Submission – Part A

to the

Productivity Commission Inquiry

Draft Report

on

Disability Care and Support

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About DANA

The Disability Advocacy Network Australia (DANA) is a company limited by guarantee, established in October 2008 and incorporated in May 2009 to strengthen and support disability advocacy organisations across Australia. DANA's purposes include to promote the role and value of independent advocacy and to provide a collective voice for members. The DANA membership includes disability advocacy organisations from each of the States and Territories of Australia.

DANA works to a vision of a nation that includes and values persons with disabilities and respects human rights for all.

DANA has a membership of 59 agencies whose primary purpose is to provide independent advocacy support to people with disabilities. These agencies receive their core recurrent funding from State and/or Commonwealth Government advocacy programs targeted at people with disabilities, frail older people and people with mental health issues. Some agencies receive only a single source of funding for a specific target group while others receive multiple sources of funding for different target groups (disability, mental health and frail aged).

Independent advocacy agencies address the advocacy needs of those people with disabilities who are more likely to be vulnerable to abuse, neglect and/or breaches of their fundamental human rights. They do this through a variety of delivery models that include systemic advocacy, legal advocacy, individual advocacy support by paid advocates, citizen advocacy using volunteer advocates, self advocacy development and family advocacy development and support. Some agencies focus wholly on the provision of independent human rights focused information for people with disabilities.

Introduction

DANA began the development of this submission by working with organisations of people with disabilities to consider together how well the Productivity Commission (PC) Draft report on Disability Care and Support addressed the issues raised by us in our earlier submissions. We then invited disability advocacy organisations across Australia to attend face to face or telephone consultations to discuss the content of the Draft Report and provide feedback. Consultations were held in Melbourne, Sydney, Adelaide, Perth, Hobart, Canberra and Brisbane. Telephone feedback was also received from two Northern Territory based advocacy organisations. This DANA submission reflects input from 50 disability advocacy organisations from all the States and Territories of Australia.

DANA' member organisations have played an active role in the prevention of abuse and neglect and the protection of the human rights of people with disabilities for more than 20 years. Those people with disabilities who are supported by advocacy agencies are likely to be less able to articulate their own needs or require assistance and support to express their wishes and represent their own interests. Many live in settings where other people decide how most aspects of their daily lives are conducted.

While the PC Draft Report deals in great detail with many varied aspects of the proposed future support arrangements, this submission will focus on looking at how well the recommendations address the key elements required of a new Scheme as identified in our earlier submission; whether the proposed Scheme incorporates the safeguards necessary to ensure that the Scheme will operate effectively, particularly for those very vulnerable people with disabilities who rely on others to articulate their needs and promote their interests; and on how the Scheme might be improved to ensure that it enables people with disabilities to enjoy the fulfilment of their human rights and fundamental freedoms; and their participation and inclusion in Australian society on an equal basis with others.

Advocacy organisations across Australia have expressed general support for many of the overarching findings and principles expressed in the Report together with the new federalized and individualized funding and administrative arrangements proposed by the Commission. It is felt that the proposed Schemes represent a necessary shift towards a more consumer focused and directed system of supports and service provision but that much more work needs to be done to ensure that the proposed Scheme delivers on this promise and on Australia's obligations under the United Nations *Convention on the Rights of Persons with Disabilities* (CRPD).

The DANA submissions are therefore devoted to making recommendations about areas for improvement and/or clarification. At the same time we recognise that some of the more detailed implementation issues here addressed might be better noted by the Commission and considered at a later date when the broader structural funding, legislative, governance and management frameworks have been established.

Advocacy organisations have identified that the most significant structural issue requiring attention and further recommendation by the Commission is the need to make independent[1] advocacy support available to all people with disabilities who face decision making challenges or matters requiring them to speak up for themselves as a group or as individuals. The ready availability of advocacy support is a key safeguard in any society striving to promote and protect the rights and interests of very vulnerable and marginalised people.

This document is **Part A** of the DANA submission in relation to the PC Draft Report on Disability Care and Support. It summarises the DANA response to the key PC findings and provides guidance about how independent advocacy should be connected to, yet maintain independence from, the proposed National Disability Insurance Scheme.

Part B, will contain DANA commentary on the PC Recommendations and **Part C** will provide additional guidance on a framework for providing equity of access for people with disabilities to independent advocacy support across Australia.

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[1] In this Submission and in the advocacy context "independent" means free from influence by the service system or government agencies with responsibility for the provision of supports and services to people with disabilities.

NDIS Scheme Design

The following key findings from the report have found general support across the advocacy sector. Noted briefly with them, in general terms, are the additional measures, improvements or clarifications we believe are necessary to ensure that the system operates fairly and delivers the kinds of services and supports that are appropriate to one of the richest countries, per capita, in the world. More detail is contained in our commentary on the specific PC recommendations to be provided later in **Part B** of the DANA submission.

DANA supports the following PC Report findings:

- that the current system of services and supports is broken and needs replacing

  Noting that government should ensure that it retains ultimate responsibility for the effective governance, funding and administration of the proposed replacement Schemes.
- that the current lack of funding for supports and services for people with disabilities is a significant problem and needs to be remedied by a doubling of the available resources

  Noting that there is a need for more clarity about how the figures have been reached and an evidence based assurance that the level of recommended additional funding will be sufficient to meet the need.
- that eligible people with disabilities should have an individualised entitlement to adequate and timely support

  Noting that the entitlement should extend to all those people with disabilities who need support to live their lives and participate and be included in society on an equal basis with others.
- that people with disabilities will have changing support needs over time and that their assessed entitlement will be responsive to this

  Noting that entitlement levels should build in automatic price adjustments to reflect the inevitable service delivery cost increases.
- that people with disabilities should have the option to choose, direct and manage their own supports and services

  Noting that they should also have ready access to the decision-making and other supports they need to do this rather than face unnecessary restrictions on who is permitted to exercise this option.
- that the proposed NDIS will be portable throughout Australia

  Noting that it is unclear whether supports and services provided under the NIIS will be portable throughout Australia.
- that services funded under the NDIS may, at the option of the person, continue to be available into older age

Noting that this option should be extended to anyone over the age of 65 years, who meets the NDIS eligibility criteria, to choose to access NDIS services.

- that the Scheme is for everyone

  Noting that more certainty is needed about how people, not regarded as eligible for Tier 3 supports and services, will have their specific disability needs met.
- that the Scheme should be based on equity

  Noting that equity must take into account the additional costs of support that can arise from the intersection of disability and: gender, Aboriginal or Torres Strait Islander background, cultural diversity, geographic location and the specific needs of children.
- that the Scheme will fund early intervention and prevention

  Noting that the criteria for access to support should be based on the benefit to be derived by the individual.

Independent Advocacy

As noted previously, a significant structural issue that has not been well provided for in the PC Report is the ready availability of independent advocacy support for people with disabilities and those who advocate on their behalf. This will be as vital as it has been in the past because many of our mainstream systems and services continue to respond poorly to the needs of people with disabilities, because the proposed NDIS relies heavily on personal choice and decision-making, and because many people with disabilities need advocacy support to ensure that their views and interests are represented and valued.

The ready availability of advocacy support is a key safeguard in any society striving to promote and protect the rights and interests of very vulnerable and marginalised people. It ensures that very vulnerable people with disabilities are as able to pursue their interests as those who are powerful self advocates or who have powerful family or allies and it assists in ensuring that injustice and inequity, abuse, neglect and discrimination is brought into the open and addressed, or prevented from occurring in the first place. This is particularly important when considered in the context of the Shut out Report[2] findings that "discrimination is a feature of daily life for many people with disabilities and their families" and that "More than 39 per cent of submissions [to the Inquiry that resulted in the Report] identified discrimination and rights as a vital issue".

A number of speakers[3] at the recent National Disability & Carer Congress[4] made the point that the structures and processes in a system locate the power in that system. The availability of independent advocacy assists in locating the power over a person's life where it belongs - with the person with disability. Independent advocacy support assists a person or people with disabilities to speak up for themselves and effectively engage with systems, services, businesses and individuals to achieve their goals when they otherwise might be prevented from doing so by lack of knowledge, support, confidence, experience, or/or skills.

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[2] Shut Out: The Experience of People with Disabilities and their Families in Australia; National Disability Strategy Consultation Report; prepared by the National People with Disabilities and Carer Council. p4.

[3] Steve Dowson, Consultant and Trainer, UK; Monsignor David Cappo AO, South Australia Commissioner, Social Inclusion.

[4] Held in Melbourne on 2 - 3 May 2011.

Advocacy and the PC Draft Report

The PC proposes a 'consumer choice' model of service and support with the aim of giving people with disabilities more power over what and how their support services are delivered (p25 Overview). Consumer choice will be assisted in the PC model, by the NDIA case manager and Disability Support Organisations (DSOs). Advocacy agencies are regarded as falling into the category of DSOs. As such they are viewed as part of the NDIS and subject to broad NDIA funding and administration arrangements.

The Commission envisages that the NDIA case manager would, amongst other things, "provide advice, and oversight and monitor the interaction between clients and the NDIS and the delivery of services to them" (Box 7.1 at p7.4), tailor "support according to the needs of the client" (p8.15), "liaise with other government services on their behalf", assist in the establishment of self-management arrangements and "negotiate, if requested, with service providers in the event of a dispute or complaint" (Box 7.1 at p7.4). It is also anticipated that the NDIA case manager would be accountable for the "welfare of the client" (p8.14) and model their approach on that used by Local Area Co-ordinators in Western Australia.

DSOs in the PC model may be appointed by a person with disability "to act as an agent for the person with a disability on matters concerning the NDIS" (p7.13), to advise "on the quality and choice of support services", to "act as brokers by assembling 'packages' of supports", to provide personal planning services, to act as mentors or motivators to people with disabilities to gain greater control over their lives (p7.14) to assist them to meet the administrative tasks associated with self directed funding (p7.15) and to advocate on their behalf in relation to complaints or disputes with service providers (p7.14). DSOs are envisaged as initially being funded directly by the NDIA and later on, drawing their funding from the entitlement of individuals.

DANA is strongly of the view that independent advocacy support for people with disabilities is fundamentally different in nature from disability service provision and from the role identified for NDIS DSOs; that its independence from service administration, funding and delivery is key to its effectiveness in promoting the rights and interests of people with disabilities, and that this must be safeguarded by careful attention to system design. How the system should be designed to give effect to these considerations will be addressed below.

As can be seen from above, there is some overlap between the functions recommended by the PC to be performed by the NDIA case manager and those proposed for DSOs. Despite this, there is recognition by the PC of the distinct differences in the focus, accountability and other functions involved in the two roles sufficient to mean that the roles cannot be performed by the one agency.

In the same way, there are certain functions undertaken by independent advocacy agencies that overlap with those of the NDIA case managers and DSOs, but this does not mean that all or even the majority of advocacy agency functions can be performed by DSOs or NDIA case managers. Nor does it mean that advocacy agencies can sensibly carry out all the functions of, or intended for DSOs, or that they will carry out their overlapping functions in the same way as would NDIA case managers or DSOs.

The person with disability should be able to choose who it is that best meets their needs in performing the overlapping functions. They should be able to choose to get their information about options, their advocacy in relation to service provider disputes and their encouragement to self manage from any or all of the available options i.e. their NDIA case manager, a DSO or an independent advocacy agency. In many cases all will be involved because each provides something different in this process, all of which may be valuable and necessary to the person. Independent advocacy agencies commonly become involved when the person requires more detailed or specialised assistance than is able to be provided by a case manager or DSO or when a conflict of some kind arises.

One of the key differences between DSOs, NDIA case managers and independent advocacy agencies is that unlike the DSOs and NDIA case managers, independent advocacy agencies do not arrange, manage or conduct service provision for a person with disability. An advocacy agency is therefore, when conducting its advocacy support, wholly focused on promoting and protecting the rights and interests of the person with disability and on ensuring that the person’s voice and choices are respected.

Unlike NDIA case managers and DSOs, advocacy organisations are not also required by their role in the system to balance the competing fiscal and service interests of their agency or the system, so they are able to, in effect, stand in the shoes of the person with disability and fully support them in pursuing their interests. No other part of the system is in a position to do this and not all people with disabilities have the personal or societal resources to pursue their interests without funded advocacy support.

In this way the availability of independent advocacy support provides a rights and well-being counterpoint to an otherwise economically driven system and serves to rebalance the power dynamic which pits an otherwise unsupported vulnerable person against the driving economic imperative of keeping costs down for the taxpayer.

DANA recognises that people with disabilities accessing the NDIS and NIIS, will receive support to pursue their interests from many sources: family, friends, other allies, service providers, NDIA case managers and non-advocacy DSOs. From time to time each of these groups of people will find that their interests are in conflict with those of the person with disability or that their capacity to advocate for the person with disability is limited by lack of knowledge, skills or resources. This is where the ready availability of independent advocacy support is most important.

Independent Advocacy agencies that provide advocacy support to individuals with disability always seek to minimise any potential conflicts of interest and to ensure that advocates have the knowledge and skills to support people with disabilities to meet their needs and achieve their goals. Advocates thus become experts in assisting people with disabilities to engage effectively with systems, processes, governments, businesses, community organisations and individuals for these purposes.

In the context of the NDIS and the NIIS, independent advocacy support should be offered and made available to all people with disabilities at their request:

- before and during the NDIA assessment processes
- when any issue or conflict arises with the NDIA, particularly in relation to assessments, case management or the capacity of a person with disability to self-manage
- to support people with disabilities engaging in service quality or NDIS or NIIS quality assurance processes
- when any issue or conflict arises with a DSO or service provider
- to support a person in their decision-making in relation to the NDIS and the NDIA
- when an issue arises in relation to services or supports provided in conjunction with other arms of government

Some have argued that the introduction of an entitlement based, consumer led service provision model when supported by NDIA case managers and DSOs will lead to a reduction in the need for independent advocacy support. If the NDIS and NIIS work as well as is hoped, fewer people may need independent advocacy support to access the disability supports and services appropriate and sufficient for their needs; however, advocates will always be needed to assist very vulnerable people to exercise choice and make decisions, to provide support when conflict arises, to promote positive practices and processes, to resist inappropriate cost cutting and to promote intersystem co-operation.

There is no doubt that the introduction of the NDIS and the NIIS will change a significant part of the environment in which advocacy support is provided, as well as the options available to people with disabilities and the mechanisms available for them to achieve their goals. However, It will not change the way in which advocacy organisations carry out their work with people with disabilities or their key roles and functions. Independent advocacy agencies have always operated across extremely diverse environments, systems and communities, working with local, State and Federal governments and a wide variety of businesses, community organisations and individuals to promote and protect the rights and achieve the goals of people with disabilities. They have done this by ascribing to key advocacy principles and remaining focused on the rights, fundamental freedoms and well-being of people with disabilities while operating flexibly and as required in their interests.

Advocacy beyond the NDIS and NDIA

The availability of independent advocacy support is vital not only to those people seeking or in receipt of services or supports under the NDIS or NIIS. It is important for those people with disabilities wishing or needing to assert their rights and interests in other areas of life: with other parts of government, business, the community or even their family. Much current government funded advocacy for people with disabilities is directed towards the health, education, housing, justice, transport and planning systems. It is also directed to raising government, service provider, family and general community awareness about the rights and interests of people with disabilities. Without independent advocacy support only those people who are good self advocates or those with knowledgeable and committed families or allies will be able to effectively take advantage of the rights and justice protection provided to Australian Citizens for this purpose. Those residing in institutions, and thus out of public sight, will be particularly disadvantaged. This would clearly be an inequitable outcome resulting in those who are most in need of the protection afforded by our administrative review, human rights and justice systems being among those least likely to get access to it.

Independent advocacy support is also vital for the protection of very vulnerable people with disabilities who are more subject to abuse, neglect, discrimination and the denial of their human rights and fundamental freedoms than the rest of the Australian population. The ready availability of strong advocacy support for a vulnerable person with disability can reduce their vulnerability to rights abuses and can also function as an early warning signal when things are not going well so that this can be remedied before anything worse can occur.

Advocacy support needs to be available to all people with disabilities, i.e. those identified by the PC as being in Tier 2 of the NDIS because abuse, discrimination and infringement of rights arising from disability does not only happen to those who will be eligible for the NDIS or NIIS: see the *Shut Out* report. These kinds of issues, when they occur, can be very difficult for a person with disability, or indeed any person, to address and have remedied without skilled and knowledgeable advocacy support. The fact that the issue occurred in the first place is an indication of a significant power imbalance between the perpetrator and the victim. The involvement of an advocate will immediately serve to a certain extent to redress the imbalance of power and make more resources available to address the issue. In some cases the only effective avenue for remedy is a legal one requiring dedicated legal advocacy.

Independent advocacy agencies also make an important contribution to public policy debates on behalf of people with disabilities and work for systems change across all areas of government business and community life to improve the lives of people with disabilities. Implementation of the NDIS and NIIS will inevitably create a need for additional systemic advocacy to ensure that wrinkles in the Schemes are ironed out, that the Schemes comply with Australia's obligations under the CRPD and that they continue to work towards the progressive realisation of the rights of people with disabilities as set out in the Convention.

In addition to making advocacy support available directly to individuals with disability, independent advocacy agencies work to support others engaging in advocacy for people with disabilities. Family advocacy agencies work with family members, citizen advocacy agencies support volunteer advocates, self advocacy organisations support people with disabilities to learn advocacy skills and to speak up for themselves and others. In a changing system that offers greater choice and flexibility, the work of these organisations will be even more important.

A small number of agencies focus wholly on the provision of independent human rights focused information to people with disabilities and their supporters. For many independent advocacy organisations the dissemination of this kind of information is also part of core business. The ready availability of human rights focused information is vital in a system that is to be built on personal choice and committed to compliance with the UNCRPD.

Safeguards for Advocacy Independence

Ensuring that advocacy agencies are able to advocate independently of other interests and effectively and consistently for the benefit of people with disabilities requires that attention be paid to the following matters:

1. removing the potential for any conflict of interest to arise from a disability service provider also seeking to provide advocacy support
2. removing the potential for any conflict of interest to arise between an advocacy agency and their funding body; and
3. ensuring that advocacy agencies are appropriately resourced to carry out their important roles

1. **Independence from service providers**

   This is easily achieved by ensuring that service providers are not funded by government to provide independent advocacy support.

   Advocacy support to people with disabilities must be provided by agencies that are able to demonstrate independence from the actual, potential and perceived conflicting interests involved in service delivery. This means that an agency, to be independent from service provision, needs, at a minimum, to have advocacy as its core business and to not be a provider of any of the following services: employment, accommodation support, personal care support, independent living support, respite, vocational training, brokerage, and mediation or case management.

   Independence cannot be assured and will always be at risk, if it is sought to be achieved by partitioning non-advocacy services, for example direct service provision, from advocacy within the one organisation. This is because all the elements of an organisation are accountable through their governing body to the whole and the governing body must govern the organisation in a way that minimises organisational risks. Thus the advocacy component of the organisation must tailor its advocacy so as avoid adversely impacting on the work or reputation of other parts of the organisation and it must seek to avoid damaging organisational working relationships with key industry colleagues in other organisations. By fulfilling its responsibility to be a good corporate citizen within its own organisation, the advocacy component will lose its capacity to be vigorous and committed for people with disabilities.

Agencies that have advocacy as their sole focus are not subject to these kinds of pressures to diminish the strength of their advocacy to protect the reputation of their agency. An advocacy agency's reputation relies wholly on its effectiveness in promoting, protecting and defending the rights and interests of people with disabilities.

2. Independence from Service funding and administration

DANA members have experienced advocacy funding being administered by Government Departments that also administer disability services funding at either the State or Commonwealth levels. This duality of responsibility has commonly created conflicts of interest for such Departments and for the agency. Departments struggle not to react negatively when their service administration is called into question and advocacy organisations struggle with the need to bite the hand that feeds them.

The creation of a new system of disability services and supports offers an opportunity to redress this problem; however, the PC in its draft report, has not paid attention to the issue and instead recommends structural arrangements which would serve to seriously aggravate and extend the problem.

Under the new service and support arrangements proposed by the Commission, the NDIA will be responsible, not only for service funding and monitoring service quality, but also assessing consumer needs, providing case management, information and much more. The NIIS will provide for the care and support for all people experiencing a catastrophic injury. DSOs will provide personal planning services, undertake administrative tasks for those people self-directing their funding and assemble packages of supports. Thus the NDIA, NIIS and DSOs will all, alongside service providers, exercise a high level of power over, and involvement in, the provision of services and supports to people with disabilities.

In such circumstances, for advocacy agencies to remain independent and effective, they must retain the freedom to advocate without fear or favour in relation to the activities of them all. This means that advocacy administration; funding and delivery should occur separately from the NDIA, the NIIS and disability service and support organisations.

The PC in its Draft report proposes exactly the opposite: that advocacy support provision be regarded as a disability support organisation function; that it may be delivered also by service providers and that it will be administered and funded, at least initially, directly by the NDIA. If this were to be implemented it would effectively result in the disappearance of strong and effective advocacy support for people with disabilities and the removal of one of the prime system safeguards for the safety and well-being of very vulnerable people with disabilities.

3. **A proper level of funding**

   The PC Draft Report proposes that the NDIS will be the prime funding source directed to meeting the support needs of people with disabilities, not covered by the NIIS, into the future. As this funding source grows to address the recognised need for services and supports for people with disabilities, so too should advocacy funding grow to assist people with disabilities to engage effectively with these and other service and support mechanisms and to ensure that their rights, interests and fundamental freedoms are promoted and protected. This suggests that the appropriate way in which to avoid the politicisation of advocacy, while still ensuring a proper level of funding, is to set aside an identifiable and justifiable portion or percentage of the NDIS bucket to fund independent advocacy for people with disabilities.

   As with the services and supports for people with disabilities identified by the PC, there is a significant unmet need for independent advocacy for people with disabilities. This unmet need should be recognised and addressed in the first allocation of NDIS funding for advocacy.

   Advocacy funding has historically varied over time and across the States and Territories according to the interests of the relevant Ministers and Departmental officials and the policies of their respective governments. There has been no rational determination of the principles to apply in determining an appropriate level of advocacy provision and hence of independent advocacy support funding. DANA is currently undertaking more detailed work in this area to try to provide the Commission with some guidance on this matter.

   This allocated portion should be then made available to a separate body to fund and administer the provision of independent advocacy support.

A National Statutory Advocacy Authority

DANA is proposing that a separate Statutory Advocacy Authority be established to manage the funding for and administration of a national independent disability advocacy program that maintains links through its Board structure to the NDIA and NIIS. The Program would be administered in accordance with a set of principles that establish the core elements and functions of an independent advocacy program. It would be governed by a Board that includes people with disabilities, advocacy organisation representatives, independent advocacy experts, and people with governance and fund management experience. It is anticipated that some Board members would have a combination of these attributes.

The functions of the proposed new authority would be as follows:

- Promotion of the value and importance of independent advocacy
- Advocacy sector planning and development including identification of demand and development of a comprehensive Program framework incorporating the elements indentified in the Principles above
- Management of core recurrent advocacy funding perhaps via State based officers
- Development and Implementation of a Performance Reporting and Quality Assurance Framework for advocacy providers
- Research in relation to advocacy practice, administration and demand
- To Influence Government policy development and implementation in favour of advocacy.

Such an Authority, properly constituted and funded, would, through driving quality improvements to advocacy, also drive a culture of respect for and inclusion of people with disabilities in the life of the community.

The mechanics of funding Independent Advocacy

The role that advocacy organisations play and the circumstances in which they get involved in the lives of individuals with disability, means that it is inappropriate that the funding for their work be tied to the NDIA assessment and entitlement system:

- Much independent advocacy work is appropriately directed to systems change for the benefit of a large number of people with disabilities.
- The systemic advocacy work undertaken by advocacy organisations is commonly informed by the experiences of individuals as identified by organisations carrying out individual advocacy.

- Work done on behalf of an individual can commonly lead to systems change for the benefit of many.
- It is not possible to make an accurate prediction up front about the amount of work that will be involved in resolving an advocacy issue for an individual because this will be entirely dependent on third party responses to the work as it is undertaken.
- Agencies that provide citizen advocacy and family advocacy do not support an individual directly but rather provide education and support to volunteer family members and others who then carry out the advocacy.
- Independent Advocacy is commonly required to assist individuals to access the support and services they need. The level of support required from the NDIA or NIIS can depend on how well other systems are performing. Advocates can be called upon to assist a person long before any NDIA or NIIS entitlement is identified for a person with disability.
- Independent advocacy for individuals is commonly required when the systems or services they are involved with are failing to meet their needs. Those for whom the system and services are working well will not need advocacy. Disability Services Commissioners and Human Rights Commissions do not charge for access to their services for similar reasons.
- A person with disability may need advocacy support to assist them to assert rights and/or interests when they are in conflict with those of their guardian or other members of their family. In such circumstances a family member guardian will be unlikely to agree to the use of the person's individual entitlement to fund advocacy support.
- The benefits of self advocacy training are often only apparent and recognised after training is complete and participants usually need considerable but hard to quantify ongoing direct advocacy support to benefit from it.
- Much advocacy work, both individual and systemic, will relate to the NIIS and to generalist services and systems, business and the community that are not within the ambit of the NDIA or NIIS.
- Current no fault insurance schemes do not fund independent advocacy support for the people accessing their schemes for many of the reasons identified above.
- Not all those people with disabilities in need of advocacy will be eligible for the NDIS or NIIS. People with mild to moderate disability also experience abuse, neglect, discrimination, and exploitation because of their disability.
- Independent advocacy work undertaken in response to abuse, neglect, exploitation or discrimination should not, for equity reasons, be drawn from the entitlement of an individual who should not have to pay twice for the bad behaviour of another.

- Independent advocacy agency work is commonly preventative, generalised and directed to educating various elements of the community about the rights and interests of people with disabilities.

Recommendation:

An identifiable, justifiable proportion of the total NDIS bucket of funding should be provided to an independently constituted statutory advocacy authority to administer and distribute to independent advocacy organisations so as to ensure that the strength and effectiveness of advocacy is assured and that the advocacy provided remains focused wholly on the rights, interests and well-being of the person with disability.

Submission – Part B

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For further information please contact:

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Part A of the DANA Submission was provided to the Productivity Commission (PC) on 22 May 2011. It summarised the DANA response to the key PC findings and provided guidance about how independent advocacy support for people with disabilities should be connected to, yet maintain independence from, the proposed National Disability Insurance Scheme.

This, Part B of our submission, contains the DANA response to each of the PC Recommendations. Our response is informed by consultations we carried out in April 2011 with 50 organisations across Australia.

Part C of our submission, to be made available to the Commission in a few weeks, will put forward a framework for providing equity of access for people with disabilities to independent advocacy support across Australia.

Chapter 3 Who is the NDIS for?

DRAFT RECOMMENDATION 3.1

The National Disability Insurance Scheme (NDIS) should have three main functions:

- *to cost-effectively minimise the impacts of disability, maximise the social and economic participation of people with a disability, and create community awareness of the issues that affect people with disabilities. These measures should be targeted at all Australians*
- *to provide information and referral services, which should be targeted at people with, or affected by, a disability*
- *to provide individually tailored, taxpayer-funded support, which should be targeted at the subset of people with disabilities who are assessed as needing such support.*

DANA supports the finding that the Scheme is effectively for everyone but that different groups of people should get different things from the Scheme.

The Report is however unclear about where the responsibility lies, in term of administration and funding, for those supports that cannot sensibly be individualised, that should be accessible to all people with disability and that will not be provided by mainstream services. More attention in the final Report needs to be paid to this aspect of the Scheme and to the relationship between the three proposed Scheme tiers.

DANA supports the view that supports and services should be provided in a cost effective way but believe that this should not occur at the expense of service quality or flexibility to respond to the needs of the person with disability. The consideration of cost effectiveness, we believe, must be carried out having regard to the broader context of what is lost or what additional costs: economic, social and cultural (to rights, freedoms, inclusion, participation) are incurred by a failure to provide appropriate services.

DRAFT RECOMMENDATION 3.2

Individuals receiving individually tailored, funded supports should be Australian residents, have a permanent disability, (or if not a permanent disability, be expected to require very costly disability supports) and would meet one of the following conditions:

- *have significant difficulties with mobility, self-care and/or communication*
- *have an intellectual disability*
- *be in an early intervention group, comprising:*
  - *those for whom there was a reasonable potential for cost-effective early therapeutic interventions (as in autism and acquired brain injury)*
  - *those with newly diagnosed degenerative diseases for whom early preparation would enhance their lives (as in multiple sclerosis)*
- *have large identifiable benefits from support that would otherwise not be realised, and that are not covered by the groups above. Guidelines should be developed to inform the scope of this criterion.*

DANA does not support the restrictions to eligibility for individualised supports that are contained in this recommendation.

We support Tier 3 of the Scheme being available to all those people with disabilities who need specialist disability supports to live their lives and participate and be included in society on an equal basis with others. People with disabilities, supported by the Scheme, should encompass those people with disabilities as defined in the United Nations Convention on the Rights of People with Disabilities (UNCRPD). This includes those people with chronic health conditions, mental health conditions and people with disabilities over the age of 65 years.

DANA is clear that the NDIS should not consider how a disability arose in determining whether a person is to be supported under the NDIS. It is the existence of the disability and the fact that it gives rise to a need for support that is important. Otherwise the focus of the Scheme once again turns to diagnoses, severely disadvantaging those who are not easily labeled, who are susceptible of multiple labels or whose label is not popular. Such an approach leads to people with disabilities, in serious need of support, falling between artificially created cracks and becoming the victims of bureaucratic cost shifting.

It is a false economy to seek to exclude those people who would benefit from support from the Scheme because in doing so we inevitably make it more difficult for them, and their loved ones to participate in and contribute to society. For some people, currently proposed to be excluded from the NDIS , for example those with mild to moderate disability, it may mean the difference between being able to get a job, participate in education, or volunteer for a local community group. For others it may mean the difference between being able to care for children, other family members or their own home.

It is not clear from the Report how the NDIS interfaces with the criminal justice system. DANA would argue that prisoners with disability should, at a minimum, be entitled to the same level of disability support inside the prison system as outside and that, in many cases, the failure to provide appropriate disability support has contributed to the person’s incarceration in the first place.

DANA also supports the Scheme being available to people who are undergoing extended immigration and citizenship processes. All people residing in Australia are entitled to be treated as human beings and have their rights, dignity and needs respected. Most go on to become valuable contributors to the Australian community. Failure to provide proper supports at an early stage simply delays or prevents this contribution from taking place.

People deprived of meaningful activity or occupation, because they cannot access the necessary supports also have a greater tendency to develop depression or other serious illnesses that have significant associated healthcare and other costs.

DRAFT RECOMMENDATION 3.3

The NDIS should provide advice to people about those instances where support would be more appropriately provided through non-NDIS services. Support should be provided outside the NDIS for people whose:

- *disability arose from a workplace accident or catastrophic injury covered by insurance premiums*
- *support needs would be more appropriately met by the health and/or palliative care systems, comprising:*
  - *those who would benefit from largely medically oriented interventions (including less restrictive musculoskeletal and affective disorders, and many chronic conditions)*
  - *many people with terminal illnesses*
- *support needs would be more appropriately met by the aged care system*
- *needs were only in relation to mainstream employment, public housing or educational assistance.*

While it is appropriate to expect that the NDIS would provide referrals to the more relevant agencies for the health, education, housing, palliative care, or aged care needs of the person, the NDIS should retain responsibility for ensuring that the specialist disability support needs of the person are provided for regardless of the setting.

DRAFT RECOMMENDATION 3.4

The NDIS should put in place memoranda of understanding with the health, mental health, aged and palliative care sectors to ensure that individuals do not fall between the cracks of the respective schemes and have effective protocols for timely and smooth referrals.

DANA supports greater clarity being reached in relation to the relative responsibilities of the parts of the systems that most commonly respond to the needs of people with disabilities, in particular, to ensure that there are no gaps in the services and supports provided. It is important however to ensure that this clarity is not reached at the expense of flexible and sensible service delivery or individual choice.

DRAFT RECOMMENDATION 3.5

Whatever the actual funding divisions between the NDIS and aged care that are put in place, people should have the option of migrating to the support system that best meets their needs, carrying with them their funding entitlement. Upon reaching the pension age (and at any time thereafter), the person with the disability should be given the option of continuing to use NDIS-provided and managed supports or moving to the aged care system. If a person chose to:

- *move to the aged care system, then they should be governed by all of the support arrangements of that system, including its processes (such as assessment and case management approaches)*
- *stay with NDIS care arrangements, their support arrangements should continue as before, including any arrangements with disability support organisations, their group accommodation, their case manager or their use of self-directed funding.*

Either way, after the pension age, the person with a disability should be subject to the co-contribution arrangements set out by the Commission in its parallel inquiry into aged care.
If a person over the pension age required long-term aged residential care then they should move into the aged care system to receive that support. In implementing this recommendation, a younger age threshold than the pension age should apply to Indigenous people given their lower life expectancy, as is recognised under existing aged care arrangements.

DANA supports this recommendation to the extent that it allows for a person receiving support under the NDIS to continue with their NDIS support, if they wish, once they have reached pension age. It should also allow the person to continue to access their existing disability advocacy support.

Additionally, people who acquire a disability after they have reached pension age should be given the option of having their support needs met using the NDIS, if they wish, and of being treated in all other respects as would a person who continues on with the NDIS once they reach pension age.

This would allow for far more logical service delivery arrangements in the many instances where the support needs of the older person are better aligned with those of younger people with disabilities than they are with the suite of the services provided by the aged care industry.

This approach also has the advantage of allowing older people more choice about how their support needs might be met and is better aligned with the UNCRPD social construction of disability which does not make distinctions on the basis of age.

DRAFT RECOMMENDATION 3.6
Following the transition spelt out in draft recommendation 17.1, the NDIS should fund all people who meet the criteria for individually tailored supports, and not just people who acquire a disability after the introduction of the scheme.

DANA agrees that the Scheme should fund all people who meet the established criteria regardless of when they acquired their disability. It will also be important for the Scheme to seek out those who might be eligible because not all eligible people will be known to the current service systems. This will not be because they don't need support. It will be because they did not know it was available, did not know how to access it or did not succeed in accessing it in the past.

DRAFT RECOMMENDATION 3.7
The supports to which an individual would be entitled should be determined by an independent, forward-looking assessment process, rather than people's current service use.

A person's current service use has commonly been determined by what was available and offered at a time of great need rather than by what is desired or needed by them going forward. It does not therefore provide a good basis for determining future entitlement.

At the same time it is important to recognise that many people with disabilities and their supporters have worked hard to arrange the services and supports they now have and they have structured their lives accordingly. It would be inappropriate, in such circumstances to disturb this by reducing a person's entitlement unless this was agreed by the person.

The PC has indicated that it believes it to be unlikely that many people will be entitled to less under the NDIS than they are currently receiving however it envisages some situations where this might occur. The small financial gains to be made for the system by reducing entitlement in a small number of cases would almost inevitably by outweighed by the personal cost to the individuals of forcing unwanted change. No one under the NDIS should be worse off than they were previously.

Chapter 4 What individualised supports will the NDIS fund?

DRAFT RECOMMENDATION 4.1

The NDIS should cover the current full range of disability supports. The supports would need to be 'reasonable and necessary'. The NDIS should also support the development by the market of innovative support measures (using the approaches set out in draft recommendation 8.3).

The NDIS should cover the full range of disability supports and services a person needs to address barriers to their participation and inclusion in the community on an equal basis with others. This should include the full range of assistive technology including the newer more advanced technologies.

The supports and services available should not be limited to those that are currently provided by recognised disability service providers but should extend to services and supports tailored specifically to meet the needs, preferences and goals of the individual.

Not all the currently provided services comply with the requirements of the UNCRPD, nor the *Disability Services Acts*, both State and Federal. Some continue to congregate and segregate people with disability from the rest of the community. Funding under the NDIS should not be permitted to be used for purposes not compliant with the UNCRPD and State and Federal laws.

There are some people with disabilities for whom it is not easy to find appropriate services and supports. In some cases this will be because insufficient funding has been made available to meet the true costs of the necessary support. This will require a revision to the person's assessed entitlement. In other cases it may be due to a market failure and will require the NDIA to step in to directly ensure the availability of the necessary support.

DRAFT RECOMMENDATION 4.2

There should be no income or asset tests for obtaining funded NDIS services.

DANA strongly supports this Recommendation. It appropriately takes account of the reality that most people with disabilities face significant everyday costs over and above those experienced by people without disabilities.

It also recognises that because the proposed NDIS is an insurance scheme, funded by the taxpayer, higher income earners will already be contributing more through paying higher taxes.

DRAFT RECOMMENDATION 4.3

There should sometimes be a requirement to pay a modest fixed upfront contribution to the NDIS, with free access to services after that point. The NDIS should waive the amount where families have already contributed significantly towards the costs of support through unpaid care.

The PC supports this Recommendation by analogy with the benefits said to accrue from front end deductibles in other insurance schemes eg health or motor vehicle.

DANA does not support this Recommendation. Nor do we agree that the analogy with health insurance supports the Recommendation. Private health insurance schemes more often impose a cap on the quantum of benefits provided and when a front end deductible is payable it has been chosen by the insured person to reduce their premiums. The publically funded health insurance Scheme, Medicare, (most similar in its customer profile to the proposed NDIS), pays a set amount for Scheduled services and provides free access to hospital and follow-up care by the treating doctor.

The analogy with motor vehicle schemes is not useful because these schemes are so different in style and target group from the NDIS. Only car owners hold motor vehicle insurance, so this immediately rules out many people with limited income. In a motor vehicle insurance scheme potential claimants know, without any additional cost to the insurer, whether they are eligible to make a claim and how much it might be worth. The schemes have the potential to receive multiple claims from the one person in relation to a vast number of one-off events, both large and small. Each claim, large or small, requires a minimum basic level of administration, which increases as the numbers of claims increase. A front end deductible is charged in relation to each event. This practice serves as a deterrent not only to making multiple small claims but also to the kind of careless driving that easily gives rise to small claims. When a person is deterred by the deductible from making a claim in most cases they are easily able to remedy the matter themselves and it has only a short term fiscal impact on their life.

By contrast NDIS services and supports, if provided, are likely to be long term and life changing. A front end, often quite time intensive, assessment to establish eligibility and entitlement is required before any choices can sensibly be made by the person about whether to use the Scheme. Once this has occurred, however, it does not need to be repeated on multiple occasions. Thus there is no sensible linking of the proposed annual upfront contribution to minimising administration costs or to deterring careless behaviour. The possibility that an upfront deductible might, however, deter someone with significant support needs from approaching the Scheme could have major long term negative impacts on the life of the individual, their families and their capacity to participate in and contribute to their community.

Most people accessing NDIS supports will be receiving pension or part pension income. The disability support pension (DSP) per annum is currently around $17,443 for a single person over the age of 21. The proposed level of co-payment of $500 thus represents a huge outlay for such a person and a very significant deterrent for someone on the DSP to using the Scheme.

It is vital also to understand that for some people, a small amount of additional support, say in the form of the purchase of a piece of assistive technology or 1 hour per day of personal care can make the difference between living a life, working and socialising; and simply surviving. Yet when people have minimal financial resources, already overcommitted to the basics like rent, utilities, food and costs associated with their disability, it can prove impossible to set aside an additional

$500, either to pay for the small amount of support required or to pay to access the NDIS. It is poor public policy to deter from using a system, the very people it is designed to assist.

People needing only small levels of additional support who do not receive it, frequently end up engaging in other costly government systems eg health, justice etc. It is also likely that what is taken in the form of a levy will need to be replaced in some fashion by additional NDIS support because people are commonly using their DSP pension in part to meet costs associated with their disability. It makes little sense also for government to create the administrative infrastructure to impose such a levy when in most cases the money to pay for the levy will simply come from another arm of government and when significant costs will be involved in imposing and collecting the levy.

The proposal to waive the levy only for someone benefiting from significant family supports serves to further disadvantage those already most disadvantaged. The availability of strong family and/or other community support is probably the single most important contributing factor to the well-being of a person with significant disability. Where a person with disability does not have family and or other community support they are much more at risk of abuse, neglect and exploitation. They will also generally need a greater level of paid support to survive and will need to use whatever financial resources they have available to them to create opportunities for connecting with their community and covering the additional costs of disability not covered by the NDIS.

DRAFT RECOMMENDATION 4.4

People should pay the full costs of services (primarily therapies) for which clinical evidence of benefits are insufficient or inconclusive if they wish to consume those services.

DANA disagrees with this recommendation and finds it hard to understand the rationale for it provided by the PC. Often the evidence for the benefit to be derived will be available from sources that could not be described as clinical but would be regarded by the general community, either in Australia or overseas, as authoritative.

Many issues that can be addressed using the services of a health professional can be addressed in other ways. For example it may be as beneficial for a person to take up swimming or a gym membership as it is for them to attend a physiotherapist. Likewise a person may get as many benefits from taking up yoga or meditation as they would from attending a psychologist. People will generally do better if they are committed to and believe in what they are doing.

The appropriate criteria to be applied, is whether the service is delivering on the outcome desired by the individual. Activities that are undertaken initially for therapeutic purposes but that also incorporate a social aspect can often deliver on the therapeutic purpose while also providing all the additional benefits commonly associated with recreation, for example, friendship, enjoyment, fitness, a sense of achievement or mastery etc.

DRAFT RECOMMENDATION 4.5

Services that meet the needs of much wider populations, including people with disabilities not covered by the NDIS, should lie outside the scheme:
• health, public housing, public transport and mainstream education and employment services, should remain outside the NDIS, with the NDIS providing referrals to them
– but specialised employment services, disability-specific school to work programs, taxi subsidies, and specialised accommodation services should be funded and overseen by the NDIS.

Services provided by Government for the general population, for example health, education, transport and housing should make the necessary adjustments to enable people with disabilities to have access on an equal basis with others. The funding to support this adjustment should come from the Budget for that area and not the NDIS.

If, however, a person needs specialised disability support (of the kind that the NDIS would ordinarily provide to the person in other settings) to assist in accessing mainstream services this will fall within the responsibility of the NDIS.

When mainstream services do not make the necessary adjustments to allow easy access to people with disabilities it is likely that additional NDIS funded specialised disability supports will be needed. This clearly points to an important role for the NDIS in working with mainstream services to ensure that they meet their responsibilities to people with disabilities and that any service gaps are identified and filled from the most appropriate funding bucket. Independent advocacy agencies often get involved in circumstances like these to convince the relevant agencies that a gap exists and that they have a responsibility to work together and with affected people with disabilities to find a solution that works for the people concerned.

DANA endorses the interest shown by the Commission in exploring innovative approaches to unbundling accommodation support funding to achieve greater flexibility in accommodation choice for people with disabilities.

DRAFT RECOMMENDATION 4.6
The Disability Support Pension (DSP) should not be funded or overseen by the NDIS. The Australian Government should reform the DSP to ensure that it does not undermine the NDIS goals of better economic, employment and independence outcomes for people with disabilities. Reforms should aim to:
• encourage the view that the norm should not be lifelong use of the DSP, among:
– people with non-permanent conditions
– people with permanent conditions who could have much higher hopes for employment participation
• provide incentives for people to work (even if only for a few hours per week) and for targeted rehabilitation for those with reasonable prospects of employment.
These reforms should not be limited to new entrants into the DSP.

DANA agrees that the DSP should not be funded or overseen by the NDIS. The DSP is an income support payment which is fundamentally different in nature from an entitlement to receive the specialist disability support necessary to participate and be included in the community on an equal basis with others.

Any potential changes to the DSP should be the subject of consultation with potentially affected people and their representatives. There are many impediments to people with disability entering the workforce that cannot be overcome by the individual alone and so will not be rectified by harsher pension eligibility requirements. Attention needs to be paid to the availability of appropriate supports, disability friendly working conditions, accessible transport options and community acceptance of disability friendly workplaces.

Many people with disabilities have large time and energy commitments involved in managing their own disability support and health related needs. Some additionally provide similar support to others. These factors need to be valued and considered in a realistic consideration of a person's capacity to engage in the workforce.

The ongoing government and community emphasis on businesses and organisations increasing productivity does not make it easy for them to employ people who need additional outlays of time or technology to get started. Employment of people who cannot hit the ground running will generally lead to diminished productivity in the first instance.[5] Employers thus need encouragement to breach this hurdle.

Chapter 5 Assessing care and support needs

DRAFT RECOMMENDATION 5.1
Working within the International Classification of Functioning, Disability and Health (ICF), the assessment process should identify the supports required to address an individual's reasonable and necessary care and support needs across a broad range of life activities, and should take account of an individual's aspirations and the outcomes they want to achieve.

DANA supports a system of assessment that complies with the requirements of the UNCRPD. Assessment should focus on determining the supports a person needs to enjoy the fundamental rights and freedoms belonging to all human beings and to participate and be included in society on an equal basis with others.

Such an assessment should enable the person with disability to live an ordinary valued life of their choosing with support as required to engage in all the usual life domains of work, social engagement, family, education, recreation etc. It needs to pay attention to the self care,

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[5] Saul Eastlake, ACOSS Conference 2011

communication and mobility needs of a person but it also needs to pay attention to their relationships with others, their learning needs and capacity to manage their affairs etc[6].

DANA also supports an assessment process that, from the beginning, empowers people with disabilities to be the decision-makers in their own lives. Work undertaken in relation to the Social Determinants of Health[7] shows that the well-being of a person (when immediate material needs are satisfied) depends in large part on the level of control a person has over their life. The assessment process thus needs to involve mechanisms that as far as possible enable people to make the decisions about the type and level of support they need and by whom and how it is to be provided.

The Draft Report envisages that a variety of assessment tools will be trialled and used by the NDIA. This provides the opportunity to test self assessment approaches along with other suitable models.

It is vital that the assessment process does not simply become the means by which the Scheme's liabilities are minimised. The success of the Scheme relies on it operating in a way that supports people to focus on their strengths and fulfil their potential.

DRAFT RECOMMENDATION 5.2
The assessment process should be a valuable intervention in its own right, rather than just an entry point to supports. The process should:
- *draw on multiple sources of information, including:*
  - *information provided by the individual with a disability, including their aspirations and requirements for supports*
  - *information provided by unpaid carers*
  - *current medical information on the person with a disability*
- *assess the nature, frequency and intensity of an individual's support needs. The process should be person-centred and forward looking and consider the supports that would allow a person to achieve their potential in social and economic participation, rather than only respond to what an individual cannot do*
- *determine what supports outside the NDIS people should be referred to, including referrals to Job Network providers and mental health services*
- *consider what reasonably and willingly could be provided by unpaid family carers and the community ('natural supports')*
- *translate the reasonable needs determined by the assessment process into a person's individualised support package funded by the NDIS, after taking account of natural supports*
- *provide efficiently collected data for program planning, high level reporting, monitoring and judging the efficacy of interventions.*

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[6] International Classification of Functioning, Disability and Health.

[7] Michael Marmot; Status Syndrome: how your social standing directly affects your health and life expectancy.

The assessment process needs to comply with the person's right to privacy. It cannot therefore include, as a matter of course, information provided by a carer or through medical records, without the permission of the person. The focus of the assessment process must be on the needs and wishes of the person with disability so it is for the person themselves to decide who else would be useful to participate alongside them in the assessment process. They need access, if they wish, to independent advocacy support to assist them in preparing for and engaging in the assessment and to make these kinds of decisions.

Support that the person with disability receives from a family member or friend, that is willingly and freely given and happily received, must be a factor in the overall consideration of the level of support to be provided by the NDIS. Family members and friends commonly interact with and show their love and care for each other by supporting each other in a variety of ways. Work on the social determinants of health[8] has shown that another critical factor in a person's health and well –being is their access to supportive social relationships. The NDIS provision of services and supports to people with disabilities must not be permitted, therefore, to have the effect of driving out or replacing the ordinary provision of support by and relationships with family and friends.

At the same time we have long lived in a society that has avoided its obligations to support its members with disabilities by reliance on the goodwill and capacities of the families of people with disabilities. This has served to limit the life opportunities for many people with disabilities and for many of their family members. The UNCRPD is clear that States must take responsibility for providing the disability specific services necessary to support the full participation and inclusion of people with disabilities. This means then that the freely given support that is offered and accepted in the family and friendship context must sit within a broader framework that accepts responsibility for the provision of an alternative source of support if this is not available.

It is vital also that the availability of this support is not used to drive the decision-making of the person with disability about the kind of life they wish to live. For example, an adult with disability should not be required to live with their parents simply because their parents are willing for this to happen.

DRAFT RECOMMENDATION 5.3

Any tools employed by the scheme should exhibit validity and reliability when used for assessing the support needs of potential NDIS users. The preferred assessment tools should be relatively easy to administer and exhibit low susceptibility to gaming. The toolbox should be employed nationally to ensure equitable access to nationally funded support services (and allow portability of funding across state and territory borders when people move).

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[8] Michael Marmot, Status Syndrome: how your social standing directly affects your health and life expectancy,

It is important that the assessment tools used are easy to understand, easy to use and reliable in delivering on the supports that people need to live an ordinary valued life of participation and inclusion in society. To do this the tools must take account of all of the circumstances of a person's life and of the person's vision for their life. The locality in which the person lives, their family, social and economic circumstances will all be relevant. For example, a person, all other things being equal, who enjoys receiving the support of many family members, will need a different level of NDIS assistance from a person without access to family support. A person who wishes to attend university and become a teacher may need a different level and form of NDIS assistance from someone who wishes to leave school at age 16 and take up an apprenticeship. The mainstream services in different regions and States of Australia will also take up their responsibilities to reasonably accommodate the needs of people with disabilities differently thus leading to a requirement for different levels of NDIS support for people depending on where they live.

People who live in rural, regional and remote locations face particular difficulties in finding services and supports that conform to their requirements. The costs of providing appropriate support can be much greater in rural and remote areas and a greater level of support may be needed to counter the deficiencies in mainstream provision.

People from non-English speaking backgrounds will also need access to interpreters throughout the assessment and subsequent decision making processes and when accessing services and supports. Costs associated with interpreter services should be recognised and funded additionally to the person's support needs. Where a person uses an interpreter, the time taken to communicate needs and wishes is greater, so this needs to be factored into the assessment of cost. There may also be additional expenses in finding or creating culturally specific services and supports.

DRAFT RECOMMENDATION 5.4
Trained assessors should undertake assessments. To promote independent outcomes, assessors should not have a longstanding connection to the person. Assessors' performance should be continually monitored and assessed to ensure comparability of outcomes and to avoid 'sympathetic bracket creep'.

The needs of the person being assessed should be paramount in any assessment process. Assessments should take place in a location that feels comfortable for and is fully accessible to the person with disability. The NDIA Assessor should be someone culturally appropriate for the person to discuss their personal details with and someone who understands the differing communication styles and needs of people with disabilities. As far as possible, the person with disability (assisted by their supporters) should self assess, with the Assessor simply acting as a facilitator in the process, ensuring that the person has the necessary supports and information to engage effectively with the process and communicate their needs and wishes.

DRAFT RECOMMENDATION 5.5
The NDIS should periodically reassess people's need for funded support, with a focus on key transition points in their lives.

The frequency of periodical reassessment should be discussed and agreed as part of the assessment process, taking into account the likelihood of any change to support requirements over time. It should also be open to a person at any time to indicate that their support needs have changed and that they need an updated assessment.

In the early stages of the Scheme it would be reasonable to expect that people may wish to update their assessment as they become more familiar with making choices and directing their own supports and services.

To avoid the need for annual reassessments it will be important for the person's level of entitlement to be indexed each year by a factor that reflects the cost increases that they face.

DRAFT RECOMMENDATION 5.6
Where an informal carer provides a substantial share of the care package, they should receive their own assessment. This should seek to identify their views on the sustainability of arrangements and the ways in which they could be supported in their role, including through the initiatives recommended in draft recommendation 13.3.

The role of the NDIS is to provide disability specific supports to people with disabilities. If the supports provided are adequate and appropriate for the person, an informal carer will usually find that they are in a better position to take care of their own needs and get on with their life.

Where an informal carer needs support for themselves in their capacity as a carer they should receive a referral for this to be provided from outside the NDIS. Unless carers are supported separately there will continue to be confusion about whose needs are being served by the NDIS and who is entitled to exercise the choices proposed under the Scheme.

DRAFT RECOMMENDATION 5.7
The NDIS should establish a coherent package of tools (a 'toolbox'), which assessors would employ across a range of disabilities and support needs (attendant care, aids and equipment, home modifications).

DRAFT RECOMMENDATION 5.8
The assessment tools should be subject to ongoing monitoring, as well as a regular cycle of evaluation against best practices, including the ICF framework, and, if necessary, recalibration. The scheme should have systematic internal mechanisms to ensure that anomalies can be analysed and addressed.

Ongoing monitoring of the performance of the assessment teams and the assessment tools is an appropriate function for the NDIA. This monitoring should involve a consideration of the views of the Scheme's participants about the performance of and outcomes delivered by the tools and the assessors.

Rigid processes for achieving standardisation of decision making are, however, neither necessary nor appropriate in a system of supports that is seeking to respond to the needs and wishes of individuals. Rather what is required is an assurance that the tools being used are appropriate for their function of assisting people with disabilities to identify and gain access to the supports they need to live an ordinary valued life participating in the community on an equal basis with others.

People who have for so long been deprived of necessary supports have rightfully questioned the inequity involved in a system which provides well for some and not at all for others. The equity that is required, however, is one of opportunity to live a fulfilled life rather than equity that relies on a flawed notion of sameness.

DRAFT RECOMMENDATION 5.9
The NDIS should use the best available tools in its initial implementation phase, with the on-going development of best-practice tools.

DANA supports this recommendation however the decisions about the appropriate tools to use in the first instance and the improvements to be made ongoing need to be informed by the experience of those people with disabilities using the tools, particularly those for whom the NDIS supports are most important in delivering the opportunity to live an ordinary valued life.

Chapter 6 Who has the decision-making power?

DRAFT RECOMMENDATION 6.1
Governments should give people with disabilities eligible for benefits under the NDIS, or their nominated proxies, various options for exercising choice, including the power to:

- *choose directly the service provider/s that best meet their needs*
- *choose disability support organisations that would act as intermediaries on their behalf when obtaining services from service providers, and/or*
- *'cash out' all or some of their individual budgets if they wish, with the NDIA making direct payments to their bank accounts, and allowing people to purchase directly the detailed package of supports that best meets their preferences ('self-directed funding'), subject to the constraints set out in draft recommendations 6.2, 6.7 and 6.8.*

– The specific arrangements for self-directed funding should be underpinned by the principle that, subject to the assessed individual budget and appropriate accountability requirements, the arrangements should maximise the capacity for a person to choose the services that meet their needs best and that promote their participation in the community and in employment.

Self-directed funding should include the following key stages.

- *It would be informed by any prior planning and aspirations expressed by the person during the assessment phase (draft recommendation 5.2).*
- *The individual budget for self-directed funding would be based on the formal individual assessment of the person's needs and would include the cashed out value of all goods and services covered by the NDIS, except those where specialist knowledge is required for informed choices.*

DANA supports giving people with disability the power to choose how and by whom they manage and receive their services and supports. Their choices in this regard should be constrained only by what is possible, safe and supports the inclusion, participation and enjoyment by the person of their fundamental freedoms and human rights as envisaged under the UNCRPD.

Many people in the early stages of the Scheme will need support to make the choices involved because some aspects of choice are complicated and because possible alternatives will not always be known or understood. Some people who are unused to exercising choice may need a graduated process of learning to do so. Some people will need ongoing long term decision-making support and there are some for whom decisions will need to be made by others based on an informed understanding of their preferences and goals. All people with disabilities should have opportunities to learn about the Scheme and how to use it to progress their life goals prior to the Scheme's introduction.

The starting point should, however, be an assumption of the capacity and willingness of the person with disability to make choices about the things that are important to them. All people with disabilities have preferences on certain matters and almost all will have the means to communicate these preferences to others if others are willing to take the time to allow this to occur. The absence of legal decision-making capacity arising from a guardianship order should not prevent the supported decision-making process from operating. Guardians are generally required under their legislation to as far as possible give effect to the wishes of the person subject to their guardianship. A good supported decision-making process will assist the Guardian to understand and give effect to the person's wishes. Independent advocates have considerable experience in working with people with disabilities under guardianship orders to ensure that their wishes are heard and given effect.

Funding needs to be made available as soon as possible to educate people with disabilities about the kinds of choices that are possible and how to go about exercising choice so that more people with disabilities will be ready to self direct their services and supports when the opportunity arises. Funding will also need to be separately allocated by the NDIS for decision-making support to ensure that the person with disability is enabled as far as possible to be the decision-maker.

Independent advocacy organisations are well placed, both to support people in their decision-making and to empower them to use the Scheme effectively to further their individual goals. Advocacy organisations work only from the perspective of the person with disability and have always done so. Because they are independent, the information and support they provide is not tainted by other interests and is trusted and valuable to the person with disability.

DRAFT RECOMMENDATION 6.2

- *The person with a disability — and/or their support network or chosen disability support organisation — would create a personal plan and a concrete funding proposal to the NDIA that outlines the person's goals and the type of support that is necessary and reasonable to achieve these within the allocated budget.*
- *The resulting funding proposal would require approval by the National Disability Insurance Agency (NDIA).*

There should be a capacity for a person to:

- *obtain quick approvals for changes to a funding proposal*
- *add their own private funds to a funding proposal*
- *allocate the individual budget to any mix of preferred specialist and mainstream goods and services, subject to the requirements that:*
  - *the person spend the budget in areas related to his or her disability needs and consistent with the funding proposal*
  - *the scope to cash out funds set aside for large non-recurrent spending items should be limited to the (rare) circumstances where the NDIA has approved this as an appropriate decision.*

Guidance on what works well for people with disabilities should be sought from those people who are already self-directing their support in Victoria and elsewhere. There is much to be learned about how to minimise the administration involved in ensuring that good support is provided in a cost effective way.

DANA agrees that people with disabilities should be able to get quick approval for changes to a funding program; allocate their Budget to any mix of preferred specialist and mainstream goods and services that meet their disability support needs; and cash out funds set aside for large non-recurrent spending items.

It does not seem appropriate to place restrictions on the capability of a person to cash out large non-recurrent items if the proposed alternative expenditure meets the person's disability support needs in a different way and is still subject to approval from the NDIA. People's lives change, their understanding of what is possible changes, technology changes and their environment changes. People with disabilities should be in a position to respond to their evolving world by changing the way they spend their disability support dollars.

The requirement that the funding proposal be submitted to the NDIA for approval may be an initial important safeguard, particularly in circumstances where guardians and others are involved in the decision-making processes alongside a person with disability however the approval process should be a formality if:

- the proposal conforms to the requirements of the UNCRPD,
- the proposal allocates funding in accordance with an established NDIA criteria and
- the NDIA is satisfied that the proposal represents, as far as possible, the wishes of the person with disability.

What should be automatically admissible expenditure under the NDIA criteria requires a detailed discussion with potential NDIS users and their advocates. They are the people in the best position to provide advice about what is reasonable in this context.

Proposals directed to the expenditure of funds on things outside the automatically admissible criteria should still be approved if good reasons are presented for their inclusion in the proposal. The NDIA should periodically review its admissible criteria with a view to adding to it those things that it has commonly approved when exercising discretion.

DANA disagrees that people should not be able to self direct the part of their entitlement dedicated to specialist therapies or to job readiness. In both cases there are a variety of ways in which the desired outcomes might be met. The person with disability should have the option to choose the kind of support that best suits their needs and to respond to circumstances as they change without seeking a new assessment.

There are many paths to employment for people with disabilities just as there are for members of the general population. These will not always involve engagement with a specialised job ready service. Nor will the capacity of a person to find appropriate work necessarily be clear during an assessment process. People with disabilities should be provided with the necessary support to engage in working hours activities that are meaningful to them and of value to others (including but not limited to participation in specialised job readiness services). This may lead, as it does for so many of the general population to future employment opportunities. Alternatively it may lead to valuable ongoing connections with other people. If the NDIS quarantines job readiness services from a person's budget it will simply perpetuate the current difficulty flowing from the separate administration and funding of employment and day services.

DRAFT RECOMMENDATION 6.3

The NDIA should pay annual allocations of self-directed funding in monthly instalments paid in advance, with the capacity for the person to 'bank' up to 10 per cent of the annual allocation to the subsequent year.

There is no good reason for limiting the payment options to this degree. Most large computerised payment systems can readily handle a variety of payment options. Payment arrangements should be flexible enough to respond to the requirements of the individual. The key issue would be ensuring that the payment option and the intended uses for the money are documented in the plan submitted for approval and that it is approvable. Banking of money for a planned purpose or because planned expenditure did not eventuate should not be an issue.

DRAFT RECOMMENDATION 6.4

There should be a capacity for people to recruit and employ their own support workers, subject to the proviso that these should not be close family members, other than when:

- *care is intermittent and provided by a non-resident family member*
- *exceptional circumstances are present and after approval by the NDIA*
- *the person is in the family employment trial spelt out in draft recommendation 6.5.*

DANA agrees that the NDIS should provide the opportunity for people with disabilities to recruit and train their own support workers and should ensure that they have access to the assistance they require for this purpose. We agree also that there should be no discounting of the monies provided to a person who chooses this course of action for all the reasons identified in the Report.

DRAFT RECOMMENDATION 6.5

There should be a trial of the employment of family members under self-directed funding to assess its risks, advantages, disadvantages and optimal design, with its wider adoption if the evaluation proves positive. The trial should use an appropriately rigorous scientific approach, drawing on the evaluations used in the United States 'Cash and Counseling' programs. For the trial:

- *the NDIA should determine that there are few risks from hiring relatives for each family in the trial*
- *the individual budget should be discounted by 20 per cent*
- *support should be initially limited in duration to six months, with continuation of any arrangement for a given family based on the benefits and costs to that family*
- *risks should be carefully managed to ensure appropriate use of funds and to safeguard people with disabilities and carers (draft recommendation 6.8).*

DANA supports the proposed trial of employment of family members under self directed funding to assess its risks, advantages, disadvantages and optimal design. In particular, DANA believes that the trial needs to identify safeguards to be built into such arrangements to protect the person with disability from the risks already known and from others that may be identified in the trial.

Risks already known include:

- that establishing an employer employee relationship may overtake and diminish existing familial relationships to the detriment of the person with disability
- that the person with disability may find it hard to resist familial pressure to employ a family member that they don't want
- the loss of familial support if the person with disability is not happy with their family member employee and takes measures to deal with this
- that the employment of a family member may reduce the potential for contact with the broader community
- that it makes it easier for familial abuse to occur and to go unnoticed

At the same time DANA members can give examples of situations in which a family member is the best possible person to provide paid support to a person with disability; perhaps because the person has very specific cultural or other needs, and because the relevant family member needs to earn an income; perhaps because the community they live in is very small and there are few workers to choose from.

It is also worth remembering that those families who would put themselves forward to be part of the proposed trial are more likely to be families who are confident that their arrangements would be viewed positively by outsiders. To get a good picture of some of the associated risks, DANA would recommend that the trial also involves consultation with advocacy agencies about the instances of isolation, neglect, abuse and exploitation they have witnessed of people with disabilities by their families and the safeguards they have found to be effective protections against this.

Given that there are benefits and risks to allowing family members to provide paid support it is likely that the best answer might be to establish rigorous safeguards to manage the risks inherent in the situation and to carefully screen those families who wish to move forward with this option.

DRAFT RECOMMENDATION 6.6

The NDIA should:

- *inform people with disabilities and their proxies of the various options for self-directed funding*
- *provide support for people using self-directed funding, including easy-to understand guidance about the practical use of self-directed funding, including standard simple-to-follow forms for funding proposals, hiring employees and for acquittal of funds*
- *promote the use of self-directed funding, with examples of innovative arrangements*
- *provide training to local case managers and front-line staff about self-directed funding*

- *encourage the formation of disability support organisations to support people in the practical use of self-directed funding.*

DANA supports the aspects of the above recommendation that relate to informing people with disabilities and their allies about the various options for self-directed funding and making it as easy as possible for people to exercise a choice in favour of its use. We also support local case managers and front line staff receiving adequate training about self-directed funding options and NDIA promotion of self directed funding.

Very importantly however people with disabilities also need access to training in the use of self directed funding from organisations that they trust to provide them with independent information and guidance about the benefits and pitfalls. Advocacy organisations are well placed to do this work, because they are already trusted independent suppliers of information, decision-making and implementation support and because they already work with people with disabilities and/or their family members around how to achieve their goals and harness the services and funding available for this purpose.

DRAFT RECOMMENDATION 6.7

Before offering self-directed funding to a person, the NDIA should:

- *meet with the person with a disability and their carers, and take account of their experience and skill sets*
- *use that and any information provided during the assessment phase to determine whether the person and/or their support network are likely to beable to:*
  - *make reasonably informed choices of services*
  - *manage the administrative and financial aspects of funding if they wish to oversee these aspects by themselves.*

The NDIA should not be in the business of assessing people with disabilities and their families for their capacity to engage in self directing their funding. The NDIA role should be rather to ensure that a person with disability (together with their allies) has the information and decision making support they need to decide whether they would like to self direct their funding and if the choice is yes that they have the necessary support to make this happen.

It is vital to recognise that many people with disabilities will need initial intensive support to take up self-directed funding options because it involves them in doing things that they have not experienced before, however, as time progresses you would expect to see the level of support required diminish. Many people with disabilities will want independent advocacy support in this area to be confident that they are making the choices best suited to their needs and wishes.

DRAFT RECOMMENDATION 6.8

In offering self-directed funding, the NDIA should ensure that:

- *it reduces the risks of neglect or mistreatment of people with a disability by support workers or other service providers hired by users in the informal sector, by:*
  - *ensuring easy and cheap access to police checks*
  - *giving users the capacity to complain to the NDIA about inappropriate behaviour of providers, and to have these investigated*
  - *monitoring by local case managers*

• it reduces the risks to support workers employed under self-directed funding by requiring that they are covered by workers' compensation arrangements and have an avenue for lodging complaints
• it adopts a risk-management approach for receipting and other accountability requirements, which:
– requires less accountability for people with low risks or who have demonstrated a capacity to manage their funds well
– takes into account the compliance costs of excessive accountability measures
– allows a small component of the individual budget to be free of any receipting requirements.

DANA supports appropriate measures being taken to protect people with disability from neglect and abuse. This would include:

- easy and cheap access to police checks
- easy access to appropriate complaints mechanisms: see commentary below at recommendations 7.11, 7.12 and 7.12
- monitoring by an NDIA case manager

The other measures that are known protectors of people with disabilities from abuse and neglect involve insuring that the person is well connected to a range of people who care about their well-being including people who are willing and capable of advocating in their interest should the need arise. From an NDIA point of view this means that the entitlement needs to be sufficient to enable the person with disability to actively engage in activities that instigate or maintain connectedness with others, for example social, recreation, employment and family activities. It also means that people with disabilities need ready access to independent advocacy support, both to prevent and respond to such issues if they arise.

The other measure that will perform a preventative function is making sure that a wide variety of services are available for people to choose, from providers who have proved that their services meet a reasonable standard.

Support workers already have available to them the protections that are afforded to all Australian workers. They should not have access to additional complaints mechanisms or other protections simply because they are employed by or on behalf of people with disabilities. What does need consideration, however, is ways to make it easy for people with disabilities, as employers, to meet their employer responsibilities, and to take out cost effective insurance cover, both for worker's compensation purposes and to cover them for any other risks involved in their role as an employer.

People with disabilities, functioning as employers will also need ready access to independent advocacy support in situations where their requirements come into conflict with the interests of their employees. In such circumstances workers will be able to enlist Union support. The person with disability must have ready access to the advocacy support they need to assert their interests and rights.

Monitoring of self-directed funding should focus on whether the funding is delivering on Australia's UNCRPD obligations and on the person's desired outcomes. Some caution here needs to be exercised to ensure that it is the person's wishes and choices, in so far as they can be ascertained, that are being given effect to in the self-direction of funding and that the monies are not being used for the benefit of someone else. Where this is certain however and the person's entitlement is being used according to their plan to meet their needs it is an inefficient use of time and resources to require a detailed accounting of how the monies are spent.

DRAFT RECOMMENDATION 6.10
The NDIA should undertake ongoing monitoring of self-directed funding arrangements, with a quarterly report to the board of the NDIA on issues arising from self-directed funding. There should be a full evaluation three years after their commencement to assess any desired changes in their design.

DANA agrees with this recommendation.

DRAFT RECOMMENDATION 6.11
The Australian Government should amend the Income Tax Assessment Act 1936 and the Social Security Act 1991 so that the following are not treated as income for assessment of taxes or eligibility for income support or other welfare benefits:

- *self-directed funding paid by the NDIA and, in the interim, by state and territory governments*
- *early compassionate release of eligible superannuation amounts for disability expenditures which meet the criteria set down by the Superannuation Industry (Supervision) Act 1993.*

DANA agrees with this recommendation.

Chapter 7 Governance of the NDIS

DRAFT RECOMMENDATION 7.1
The Australian Government should establish a new independent Commonwealth statutory authority, the National Disability Insurance Agency (NDIA), to administer the National Disability Insurance Scheme.
The NDIA should be subject to the requirements of the Commonwealth Authorities and Companies Act 1997 (CAC Act), not the Financial Management and Accountability Act 1997.

DANA agrees that the Government should constitute the NDIA as statutory authority, independent from day to day government control with its own legislation specifying its roles and objectives. It is important that this legislation requires and enables the NDIA to comply with the terms of the UNCRPD in all aspects of its operation. If this were to occur it would pave the way for the progressive realisation of human rights and fundamental freedoms for people with disabilities in all aspects of their lives and would enable the Australian governments to fulfil their international obligations with respect to the UNCRPD.

DRAFT RECOMMENDATION 7.2
An independent board should oversee the NDIA. The board should comprise people chosen for their commercial and strategic skills and expertise in insurance, finance and management.

- *As specified in the CAC Act, the board should not be constituted to be representative of particular interest groups, including governments, disability client or service provider groups.*

The Australian Government and the state and territory governments should together establish an appointment panel comprising people with skills and experience in these areas, including people with a clear interest in disability

policy issues.
- *The panel should nominate candidates for each board vacancy against tightly specified selection criteria set down in the Act governing the NDIA.*

Appointments should be based on the majority decision of governments.
The Australian Government, with the agreement of the majority of state and territory governments, should have the power to remove the chair or dissolve the board as a whole.
The board would have the sole power to appoint the CEO and to sack him or her
if necessary, without authorisation from governments.

DANA believes that the Board of the NDIA should consist of people chosen for their individual knowledge and experience of matters relevant to the proper functioning of the NDIA. This clearly includes people with strong financial, governance and insurance knowledge and experience. It also clearly includes people with detailed knowledge and experience of services and systems for the support of people with disability.

The primary role of the Board is, as detailed in the Report, to provide strategic direction to the work of the NDIA, to ensure that it meets the objectives laid down in its Act, to ensure the Scheme's financial sustainability and to manage the NDIA relationship with governments. Financial sustainability, while necessary to the success of the Scheme, it is not the reason for the existence of the Scheme. The Scheme exists to ensure that people with disabilities have the supports and services they need to live an ordinary good life, making their own decisions and with rights and freedoms equal to others. Board members will thus benefit greatly, in deciding whether the Scheme is meeting its objectives and in setting NDIA strategic directions, from having lived experience of requiring supports to engage in ordinary life.

A good Board needs to be able to balance all the competing factors that will impact on the success of the Scheme. It cannot do this if the Board itself is not properly balanced in terms of its skills and knowledge base. Many community organisations providing services to people with disabilities recognise this fact and seek to ensure that their Board includes people with disabilities alongside lawyers, accountants and human services specialists some of whom may also have disabilities.

The Australian Government has, through the CSTDA, recognised the importance of the contribution of disability services consumers to the management of and planning for agencies delivering services and supports to people with disabilities. They have done this by requiring all funded agencies to comply with Disability Service Standard 8.3 which stipulates that service "Consumers have the opportunity and support to take part in the planning, management and evaluation of the service". If the involvement of people with disabilities in the management of disability services is good practice then this is even more important for the NDIA, which has the potential to positively transform or alternatively diminish the live opportunities for people with disabilities.

NDIA Board appointments thus should, as far as possible be people, not only with the requisite governance, finance or insurance background but also people with experience of needing to access supports and services to engage in ordinary life i.e. people with disabilities themselves. In this way the Board will be better enabled to focus the NDIA on ensuring that people have the supports they need to reach their potential. It will also make it possible for Board members to speak from experience when promoting the value of the NDIS to government and the community.

From the above it can be seen therefore that DANA does not support the Board being comprised of representatives of interest groups. We support instead legislative criteria for Board membership that places a high premium on Board members, alongside other necessary skills, also having lived experience of disability that has resulted in the need to access supports.

It would however make sense for the Board appointment panel to be comprised of people of standing in the disability community that are representatives of their constituencies. Board appointments would, through the recommendation of this panel, have greater credibility in the eyes of the sector. This in turn would lend weight to NDIA decisions and to the standing of the Scheme with government and in the community.

DANA also questions the heavy emphasis placed in the Report on the financial and insurance skills of the Board when the Report also seriously contemplates the possibility of the funds management for the Scheme being integrated with existing Government arrangements for investing in long term assets. If this approach were taken the Board's financial role would be limited to setting the broad framework in which investment decisions were taken and would thus require a lesser level of financial and insurance industry knowledge. The vast majority of NDIA Board work would thus relate to direction setting as regards the delivery of the other NDIA functions.

Given the likelihood that no NDIA Board member would come with the totality of the knowledge necessary to be effective in their role it is important that the level of responsibility and contribution required of NDIA Board members be reflected in the remuneration offered to carry out the role and in the level of training and mentoring provided.

DRAFT RECOMMENDATION 7.3

The Australian Government, together with state and territory governments, should establish an advisory council. The council should provide the board of the NDIA with ongoing advice on its activities and effectiveness in meeting its objectives, from the perspectives of people with disabilities, carers, suppliers of equipment and services and state and territory service providers and administrators.

- *The council should comprise representatives of each of these groups.*

DANA supports the establishment of an advisory council of representatives of the major stakeholders in the NDIA. The primary stakeholders in the NDIA are people with disabilities and amongst them there is considerable diversity in the supports they need to live an ordinary life. This requires that the Advisory Council contain people who are able to represent the broad diversity of disability consumers alongside carer, service provider and State representatives.

There is also considerable diversity of experience of people with disabilities across Australia depending on their State and whether they live in urban, regional, rural or remote communities. This geographic diversity also needs to be reflected on the Council.

DANA is clear that there should be only one representative Advisory Council, and that its composition should reflect that people with disabilities are the primary scheme stakeholders. This means that a majority of the council should be representatives of people with disabilities.

It is important to recognise that the NDIA legislative framework will operate to create the power balances in the system. As has been noted in the Report the current service system is delivered through agreements that are reached between governments and service providers, effectively delegating people with disabilities to the role of passive recipient. Any new system must operate to redress this by ensuring that people with disabilities are partners with government in delivering a system that responds to the support needs of people with disabilities. The establishment of such a partnership would provide for the negotiation about the balance to be drawn between the quantum of support provided and the cost to the taxpayer to take place directly between those most affected, support recipients, and those accountable to the Australian people, the government. Service providers are thus freed to take up their proper role of “serving” and being accountable for their work to the individual people with disabilities who use their services and supports.

DRAFT RECOMMENDATION 7.4

The arrangements between the NDIA and governments should be at arm’s length, and subject to strict transparency arrangements. The federal Treasurer should have responsibility for the NDIA.

The NDIA will be managing large amounts of money in trust for the benefit of the Australian people and people with disability in particular. The decisions it makes about Scheme eligibility and entitlement have the potential to be life changing for those involved and many people eligible for support will be amongst the most vulnerable and marginalised people in Australia. It is vital therefore that our overall system design pays careful attention to building in safeguards that will shine a light in the dark corners where thing are not working well. One important set of safeguards is ensuring transparency and accountability about decision-making at all levels of the Scheme.

This should begin at the top and move down through the administrative structure.
The Board should be accountable to the Parliament for whether the NDIA is meeting its legislated objectives by providing to the Parliament, at least annually, a Report that addresses this.

The Board should also be accountable for decisions it takes that differ from the advice provided by its Advisory Council. The Board in such cases should be required to provide reasons for its differing decisions both to the Advisory Council and to the Parliament through its Annual Report.

The Advisory Council also needs to be accountable to its constituencies for the advice it provides to the Board. This could be achieved by the Advisory Council holding annual Australia wide consultations with the broader Scheme stakeholders to discuss the advice previously provided to the Board and to gather information to inform future advice provision.

There is no sensible justification for making the Federal Treasurer responsible for the NDIS. Doing so inappropriately places the focus of the Scheme on the minimisation of costs rather than on the delivery of the required justice, well-being and inclusion outcomes. It would seem logical to place responsibility for the NDIS with the Minister that oversights other significant human services agencies i.e. the Minister for Human Services.

Another important safeguard is the availability of strong independent advocacy agencies to bring to the attention of NDIA decision-makers, on a systemic level, those elements of the system that are not working well for people with disabilities. Advocacy agencies, provided they sit outside the system, are an important counterbalance for those within the system who will inevitably at times be too close to the action to take an objective view of its workings.

DRAFT RECOMMENDATION 7.5

The Australian Government, with the agreement of state and territory governments, should provide the NDIA with its own legislation that specifies its objectives and functions, and its governance arrangements.

- *Financial sustainability should be a specific obligation of the board, the management and the minister, and this obligation should be enshrined in legislation. It should specifically guide any external review body (draft recommendation 7.8).*
- *An entitlement to reasonable support should be enshrined in legislation, together with details about people's eligibility for services and the range of services to be offered.*

Future changes to the legislative framework should be undertaken only by explicit changes to the Act itself, made transparently, and subject to the usual processes of community and Parliamentary scrutiny, and in consultation with all state and territory governments.

- *Such proposed legislative changes should be accompanied by an independent assessment of the impact of the changes on the sustainability of the scheme.*

DRAFT RECOMMENDATION 7.6

An independent actuarial report on the NDIA's management of the NDIS should be prepared quarterly and annually, and provided to the board, the regulator, the federal Treasurer, and to all state and territory governments. It should assess risks, particularly in regards to the capacity of the expected funding stream to meet expected liabilities within its funding framework, the source of the risks and the adequacy of strategies to address those risks.

DRAFT RECOMMENDATION 7.7

A specialist unit should be established within the federal Treasury to monitor the performance of the NDIA against a range of cost and performance indicators, and report its findings annually to its minister, state and territory governments and the public.

DRAFT RECOMMENDATION 7.8

The NDIA should be independently reviewed, initially after its first three years of operation, and every five years thereafter, with the outcomes publicly and promptly released.

DRAFT RECOMMENDATION 7.9

The NDIA should be subject to benchmarking with other comparable corporate entities to assess its relative efficiency in its various functions, with the federal Treasury initiating benchmarking studies.

DANA agrees that the NDIA should have its own legislation specifying objectives, functions and governance arrangements and that financial viability should be a specified obligation of the Board.

While the legislation might reasonably provide the broad parameters for eligibility, entitlement and the range of supports, consistent with the UNCRPD, it is important that it does not try to fill in all the detail of how the Scheme should operate. The support needs of people with disabilities are diverse and varying, as is the impact on a person's life if the necessary supports are not made available. The Scheme needs to have the capacity to take these factors into account in determining eligibility, entitlement and the range of supports.

Recommendations 7.5, 7.6 , 7.7 and 7.9 are all clearly directed to creating safeguards for the financial sustainability of the NDIS. No consideration of the financial sustainability of the NDIS should be undertaken, however, in isolation from a consideration of the effectiveness of the Scheme in delivering on its justice, well-being and inclusion objectives. Unless this balance is maintained at all times there is a significant danger of the Scheme focusing on driving down financial outlays to the detriment of the quality and availability of necessary supports.

The Scheme, if it properly addresses the support needs of people with disabilities and thereby facilitates the participation and inclusion of people with disabilities in the community on an equal basis with others, will also serve to drive down costs accruing to other government agencies. The agencies that appear most likely to benefit are Centrelink, Medicare, the health and hospital system and the justice system. These NDIS supported reductions in costs to other government entities must be estimated and included in any scrutiny of the effectiveness of the NDIS. They must also be considered in determining the quantum of the appropriate insurance premium paid into the Scheme, by government on behalf of the Australian people.

These factors would also suggest that the NDIS more appropriately sits under the Minister for Human Services than the Treasurer and that independent analysis about the Scheme's performance should be multifaceted, drawing on the skills and expertise of a number of agencies including Treasury, the Australian Institute of Health and Welfare, the Department of Human Services and FaHCSIA.

DANA would prefer to see an approach that settles on the objectives of the Scheme and the key performance indicators and then looks to how and who might be best positioned to measure them. The function of balancing the information from these various monitoring arrangements should sit with the Department of Human Services since it would be concerned with the overall performance of the NDIA rather than simply with its financial outcomes.

Any proposed legislative changes to the Scheme should be subject to scrutiny from the community though accessible consultation processes and from the Parliament.

DRAFT RECOMMENDATION 7.10

The NDIA should establish two service charters that specify respectively the appropriate conduct of the (i) NDIA and (ii) specialist service providers and disability support organisations.

DRAFT RECOMMENDATION 7.11

The wording of the NDIA Act should limit the capacity of merits review processes to widen eligibility or entitlement. It should require that any claims by NDIA clients would need to:

- *meet a 'reasonable person' test*
- *balance the benefits to the person with a disability against the costs to the scheme, including any adverse implications for the long run sustainability of the scheme from the review outcome*
- *take into account the obligation of people with disabilities or their families to avoid decisions that unreasonably impose costs on the scheme.*

DRAFT RECOMMENDATION 7.12

The NDIA should include an internal complaints office that would:

- *be separate from the other parts of the NDIA dealing with clients and service providers*
- *hear complaints about breaches of the service charters (draft recommendation 7.10)*
- *reassess contested NDIA decisions on a merit basis. The office would be headed by an independent statutory officer who would review appeals made by people with disabilities and support providers against the decisions of the NDIA.*
- *The NDIA legislation should create this role and specify that the officer would be independent, would act fairly and impartially, basing their decisions on the available evidence, and could not be directed in their decision-making.*
- *A person or support provider should only be able to appeal the decisions of the office on matters of law, rather than on merit, to the courts.*

The NDIA should publish the number, types and outcomes of complaints and appeals (subject to privacy protections).

DRAFT RECOMMENDATION 7.13

If the proposal in draft recommendation 7.12 for appeal processes supported by an independent statutory officer are not adopted, then the Australian Government should create a specialist arm of the Administrative Appeals Tribunal to hear appeals on merit about the NDIA's decisions subject to the constraints of draft recommendation 7.11. The Australian Government should set aside significant additional resources to fund this specialist arm and should include a larger reserve for the NDIS, calculated to take account of the higher risks of this approach.

Decisions made by the NDIA that impact on individuals should be subject to the same level of review and scrutiny as those made by other government agencies. The system should therefore make provision for the internal review of NDIA decisions, external merits review by a specialist tribunal and/or ombudsman and appeal to the courts on matters of law.

A failure to permit people with disabilities to take advantage of the same administrative law opportunities that are afforded to others in receipt of individualised funding from the Commonwealth could be regarded as discriminatory, and a breach of their human rights.

Without an external merits review mechanism the NDIA has an unreasonable level of control over the lives of very vulnerable people with disabilities. It potentially leaves very vulnerable people with no independent means of redress if the NDIA deals with their situation unjustly. The mere existence of an external merits review arrangement will also serve to encourage the NDIA to properly focus its decisions on meeting the agency's legislated objectives rather than on some more narrowly drawn financial target. This is particularly important because the life opportunities for people with disabilities will depend in large part on their access to appropriate supports.

Where issues arise for people with disabilities in relation to their service provider or disability support organisation, the Report envisages that a person's NDIA case manager may assist in achieving a resolution or that the person might shift to another provider. These options will provide appropriate mechanisms for the resolution of some but not all situations. NDIA case managers are not trained investigators or mediators so their complaint resolution options are limited. Their case management role also means that they cannot be regarded as an impartial third party so their views will be regarded as tainted by their NDIA interests. It is not generally a simple matter for a vulnerable person with disabilities to change service providers. In many cases appropriate alternative options are not available. Service providers also need to be held to account for poor performance so that other people do not experience the same problems.

People with disabilities need to have the opportunity to have their concerns verified by an independent body that has the power to investigate, conciliate and make recommendations that have some force in terms of follow-up action required. Such a body could be modelled on existing State Disability, Health and Community Services Commissioner arrangements, attached to the Australian Human Rights Commission but with a local presence in each of the States/Territories. It would be important also to ensure that the Commissioner had the power to investigate situations on their own motion so that people with disabilities who were unable to involve themselves in a complaints process could still have their issues considered and judged.

Chapter 8 Delivering disability services

DRAFT RECOMMENDATION 8.1

The NDIA should support consumer decision-making by providing:

- *a centralised internet database of service providers that indicates the ranges of products and services, price, availability and links to measures of performance and quality*
- *well resourced and effective provision of advice and information to clients, as well as monitoring of their wellbeing.*

These services should be graduated in terms of the needs of the client and concentrated at key points, such as when entering the disability system or important transition periods.

DANA agrees that the ready availability of high quality information is one of the keys to providing people with disabilities with control over their lives. If they are unaware of the choices that are available to them through the NDIS they will not be in a good position to make informed decisions and thus arrange their supports in the way that best meets their needs and interests. Nor will they be in a good position to use their power as a consumer to drive market responses to their needs and wishes.

People with disabilities and their family members need information however, not only about NDIS processes and funded services. They also need integrated information about how the health, education, employment, housing, income support and transport systems etc respond to the needs of people with disabilities, interact with each other and relate to private providers and to an individuals' personal arrangements and preferences.

DANA's view is that information provision is a responsibility of all who work with people with disabilities under the NDIS, however the information that is provided by the NDIA, NIIS, DSO, and Service providers will be limited by their organisational objectives and place in the system.

In addition, there needs to be independent suppliers of information to people with disabilities that are able to integrate the information collected by the NDIA with information from other government, community and business sources and make it available to people with disabilities in ways that are most useful to them and which assist them to assert their rights and achieve their potential.

Within the community there are a small number of independent information providers that work together with advocacy organisations to gather, collate, disseminate and explain information in ways that assist people with disabilities to exercise choice, make decisions and achieve ordinary good lives. This collaboration is well established and trusted by people with disabilities. It needs to be better resourced to support people with disabilities in their decision-making processes.

DRAFT RECOMMENDATION 8.2
The Australian Government should fund and develop a national system for a shared electronic record of the relevant details of NDIA clients, including assessed need, service entitlements, use and cost of specialist disability services, outcomes and other key data items with privacy safeguards.

DANA would support the availability of an electronic disability record that can communicate with the proposed Personally Controlled Electronic Health Record and that provides similar privacy protections for the record owner i.e. that the person with disability can choose whether to have the record, what is stored on it and who can access it. This level of privacy protection is warranted because disability information can be as sensitive and personal as health information and in the wrong hands can be used to wound and diminish.

DRAFT RECOMMENDATION 8.3
The NDIA should develop and implement a quality framework for disability providers, which would include:
- *the development of complete, nationally consistent standards that would apply to all funded specialist service providers and disability support organisations.*

The NDIA should monitor compliance with these standards and other regulations through a range of instruments, including graduated and rolling audits of service providers, community visitors, senior practitioners, independent consumer surveys, complaints, surveillance by case managers and interrogation of the electronic disability record
- *arrangements that encourage the diffusion of best practice throughout the disability sector*
- *providing consumers with information about the quality and performance of service providers on the national internet database of service providers*
- *establishing an innovation fund that providers would use for developing*

and/or trialling novel approaches to disability services.

DANA supports the availability of an accreditation process for service providers that enables them to advertise themselves as providing services that have been assessed as reaching a particular standard. At the same time, if one of the key goals of the NDIS is to give people the power to choose the services and supports best suited to their needs, people with disabilities cannot be restricted in their choices to accredited agencies only. They must be free to choose community providers that have not been accredited, private providers, or individuals they feel comfortable with.

What is important is that people with disabilities and their allies have access to relevant information about the performance of the available service and support options. This means the NDIA should collate the wide variety of service performance information available to it, including any accreditation information and user satisfaction information, and publish this in a form that is useful and accessible to people with disabilities and their supporters. If this information is publically accessible it has the potential, through empowering people with disabilities, to become a significant driver for service quality improvement.

Any accreditation process, to provide useful information to people with disabilities and their supporters, must have a focus on the outcomes achieved for people in terms their well-being, rights, inclusion and personal goals. Accreditation processes that focus on assessing service inputs rather than outcomes will be of limited use to a potential service user.

Chapter 9 Disability within the Indigenous community

DRAFT RECOMMENDATION 9.1

The Australian Government and state and territory governments should consider the feasibility of overcoming the barriers to service delivery in the NDIS for Indigenous people with a disability by:

- *fostering smaller community-based operations that consult with local communities and engage local staff, with support from larger experienced service providers*
- *employing Indigenous staff*
- *developing the cultural competency of non-Indigenous staff.*

In its initiatives for delivering disability supports to Indigenous people, the NDIS should be mindful of the wider positive measures addressing Indigenous disadvantage being adopted throughout Australia.

DANA welcomes the measures proposed for making the NDIS more relevant and effective for Australia’s Aboriginal and Torres Strait Islander people with disability. Similar approaches should be taken for all people from culturally and linguistically diverse backgrounds.

It is likely however that more still will be needed to properly respond to the needs of people from ATSI and CALD communities in Australia.

NDIA processes will need to be modified to accommodate culturally appropriate ways of working with ATSI and CALD people. Inappropriate assessment processes have, for example, in the past led to ATSI people with disability being diagnosed with dementia because they could not answer questions that had no relevance to their lives. People with disability and/or their families from some CALD and ATSI communities may not identify with the concept of disability or may be ashamed to admit to it. This will require firstly a sophisticated approach to seeking out those people with disabilities who need support and secondly a different approach to discussing their needs. In rural and remote areas simply getting to people in order to carry out an assessment may be a significant challenge.

Many issues facing ATSI and CALD people with disability are part of larger societal issues that can only be resolved by many different arms of government and the community working together. This will require the NDIA to work flexibly with other agencies to ensure that ATSI and CALD people with disabilities have the same opportunities as other Australians.

A community development approach may be needed to foster the involvement of ATSI and CALD people in the creation of culturally appropriate supports. This will be particularly true in situations where the market is unlikely to respond i.e. in rural or remote areas or in areas where there are small populations of people from a particular CALD or ATSI community.

Separate provision should be made for the costs of independent interpreters wherever possible recognising that in some locations all the people who speak a language may know or even be related to each other.

Greater flexibility about who might provide paid supports may be also required when the only suitable people available are family members.

Chapter 10 Collecting and using data under the NDIS

DRAFT RECOMMENDATION 10.1

Prior to the implementation of the NDIS, the NDIA should design and establish extensive and robust data systems, underpinned by the associated information technology and administrative systems. The systems should be used to develop a central database that would:

- *guide financial management of the scheme, and in particular, to continuously manage risks to scheme sustainability and to pinpoint areas of inefficiency*
- *inform decisions about disability services and interventions*
- *enable performance monitoring of service providers*
- *monitor and evaluate outcomes*

Disability support organisations and service providers would be required to provide timely relevant data to the NDIA.

DANA agrees that effective data collection, management and evaluation is essential to ensure that the NDIS is able to deliver the desired outcomes for people with disabilities. At the same time, it is important to ensure that all data collected is done so for a valid purpose, that the privacy and dignity of people with disabilities is respected along the way and that people with disabilities are not required to provide information that is unnecessarily intrusive and not directly relevant to their support needs.

The costs for services and support organisations associated with the collection and provision of data to the NDIA should be factored into the level of entitlement made available to an individual. It is vital also that the reporting obligations imposed on services and support organisations do not operate in such a way as to deter small or niche providers or individuals from providing service or supports to people with disabilities.

It is not clear from the Report how the self directed funding model would enable the collection of information from services, supports or individuals receiving their funding directly from a person with disability. The NDIA in such a situation would have no direct relationship with the services and support providers and so would not be in a good position to compel them to provide information. Requiring people with disabilities using the self directed funding model to carry out comprehensive reporting risks deterring them from taking up this option.

DRAFT RECOMMENDATION 10.2
The NDIA should establish an independent research capacity under the NDIS. It should determine how research is undertaken and the research agenda, following public consultation.

DANA supports the establishment of a well-funded independent research capacity associated with the NDIS. The nature of the research to be undertaken should be determined through a process of consultation with people with disabilities and other disability sector stakeholders. Once the nature of the research to be undertaken is established, this should then drive the choice of the most appropriate body to do the work.

It is unlikely that market mechanisms on their own will be able to drive the structural and cultural changes that are needed to give people with disabilities the power over their lives that is envisaged by the Report. Funding for this purpose will need to be directed to community education and to researching and supporting innovation in this area.

Some research will need to take the form of action research and be conducted by community agencies working together with people with disabilities to determine what works and to provide models for other to follow.

DRAFT RECOMMENDATION 10.3
The NDIA should make relevant data, research and analysis publicly available, subject to confidentiality, privacy and ethical safeguards.

DANA agrees that in the interests of transparency and of ensuring that people with disabilities and other sector stakeholders are enabled to make informed decisions, the public availability of research data and analysis is vital.

DRAFT RECOMMENDATION 10.4
In implementing draft recommendation 10.1, the NDIA should determine after

consultation with relevant stakeholders, including the Australian Privacy Commissioner:

- *the key actuarial information needed to underpin sound scheme management*
- *data standards, definitions, terminology and collection processes*
- *data reporting standards, taking into account the Australian Government's initiatives for standard business reporting*
- *arrangements for achieving inter-connectedness of information technology systems among the NDIA, other relevant government agencies and service providers*
- *rules for accessing data, including confidentiality and privacy safeguards*
- *arrangements for integrating data and associated information technology and administrative systems with eHealth initiatives.*

The NDIA should then establish data collection and associated IT and administrative systems that link all agencies and service providers within the disability system.

Also required for the implementation of good data collection systems is the key actuarial information for determining whether people with disabilities are experiencing their desired outcomes from their support and services and whether all of the Australian population has equal access to the support provided by the Scheme. Of particular importance will be collecting the relevant data to determine whether the Scheme is appropriately responding to the needs of key groupings of people who we know have not had equal access to the current systems, for example people from CALD, Aboriginal or Torres Strait Islander backgrounds and women.

Chapter 11 Early intervention

DRAFT RECOMMENDATION 11.1

Early intervention approaches used by the NDIA should draw on evidence of their impacts and be based on an assessment of the likelihood of cost effectiveness.

NDIS funding for early intervention should be additional to that allocated to clients for their ongoing care and support and should not be able to be cashed out under self-directed care packages.

Early intervention approaches should be funded by the NDIA if they are likely to yield a benefit to the person with disability in terms of their desired outcomes and well-being. Cost effectiveness is too limited a criteria on which to base a determination about eligibility because it will always fail to appropriately take into account the indirect costs to the person, their families, the government (for example through additional health costs) and the community (in terms of lost participation and contribution) of failing to provide the intervention.

It should be possible for funding provided for early intervention purposes to be cashed out and self directed provided it is self directed to achieve the original early intervention purpose. There is often more than one route available to achieve a desired outcome. People with disabilities must be enabled to change their decisions about how to achieve an outcome at any time without seeking a new assessment. Changes in the intervention chosen may occur for a myriad of reasons, for example, due to changed person circumstances, new information that has come to hand, or further personal experience about what works on a personal level and what doesn't.

DRAFT RECOMMENDATION 11.2

The NDIA should build an evidence base on early intervention. It should commence this task by identifying, in consultation with stakeholders, existing or potentially promising approaches for further research.

Agreed

Chapter 12 Where should the money come from? Financing the NDIS

DRAFT RECOMMENDATION 12.1
The costs of supporting people with a disability from year to year should be met from claims on general government revenue (a 'pay as you go' scheme):
- *but would be subject to the strong disciplines for certainty of funding specified in draft recommendation 12.2*
- *supplemented by payments to create reserve funds.*

However, the scheme should be managed and reported as if it were a 'fully funded' scheme in which each year's funding is considered in the context of the scheme's expected future liabilities.

DRAFT RECOMMENDATION 12.2
The Australian Government should direct payments from consolidated revenue into a National Disability Insurance Premium Fund, using an agreed formula entrenched in legislation that:
- *provides stable revenue to meet the independent actuarially-assessed reasonable needs of the NDIS*
- *includes funding for adequate reserves.*

If that preferred option is not adopted, the Australian Government should:
- *legislate for a levy on personal income (the National Disability Insurance Premium), with an increment added to the existing marginal income tax rates, and hypothecated to the full revenue needs of the NDIS*
- *set a tax rate for the premium that takes sufficient account of the pressures of demographic change on the tax base and that creates a sufficient reserve for prudential reasons.*

DRAFT RECOMMENDATION 12.3
The Australian Government and state and territory governments should sign an intergovernmental agreement specifying that:
- *the Australian Government should:*
  - *– collect all of the revenue required to fund the NDIS through the National Disability Insurance Premium Fund*
  - *– make no further special purpose payments to state and territory governments for disability supports.*
- *state and territory governments should offset the Australia-wide fiscal implications of the transfer of responsibility by either:*

However, the scheme should be managed and reported as if it were a 'fully funded' scheme in which each year's funding is considered in the context of the scheme's expected future liabilities.
(a) reducing state and territory taxes by the amount of own-state revenue they used to provide to disability services or
(b) transferring that revenue to the Australian Government.
The Commission sees particular merit in option (a).
Any NDIS funding arrangements should ensure that state and territory governments that provide less own-state funding for disability supports than the average should not be rewarded for doing so.

DANA agrees that the NDIS should be funded from Government revenue on the basis of an agreed formula that ensures the capacity of the Scheme to meet its liabilities in terms of providing for the ongoing support needs of people with disabilities.

DANA is concerned that the current projections for the cost of the Scheme under-represent the numbers of people who should be considered eligible for support, partly because we have recommended at 3.2 that eligibility for the Scheme be broadened and partly because we feel that the projected numbers of eligible recipients, 360,000, does not reflect the numbers of people who are in need of support. The Australian Bureau of Statistics in 2009[9] found the number of people with a severe to profound core activity restriction to be 680,400 and a further 392,200 to have a moderate core activity restriction. In 2008-09, 279,375[10] people accessed CSTDA funded services and 200,344[11] people under the age of 65 years were reported to have accessed HACC services. There is some limited cross-over of people accessing the two Programs however the client groups have tended to be discrete arising from government policies enforcing separation. In addition there is an unknown number of people who access HACC services, but are not reported, because they have opted out of the Minimum Data Set, because they were assisted as part of a group or anonymously or because their service provider did not provide their information. Many other people with disabilities, in need of support, have been unable to access either Program, because of limited availability of places or because fees were charged.[12]

Some population groups, for example women, and people from CALD, Aboriginal and Torres Strait Islander background seem to have been disadvantaged by the way services and supports have been allocated in the past. It is surprising, for example, that only 40% of the people receiving NDA funded services and supports are women[13] when women make up more than 49% of those with a profound or severe core activity restriction under the age of 65 years and more than 54 % of those with a moderate core activity restriction under the age of 65[14].

If the Scheme eligibility is broadened to encompass the broad range of people with disabilities recommended by DANA there are other government funded programs operating at the Commonwealth and State and Territory levels that should be incorporated into the funding made available for the NDIS, for example, certain community health and mental health programs, respite and other support programs.

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[9] Australian Bureau of Statistics. Disability, Ageing and Carers Australia: Summary of Findings. Table 3, p8.

[10] Australian Institute of Health and Welfare 2011. Disability support services 2008–09: report on services provided under the Commonwealth State/Territory Disability Agreement and the National Disability Agreement. Disability series. Table 3.1, p 13.

[11] Home and Community Care Annual Report 2008-09. Table A2, p 44.

[12] Some HACC services charge a fee depending on the level of a person's income.

[13] Australian Institute of Health and Welfare 2011. Disability support services 2008–09: report on services provided under the Commonwealth State/Territory Disability Agreement and the National Disability Agreement. Disability series, p viii.

[14] Australian Bureau of Statistics. Disability, Ageing and Carers Australia: Summary of Findings. Table 3, p8.

Chapter 13 Workforce issues

DRAFT RECOMMENDATION 13.1

The Australian Government should attract further support workers into the disability sector:

- *by marketing the role and value of disability workers as part of the media campaign launching the creation of the NDIS*
- *by providing subsidies to training of disability workers through immigration of support workers, but only in the event that acute and persistent shortages occur, and drawing on the lessons from the Canadian Live-In Caregiver program and other similar programs.*

DANA agrees that the proposed NDIS will require a reinvigorated workforce to implement it and that this reinvigoration will require measures to attract new people into the workforce and measures to assist those currently in the workforce to reorient their work towards responding as far as possible to the wishes of the person with disability.

It is likely that many new workers will be attracted into the workforce by the more individualised approaches and some will choose to leave for the same reasons so it is not easy to determine ahead of time what exactly will be required to ensure the availability of an adequate workforce. This is particularly true because the Scheme envisages that people with disabilities will be able to maintain their existing arrangements or transition as they choose to new arrangements. It is clear however that, with many existing workers needing to change the way they work and with many new workers in the system, it will be important that appropriate training opportunities are readily available and inexpensive for the worker and their employer.

It is likely that in addition to the recommended measures there will need to be an ongoing recruitment and training strategy that involves monitoring of the existing capacity of the workforce to meet the demand and then responding on, an as required basis, with campaigns and training incentives to meet identified gaps.

There will also clearly be a need for people with disabilities and their families to have access as soon as possible to opportunities to learn about directing their own supports so that they are ready to take advantage of the new Scheme when it becomes available.

DRAFT RECOMMENDATION 13.2

Australian governments should ensure that, across all jurisdictions, police check arrangements for paid workers providing services to people with a disability:

- *apply only in cases where both the person with a disability is vulnerable AND the risks associated with delivery of services are sufficiently high*
- *not include disclosure of crimes covered by spent convictions legislation*
- *cover people for a given period, rather than for a particular job.*

It is appropriate to require police checks for all those workers who are providing services and supports to vulnerable people with disabilities in circumstances where the person with disability will be alone with the worker. It should still be open however for the person with disability to decide that the conviction information revealed in the police check is not sufficient to deter them from accepting support or service from the worker.

It is also reasonable that police checks apply for a period and that a worker not be required to have a new check done each time they change employer however they should be able to warrant in such cases that do not have any recent convictions.

DRAFT RECOMMENDATION 13.3
In order to promote training and counselling for carers, the NDIS should:
- *assess carer needs as well as those of people with disabilities (draft recommendation 5.6) and, where needed, use the assessment results to:*
  – *refer people to the 'Carer Support Centres' recommended in the Commission's parallel inquiry into aged care and to the National Carers Counselling Program*
  – *include the capacity for accessing counselling and support services for carers as part of the individual support packages provided to people with a disability*
- *assess the best training and counselling options for carers of people with disabilities as part of the NDIS research and data collection function.*

As indicated in our response to Recommendation 5.6, DANA does not agree that the NDIS should involve itself in assessing or responding to carer needs. Where a carer is thought likely to benefit from direct support they should be referred elsewhere for the necessary assessment and service provision. This ensures that the NDIS does not become conflicted in relation to whose interests it is intended to serve.

DRAFT RECOMMENDATION 13.4
The Australian Government should amend s. 65(1) of the Fair Work Act 2009 to permit parents to request flexible leave from their employer if their child is over 18 years old, but subject to an NDIS assessment indicating that parents are providing a sufficiently high level of care.
After monitoring the impacts of this legislative change, the Australian Government should assess whether it should make further changes to the Act toinclude employees caring for people other than children.

This recommendation should not apply only in relation to parents of a person with disability but to anyone who provides high level unpaid support on a regular and ongoing basis to a person with disability.

Chapter 16 A national injury insurance scheme (NIIS)

DRAFT RECOMMENDATION 16.1
State and territory governments should establish a national framework in which state and territory schemes would operate — the National Injury Insurance Scheme. The NIIS would provide fully-funded care and support for all catastrophic injuries on a no-fault basis. The scheme would cover catastrophic injuries from motor vehicle, medical, criminal and general accidents. Common law rights to sue for long-term care and support should be removed.

DRAFT RECOMMENDATION 16.2
State and territory governments should fund catastrophic injury schemes from a variety of sources:
- *compulsory third party premiums for transport accidents*
- *municipal rates and land tax for catastrophic injuries arising for victims of crime and from other accidents (excluding catastrophic medical accidents)*

Once the NIIS is fully established, the Australian Government should examine the scope to finance catastrophic medical accidents from re-weighting government subsidies and doctors' premium contributions.

DRAFT RECOMMENDATION 16.3

The NIIS should be structured as a federation of separate state catastrophic injury schemes, which would include:

- *consistent eligibility criteria and assessment tools, and a minimum benchmarked level of support*
- *consistent scheme reporting, including actuarial valuations and other benchmarks of scheme performance*
- *shared data, cooperative trials and research studies*
- *elimination of any unwarranted variations in existing no-fault schemes.*

State and territory governments should agree to a small full-time secretariat to further the objectives outlined above. The NIIS and the NDIA should work closely together.

DRAFT RECOMMENDATION 16.4

State and territory governments should consider transferring the care and support of catastrophic workplace claims to the NIIS through a contractual arrangement with their respective workers' compensation schemes, drawing on the successful experiences of Victoria's Worksafe arrangements with the Transport Accident Commission.

DRAFT RECOMMENDATION 16.5

The initial priority for the NIIS should be the creation of no-fault accident insurance schemes covering catastrophic injuries arising from motor vehicle and medical accidents in all jurisdictions, with schemes in place by 2013. Other forms of catastrophic injury should be covered by at least 2015.

An independent review in 2020 should examine the advantages and disadvantages of:

- *widening coverage to replace other heads of damage for personal injury compensation, including for pecuniary and economic loss, and general damages*
- *widening coverage to the care and support needs of non-catastrophic, but still significant, accidental injuries, except where:*
  - *the only care needed can be provided by the health sector*
  - *the injuries arose in workplaces covered by existing workplace insurance arrangements*
- *merging the NIIS and the NDIS.*

DANA agrees with the establishment of a no-fault national injury insurance scheme of the kind described above to cover people who have experienced a catastrophic injury if measures are taken to ensure:

- that the NIIS operates within a framework of compliance with the UNCRPD
- that there is equity in the level of supports available to people regardless of whether they are accessing the NDIS or NIIS
- that there is Australia-wide portability of NIIS entitlements
- that after 5 years the possibility of merging the NDIS and NIIS is comprehensively considered.

Chapter 17 Implementation

DRAFT RECOMMENDATION 17.1

In the second half of 2011 or early 2012, the Australian Government and the state and territory governments should, under the auspices of COAG, agree to a memorandum of understanding that sets out an in-principle agreement:

- *that the NDIS should commence in stages from January 2014, be rolled out nationally in 2015 and be fully operational by 2018*
- *to follow the reform timetable for the NIIS specified in draft recommendation 16.5.*

DANA agrees with the implementation timetable proposed on the basis that many people with disabilities need urgent action to address their needs but that the proposed Scheme allows people to continue to use their existing service and supports unless or until they wish to change**.**

We would like however to see the trial take place in an area that includes somewhere quite remote so that the evolving Scheme can, at an early stage, establish frameworks and processes that work as effectively for people in remote areas as it does for those in urban areas. For similar reasons we would also like the trial to include people living in institutional settings.

DRAFT RECOMMENDATION 17.2
The Australian Government and the state and territory governments, under the auspices of COAG, should create:
• a full-time high level taskforce from all jurisdictions to commence work on the detailed implementation of the NDIS
– to be headed by a person with insurance or disability experience who has driven change successfully in a large organisation, appointed with the agreement of all jurisdictions
– with a draft intergovernmental agreement to be prepared for final consideration and agreement by COAG in February 2013
• a full-time high level taskforce from all jurisdictions to commence work on the implementation of the NIIS by the states and territories.

The NDIS Advisory Council should be established at the same time as the proposed NDIS Taskforce to guide it in its work.

An NIIS Advisory Council, with similar composition as that proposed for the NDIS, should also be established to guide the NIIS Taskforce in its work.

DRAFT RECOMMENDATION 17.3
In the period leading up until the full introduction of the NDIS, the Australian Government should supplement funding under the National Disability Agreement to reduce some of the worst rationing of support services.

DANA Strongly supports this recommendation. Where the need for additional services and supports is clear there is no good purpose served by making people with disabilities wait until 2014. The more people whose supports are working well for them when the Scheme begins the easier will be the transition into the new Scheme.

DRAFT RECOMMENDATION 17.4
In 2020, there should be an independent public inquiry into the operation of the NDIS and its effectiveness in meeting the needs of people with disabilities. The review should also encompass the review of the NIIS as set out in draft recommendation 16.5.

DANA agrees that there should be a comprehensive independent public inquiry conducted into the operation NDIS and NIIS in 2020 with a particular focus on whether it is meeting the needs and expectations of people with disabilities and whether it is assisting Australia to progressively implement the terms of the UNCRPD.