advocate, and employing people with disability. Building capacity of people to self-advocate, rather than building dependency should be a very important measure of success. At a systemic level a key objective should be to monitor the effectiveness of the NDA and advocates should be formally consulted as part of the annual reporting under the NDA.

In summary the new NDA should:

- 1. Allocate \$80 million per annum for independent advocacy, with this amount to be indexed annually by AWE*
- 2. Source the funds for independent advocacy equally from the Commonwealth, NDIA, National Quality and Safeguards Commission and States and territories (on a per capita basis) and so ensure that this funding can be provided within existing resources, and*
- 3. Ensure that advocacy funding is allocated by an Independent Committee which should set transparent criteria and formally consult with key stakeholders on a regular basis.*

Universal Systems not covered by Intergovernmental Agreements

Justice System

The data on people with disability in the justice system are incomplete. However key statistics include:

- In NSW, young people with mental health disorders and/or cognitive impairments are at least six times more likely to be imprisoned compared with young people without a disability
- In Victoria 42 per cent of male prisoners and 33 per cent of female prisoners have an acquired brain injury, compared with 2.2 per cent of the general population, based on data from the Victorian Department of Justice
- Research by the Australian Institute of Criminology has revealed that between 1989 and 2011, of the 105 people shot by police, 42 per cent had a mental illness, and
- The significant number of people with cognitive impairments who are being held in indefinite detention, because they are unfit to plead.

The Australian community spends \$11.7 billion, annually, on the criminal justice system. In research conducted in 2013 on the cost-benefit analysis of early support and diversion it was found that for every dollar spent on early intervention and diversion, there is a saving of between \$1.40 and \$2.40.

Given that people with disability are significantly overrepresented in the criminal justice system focus on this area should be a high priority for the new NDA.

There are also very important intersections which should be measured and assessed. One such very important area is the intersection between Indigenous Australians, disability and the criminal justice system. For example, many of the Indigenous Australians in prison in the NT are hearing-impaired and had no access to hearing assistance when they were before the courts. This means there are very significant questions regarding access to justice and whether or not they should be in prison.

The National Disability Strategy includes an important section on rights protection and justice. However, there are no performance metrics, targets or action plans to correct this national disgrace.

In summary, the priorities of the new NDA in relation to justice and disability should be to:

- 1. Collect comprehensive data on the number of people with disability and their disabilities in the criminal justice system*
- 2. The supports available to people with disability in prison*
- 3. Set targets and action plans designed to ensure that people with disability are not over-represented in prisons and better support their disability needs in prison*
- 4. Set targets to reduce the number of people with disabilities who are having their first contact with the criminal justice system each year and reduce recidivism amongst people with disability*
- 5. Measure how the NDIS and other systems are effectively supporting people with disability when they have been released from prison.*

Transport Systems

The National Disability Strategy in the section on Inclusive and Accessible Communities includes a Policy Direction: A public, private and community transport system that is accessible for the whole community. There are also Disability Standards for Accessible Public Transport 2002.

An insufficiently accessible public transport system is a major barrier to the inclusion of people with disability, which is also creating significant on-going costs as, for example, people with disability are forced to use taxis rather than public transport. There are also examples of discrimination with some airlines setting quotas on the number of people with disability they will take on each flight and new transport infrastructure, which is not fully accessible.

There are also no firm targets to make Australia's transport systems more accessible and very limited data on current accessibility conditions. A national audit is needed.

At the same time, there are some interesting and potentially highly beneficial innovations underway, such as Blindsquare, which is technology available on a smart phone which uses Wi-Fi and enables people with vision impairment to accurately find their way. It is being trialed at Southern Cross Station in Melbourne. Google Maps is increasingly including information on access and apps such as 'Snap, Send and Solve' are very beneficial for people with disabilities. More generally, there are many examples of smart technology which includes accessibility features and benefits.

In summary, the priorities of the new NDA in relation to transport and disability should be to:

- 1. Audit accessibility standards in public, private and community transport systems and make the data available*
- 2. Ensure that all new transport infrastructure meets accessibility standards and provide annual updates on innovation and improvements in accessibility of transport systems*
- 3. Provide annual estimates of the cost of transport for people with disability through the NDIS and Taxi Subsidy Schemes, so that we are measuring the costs of inaccessible public transport not just the costs of making public transport more accessible*
- 4. Consider targets for making Australia's transport systems universally accessible and supporting technological innovation to improve access and inclusion.*

Residential Building Code

The National Disability Strategy "identifies and will monitor action to ensure ... building codes become part of the solution to overcoming barriers for people with disability." The Strategy then identifies "improved provision of accessible and well-designed housing with choice for people with disability about where they live" as a policy outcome, direction and commitment.

The National Disability Strategy then further notes:

The Australian Government is working with representatives from all levels of government, key stakeholders from the disability, ageing and community support sectors and the residential building and property industry on the National Dialogue on Universal Design to ensure that housing is designed and developed to be more accessible and adaptable. An aspirational target that all new homes will be of agreed universal design standards by 2020 has been set, with interim targets and earlier completion dates to be determined.

Regrettably, this aspirational, voluntary target, which was set in 2008, will not be met. In fact, there has been no progress toward more accessible dwellings over the past decade. This is a major lost opportunity given the boom in residential development and construction over the past 10 years.

This has now been recognised and the Australian Building Codes Board has now been directed by COAG to proceed with a Regulatory Impact Assessment for regulation for access in housing. The consultation process will start soon with the release of an Options Paper.

It is essential to link this work with the National Disability Strategy, through the NDA and to provide a formal mechanism for Disability Ministers to be engaged in ensuring that the Australian Building Code meets accessibility standards for residential dwellings as soon as practicable.

There is also excellent work by the Australian Network for Universal Housing Design and Livable Housing Australia which should be used extensively to inform the new accessible building standards and set minimum targets. At least 5 per cent of all new dwellings should meet the Platinum Standard, so that the significant new access needs of an ageing population as well as people with disabilities are met.

In summary, reform of the Australian Building Code to set mandatory minimum accessibility standards and targets is essential. This should be incorporated into the NDA and this reform should build on excellent work in recent years by the Australian Network for Universal Housing Design and Livable Housing Australia. At least 5 per cent of all new dwellings should meet the Platinum Standard set by Livable Housing Australia.

Data

Data access and linkage is essential for evidence-based disability policies and practices and so data and access for research, under the '5 Safes', should be a key priority of the NDA. In essence the NDA should 'Democratise Disability Data'.

Data is also essential to allow for performance metrics to evolve over time.

Having been closely involved with the development of the performance metrics for the NDIS, before the Scheme commenced, it became clear within the first year of operations of the NDIS that the performance metrics were far from optimal.

We therefore need a dynamic performance management framework to be embedded in the NDA.

Einstein was right when he said: "not everything that counts can be counted, and not everything that can be counted counts".

Improved data collections would also align closely with and support Australia's commitments under the UNCPRD, which states in Article 31:

States Parties undertake to collect appropriate information, including statistical and research data, to enable them to formulate and implement policies to give effect to the present Convention. The process of collecting and maintaining this information shall:

- a) Comply with legally established safeguards, including legislation on data protection, to ensure confidentiality and respect for the privacy of persons with disabilities;
 - b) Comply with internationally accepted norms to protect human rights and fundamental freedoms and ethical principles in the collection and use of statistics.
2. The information collected in accordance with this article shall be disaggregated, as appropriate, and used to help assess the implementation of States Parties' obligations under the present Convention and to identify and address the barriers faced by persons with disabilities in exercising their rights.
 3. States Parties shall assume responsibility for the dissemination of these statistics and ensure their accessibility to persons with disabilities and others.

The NDA should therefore set out the obligations of the Commonwealth and States and territories to identify people with disability accessing all services. Then the progress of people with disability can be compared with the population as a whole.

Survey of Disability Ageing and Carers (SDAC)

The Survey of Disability, Ageing and Carers (SDAC) is an essential data base for disability research and even following the full implementation of the NDIS, it will be vital, because it will provide the most comprehensive source of information on disability in Australia, as it covers all people with disabilities, not just NDIS participants.

The SDAC is aligned with the National Disability Agreement, without being formally part of it. For example, it was as a result of discussions between the Commonwealth and the States and territories that agreement was reached to collect SDAC data every three years, rather than every six years. This has applied since 2009 and the SDAC data has also been expanded to capture additional data that enables progress on the National Disability Strategy to be measured better.

In the years which correspond with the original six-year collection, the ABS pays for the base sample out of its budget. This was the case in 2009 and 2015. In 2015 the Department of Social Services also contributed an additional amount to allow for greater information at the State level.

For the 2018 survey, which is an example of an additional survey reflecting the decision to collect data every three years, 50 per cent of the funding is being provided by the Commonwealth, through the Departments of Social Services and Health, and 50 per cent from the States.

With this year's survey New South Wales, Victoria, Queensland and WA have all contributed their additional funding. This will allow for over-sampling and will therefore provide data at the State level, for these jurisdictions. However, the other jurisdictions have declined to contribute additional funding and so accurate State and Territory level data will not be available for South Australia, Tasmania, the ACT and Northern Territory. This is unfortunate.

SDAC data at the State and territory level will be vital to measuring outcomes as each jurisdiction has entered the NDIS from very different systems. The implementation challenges and outcomes are therefore different as are the appropriate policy and implementation responses. For example, the implementation challenges in the NT are very different to all other jurisdictions, given its vast remote areas and higher incidence of disability and its intersection with indigeneity.

SDAC data is also vital for measuring outcomes for people with disability, who will not be eligible for the NDIS. We know that the State and territories are each responding differently to their responsibilities for "Tier 2", so measuring outcomes through the SDAC will be very important in terms of optimising future policy settings for those not eligible for the NDIS.

Looking ahead, there will certainly be important additional questions which should be added to the SDAC, with discussions about the 2021 SDAC scheduled to commence later this year.

Report on Government Services (ROGS)

The National Disability Agreement determines the reporting requirements on disability for inclusion in the Report on Government Services (ROGS). It is an important data source as it is the primary data for measuring the outcomes under the National Disability Strategy.

Going forward, the ROGS Disability Data should continue to be collected, while its scope (coverage, frequency, etc) should be adjusted to reflect the emerging disability policy environment.

The current experience with the 2018 SDAC Survey highlights the risks of emerging data gaps and so it will be essential to ensure that the ROGS Disability Data is collected nationally and individual jurisdictions do not opt out.

More generally, good quality data and its availability is going to be essential for the assessment of the impact of the major changes now underway in the disability sector. We need to be gathering the data to guard against retrograde changes and unintended consequences, while ensuring that the potential benefits of the NDIS are realised.

NDIS Data (including data from the National Quality and Safeguards Commission)

The NDIA is building the best population-based database on disability in the world and the Productivity Commission Review of NDIS Costs, last year, recommended that this data should be made available for research by the middle of this year. This continues to be an essential priority for the optimisation of the NDIS.

In recent consultations with the disability sector undertaken by the Melbourne Disability Institute, data availability emerged as the major challenge for the disability sector and its advocates.

Further, now that the National Quality and Safeguards Commission has been established, data from the Commission should be available for research and linked.

The NDIS and Quality and Safeguards Data should be included in the proposed Data Sharing Release Act, noting that all of this data would be de-identified and could only be used in accordance with the '5 Safes'.

The ABS is well-placed to be a key Accredited Data Authority, as it is already collecting data and linking it from multiple sources through the Multi-Agency Data Integration Project (MADIP). In addition to a national linked dataset, there should be State data subsets, which can then be held at the State level, such as the Victorian Centre for Data Linkage, and then linked to State level data.

In summary, comprehensive disability data and data linkage is essential for the optimisation of disability policy and practice and should be a key priority of the NDA.

Governance of the NDA

The NDA should be governed through the Disability Reform Council (DRC), which should then report to COAG.

The DRC should receive an annual report prepared by senior officers of the Commonwealth, States, territories and the NDIA. The report should include agreed performance metrics and action plans, responsibilities and timelines, when agreed performance benchmarks are not met.

Prior to finalisation, the report should be reviewed by an Independent Advisory Committee, comprising a majority of people with lived experience of disability. The Committee should have access to a small budget to commission independent research and analysis to support its work and findings.

The comments from the Independent Advisory Committee should be included in the final annual report to DRC and then COAG, with officials being provided with an opportunity to respond where the Independent Advisory Committee is dissatisfied with performance and progress.

In summary, the NDA should be governed through the Disability Reform Council and COAG, based on an annual report prepared by senior officers of the Commonwealth, States, territories and the NDIA supported by an Independent Advisory Committee, comprising a majority of people with lived experience of disability.

The report should include agreed performance metrics and action plans, responsibilities and timelines, when agreed performance benchmarks are not met.

**Professor Bruce Bonyhady AM
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31 August, 2018