

Submission to the Productivity Commission on Disability Care and Support

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Previous Submission to the Productivity Commission on Disability Care and Support:
Submission 493 on <http://pc.gov.au/projects/inquiry/disability-support/submissions>

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Summary

The authors of this submission welcome the Productivity Commission (PC) Draft Report and many of the key features of the proposed NDIS including:

- the proposal for a scheme to provide long term care and support on an entitlement basis,
- many of the accompanying features of the approach outlined, including the no fault basis of provision, the inclusion of aids and equipment, and the recognition of the need to include the full range of support services,
- the acknowledgment of unmet demand and the need for significant new funding.

Our comments on the draft report are made in the spirit that we endorse the main directions of the proposed scheme, which would be of great benefit to the Australian people, most especially people with disabilities and their families. We sincerely hope that governments will respond positively and promptly to the vision laid out in the Draft Report. We offer constructive criticism to maximise the chances of the scheme's success, in terms of enabling people to access the supports they need, on an equitable basis.

In this submission we focus on 5 areas:

1. Eligibility and assessment

Our aim in making these comments is to improve the scheme's equity and administrative feasibility in relation to eligibility and assessment. Eligibility, assessment processes and services delivered should be connected conceptually and in a structured and systematic manner, and in line with current concepts of disability including the UN Convention on the Rights of Persons with Disabilities and the International Classification of Functioning, Disability and Health (ICF). We welcome the recommendation that assessment be based on the framework of the ICF and recommend that eligibility likewise focus on functioning and support needs using this framework.

We have concerns about the eligibility criteria (the four included groups) and we explain these concerns in the submission.

- a. Eligibility criteria and assessment tools and processes must be logically aligned, with a primary focus on functioning and need for support; to achieve this requires further work. 'Headline' logical connections between eligibility, assessment and service provision are essential to (i) ensure fair and equitable access, (ii) achieve administrative clarity and efficiency, and (iii) facilitate community understanding.
- b. There should be more evidence about and consideration of groups potentially excluded by the current eligibility criteria, even though eligible for current schemes; the eligibility criteria could create new excluded groups if they rely unduly on health conditions, or a limited set of activities (self care, mobility, communication).

- c. The UN Convention on the Rights of Persons with Disabilities – as well as the Australian Disability Discrimination Act and the International Classification of Functioning, Disability and Health (ICF) – all take a broad inclusive view of disability, and do not slice and dice according to health conditions. Health conditions do not reliably predict needed supports for activity and participation in typical environments.
- d. In the case of mental health conditions, there should be less focus on boundaries and ‘overlapping services’ (in the disability and mental health sectors where shortages are acknowledged to exist). Rather, we should focus on individualized funding processes which enable a person to obtain the services they need from either sector, without ‘double dipping’.
- e. Ways of involving the person concerned in their ‘assessment’ are required. There is no better way than asking the person directly what their goals are and what supports they need. We are very doubtful about the proposal that assessment should be carried out by allied health practitioners with no prior involvement with the person or family. Australian population statistics, widely used including by the PC in estimating costs of the new scheme, rely on well-tested self reporting of needs for assistance with various activities. While ‘objectivity’ is important and has a place in assessment, it should not be given primacy over the knowledge and perspective of the person concerned. The process must combine a range of perspectives, and the real question is how this process is designed.

2. Assessment tools

The PC Draft Report lists 5 tools on which it requests comments:

- a. Four of the tools listed have desirable qualities for ‘assessment’ of people with intellectual disabilities. It is not clear how they translate to the assessment of supports needed, and for all disabilities in general.
- b. Further work, along the lines suggested in Chapter 5 of the Draft Report, is needed. A firm grip must be maintained on the relationship between assessment and eligibility criteria (see comments above).

3. Overcoming access and equity barriers for Aboriginal communities

We agree that the scheme must radically enhance services for Aboriginal and Torres Strait Islander peoples.

- a. A twin track approach is required to strengthen the cultural responsiveness of generic services and to further develop promising specialised approaches. Details and useful models are discussed in our submission, including our recommendation about the importance of community targeted information.

- b. Empowering Aboriginal communities is an essential component of improvement, for instance by involving emerging peak bodies such as the Aboriginal Disability Networks (state and national).
- c. Continuing and appropriate efforts are required to improve data and research; related issues are discussed in our submission.

4. Research and data

- a. The best model for supporting disability research in Australia is an enhanced ‘hub and spoke’ model which builds on the strengths of the existing field (see our discussion and previous submission).
- b. Similarly, data improvements should build on some unique strengths of the Australian system, such as the existing formal processes for creating, endorsing and implementing national data standards in the health and community services fields. Continuity of key data series must be preserved. As outlined in the PC Draft Report, improvements in financial data and management can no doubt learn from the insurance sector but, as little is publicly available from this field, it is hard to judge whether this should be the sole model of enhanced financial data.
- c. There must be a commitment to transparency in both data and research, with data being made publicly available (via publication and release of data sets for further analysis) and all research and evaluation being published, including that commissioned by governments.

5. Governance

As well as financial expertise, the Board of the NDIA should possess expertise in disability life, policy and administration, to ensure that it can indeed provide ‘strategic direction’.

Submission on Disability Care and Support (Draft Report of the Productivity Commission on a proposed NDIS)

Principles and focus of our submission

The authors of this submission welcome:

- the proposal for a scheme to provide long term care and support on an entitlement basis,
- many of the accompanying features of the approach outlined, including key features such as the no fault basis of provision, the inclusion of aids and equipment, and the recognition of the need to include the full range of support services,
- the acknowledgment of unmet demand and the need for significant new funding
- the recommendations that assessment be based on the framework of the International Classification of Functioning, Disability and Health (ICF), and the plans for achieving this.

We endorse the main directions of the proposed scheme, which would benefit the Australian people most especially people with disabilities and their families. We sincerely hope that governments will respond positively and promptly to the vision laid out in the Draft Report.

In this submission we offer constructive criticism to maximise the chances of the scheme's success, in terms of enabling people to access the supports they need, on an equitable basis.

1. Eligibility and assessment

In this section of our submission we

- question the proposed scheme's equity and administrative feasibility in relation to eligibility and assessment; in particular we urge that the logical connection between eligibility and assessment (and between Chapters 3 and 5) should be further explained or re-examined;
- argue that better evidence and data should be provided to substantiate the eligibility criteria suggested, including better evidence about who may be excluded from the new scheme although eligible for current schemes;
- propose that the reasoning behind the proposed criteria and the associated estimates should be made available for peer review or work-shopping to ensure transparency and a robust approach prior to finalisation of criteria; such review work should include further exploration of functioning-based criteria that will not raise the costs of the scheme; the authors of this submission are willing to participate in such work-shopping.

Discussion of the four proposed assessment criteria

The proposed 'assessment criteria' for the scheme are neither fully explained nor fully justified by evidence. They do present some useful new proposals compared to the previous Issues Paper. However given that the report acknowledges that 'state and territory definitions are a useful starting point' (PC 2011, page 3.13), there is a need for more comparisons to be made between the current criteria and the proposed ones, to examine what current eligibility problems are solved and who will be disadvantaged by the new scheme.

'Headline' logical connections between eligibility, assessment and service provision are essential to achieve, for at least three reasons. First, to ensure fair and equitable access, noting that those with disability feature prominently in the multiple and entrenched disadvantage category of the monitoring and reporting framework for social inclusion (Australian Social Inclusion Board, 2010). Elsewhere, and in many places, there is now good evidence of the social determinants of disability, that is, that those most disadvantaged are more likely to experience disability at some time in their life course, according to a steep socio-economic gradient (Burchardt, 2003; Emerson et al., 2011) and that those who become disabled experience socio-economic decline. Second, to facilitate community understanding such that individuals and their families are aware of and understand their entitlements, and particularly those currently underserved due to limited knowledge of or lack of trust in current services or those for whom current services are culturally inappropriate. Third, to achieve administrative effectiveness, and particularly given the very real concern – well articulated by personal and organisation submissions to the Commission – about eligibility criteria for current services that result

in services denying access or over-servicing based on poorly conceptualised and articulated criteria.

In Australia's major national disability programs at present there is a reasonably coherent conceptual relationship between eligibility, assessment and service provision that is easily understandable. The Disability Support Pension has an eligibility criterion centred on ability to work and earn – and the assistance provided is income replacement; while the process of assessment is spelled out in legislation and regulations, the core eligibility concept is clearly related to the key assistance provided. (Further, recent changes suggest it is evolving away from reliance on medical criteria, towards functioning-based criteria). State based criteria typically have been inclusive of disability group and health conditions, and have focussed on the need for support as the distinguishing indicator of people to receive disability support services. This fundamental connection, between what is provided and how the need for it is assessed, must be retained.

The UN Convention on the Rights of Persons with Disabilities – as well as the Australian Disability Discrimination Act and the International Classification of Functioning, Disability and Health (ICF) – also take a broad inclusive view of disability, and do not slice and dice according to health conditions. Health conditions do not reliably predict needed supports for activity and participation in typical environments.

The PC Draft Report proposed four groups to be included (suggested eligibility criteria), which we now discuss in turn:

'Significant limitations in communication, mobility or self-care'

In our previous submission we pointed to the lack of rationale for singling out the life areas of communication, mobility or self care for special attention, and provided evidence for this (Madden et al 2010 – our previous submission). The UN Convention on the Rights of Persons with Disabilities emphasises participation in all life areas. As previously noted, current recipients of disability support services have support needs across all life areas and only 50% have needs in these three areas (see Appendix to this submission). We remain concerned about this emphasis. This is a significant problem with the proposed criteria although the importance of these life areas should not be overlooked.

We are also concerned about the term 'significant limitations' which remains to be defined.

In our view, and as in the current schemes, the emphasis should be on 'need for support' and this should still be the major focus, as 'support' is what this scheme is to supply. [The estimates in Chapter 14 (e.g. Table 14.1) require that daily assistance is needed, although this is not discussed as a criterion in Chapter 3 or 5.]

'Have an intellectual disability'

The arguments presented for this inclusion are sound. However the term 'intellectual disability' requires definition. For some decades now, intellectual disability has been

defined beyond an IQ score of intelligence and has required a measure of adaptive behaviour which more recently appropriates functioning difficulties across the full range of Activities and Participation (ICF) domains. The estimates in the Draft Report (e.g. Table 14.1) allow 'schooling and employment restrictions' to be introduced into the estimates, but these are presumably not proposed eligibility criteria. To return to the concept of intellectual disability as an outcome of lower intelligence without clearly aligned functioning criteria would place Australia out of step with current best practice internationally.

'Be in an early intervention group'

This is the vaguest group of all, requiring evidence about efficacy of early intervention, and information about the evidence standards required (to bring one health condition 'in' and leave others 'out'). The assumptions underlying the estimates should be made available for peer review. Early intervention requires early identification – sometimes a challenge for children with mild autism, for instance, and people with mental health conditions for whom there was a reasonable potential for cost-effective early therapeutic interventions that would improve their level of functioning. In the potentially expanded 'early intervention framework for mental health, the group amenable to early intervention could be large. It is hard to see how the present description could be translated into clear, implementable and equitable eligibility criteria. Although there is sound evidence for early intervention with children with impairments and particularly for those from disadvantaged backgrounds (Carneiro & Heckman, 2003) the evidence is less clear for older children and adults. That said, early intervention is intuitively attractive as the Draft Report makes clear. Apart from definitional difficulties there is also the reliance on the first point of entry to early intervention schemes with adult populations. Referral at an early stage for early intervention assistance for some chronic conditions is variable unless clear criteria are specified. If first point of entry practitioners are well informed about and subscribe to the utility of early intervention, and consequently refer their clients, then potential clients can easily access, appreciate the benefits of, and profit by engagement with the early intervention scheme for example the National Diabetes Services Scheme. If the proposed National Disability Insurance Scheme is to address the disadvantage currently experienced by people with disabilities, appreciating the dynamic nature of disability will be critical to its success. Hills (2002), offers a useful classification of policies under four P's: prevention-reducing the risk of entering an undesirable state, protection- reducing the impact of an event, promotion, increasing the chance of exiting an undesirable state, and propulsion- reinforcing the benefits of exit and guarding against return to the undesirable state. All aspects of the current proposal could be seen to contribute to, at varying levels, prevention, protection, promotion and propulsion as defined by Hills (2002). The concept of early intervention, acknowledged yet not clearly articulated in the Draft Report, may traverse all four states and therefore is of critical importance to the overall success of the proposed scheme. We encourage the

Commission to address their concept of early intervention more fully at the earliest possible time.

It is not clear from the PC Draft Report whether early intervention is a criterion for receiving *any* service (as apparently proposed), or whether it is a type of service available to anyone with current or predictable functional limitations, where there is evidence of efficacy of the intervention? (Chapter 11 acknowledges the lack of evidence on efficacy and talks more about purchasing particular early intervention services.) As described on page 3.14 in the report, it is even difficult to see who is *not* eligible for early intervention?

‘Have large identifiable benefits from support that would otherwise not be realised’

This is a useful category; some people may require very little support to receive great benefit, including becoming fully participating members of society. Because it may lead to complex decision making, it is all the more important that the other criteria be clear and assessable.

Discussion of eligibility: some main issues

Overall, eligibility criteria (Chapter 3) are improved but need more work and need to be related to assessment (Chapter 5). Such work should provide answers to the following questions and comments raised by our reading of the Draft Report:

Eligibility, assessment and an underlying framework: The nexus between eligibility and assessment

In our previous submission we stated, and we now re-emphasise:

‘Clear, non-technical statements about policy and eligibility are pre-requisites to the more technical consideration of eligibility assessment. An ideal development process might follow two broad stages: a plain English statement about the program, purpose and related eligibility criteria; and a process of translating these criteria to assessable eligibility criteria.’

Remaining questions and issues include:

- What is the underlying framework of the four criteria and of Table 14.1 – where do they sit in disability theory? Might they lead to a confused eligibility assessment process? Why is the focus on self care, mobility and communication – apart from reasons of Australian statistical history? As we previously submitted: ‘There is no evidence that needs in one area of Activities/Participation can be used to predict needs in another, in such diverse populations’ (see Appendix to this submission).
- The nexus between eligibility and assessment appears not adequately recognised in the PC proposals. It is useful that assessment (Chapter 5) is to be related to ICF, but this does not make sense if the eligibility criteria are not similarly logical and related clearly to ‘functioning’. The assessment criteria and process must relate to

the eligibility criteria and the philosophy of the new scheme. [‘The terms of reference for the inquiry indicate that the scheme is not intended to address the *care and support* needs of all individuals, but rather should focus on those where such needs are greatest.’ (PC 2011, page 3.10) Have the proposed eligibility criteria met this test? How do the criteria sit with the desire to assess the ‘nature, frequency and intensity of a person’s support needs’ (PC 2011 page 3.32)?]

- Health conditions are not reliable predictors of support needs, even though knowledge of them may assist the understanding of the nature of disability. First, great functional need may be evident without an ‘acceptable’ diagnosis. Schemes relying on health conditions to guide access to disability supports are fraught with problems. A recent example in Australia is the ‘Helping Children with Autism’ package which supports children with disabilities and their families according to an ICD criterion, i.e. the diagnosis of autism, instead of an ICF criterion. As a consequence, clinicians report pressure to diagnose any child with developmental disability with autism in order to access the package of care. (Einfeld: personal communication). The contribution of “diagnostic substitution” to estimates of the incidence of autism has been documented in the US (Shattuck 2006). The package has since been extended to include children with sight and hearing impairments, cerebral palsy, Down syndrome and Fragile X Syndrome as well as autism. If the child has one of the large number of other syndromes causing developmental disability they are not included. Support for children with developmental disabilities would be distributed more equitably and more effectively if it were targeted according to functional need and potential to benefit, rather than diagnosis. That is, using the framework of the ICF rather than the ICD. That is, the new scheme should align itself with modern conceptions of disability.

People with disabilities associated with mental health conditions

While the PC Report does not specifically propose to exclude people with mental health conditions from the NDIS, the eligibility criteria create that possibility.

- Why are people with other disability ‘types’ and other health conditions – notably those with mental health conditions – not also subject to many of the same arguments for inclusion as were made for people with intellectual disability (e.g. that they need extra assistance at times of transition, and that their main needs may be in areas other than self-care, mobility or communication)? For some people with mental health conditions, it is interpersonal and role functioning that are falling apart and they then lose the ‘social scaffolding’ that provides support leading to further decline and dependency (Glozier: pers. comm.)
- The complexities of the health and disability systems for people with mental health and chronic conditions are well recognised in the report, but the problem of their ‘falling between the cracks’ is not resolved by the Report’s recommendations. These problems have existed for a long time. Until there is certainty that the mental health system is providing long term ‘non-health’ support in the community, and deal capably with dual diagnoses (e.g. mental health and

intellectual disability, brain injury and emotional problems, various chronic diseases and depression) there should not be an exclusion of people with mental health conditions from the NDIS (and coordination with housing and employment support is also required). Because of the prevalence of dual diagnosis the NDIS will have to deal with people with mental health problems and will need to work with the mental health system. There is no escape from this. Future plans for MoUs in every state will not be satisfactory for the 18% of current disability support services users who have ‘psychiatric disability’ as the primary disability and whose eligibility for support is called into question by the new scheme (AIHW 2011:24).

- While the need to spell out the separate responsibilities of the health and disability systems may be most obvious for people with mental health conditions, the same is true for many other health conditions. The issue is the same: generally the health system deals with medical conditions rather than disability per se and short term treatment needs; the disability support system deals with ongoing support needs not usually requiring intervention by health professionals. Disability support service providers need to understand the health conditions of the people they serve; health professionals need to understand disability and the support needs and environmental barriers of the people they serve.
- In the case of mental health conditions, there should be less concern about boundaries and ‘overlapping services’ (in the disability and mental health sectors) and more focus on individualized funding processes which enable a person to obtain the services they need from *either* sector, without ‘double dipping’. There are acknowledged shortages in this sphere. In such a field we should not ‘vacate the borders’ of the two sectors while sorting out a neater border solution, but allow some creative overlap and make it work better.

Involving the person in their own ‘assessment’

In our previous submission we also discussed the importance of fully involving the person concerned in the assessment process. We welcome the statement that ‘Assessment should be carried out as a collaborative process, and in a way that is understandable for the person seeking support ...’ (page 5.20; see also Figure 5.2). This process should include asking them what their goals are and what supports they need. We are concerned that the PC Draft Report recommends (PC 2011, page 5.1) that ‘assessments would be conducted by allied health professionals approved or appointed by the NDIA and trained in the use of the tools. They would be continually assessed for their appropriate use of the assessment tools’. The PC then goes on to say (page 5.21): ‘In order to promote independent outcomes, assessors should be drawn from an approved pool of allied health professionals. Assessors should also be independent of the person being assessed to reduce the potential for ‘sympathy’ bias. This means that health professionals — GPs and others — with past treatment and support responsibilities for the person, would not undertake assessments’.

While ‘objectivity’ is important and has a place in assessment, it should not be given primacy over the knowledge and perspective of the person concerned. The process must combine a range of perspectives, and the real question is how this process is designed. If person-centred care and individualised funding are to be realities, the role of the person concerned in the assessment process must be central. This is not an ‘either-or’ question, but a question of how to blend various expertise – the person’s and possibly more than one professional’s view. Our understanding is that the UK experience with individualized funding may shed light on how to do this.

The development of new processes and tools, outlined in Chapter 5, should draw on Australian statistical experience, and on new developments around the world. For three decades Australia has relied on statistics reflecting self-reports of the need for assistance and indeed the PC relied on these data in preparing costs estimates for the proposed NDIS. The same framework underpins the current national data collection on disability services (Anderson and Madden 2011). Further developments based on the national data standards (self reporting of participation and environmental factors) are proceeding at the University of Sydney.

2. Some comments on tools

The PC requested feedback on whether any of 5 tools would be ‘appropriate for assessing the care and support needs of individuals’. As noted in our previous comments (section 1 above and our previous submission) it would be useful if the report made clearer the relationship between eligibility assessment and support needs assessment. In our view they should be part of the same process, and based on the same concepts.

Emphasis should be on toolkits that enable targeted supports to individuals with disability to engage in preferred activities or participation in typical environments.

More work is required to consider how self-assessment fits into the assessment process, as outlined in the previous section of this submission. Australia’s statistical experience with self reporting of the need for assistance with activities merits attention in any further work, as do the national data standards.

Another key issue relating to tools used to assess support needs is exactly how such support-needs assessment information is translated into individual funding and how that funding is applied within the larger disability service system. Stancliffe and Lakin (2004) compared the outcomes of different individualized funding systems used in Minnesota and Wyoming and concluded that such systems are more effectively needs based when:

- “a) needs-based funding systems are applied to *all* recipients, not just those entering the system for the first time;
- b) continuous *individualized* funding amounts are provided (rather than a small number of discrete funding levels);

c) a specified amount allocated to pay for services is received *by the individual* rather than infusing it into an overall pool to be managed by an intermediate agency for multiple service recipients; and d) variations in allocated amounts reflect different circumstances (e.g., people living with family members versus in residential settings; children who are enrolled in public schools).” Stancliffe and Lakin (2004, p. 4)

Specific comments on tools

On the issue of support needs assessment, the SIS, ICAP, SNAP and I-CAN [tools mentioned] are among the best available tools from an intellectual disability perspective. However it is less clear how well these tools apply across all disability types. Having said that, any tool must be able to demonstrate that it produces valid and reliable scores for people with ID given their heavy use of high cost disability services.

All four of these tools map to all life areas represented by the ICF Activities and Participation domains (some consciously referring to the ICF). This emphasises our previous and current submission that the need for support in ANY of these 9 domains should be seen as relevant to the consideration of eligibility. The SIS, for instance, has far more questions about the supports in areas *other than* mobility, self care and communication.

Overall, evidence is needed for the instruments to yield scores to allow for valid inferences regarding support needs for meaningful activities and participation in typical or inclusive environments.

Relevant references are provided below, along with brief comments. These brief comments do not constitute endorsement of any one instrument.

See generally: Mpofu and Oakland 2010

Supports Intensity Scale (SIS)

This is a US tool developed by AAIDD. Internationally prominent and widely used, it is ID specific. There is a substantial and growing research base. However, the tool has limited capacity to derive an overall support needs score.

See: Stancliffe 2004; Thompson et al 2004

Inventory for Client and Agency Planning (ICAP)

The ICAP (Bruininks et al., 1986) is a US measure of adaptive behavior and challenging behavior published in 1986. It is ID specific. It has excellent psychometrics and good evidence that it is a valid measure of support needs for people with ID. The tool forms the basis of an excellent individual funding system in Wyoming (Fortune et al., 2005).

See: Bruininks et al 1986; Fortune et al 2005.

I-CAN

Developed by the Centre for Disability Studies at the University of Sydney, the key contacts are Dr Vivienne Riches and Mr Sam Arnold. The tool is ICF-based, comprehensive but time consuming, and is considered able to be used with a variety of disability types, not just ID.

See: Riches et al 2009a; Riches et al 2009b

SNAP

An Australian tool, originally developed for ID, it has been used in New South Wales and trialed in South Australia.

See: Gould 1998; Guscia et al 2006

Further research references on these tools are provided at the end of the reference lists.

Other tools that could be worthy of investigation include: Pediatric Evaluation of Disability Index (Haley et al 1992) or School Function /Assessment (Coster et al 1998 and Haley et al 1992) and the Vineland Adaptive Behavior Scale (Sparrow et al 2005).

3. Overcoming access and equity barriers for Aboriginal communities

The PC identified a range of issues affecting the participation of Aboriginal people in disability services in Australia. It is heartening that the PC recommends that the NDIS must complement all existing community initiatives and programs that are making a positive impact on Aboriginal families. This segment of our submission will address some of the key issues that are under consideration and draw attention to some proven strategies that make a positive difference for Aboriginal people.

Developing a culturally responsive disability services sector

The PC should be mindful that a culturally responsive disability services sector requires all disability service providers to be engaged in Aboriginal communities, not just larger providers. By engagement, we mean that mechanisms are established to assist disability service providers and Aboriginal communities bridge the cultural interface at a local level (Gilroy 2008; Gilroy 2009; NDS 2010a; NSW Aboriginal Community Care Gathering 2007). Culturally responsive disability services for the Aboriginal communities must be developed with them and not for them.

Engagement between disability services and Aboriginal communities

There are two major inhibitors in achieving effective engagement of disability service providers in Aboriginal communities. Firstly, there is a lack of knowledge on how best to use existing resources. Aboriginal community managed organisations and mainstream providers are stretched to capacity to meet existing unmet service demand. Disability affairs are a low priority for Aboriginal community managed organisations (such as Aboriginal Medical Services) and Aboriginal affairs are a low priority for disability service providers. As such, Aboriginal people seeking a culturally appropriate service fall through the cracks of an under-resourced community service system (Gilroy 2008; NDS 2010b).

Secondly, the practice of competitive tendering is hindering relationship building between provider groups and Aboriginal communities. There is a misconception in the industry of a culture of gate-keeping of Aboriginal communities by Aboriginal stakeholders. Some service providers feel that Aboriginal community managed organisations do not wish to collaborate with mainstream agencies to overcome access and equity barriers for Aboriginal people. The issue, however, is that Aboriginal stakeholders are frustrated with those mainstream service providers that have no existing dealings with Aboriginal communities winning government tenders for Aboriginal specialised services. These providers then request Aboriginal community managed organisations to operate like intake and referral agencies without additional funding for those roles. Such practice is regarded as offensive by Aboriginal communities (NDS

2010; NSW Aboriginal Home and Community Care Gathering 2007; NSW Aboriginal Home and Community Care Gathering 2008). Disability support services for the Aboriginal communities must be genuine long-term partnerships with those communities.

There are many successful models that have helped bridge the cultural interface that could be resourced under a NDIS. For instance, the National Disability Services (NDS) Aboriginal Resources and Pathways (ARP) project established local networks of Aboriginal communities and disability service providers to help overcome access and equity barriers for Aboriginal people. Between 2007 and 2009, NDS developed six local networks in Sydney and the NSW South Coast. NDS and the NSW Ombudsman found that the ARP was successful in streamlining stakeholder engagement with disability service providers and Aboriginal communities (NDS 2010; NSW Ombudsman 2010).

A NDIS could resource disability service providers to establish a consultation strategy that allows Aboriginal communities to be involved in the NGO's decision making process. For example, The Spastic Centre of NSW (now the Cerebral Palsy Alliance) regularly hold Aboriginal community forums in Sydney to allow Aboriginal community members to be involved in the strategic planning and development of disability TSC services. Also, Uniting Care Burnside has a consultative strategy under their Aboriginal Intensive Family Support Options (IFSO) programs for families who are caring for a person with a disability (Uniting Care Burnside 2007).

The Aboriginal Disability Network of NSW (ADN) provides a platform for Aboriginal people with a disability to have their voices heard at a systemic level to government and community service industry peak bodies. There are ADNs established in other states and territories. Just recently, the Australian Government funded ADNNSW to establish itself as a national peak body for Aboriginal people with a disability. The national body could be resourced to support disability service providers to engage with Aboriginal communities. Successful disability support services with the Aboriginal communities should have the qualities of programmes rather than projects or consultancies. Projects and consultancies have a shorter lifespan and deliver specific outcomes that may well address selected needs. Programmes combine interlinked and mutually reinforcing projects with built-in long-term sustainability (WHO, 2010). Programmes are locally driven and more responsive to ongoing community needs than projects. Projects as platforms for delivering disability support services in indigenous communities may create perceptions of being used by outsiders who have vested interests elsewhere.

Aboriginal Cultural Competency Training used as a tool for engagement

There is a widely held belief that all disability service providers need is cultural competency training to effectively improve the participation rates of Aboriginal people in funded services. Cultural competency training, on its own, has no impact on the

participation rates of Aboriginal people in disability services. No person can learn about a culture different from one's own in a short training course and be competent to work with that community.

NDS (2010) reported that many service providers consider Aboriginal cultural competency training to be a waste of resources as it provides limited (or no) outcomes for the organisation. Also, a good number of providers lack the resources for staff members to participate in the training. In some cases, service providers reluctantly participate in the training to fulfil government policy requirements.

The disability services sector must understand that such training is only effective when used as a tool to engage with Aboriginal communities. Cultural competency is not about making token gestures to fulfil government requirements. The purpose of the training is to help disability professionals to gain a broader understanding of the social issues and political and cultural dynamics of local Aboriginal communities whilst working with Aboriginal communities (Gilroy 2008). Cultural competency training must include a component on participation in programmes with indigenous communities in their localities.

Twin Track approach for Aboriginal people

The PC is right that a market based system, on its own, will not address the access and equity barriers for Aboriginal people. Research into individualised funding approaches found that Aboriginal people participate at a lower rate than non-Aboriginal people within their population categories. The barriers and challenges experienced by Aboriginal people are so complex, interwoven and culturally imbedded that an individualised funding strategy on its own will not improve the participation rate of Aboriginal people in disability services (Fisher et al 2010). Aboriginal communities should be trusted to provide the leadership in disability support services that work for them.

The Twin Track approach, as defined under the United Nations Declaration and recommended by the PC, is the right path towards addressing access and equity barriers for Aboriginal people. Many Aboriginal families are overburdened with interventions from a range of agencies that a market based system could push families to crisis point. Below are some examples of service types that could be block-funded to help Aboriginal families navigate a market-based NDIS:

- *The Intensive Family Support Options program*

IFSO is a short-term intensive family support service for families that are at risk of family breakdown. Each family is provided with a case manager to assist them reconnect with appropriate services and supports (DADHC 2006).

- *Local Aboriginal community liaison officers*

Aboriginal community liaison officers can develop localised networks of disability service providers and Aboriginal community members to foster service planning and development. Such a strategy could improve the flow of referrals and information between Aboriginal community managed services and mainstream disability services.

Aboriginal community liaison officers could also facilitate localised cultural competency training for all disability service staff. Such a strategy will help improve the quality of service delivery for Aboriginal families.

- *Aboriginal culturally appropriate information material and resources*

It is strongly recommended that the Australian government develops Aboriginal community targeted information material on the proposed reforms to the disability services sector. The current reforms to the Home and Community Care Program have generated a high level of anxiety in all Aboriginal communities. The recommended changes proposed in the PC draft report may have added to this anxiety.

There are some great examples on Aboriginal community targeted information material on disability services that can be replicated (DADHC 2008; National Disability Services 2010).

- *Advocacy support*

Individual advocacy is an essential element in the NDIS. Aboriginal advocates, such as those employed by the Indigenous Disability Advocacy Service, support Aboriginal people and their families to navigate the disability services sector. The submission made by the NSW Aboriginal Disability Network has adequately addressed this point.

Quantifying the prevalence of disability in Aboriginal communities

The PC acknowledged the difficulty in accurately quantifying the prevalence of disability in Aboriginal communities. It must be brought to the PC's attention that government agencies have not yet found appropriate data collection methods since the disability services reforms of the 1980s (Gilroy 2010a; O'Neill, Kirov, Thomson 2004).

Consequently, regional and localised service planning has not been properly informed to respond to local service demand in Aboriginal communities for decades.

The efforts of national statistical agencies, in consultation with Aboriginal stakeholders, have resulted in some improvements in the last decade. The NATSISS (e.g. ABS 2009) included questions that enabled some comparisons of disability prevalence rates of Aboriginal and Torres Strait Islander peoples and other Australians, even though limitations in the statistical validity comparisons were acknowledged (ABS and AIHW 2005). For the purposes of disability service statistics, it was estimated and accepted by national administrators that Aboriginal people experienced disability at some 2.4 times the rate of the rest of the Australian population (AIHW 2006).

The 2006 Census of Population and Housing included a question on need for assistance. This gives the opportunity to look at the data for Indigenous people in small areas, and to compare this with the data for the total population.

Interpretation of the results requires care. Some ABS Local Government Area (LGA) Census data-tables do not accurately capture the prevalence of disability in Aboriginal communities. For example, the ABS Census shows that there are no reports of Aboriginal

people with a need for assistance under the age of 4 years and between the ages of 15 and 19 years residing in Moree Plains LGA (Australian Bureau of Statistics 2006). This contrasts with the earlier anecdotal evidence indicating a high need for additional support and services for Aboriginal communities in many rural regions of NSW, including Moree (ADN 2007; DADHC 2009a; O'Neill, Kirov, Thomson 2004). However the data for the population aged 0-64 in the LGA clearly show that Indigenous people have a higher relative need for assistance.

Also, the disability services National Minimum Data Set does not accurately capture the participation rate of Aboriginal people in government funded services. The proportion of service users who do not report their Aboriginality in service forms oscillates. For example, the proportion of users in the NSW disability services sector who did not report their Aboriginality increased from 7% in 2006-07 to 17% in 2008-09 (DADHC 2007; DADHC 2009b). Nationally, around 5% of services users do not have their Indigenous status reported in the national collection (AIHW 2011, AIHW 2009a). This percentage has generally improved in response to efforts to do so, with the worst quality data in 2003-04 (almost 21% unknown).

There have been several contributing factors suggested for the difficulties in recording of the prevalence of disability in Aboriginal communities and the participation rates of Aboriginal people in disability services:

The word 'disability' is a concept that is foreign to many Aboriginal communities

Although many Aboriginal communities have traditional words for some disability types, such as hearing and vision impairments, there is no known word in any traditional language equivalent to the perhaps westernised concept 'disability'.

Generally, Aboriginal people do not segregate people from their communities based on the westernised concept 'disability'. Aboriginal communities have a holistic world view which is inclusive of all family members despite perceived 'abilities' (ADN 2007, Gilroy 2009, NSW Aboriginal Community Care Gathering 2007; NSW Aboriginal Community Care Gathering 2008; O'Neill, Kirov, Thomson 2004). They may embrace ICF concepts of restrictions on activity and participation in environments (Senior 2000).

Disability, "shame" and Aboriginal workers

The PC report mentioned that Aboriginal people generally have a preference for Aboriginal workers over non-Aboriginal workers. This is not always true for all Aboriginal people.

Some Aboriginal people do not access disability services fearing that doing so may 'shame' their family. The concept of 'shame' in Aboriginal communities is slightly different to non-Aboriginal populations. Aboriginal communities are very small as everyone is either related or they know each other. A family may not access a disability service, the immediate carers fearing being viewed in a negative light by their whole community. A family choosing to access a disability service can cause political tensions between families in the community.

The concept of 'shame' therefore influences how Aboriginal people interact with the disability services system. Some Aboriginal people do not access Aboriginal community managed services or a mainstream disability service that has Aboriginal staff because they do not want their local community to know about their private issues. As such, there is an unknown number of Aboriginal people accessing a mainstream service that do not report their Aboriginality for fear that they may be referred to an Aboriginal community managed organisation or be referred an Aboriginal caseworker (NDS 2010a).

Fear of government agencies

The PC noted that there exists a high level of distrust of government agencies in Aboriginal communities.

The ABS is getting more involved in Aboriginal communities to build a shared understanding of the benefits available to Aboriginal communities from participating in the Census data collection. The ABS Census Aboriginal Engagement Teams are recruiting Aboriginal people as Aboriginal Community Area Supervisors and Community Coordinators in discrete Aboriginal communities in each state and territory. The ABS must continue these efforts to build a trusting relationship with all Aboriginal communities as a means to increase the participation rate of Aboriginal people (ABS 2011).

Empowering Aboriginal communities

The disability services sector is witnessing a paradigm shift in how the Australian community view and treat people with a disability. This transition requires Aboriginal people to take responsibility for how their communities are involved and represented. There are two ways the NDIS can achieve this.

Localised Aboriginal Community Reference Groups

A local reference group will ensure that the transition is responsive to the needs of Aboriginal families at a local level. Such reference groups could function as working groups of local indigenous community forums. The chairperson of each reference group could form the membership of a state or national reference group.

An Aboriginal Disability Research Agenda

Much of the research that emphasise on Aboriginal people was mostly undertaken by non-Aboriginal researchers. In fact, many of the major enquiries (such as the CSTDA review and the NSWDSA review) undertaken over the past few decades only had Aboriginal committees and focus groups (Ernst and Young 1996; New South Wales Law Reform Commission 1999). However, Aboriginal people were not the drivers of research about Aboriginal people

An Aboriginal Disability Research Agenda is a way that Aboriginal spokespeople and researchers can take responsibility for what is written about Aboriginal people. Non-Aboriginal people should not be forbidden to be involved in research with Aboriginal

people. Such an agenda requires both Aboriginal and non-Aboriginal researchers and spokespeople to be involved.

4. Research and data

We support the need for improvements in both research and data, and the need for greater consultation on research priorities.

Research

There are various centres around the country which contribute to research in the disability field; while they make valuable contributions their effort could be enhanced by more financial support and opportunities to participate in discussion of national priorities. In our previous submission, we stated our views (which we still hold) on research as

‘There is a need for an injection of funds into disability research in Australia, to improve the evidence and information available to the field and to policy makers. This should be designed to create a critical mass of research in various centres around the country, integrated and coordinated nationally. The submission of the Australian Human Rights Commission supports the idea of an Australian National Disability Research Institute, as recommended by the Disability Investment Group. We suggest that a strong, balanced hub and spoke model would work most effectively, with a small ‘Institute’ playing a coordinating role, fostering the development of centres of research excellence in the field.’

The PC needs to better consider how big a bureaucracy the NDIA will be. Certainly it must do data collection and basic analysis – and publish it. It must also make data available to researchers. It should not and cannot do all the research and, insofar as it has a role in commissioning research, must have a range of external advisors on priorities. There needs to be more consideration of existing models of national research funding in Australia.

In the PC report on aged care (PC 2011a *Caring for older Australians 2011*) there is thoughtful discussion of research and data and it would be of value to consider how well the principles and recommendations in the two reports can be combined. For instance, we strongly endorse the principle, stated by several researchers submitting to the aged care report, that publicly funded research and evaluation, commissioned by governments, should always be placed in the public domain.

Data

In relation to data it is important not to throw the baby out with the bathwater. There are needs to improve data in the disability field, including publicly available data and data for research. Improvements should be made on the hard-won foundations laid over recent decades, features of which include:

- Long-standing national mechanisms for agreeing data standards (Madden et al 2003).
- National data standards, including for disability, agreed by all Australian health and community services administrators (NCSDC 2008), and their value in national statistical collections (Anderson and Madden 2011).
- The presence in the field of an independent statistical body (AIHW), charged with the responsibility of reporting to the Australian Parliament and the Australian people on welfare including disability services, and generally publishing its findings.
- Statistical series created by both ABS and AIHW which have informed policy debates over the last 2-3 decades, the integrity of which must be maintained if trends and longitudinal evaluations are to remain possible.

Management data

Chapter 10 focuses on data to manage the NDIS. Financial data are required to estimate liabilities for existing claims and project future claims. The PC states that some databases exist for funded schemes where such estimates are essential for viability and for statutory reporting. The chapter then argues for a good data set to manage the scheme, including longitudinal data on each claim.

Much is said in Chapter 10 about the value of insurance industry data. However it is not explained where these are published and how they have contributed to public policy. Certainly disability services nationally could and should have much better financial data but, without greater transparency, it is hard to appreciate why insurance business data provide the model.

Data more generally

Chapter 10 of the Draft Report seems to extend its criticism of financial data to other national data more generally. Such comments have been made periodically since the early 90s. Over this period there has also a significant national effort to: create national data on disability services (there were none at all in the early 90s); make better use of the national disability survey; introduce disability modules into a wide range of social surveys. This has enabled a great deal of policy relevant analysis to be carried out and published. There is still inadequate use of published data by researchers and advocacy groups, and generally inadequate recognition of the costs and value of data systems that we have.

The PC should acknowledge data available outside insurance based schemes, including:

- SDAC
- Disability services NMDS and reports
- 2006 Census question
- ABS disability module and related social data

- Medical indemnity data collection
- Welfare expenditure data (published by both ABS and AIHW)
- Various longitudinal data sets such as HILDA and LSAC

Available data and their limitations are regularly explained in AIHW publications, notably the biennial welfare reports (e.g. AIHW 2005; AIHW 2004).

These data are (also) useful for the management of disability services, which are pay as you go. They allow projections, small area estimation and estimation of specific population needs (which insurance data may not do).

This is not to suggest that improvements should not be made. It is to suggest that general criticism must give way to description and explanation of the new data are needed, careful evaluation of what exists, and cost-benefit analysis of priorities.

Key principles are:

- Build on those good data that exist and preserve the ability to analyses key trends.
- Follow existing national data standards the existing national data on support needs, conforming to ICF and agreed national data standards, need to be continued into the future so that long terms trends, including the effects of major policy change, can be understood.
- Establish new standards through the existing formal processes (NCSIA /NHIA)
- Provide comprehensive data from NDIS to AIHW for national publication
- Augment the content of ABS and AIHW data collections and analyses rather than starting new collections
- Provide funding to ABS to increase the frequency of the SDAC, both for the public good and to assess the impact of the NDIS on disability in Australia

5. Governance

It is proposed in the PC Report that the NDIA should have ‘a governing board that would be skill-based, not representational’ (PC 2011, page 7.21). However the main skills suggested as being essential are financial: ‘NDIA board members would need to be chosen for their commercial skills and experience. The scheme would also benefit from having some board members who have experience with long-term care *or* insurance schemes’ (page 7.24) (our emphasis).

As well as financial expertise, the Board of the NDIA should possess expertise in disability life, policy and administration, including people with disabilities; this does not imply that such experts have a representational role. The presence of such expertise on the Board is essential to ensuring that the Board can indeed ‘provide strategic direction and oversight of the scheme’s success in meeting the objectives laid down in its Act’ (PC 2011, page 7.24).

APPENDIX: Profile of existing recipients of disability support services

From our previous submission:

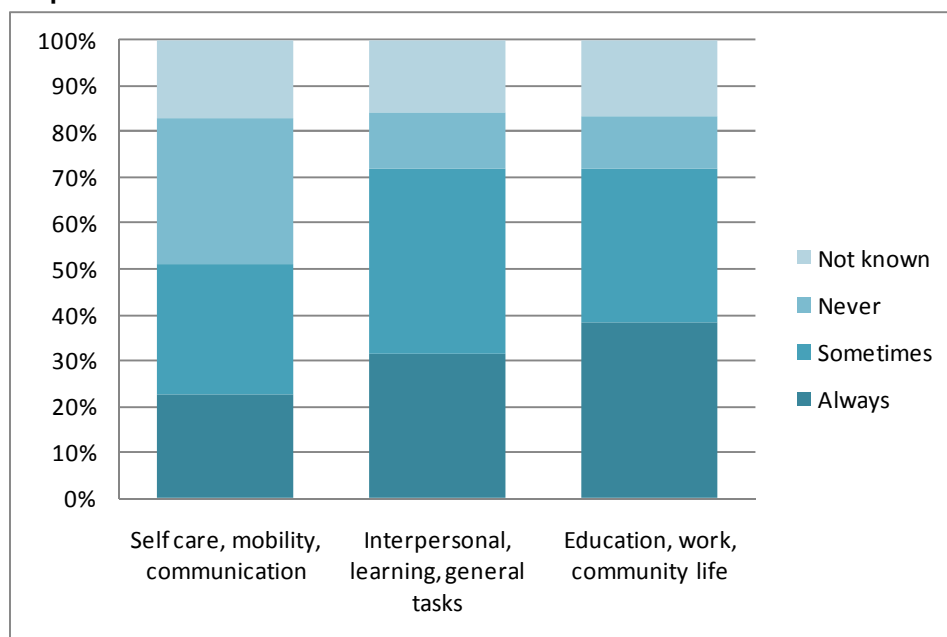
Submission 493 on <http://pc.gov.au/projects/inquiry/disability-support/submissions>

The support needs of recipients were relatively high (Figure 2):

- almost 70% of service users needed support in education, work and/or community life;
- around 70% needed support in interpersonal interactions and relationships; learning, applying knowledge and general tasks and demands; and domestic life;
- some 50% needed support in self care, mobility and/or communication; this compares with 6.3% of people of all ages in the general population who needed assistance with self care, mobility and/or communication in 2003 (ABS 2004).

Of service recipients needing support, almost half needed support ‘always’ in order to carry out the activity or to participate in that area of life, or else were unable to do so at all.

Figure 2: Frequency of support needed in 9 life areas (grouped): Disability support services recipients 2007-08



Source: AIHW 2009

Thus we see that:

- **In terms of the three activities on which there is comparative information (self care, mobility and communication) national disability support services are well targeted, with much higher rates of needing support among service recipients than in the general population**
- **Current service recipients have a range of important support needs across all areas of Activities and Participation and are in fact more likely to need support in areas such as interpersonal relations, learning, work and community life than in self care, mobility and communication.**

Moreover, from other analyses, we know that:

- **These latter needs – including interpersonal relations and domestic life – are very often unmet, as are needs in the area of communication (AIHW 2005: 255).**
- **There is no evidence that needs in one area of Activities/Participation can be used to predict needs in another, in such diverse populations (Anderson and Madden in press). That is, needs in the areas of self care, mobility and communication cannot be used as indicators of the level of support needed in domestic or community, social and civic life, or interpersonal relationships, work, education or learning.**

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