



Australian Federation of Disability Organisations

Submission to the Senate Inquiry into inclusive and accessible communities

April 2017



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Who is AFDO?

The Australian Federation of Disability Organisations (AFDO) is a peak organisation in the disability sector representing people with disability. AFDO and its member organisations are run by and for people with disability. AFDO is the place for organisations that represent people with disability to work together to achieve common goals. AFDO's mission is to champion the rights of people with disability in Australia and support them to participate fully in Australian life. AFDO has strong relationships not just with its member organisations, but across the disability sector including peaks representing service providers as well as those representing families and carers.

AFDO's members include:

Blind Citizens Australia

Disability Advocacy Network Australia

Brain Injury Australia

Disability Justice Advocacy

Deaf Australia

Disability Resources Centre

Deafblind Australia

People with Disabilities ACT

Autism Aspergers Advocacy Australia

Enhanced Lifestyles

Down Syndrome Australia

Deafness Forum of Australia

Physical Disability Australia

People with Disabilities WA



Introduction

AFDO welcomes the Senate Inquiry into Inclusive and Accessible Communities and the opportunity to examine progress made towards the goals outlined in the National Disability Strategy.

AFDO and its members played an important role in the consultations which informed the development of the National Disability Strategy, and have continued to keenly watch progress in implementation over the last seven years. Undoubtedly the most significant achievement is the introduction and roll out of the National Disability Insurance Scheme (NDIS). AFDO and its members are unwavering in their support for the NDIS. We regularly hear from people with disability and their families about the difference the scheme is making to their lives. People who now have the dignity of appropriate and timely support, the opportunity to be more involved in their communities, the chance to move out of home, the economic freedom of a new job. These are the kinds of differences the scheme has already made in a short period of time.

The NDIS has undoubtedly already made a contribution to increasing the social and economic participation of people with disability in Australia. But as important as the scheme it, it alone cannot achieve the kind of change we want and expect to see for people with disability. Closing the gap in life outcomes between people with disability and those without can only be achieved through progress in all six areas identified in the National Disability Strategy.

And sadly this is where we feel little progress has been made.

Lack of access to mainstream services, poor service response and failure of communities to address issues of inclusion not only contributes to poor life outcomes for people with disability but also poses a significant risk to the sustainability of the NDIS. Without progress in these areas, the risk of cost-shifting remains as people with disability seek individual funding for supports that should be provided by the mainstream.

While we have seen some improvements in the lives of people with disability during the last seven years, there remain many significant barriers which require strong, effective and urgent systemic reform and action. AFDO made a lengthy submission to the review of the NDS in 2015. Unfortunately, many of the observations we made in our report remain true.

AFDO and its members believe the lack of an operational plan with matched funding has fundamentally compromised efforts to ensure the National Disability Strategy moves from words on a page to action.

While we welcome the release of the second implementation plan late last year, and are supportive of its target areas of action, we regret that it remains a high-level plan that does not contain specific actions or measurable indicators of success. A high-level plan

requires and produces only high-level reporting. We note that regular reporting to COAG has proved an ineffective mechanism to ensure either action or accountability. This is not a problem unique to disability but experienced in other areas of public policy where high level strategies fail to drive change. Nevertheless after seven years, it is unacceptable to see such little change beyond the introduction of the NDIS.

The following submission will examine each of the six parts of the Strategy and shine a light on areas where people with disability continue to experience significant disadvantage, discrimination, and exclusion. This submission is not intended to comprehensively address every issue experienced by people with disability but highlight some areas where we believe urgent change is required. AFDO recommends that the Senators, in addition to reading this submission, consult submissions made by peer-led organisations which are rich with the stories and every day experiences of people with disability to fully understand where action is required.

We will also confine our comments in this submission to areas in the strategy other than the NDIS. We have recently made a submission to the Productivity Inquiry into NDIS costs, and in the interests of brevity, do not intend to replicate our remarks. Our submission to the Productivity Commission can be found at Appendix A.

Outcome 1: Inclusive and accessible communities

People with disability live in accessible and well designed communities with opportunity for full inclusion in social, economic, cultural and sporting life.

Public transport

Barriers to the use of public transport experienced by people with disability vary considerably. Despite the differences the outcome remains the same - the inability to move in and through the community with ease presents a significant barrier to broader economic and social participation. Greater attention to improving the accessibility of public transport is therefore essential to ensuring progress in all other areas identified in the strategy.

The Disability Standards for Accessible Public Transport (Cth) were introduced in 2002, with full compliance of all public transport and infrastructure across Australia set within a 20 to 30 year timetable. More than 15 years on, many people with disability remain unable to independently use public transport in and outside of their community. The list of issues is long:

1. inaccessible infrastructure or vehicles;
2. inaccessible or poor information to aid travel;
3. poor availability of public transport, particularly in rural areas;
4. poor planning which segments travel and fails to take into account door to door journeys; and
5. poor training and development of staff.

The extended timeline for full compliance to the Transport Standards means that many people with disability will not have equal access to public transport in their lifetime. Further, when compliance with Transport Standards becomes difficult for transport providers or operators, exemptions from compliance or a time extension are sought and granted. These alternatives are to the detriment of people with disability. In light of the legislative framework in Australia, and Australia's obligations under the UNCRPD, the long timelines specified in the Transport Standards are not acceptable.

School buses remain exempt from the application of the Transport Standards. The 2007 review of the Standards recommended the proposed process for equal access to school buses by children with disability should commence in 2029 with compliance by 2044. The Australian Government has committed 'in principle' that school buses need to be accessible to students with disability, yet state jurisdictions have argued that there is no

unmet need in regard to students with disability accessing school with the current school bus exemption in place. A student with a disability in Grade 1 will complete year 12 before the process for making school buses accessible begins, assuming that it begins at all.

For people who are blind or vision impaired, insufficient or limited access to public transport information in accessible formats (including web based applications) can mean the difference between using public transport safely and independently and being forced to rely on more expensive options, such as taxis, in order to safely complete travel. Insufficient audible information on board vehicles providing real-time information remains a significant barrier. The increased use of hybrid 'silent' vehicles, particularly in the taxi fleet, and the increased prevalence of large integrated transport interchanges, where multiple buses utilise the same stop, are also presenting significant access issues. These issues are compounded for people who are Deafblind.

Failure to provide simple and clear transport information also hampers the use of public transport by people with a cognitive impairment and/or complex communication needs.

People who are Deaf or hard of hearing report a number of issues including the inconsistent availability of hearing loops in public transport buildings and vehicles; the lack of visual warning and information systems in emergency situations and inconsistent quality of audible and visual information on board vehicles and in buildings, which can be difficult when services are rescheduled. The current requirement for public transport places, and for public transport conveyances, is 25 years old, and grossly out of date in relation to hearing augmentation. Airports and train stations are being constructed and refurbished with as little as only 10 percent hearing augmentation coverage instead of the 80 percent coverage required of other buildings.

Furthermore, there is also an overreliance on new technology as the solution to some of the issues experienced by people who are Deaf or hearing impaired. While many people who are Deaf are frequent users of SMS facilities, not all of them are competent users of new technology. New technology to provide information should not be seen as the total solution to the information needs of people who are Deaf or hard of hearing.

People with a physical disability continue to experience problems with public transport infrastructure (such as train stations and tram stops) as well as with vehicles and rolling stock. The lack of consistency in the dimensions of new trains, trams and buses resulting from different suppliers of these vehicles, coupled with the rollout of accessible tram infrastructure which is not serviced by accessible tram vehicles, also present issues for people with disability in Melbourne in particular.

In response to calls for greater accessibility, we are aware that many transport providers have responded by providing "assisted access". It is AFDO's view that assisted access is still discriminatory. It requires people with disability to be in designated places at designated times. People with disability routinely report that

despite its advertised availability, staff are often reluctant to assist and that they are often made to feel “like a nuisance”.

The delivery of disability awareness training for public transport management and staff is not mandatory in the Transport Standards. As a result there is poor understanding amongst managers, planners and front line staff of how to meet the needs of a diversity of people with disability. The additional needs of people with disability from Culturally and Linguistically Diverse (CALD) backgrounds are also not adequately addressed in the Transport Standards.

Airlines

People with disability have not experienced the benefits of increased competition in the airline industry, despite the changes in the Australian airline market over the last decade. For many people with disability, particularly those with mobility restrictions, it has become more, rather than less, difficult to travel by air. Some passengers who have travelled independently for many years now find themselves barred from travel or face the imposition of unreasonable conditions.

The two wheelchair policy on domestic airlines is an issue which remains problematic and discriminatory. AFDO believes the two wheelchair policy contravenes anti-discrimination legislation in Australia and is not consistent with Australia's obligation as a signatory to the UNCRPD. Our members also report that the policy appears to have been extended beyond wheelchair users to people who use mobility aids other than wheelchairs, significantly increasing the number of people affected by the policy.

AFDO believes many of the economic, operational and safety concerns raised by airlines to justify the policy could be successfully resolved. Evidence from overseas suggests there are workable alternatives. We therefore suggest this policy requires immediate attention.

Compliance

Compliance processes remain reliant on complaints being initiated by people with disability at their own cost. AFDO has been provided with many examples of public transport operators and providers not meeting the targets contained in Schedule 1 of the Transport Standards and thus being in breach of the Disability Discrimination Act 1992 (Cth). This includes response times for wheelchair accessible taxis as compared to regular taxis and the provision of information during a transport journey, with a particular focus on audible and visual information. Both targets were required to be met in 2007. Lack of enforcement has meant targets are routinely ignored or met sporadically.

For example, public transport operators in Victoria claim 100% compliance in the provision of information. This is clearly not the case with audible announcements not being made consistently on trams, trains and buses, timetables not being available in

accessible formats and information about bus routes also not being available in accessible formats. People with mobility restrictions also continue to wait unreasonable periods of time for a wheelchair accessible taxi, with some individuals waiting in excess of three hours.

The complaints process under the Disability Discrimination Act is daunting, protracted, expensive and inequitable. It is reliant on people with disability having the resources, financial or otherwise, to pursue a complaint. At present, there is no systemic recourse available to people with disability or their representative to address discrimination, including in the use of public transport.

Access to the built environment and universal design

The economic, social and environmental benefits derived from the introduction and application of Universal Design principles are well researched, documented and accepted. Economic benefits are achieved by greater numbers of people having access to businesses as customers and employees, social benefits are achieved by reducing social isolation and promoting more connected communities, and environmental benefits are achieved by lower energy costs and greater longevity of buildings and infrastructure.

Universal Design principles give the highest level of access to the greatest number of people and can be applied to all infrastructure including transport, housing, public buildings, road and pedestrian infrastructure and communication.

Despite accepted benefits, everyday practice in both government and private industry remains poor. People with disability continue to experience difficulty accessing the built environment – from access to premises offering goods, services and entertainment to commercial buildings, to the most basic facilities, including bathrooms and toilets. Inaccessibility extends to schools, government buildings and the offices of our elected representatives. Access can be compromised even where a building may comply with the Access to Premises Standards (2010) (Cth), Australian Standard 1428 and current Building Codes which provide minimum standards for access for people with disability. It is also important to note that the Building Codes and the Access to Premises Standards only apply to new buildings. As a result most existing buildings remain inaccessible.

As with public transport, there are also issues with monitoring and compliance. Again, there is a lack of monitoring and an over-reliance on individual complaints. At a minimum, AFDO recommends that any infrastructure or capital works project in receipt of government funding should demonstrate that all works are compliant with the Disability Access to Premises Standard. AFDO also recommends that sufficient resourcing is made available to ensure effective monitoring and rigorous compliance.

Accessible procurement

Considerations of accessibility should not be limited to the built environment. All producers of goods and services should give consideration to the ways in which their product is accessible. Again the social and economic benefits of universal design cannot be overstated.

Government is in a unique position to drive the shift to universal design. As one of the largest procurers of infrastructure and goods and services, the Australian Government is in an unparalleled position to influence the market, and in turn, the development of products and services by how they choose to source and tender. As noted by the Australian Communications Consumer Action Network (ACCAN) in their report titled 'Accessible Communications: Tapping the Potential in Public ICT Procurement Policy' (2012):

'once accessibility criteria are signalled by government as part of their purchasing strategy, greater certainty for manufacturers is created. Companies that already have accessibility features in their products are more competitive when government considers tenders. This in turn encourages competitors to innovate for improved accessibility. With additional demand, costs for components fall making accessible products more affordable, not only to government but to the private sector and the community in general.'

Many OECD countries have introduced procurement regulations and guidelines to ensure government departments purchase ICT that is accessible to people with disability. As an example, Section 508 of the US Rehabilitation Act requires that electronic and information technology used by US Federal Agencies is accessible to people with disability.

Embedding universal design principles and a commitment to accessibility within Australian Government procurement procedures and tenders would also have a positive and significant impact in addressing disparities in the employment participation of people with disability. Embedding universal design from the outset negates the need to make retrospective adjustments to technology – adjustments which can have a direct impact on the employment participation of people with disability which is examined in detail later in this submission. This could include more accessible employment within government and by suppliers who are committed to employment practices which are inclusive of people with disability.

Outcome 2: Rights protection, justice and legislation

People with disability have their rights promoted, upheld and protected.

Strong disability discrimination legislation and enforcement

It is 25 years since the landmark introduction of the Disability Discrimination Act 1992 (Cth). Despite the legislation's positive intent, people with disability continue to experience significant levels of direct and indirect discrimination in all areas of life – education, employment, access to goods and services and participation in the electoral and justice systems.

The daily discrimination experienced by many people with disability reflects unchanged attitudes towards disability in the community. That kind of cultural change takes time to achieve. The failure to deal appropriately with discrimination and the prevention of rights abuses lies however with the legislation. The Act has a number of limitations as a tool in preventing human rights abuse and ensuring the protection of rights. In particular:

1. Overuse of the 'unjustifiable hardship' provision has weakened the claim for fair and equitable access by people with disability to services or facilities and reduces opportunities for employment, cultural and civic participation, access to housing and other fundamental aspects to full citizenship.
2. The real or perceived risk of having costs awarded against someone is a significant deterrent to many who face discrimination on the basis of disability.
3. Respondents to a complaint have no mandatory, legally enforceable requirement to attend conciliation and/or attempt to resolve a complaint lodged by a person with disability. This leaves people with disability with no choice other than to take the matter to a higher jurisdiction at their own cost, or accept the discrimination that has occurred.
4. Exemptions under the Act allow for people with disability who are applying to migrate to Australia to be discriminated against under the Migration Act on the basis of disability or a health condition of an individual or a member of a family seeking to migrate together.
5. Exemption from the Social Security Act prevents migrants with disability access to social security payments for ten years. The impact of this discrimination fosters potential dependencies and inadequate access to support and health services.

Annual reporting by the Australian Human Rights Commission demonstrates the continuing discrimination experienced by people with disability. In 2015/16, the largest

number of complaints received by the Commission were related to disability - 37 per cent of all complaints were lodged under the Disability Discrimination Act. This number has remained relatively unchanged since the introduction of the National Disability Strategy. The majority of complaints were related to employment (35 per cent) followed by goods, services and facilities (33 per cent) and education (11 per cent). Of the 750 complaints received, it is important to note that 145 (21 per cent) were terminated because there was 'no reasonable prospect of conciliation'. Only 364 or just over 54 per cent were successfully conciliated.

The experience of the national commission is replicated at state and territory level. The number of complaints received by state-based commissions relating to disability discrimination is also high, with the Victorian Human Rights and Equal Opportunity Commission reporting, for example, that disability discrimination in all areas is the most common cause of complaints received.

Despite these persistently high numbers, there are many barriers to people with disability lodging a complaint. The first is that many people with disability continue to be unaware of their rights under the Act, do not understand the process of lodging a complaint or understand the assistance available through the Australian Human Rights Commission and advocacy organisations across Australia. Even when people understand their rights and are able to take action, the process is long (a complaint can take up to twelve months to resolve), exhausting and focused on the experience of one person with very little scope to effect broader systemic change to improve the lives of people with disability experiencing the same barriers.

The Concluding Observations of the initial report on Australia, adopted by the UNCRPD Committee at its tenth session in Geneva in September 2014 noted the following (paragraph 14):

14. The Committee is concerned that the scope of the protected rights and grounds of discrimination in the Disability Discrimination Act 1992 is narrower than that provided for under the Convention and does not provide the same level of legal protection to all persons with disabilities.

15. The Committee recommends that the State party strengthen anti-discrimination laws to address intersectional discrimination and to guarantee protection from discrimination on the grounds of disability so as to explicitly cover all persons with disabilities, including children, indigenous people, women and girls, the hearing impaired, the deaf and persons with psychosocial disabilities.

The Australian Human Rights Commission lacks the capacity to examine systemic discrimination against people with disability and to take action on behalf of people with disability where their rights have been ignored or abused. This is in contrast to other jurisdictions, including Victoria, where the Victorian Equal Opportunity and Human Rights Commission has the power to take action on systemic issues brought to its

attention. Making this change would remove the burden for complaints from individuals and ensure systemic issues are adequately addressed.

Advocacy, rights information and training for people with disability

In order for people with disability to exercise their rights, they have to know what those rights are. AFDO believes it is essential that information and training is provided to people with disability about their rights under the UNCRPD. The information must be communicated in a variety of modes to meet individual needs, be comprehensive and accessible, and be provided and delivered by independent bodies.

State, territory and federal legislation should reflect rights outlined in the UNCRPD and ensure there are effective statutory complaints mechanisms/bodies to monitor and take action where breaches occur. It is important that people with disability have access to independent funded advocates to protect and exercise their rights. The availability of independent advocacy and representation by disability consumer organisations, critical to ensuring that the rights of people with disability are protected and upheld.

Compatibility of domestic laws with international obligations

The ultimate success of the National Disability Strategy is dependent on ensuring that all existing and new Commonwealth laws and legal frameworks are consistent with the UNCRPD. AFDO reiterates our previous recommendations that:

1. All current Commonwealth laws and legal frameworks are tested against a 'Compatibility Framework';
2. All proposed Commonwealth laws and legal frameworks submitted to the Parliament for consideration must be accompanied by a 'Statement of Compatibility' based on the 'Compatibility Framework'; and
3. The Australian Human Rights Commission maintains a register of Statements of Compatibility to monitor the compliance of Commonwealth laws and legal frameworks with the Convention.

This process is similar to the Victorian government requirement that all proposed legislation be accompanied by a Statement of Compatibility with the Victorian Charter of Rights and Responsibilities. The Victorian Equal Opportunity and Human Rights Commission maintain a register of Statements of Compatibility as part of its monitoring role of the implementation of the Charter.

Equal recognition before the law, legal capacity and supported decision making

People with disability continue to be denied or have diminished status and ability to exercise legal capacity on equal terms. Inconsistency between guardian and mental health legislation and between jurisdictions in relation to how legal capacity is determined presents significant issues in furthering and upholding the rights of all people with disability.

AFDO and its member organisations have been strong proponents for the transition from substitute decision making approaches to fully supported decision-making. Our collective voice is clearly articulated in Paragraph 187 and 188 of *Disability Rights Now – Civil Society Report to the United Nations Committee on the Rights of Persons with Disabilities*, August 2012 presented to the UNCRPD committee. Extracts are provided below:

“...there is agreement among representative organisations of people with disability and disability advocacy and legal groups that Article 12 underpins the ability of people with disability to achieve many of the rights contained in the CRPD and that it requires fundamental reform in the current legal, administrative and service arrangements that regulate legal capacity for people with disability so that supported decision making measures can be recognised, developed and promoted.

Issues in Australian legislative and policy frameworks, including estate management, guardianship and mental health laws, mean that people with disability experience serious breaches of their human rights, including widespread abuse, neglect and exploitation both because of the lack of appropriate arrangements to support their capacity to manage their affairs, to give informed consent, to make important decisions, and as a result of poorly designed, delivered and monitored supported and substitute decision making arrangements”.

The UNCRPD committee’s has made reference to the need for supported decision making in their Concluding Observations:

24. *The Committee notes that the Australian Law Reform Commission has been recently commissioned to inquire into barriers to equal recognition before the law and legal capacity for persons with disabilities. However, the Committee is concerned about the possibility that the regime of substitute decision-making will be maintained and that there is still no detailed and viable framework for supported decision-making in the exercise of legal capacity.*

25. *The Committee recommends that the State party effectively use the current inquiry to take immediate steps to replace substitute decision-making with supported decision-making and that it provide a wide range of measures*

which respect a person's autonomy, will and preferences and are in full conformity with article 12 of the Convention, including with respect to a person's right, in his or her own capacity, to give and withdraw informed consent for medical treatment, to access justice, to vote, to marry and to work.

26. The Committee further recommends that the State party provide training, in consultation and cooperation with persons with disabilities and their representative organizations, at the national, regional and local levels for all actors, including civil servants, judges and social workers, on recognition of the legal capacity of persons with disabilities and on the primacy of supported decision-making mechanisms in the exercise of legal capacity.

Put simply, without a move to supported decision making, people with disability will not be able to exercise true choice and control in the decisions which impact on their everyday life, compromising the intent and vision of the Strategy. And while it is important in all areas identified in the Strategy, it is particularly important in the context of the implementation of the NDIS.

Access to justice

The high levels of poverty experienced by people with disability also impact their personal and financial capacity to uphold their rights and seek the support of legal services.

In 2014, AFDO contributed to a joint submission into the Inquiry into Access to Justice. The following section highlights some of the key findings reported in our submission. Sadly, little has changed in the time since the report was drafted.

For people with cognitive impairment (intellectual disability, learning difficulty or Acquired Brain Injury) the complexities of the justice system present a significant barrier to the effective protection of rights. Without necessary support, people with a cognitive impairment may not be able to report a crime perpetrated against them. Even if able to report, they are often not perceived as reliable witnesses. Both of these factors means they are more likely to be targeted by perpetrators. Statistics show an over-representation of people with a cognitive impairment as victims of crime. While there has been some increased media attention to the issues presented by people with cognitive impairment as victims, it has not been accompanied by legislative or practice change which would result in improved access to justice.

People with disability from NESB and culturally and linguistically diverse backgrounds (CALD) communities experience additional barriers to accessing the legal system. The lack of easy access to interpreting services, the lack of information about the legal system in other languages and the lack of culturally appropriate support services are just a few of the barriers that need to be addressed. This is also true for newly arrived migrants, refugees and asylum seekers who are dependent on information and services that are culturally and linguistically appropriate, particularly as a fear of authority may

exist among some diverse communities which may result in a lack of confidence to report a crime.

The issues mentioned above can also be experienced by people with psychosocial disability. When a person with a psychosocial disability is unwell, they need intensive support to access the justice system. With under-resourcing of the mental health system, community legal services and advocacy services, it is likely people with psychosocial disability will have difficulty accessing the justice system. Statistics also show an over-representation of people with psychosocial disability in prison.

Access to justice can also be compromised if people with a disability do not have access to alternate communication methods when interacting with the justice system and in formats that they can understand. For example, people who are Deaf need access to Auslan interpreters, people who are non-verbal need access to electronic communication devices, people with cognitive impairment may need information in easy English or pictorial formats and people who are blind or vision impaired require information in a range of accessible formats such as large print, braille, audio and electronic formats. Access to interpreters remains problematic for people with disability in criminal and civil proceedings, particularly for people who are Deaf or Deafblind. According to the Human Rights Law Centre, in many jurisdictions, Australian courts play no role in civil proceedings in organising an interpreter to be present or to ensure that the services of an interpreter are available where required.

People who work in the justice system need to be familiar with the access and communication needs of people with disability and be required to undertake relevant training. This view is supported in Paragraphs 27 and 28 of the UN Concluding Observations Report, with the UNCRPD committee expressing concerns at the “lack of training for judicial officers, legal practitioners and court staff on ensuring access to justice, as well as the lack of guidance on access to justice for people with disabilities”. The Committee has recommended that standard and compulsory modules on working with persons with disabilities be incorporated into training programs and that legislation and policy across the states and territories be amended to ensure access to justice for persons with disabilities in line with Article 13 of the UNCRPD.

Interaction with the criminal justice system

The over-representation of people with disability in the criminal justice system – especially with cognitive, brain injury and psychosocial disability – highlights a significant problem across all Australian jurisdictions. And sadly the situation is far worse for Indigenous people with disability, who are significantly over-represented in prison populations.

The UNCRPD Committee, in their Concluding Observations (Paragraph 30) recommend that “all people with disability who have been accused of crimes and are currently detained in jails and institutions, without trial, are allowed to defend

themselves against criminal charges, and are provided with required support and accommodation to facilitate their effective participation”.

The Committee also expressed concerns regarding the experience of people with disability who are deemed unfit to stand trial and detained indefinitely in prisons or psychiatric facilities which can significantly exceed the period of custodial sentence for the offence. Paragraph 32 of the Concluding Observations state:

The Committee recommends that the State party, as a matter of urgency:

(a) End the unwarranted use of prisons for the management of unconvicted persons with disabilities, focusing on Aboriginal and Torres Strait Islander persons with disabilities, by establishing legislative, administrative and support frameworks that comply with the Convention;

(b) Establish mandatory guidelines and practice to ensure that persons with disabilities in the criminal justice system are provided with appropriate support and accommodation;

(c) Review its laws that allow for the deprivation of liberty on the basis of disability, including psychosocial or intellectual disabilities, and repeal provisions that authorize involuntary internment linked to an apparent or diagnosed disability.

AFDO recommends timely action by the Australian Government to protect the legal and human rights of some of our most vulnerable Australians.

Outcome 3: Economic security

People with disability, their families and carers, have economic security, enabling them to plan for the future and exercise choice and control over their lives.

Employment - A real job for a real wage

Inequitable employment participation continues to be one of the most significant issues compromising the life outcomes of people with disability in Australia. Only one in two people with disability (53%) participate in the workforce compared to more than 80 per cent without disability. Labour force participation rates for people with disability have not changed in more than a decade despite numerous attempts at reform.

Changes to the eligibility rules for the Disability Support Pension have forced some people with disability on to unemployment benefits with the stated aim of encouraging entry into paid employment. But without simultaneous investment in making the workplace structurally more accessible or increasing real job opportunities, these changes have only further contributed to the poverty and financial stress experienced by many people with disability. The focus of successive governments has been to treat the workforce participation of people with disability as a separate agenda to broader employment and workforce reform, rather than an essential component to redress skill shortages, increase productivity, contribute to economic growth and lessen welfare dependency.

Current labour market programs targeted at people with disability looking for work are failing to deliver effective, lasting employment outcomes, with only approximately one in four people with disability reaching an outcome rate of 26 weeks or greater. Of employers who know about Disability Employment Services, only 3% use the services available.

A much more rigorous and accountable employment support regime is desperately needed to promote greater opportunities for economic security for people with disabilities seeking paid work. With the unemployment rate almost double that of Australians without a disability (9.4% as compared to 4.9%) and Australia ranked 21 out of 29 as compared to other OECD countries, it is clear that current mechanisms are not working and that a new way forward is needed.

The barriers faced by people with disability in employment have been well documented and range from structural barriers to attitudinal ones. These include:

1. Poor awareness or negative attitudes by employers towards disability (ie. perceptions that people with disability are costly to employ and are less productive than people without disability).
2. Employers' lack of understanding and confidence to talk about disability and its impact on those who currently work, and who might work, in their organisations.

3. Employers' concern about potential risks, including superannuation implications and Workcover costs and exclusions.
4. Buildings, infrastructure and workplace systems not being disability-friendly and public transport is not always available or accessible.
5. Lack of visibility – people with disability are not well-represented in public roles, making it difficult to recognise their potential.
6. Lack of career development opportunities (ie. not included in professional development and skills training/upgrading, passed over for promotion and higher duties, lack of job rotation etc.).
7. Lack of understanding of workplace stressors – inaccessible workplaces and equipment, less secure employment and engagement in less challenging work activities that are not commensurate with education, skills or experience all contribute to workplace stress for people with disability.
8. The compliance requirements on Australian Government funded programs, such as Disability Employment Services, has taken the focus away from assisting people with disability to find meaningful long-term work onto low-skilled, short term jobs and programs in order to continue to receive funding.

There is also an expectation within the current system that people with disability will somehow find their own way through the complex and multilayered system of welfare, education, vocational training and disability employment programs into employment. While many people with disability have successfully navigated the system or have gained employment through their own efforts, the current system does not provide a continuum where all parts are intuitively connected. AFDO maintains that an effective employment system is one that recognises, plans for and provides support across the continuum and includes the following elements:

1. work experience in school to provide an insight, as well as practical experience of, and exposure to, the world of work;
2. effective transition pathways from school to post-school training and employment, and ongoing development in the workplace;
3. inclusive graduate programs;
4. peer support, job mentoring and external support, and workplace support as required;
5. access to quality disability service providers to build and support individual capacity (including employment service providers);

6. job readiness skilling and practical experience to enable people with disability to build personal confidence and demonstrate competency to employers;
7. a responsive employment service system which meets the needs of both jobseeker and employer; and
8. once in a job, access to career advancement and leadership opportunities that are available to any other employee.

In 2012, AFDO prepared a comprehensive submission to the Inquiry into Improving the Employment Participation of People with Disability which made a number of recommendations. These recommendations included:

9. Scrutiny of all employment sectors regarding their employment practices. We cannot expect business to perform well when government and the not-for-profit sector are performing dismally.
10. The Australian government provide leadership in the employment of people with disability. AFDO recommended that the Australian Public Service trial best practice approaches and development of different models for inclusion of people with disability at all levels and all departments from 'intake to leadership', in collaboration with Disabled Persons Organisations (DPOs).
11. Incentives should be provided to all employers via preference in the awarding of tenders, funding and procurement to workplaces that can demonstrate good employment practices. Government procurement policy should be adjusted to favour businesses that demonstrate their positive outcomes in employing people with disability. All government-funded contracts should only be entered into with organisations who have already achieved positive results in employing people with disability.
12. Work place subsidies should be targeted at Small to Medium Enterprises (SMEs) which employ less than 100 employees. Large employers indicate that the present workplace subsidies do not provide any incentive regarding their decisions to employ, while SMEs would employ people on a more long term basis if the subsidy was provided for a year as opposed to 26 weeks. This should be acted on in consultation with employers who are already achieving best practice outcomes such as large corporates in the banking and IT sectors.
13. Insurance (work cover) premiums are a deterrent in the employment of people with disability. Any effective changes will need to include a change to this. By lowering premiums for employees with disability, this would assist employers with any additional costs incurred when 'reporting' on disability in their workforce.
14. The question of disability's place in diversity needs to be explored and better understood. A research fund should be established for the purpose of an

investigation as to how reforms/initiatives undertaken in the diversity strands of gender, indigenous and multiculturalism can be applied to people with disability.

15. Educating all employers (private and public) on issues around workforce participation of people with disability is essential.

To address the woeful participation of people with disability and work to close the gap in workforce participation, people with disability and employers need to be at the heart of an employment system that is designed to support them. AFDO, in collaboration with stakeholders who are dedicated to increasing the workforce participation of people with disability, are committed to commencing the groundwork for the development of a new employment model which is jobseeker as well as employer centred.

Ending segregated employment

Twenty eight years after the introduction of the Disability Services Act 1987 (Cth) and seven years since the introduction of the National Disability Strategy, approximately 20,000 people with disability continue to be employed by an Australian Disability Enterprise, with workers earning as little as \$0.33c an hour. This is in spite of a Federal Court decision which judged the use of the BSWAT discriminatory and recommended the use of the Supported Wage System. This is also in spite of the recommendations of the UNCRPD committee in their Concluding Observations (Paragraph 50):

50. The Committee recommends that the State party:

a) Immediately discontinue the use of the Business Services Wage Assessment Tool;

b) Ensure that the Supported Wage System is modified to secure correct assessment of the wages of persons in supported employment;

c) Adopt initiatives to increase employment participation by women with disabilities by addressing the specific underlying structural barriers to their workforce participation.

All Australians, including people with disability, undertake work to increase financial security and independence. Work is not a social club or a hobby. While work can improve general health and wellbeing and result in improved social connections, the primary driver of employment is to earn a wage.

AFDO believes the continued operation of Australian Disability Enterprises is contrary to the objects and intent of both the DSA and the UNCRPD. The UNCRPD calls for the labour market to be open and inclusive of people with disability and does not make exception due to the degree of disability or support need. A vision of 'inclusion' in employment for people with disability requires an employment service response that supports all people with disability to find a job, receive the necessary training and support, and be assured long term ongoing support if needed. In earning a real wage,

people with disability have the opportunity to be active citizens, taxpayers, contributors to the wealth of Australia and in turn lessen their dependence on the Disability Support Pension or other welfare payments.

Welfare

Forty-five per cent of the two million Australians living with disability live on or near the poverty line.¹ This is more than 2.5 times the rate of poverty experienced in the general population and more than double the OECD average of 22%.² The Australian Council of Social Service has also released figures showing 620,600 people with disability in Australia are living below the conservative, internationally accepted poverty line used to measure financial hardship in wealthy countries.³ This accounts for over a quarter of people with disability in Australia, and is likely due, in large part to weaker employment prospects.⁴

People with disability report a gross median weekly income of \$400, almost half the gross median weekly income of Australians without disability. For a significant proportion of this population, this income is not generated from work but by welfare payments, with only 8.5% of Disability Support Pension recipients reporting any income from work and almost half of this total (4.1%) reporting earned income of less than \$125 per week. Australia is the worst performer on the indicator of poverty as compared to other OECD countries, ranking 27 out of 27 for selected OECD countries.

AFDO is clear that any reform of the welfare system must be met with parallel systemic reforms which support real jobs for real wages in open employment. A reform to welfare without a focus on job creation and workforce participation disregards the intent of the National Disability Insurance Scheme and National Disability Strategy to enable people with disability to contribute as economic citizens.

¹ PriceWaterhouseCoopers, (2011) *Disability expectations: Investing in a better life, a stronger Australia*, 3.

² Organisation for Economic Co-operation and Development (2009). *Sickness, disability and work: Keeping on track in the economic downturn – Background paper*. Figure A2.6.

³ Australian Council of Social Service (2012) *Poverty in Australia*, ACOSS Paper 194, 26. This research does not take account of the extra costs of a disability, which may include adjustments to the home or workplace, purchase of care, additional transport costs such as taxis, pharmaceuticals and medical treatment. A previous study found that taking these costs into account substantially increases the level of poverty among people with disability. See: Peter Saunders, (2005) *Disability, Poverty and Living Standards: Reviewing Australian Evidence and Policies*, Social Policy Research Centre Discussion Paper No 145.

⁴ Australian Council of Social Service (2012) *Poverty in Australia*, ACOSS Paper 194, 26. *Disability Rights Now: Civil Society Report to the United Nations Committee on the Rights of the Person with Disabilities* (2012). Compiled by Disability Representative, Advocacy, Legal and Human Rights Organisations. 135.

Housing

Limited availability of accessible and affordable housing places a significant restraint on the choice of home and lifestyle for many people with disability. Further, block funding accommodation and support packaging ensures that many people with disability who are more reliant on disability supports are forced into co-tenancy arrangements that severely limit their freedoms and lifestyle choices. In far too many of these situations, residents are victims to abuse and assaults from other residents and experience significant levels of psychological stress. Incompatibility of co-residents is one of the most significant issues facing more vulnerable people with disability.

In 2014, AFDO worked with Disability Advocacy Network Australia and the National Ethnic Disability Alliance in the preparation of a joint submission to the Senate Standing Committee on Economics Affordable Housing Inquiry. This comprehensive report can be accessed at <http://www.afdo.org.au/our-work/policy-work/>.

In October 2014, the UNCRPD Committee recommended that Australia act to close all residential institutions and conduct a mapping of the various forms of accommodation based on the needs of various kinds of people with disability. To comply with international human rights, and reflect the inclusive aims of National Disability Strategy, Australian government decisions and policies must ensure people with disability are given “a free choice of where they want to live and with whom and be able to receive the necessary support regardless of the place of residence”.

As noted in our joint submission,

“the reality of housing choices for people with disabilities in Australia is a long way from this vision. People with disability experience higher rates of discrimination and lower rates of employment, often find themselves practically excluded from owning or renting a home, vulnerable to homelessness, and reliant on public or social housing, which may be unavailable or inadequate. Difficulties in finding secure, stable accommodation may be compounded by the shortage of accessible housing, culturally appropriate housing or housing located in easy proximity to public transport, amenities and services.

Modifying accommodation to be accessible and responsive to individual needs is often problematic or costly, due to the limited use of universal housing design principles. Furthermore, people’s choices of where and with whom to live are often constrained by the tying of specialist supports and services to accommodation facilities. Many people with disabilities are currently compelled to live in institutional settings, which restrict individual freedom and decision making, and segregate and isolate people from the wider community, in environments that often foster violence, abuse and neglect.

Some of the key findings shared in the submission include:

1. Opportunities for people living with a disability to participate in the mainstream housing market are limited by high costs and low incomes. In 2012, over 15 percent of people with disability had experienced homelessness and a fifth had experienced being without a permanent place to live.
2. Many people are unable to access the funding they need that would support them to live independently in a place of their own. This results in many people with disability residing with their ageing parents who struggle with their care.
3. The increased dependence on informal family care arrangements places pressure on all family members and compromise the natural informal support that should exist between a person with disability and their family and wider community networks, and may lead to financial pressure, relationships breakdown, and poor physical and mental health.
4. Some people with disability (particularly those with high or complex support needs), are currently compelled to live in institutions in order to access the support they need. This framework is underpinned by a view that people with disability need specialist types of housing and support options, and so the provision of housing and support becomes focused on the development of special purpose care facilities.

As noted in the submission:

“People with disability are the only group within Australia, apart from those in custodial facilities, which in general have no control over where they live and with whom they live. Often they are forced to reside with people who, like them, are living with various forms of disability and with whom they have little or nothing in common apart from living with disability. This model lacks the basic respect and understanding of their needs as member of the community. More often than not people living with disability, who are in need of accommodation services, are allocated a place to live with little consultation and an inference that they should be grateful for small mercies”.

Improvements in accommodation and support systems are of particular significance for people with disability living within the nursing home system and particularly young people living in nursing homes. This group in particular are at risk and disadvantage with regards to housing and support services concerning their ability to self-determine and live within an age appropriate environment.

Accessible and affordable community based accommodation (regardless of impairment, support needs, cultural identity or socioeconomic status) is vital to creating the inclusive future that the National Disability Strategy and NDIS envisage. A healthy and safe appropriately designed environment which provides privacy, personal space, accessible facilities, legibility and adaptability is central to the wellbeing of people with disabilities. The impact of not having a long-term, national affordable housing plan

disproportionately affects people with disability and compromises ongoing advancements in other areas of disability related policy.

While the introduction of the NDIS has created the opportunity for increased options for housing for people with disability, it will only assist those eligible for an NDIS package. Furthermore, operation of the scheme in isolation from other policies and initiatives is unlikely to result in widespread change.

AFDO recommends that this inquiry review the prior report, pay particular attention to the following recommendations and develop a comprehensive housing strategy to improve housing options for all Australians with disability:

- Australian governments must refrain from supporting (for instance, through grants of land or funding) the promotion and redevelopment of institutional models that diminish the choices of people with disability to select their own supports and their own housing.
- Government policies should also avoid endorsing strongly one specific type of housing or design and rather embrace flexible responsive design that can maximise independence of residents and be adapted with ease according to needs and diverse preferences.
- A wide variety of options is needed to adequately cater for the wide variety of access, support, family, cultural, locational and personal needs of people with disabilities. As the United Nations Committee recommends in its Concluding Observations (Paragraph 42), the Australian government should “conduct a mapping of the various forms of living accommodation based on the needs of various kinds of persons with disabilities”.
- The introduction of regulations for Universal Housing Design Standards in the construction of all new housing in Australia.

Outcome 4: Personal and community support

People with disability, their families and carers, have access to a range of supports to assist them to live independently and actively engage in their communities.

National Disability Insurance Scheme

The introduction of the National Disability Insurance Scheme represents the most significant achievement of the National Disability Strategy. The significance of NDIS as a social and economic reform and its impact on the lives of those who are eligible for support cannot be overstated. For some, the NDIS represents first time they have received timely and appropriate support, tailored to their needs. For many others, it is also the first time they have been able to exercise choice and control over where, when and how those supports are delivered. AFDO and its members hear regularly from people with disability about the difference the scheme is making to their lives.

The NDIS is a complex social and economic reform. Given its complexity and sheer scale, implementation issues were to be expected. AFDO recently made a submission to the Productivity Commission Inquiry into NDIS costs. While absolutely committed to the full roll out of the scheme, AFDO and its members remain concerned about some implementation issues and their resolution. In the interests of brevity we will not repeat them here – we have included a copy of the submission at Appendix A.

Consultation with people with disability

As noted earlier in this submission, independent advocacy and representation of people with disability by people with disability is critical to both the realisation of rights outlined in the UNCRPD. Ensuring the voice of people with disability is heard is crucial to the successful implementation of the National Disability Strategy as well as significant reforms such as the NDIS.

The UNCRPD Committee in its Concluding Observations noted:

10. The Committee regrets that there are not enough mechanisms for consultation and engagement between Government and persons with disabilities and their organizations in all matters of policy development and legislative reform relating to the Convention.

11. The Committee recommends that the State party, in partnership with persons with disabilities — including children with disabilities — through their representative organizations, establish mechanisms to ensure meaningful participation in the development and implementation of legislation and policies to implement the Convention.

12. The Committee is concerned that not all organizations of persons with disabilities, including those of persons with psychosocial disabilities, and Aboriginal and Torres Strait Islander people, are provided with adequate resources for their operations.

13. The Committee recommends that the State party take initiatives to increase the resources available for independent organizations of persons with disabilities, including organizations representing children with disabilities.

AFDO reiterates our previous recommendation that Disabled Persons Organisations and advocacy organisations are appropriately resourced and supported to ensure the continued effective representation of people with disability.

AFDO is pleased to see a commitment to engaging with people with disability in the recently released second NDS Implementation Plan. It is important to ensure that the expressed views, lived experience and ongoing advice of people with disability is reflected in the development of policies and programs that affect their lives (p16). We note however that this promise to consult is expressed through a commitment to engage with representative organisations rather than individuals. We respectfully suggest that the onus is therefore on the government to consult with a broad range of organisations to ensure a diversity of voices, experiences and perspectives are captured. We also note that at the moment, the government has chosen to fund population based representative organisations rather than disability specific organisations. It is difficult for generalist or population based organisations to have a comprehensive and in depth understanding of all the issues facing people with specific disabilities or conditions. It is unrealistic to expect a small number of organisations to have the depth of both experience and contacts to ensure adequate representation on any particular issue. It is also true that while there are issues common to all or many people with disability, there are particular issues that have a disproportionate impact on specific disability types. It is important that this expertise is not lost.

AFDO is also pleased to see a recognition of the importance of advocacy in the second implementation plan. But we remain concerned about the security of funding for advocacy organisations. The reviews of both the National Disability Advocacy Framework and the National Disability Advocacy Program have been much talked about but have yet to be completed. This has created a great deal of uncertainty and anxiety both within the sector and with people with disability and their families who rely on the assistance advocacy organisations provide. It is also important to note that in a number of key jurisdictions, the amount of funding for advocacy provided by state governments has been, or will be in the future, greatly reduced. This has happened at a time when demand on these resources is high, particularly as a result of the introduction of the NDIS. We urge the government to both complete the reviews and ensure adequate funding for a strong advocacy sector to ensure the rights of people with disability are upheld and protected.

Democratic and civil participation

While most Australians with disability have the right to vote, many are not able to effectively exercise that right.

The local school, which meets the needs of most voters, is often inaccessible to a person using a mobility aid. For those who can make their way into the building, the next barrier is likely to be the voting booth which is commonly too high for a person in a wheelchair to use or a cardboard booth that may not be wide enough. Whilst more and more centres catering for accessibility through the work of state and territory electoral commissions, these centres may still be out of reach for voters who are reliant on public transport, particularly in regional and rural locations.

Whilst there has been a significant commitment and good progress made by some state and territory governments and the Federal Government to enable people who are blind or vision impaired to cast a secret, independent and verifiable vote, the availability of this process to people with other forms of disability is still many years away.

Concern has been rightfully expressed by the UNCRPD Committee in their Concluding Observations that people with intellectual and psychosocial disabilities are automatically excluded from the electoral roll. AFDO supports the Committee's recommendation (Paragraph 52) that "...Australia enacts legislation to restore presumption of the capacity of persons with disabilities to vote and exercise choice, and ensure that all aspects of voting in an election are made accessible to all citizens with disabilities".

Outcome 5: Learning and skills

People with disability achieve their full potential through their participation in an inclusive high quality education system that is responsive to their needs. People with disability have opportunities to continue learning throughout their lives.

Education – the building block to work

At present, around 13% of Australian children under the age of 18 are registered as having a disability. Over the past few decades, there has been a dramatic change in the experiences of students with disability in school systems across the country. Education practices have shifted from segregated, institutionalised settings as the norm to the inclusion of students with disability in mainstream schooling, in line with the requirements of the Disability Discrimination Act 1992 and the UNCRPD.

The cohort of students themselves has also changed over this time. Students are now more commonly diagnosed with conditions which were less likely to be detected decades ago, such as autism, ADHD and psychosocial disability.

However, in spite of the gains made in identifying and mainstreaming students with disability, significant problems remain. Many children remain in segregated schools and/or classes. While there has been an increase in participation in local schools, the increase in segregated classes and schools has been greater. New segregated settings continue to be built, committing governments to funding two separate systems now and into the future. Segregation has persisted despite the wealth of evidence that demonstrates the social and academic benefits of inclusive education. Research has consistently demonstrated the social and academic benefits extend beyond children with disability to all children educated in an inclusive classroom. There is a common assumption that the higher teacher-child ratios, as well as teachers trained in special education, would result in better academic outcomes in segregated 'special' schools or classes. In contrast, research shows that children with disability who are included into mainstream educational settings demonstrate better academic and vocational outcomes when compared to children who are educated in segregated settings.

Despite the wealth of research demonstrating the benefits of inclusion, practice on the ground remains problematic for many children with disability. Students with disability are less likely to complete secondary and tertiary education than students without disability. Students in mainstream schools still experience major difficulties in basic aspects of school life such as socialising, understanding their work and gaining physical access to their school's grounds and equipment. Without addressing these issues, there is a significant risk returning to an era of special schools as 'dumping grounds' for students with disability, contravening the UNCRPD and the basic human right to education that many take for granted in a country such as Australia. Furthermore, without an adequate – let alone useful – education, students with disability are at high risk of long term unemployment and social exclusion.

Effectiveness of the education standards

For many families with a child with disability, navigating the education system to ensure the best outcome for their child can be a daunting task. Education systems often involve complex layers of bureaucracy. Getting appropriate educational support may also mean navigating 'satellite' systems, such as aids and equipment schemes, early intervention programs, therapies, accommodation support and public transport subsidies.

Being aware of, and able to effectively utilise, the Education Standards requires time, energy and the ability to navigate as well as advocate. Even assuming adequate personal and financial resources, people with disability face many disadvantages in seeking information and articulating their needs. This is especially obvious in some disadvantaged groups, such as people with disability from Non-English Speaking Backgrounds, but it can take more subtle forms. Often women with disability and those with certain types of disability, such as intellectual disability, have experienced lifelong social conditioning to be compliant and not to make waves when things go wrong.

Similar to AFDO's assessment of the effectiveness of the Transport Standards, the Education Standards are designed to be a tool for reactively addressing the problems caused by breaches of rights. They do not require an active promotion and protection of these rights, with the onus left squarely on the person with disability or their family to resolve problems. The focus is also on individual solutions, without systemic change.

The Education Standards have failed to establish consistency throughout Australia in the following areas:

- Teacher training curricula still view the teaching of children with disability as an addition, rather than designed to include the notion of teaching for all. Professional development often focuses on information based on a medical rather than social model of disability. Such approaches do not assist new or existing teachers to modify curricula or practice.
- Schools have inadequate access to specialist assistance for assessments, speech therapy, physiotherapy, Auslan interpreters, mobility and orientation specialists and psychologists.
- Students with disabilities are often excluded from extra curricula activities such as camps, school concerts and afterschool music programs. The issue is often blamed on a lack of funding.
- School buildings remain inaccessible, and issues are often only addressed after a child enrolls.
- Disability awareness training is sporadic. Disability awareness needs to be an ongoing part of the school curricula as well as professional development for the entire school community.

- The standards suffer from a lack of clarity particularly around the notion of reasonable adjustment. This needs to be clarified as too many schools and educational departments use it to discriminate against children with disability.
- In December 2012 the DEEWR Report on the Review of Disability Standards for Education 2005 found that the existence of the Standards is not widely known nor understood by many educational institutions, resulting in inferior educational outcomes for students with disability.
- Whilst the Standards in a few situations have been used to prevent discrimination the results do not have impact across either the individual state where the complaint is settled or Australia wide.
- The obligations and requirements under the Standards are not backed up by strong accountability frameworks.

Educators and support staff across the country lack knowledge about the educational needs of students with disability. This is evident in a number of areas:

- Teachers do not receive any compulsory, nationally consistent training in the needs of students with disability, and may not consider those needs until they are faced with a student who requires adjustments. This means they may not understand different learning styles specific to disability, know the roles of a teacher's aide or itinerant teacher, or be able to adapt to working with disability specific technology.
- Specialist teachers, teacher's aides and support workers have few if any consistent qualification requirements. There is no qualification requirement to show proficiency in either Auslan or Braille, for example, and teacher's aides in the classroom need not even pass the most basic of literacy tests. AFDO is aware of instances where students who are blind learning Braille were being taught by a teacher concurrently learning Braille. This would be deemed unacceptable if the same arrangements were in place for a student without disability.

This lack of consistency means that educators and support workers not only lack the quantifiable skills listed above, but they also lack the appropriate attitudes which can be so crucial to a student's success. A teacher who does not believe that a student 'really belongs' or is capable of academic success is less likely to effectively include a child in the learning program.

AFDO has previously recommended that it should be compulsory for schools and jurisdictions to report:

- The accessibility of their buildings, facilities, transport and technology infrastructure for students with disability.

- Outcomes for students with disability (such as happiness at school, and school completion rates).
- Teacher and support staff competencies in responding to the needs of students with disability.
- Awareness of disability inclusive practices across a school community, and initiatives to promote positive attitudes.

AFDO has also supported recommendations that:

- All schools receiving Government funding should be education ready for the inclusion of children with disability. This includes full accessibility of all infrastructure, teacher training to ensure teachers teach for all children and creating a school environment that welcomes children with disability, including participation in extra-curricula activities and school community social events.
- Education for students with disability should focus on quality outcomes in academia, culture, physical activity and civic participation. Students with disability should be enabled to perform to their full potential in these areas.
- Supported with targeted resources aligned to individual need, Australian students with disability can achieve higher educational outcomes which enable their participation in the diverse, skilled workforce which is critical to meet future projected workforce shortages and tax base.

Funding for students with disability also remains inadequate and lacking in transparency. Schools do not necessarily have to allocate funding to individual students, and when they do, the funding is rarely tailored to the support required by individual students. AFDO and its member organisations strongly support the call for individualised funding for students with disabilities which follows the student from school to school and jurisdiction to jurisdiction, and allows families and students with disability the greatest say in the types of support they can purchase.

Individualised funding would need to work in concert with any other funding schemes that are available to students, such as current aids and equipment programs and/or the NDIS to avoid the creation in inadvertent gaps.

Article 24 of the UNCRPD states that the key to realising the right to an education for a student with disability is recognising individuality, promoting inclusion and providing disability specific supports as appropriate. The inadequate implementation of the Education Standards has seriously compromised Australia's legal duty in implementing the UNCRPD. The inadequacy of implementation is also flagged by the UNCRPD Committee who state:

45. The Committee is concerned that despite the Disability Standards for Education established to ensure access to education on an equal basis, students

with disabilities continue to be placed in special schools and many of those who are in regular schools are largely confined to special classes or units. The Committee is further concerned that students with disabilities enrolled in regular schools receive a substandard education due to lack of reasonable accommodation. The Committee is also concerned that secondary school completion rates for students with disabilities are about half of those for people without disability.

46. *The Committee recommends that the State party:*

a) Step up its efforts to provide reasonable accommodation of necessary quality in education;

b) Conduct research into the effectiveness of current education inclusion policies and the extent to which the Disability Standards in Education are being implemented in each state and territory;

c) Set targets to increase participation and completion rates by students with disabilities in all levels of education and training.

With the lack of funding commitment, AFDO is concerned that young people with disability will fail to develop the building blocks they need to obtain employment and full economic participation.

Transition from school

Staggeringly, one third of 15-19 year olds who are not in education, employment or training are people with disability on income support. Professor Richard Sweet in his advice to the COAG Reform Council recommended:

“A Commonwealth approach to inactive youth that spans its income support, disability, health, employment, and education and training portfolios: this in recognition of the fact that around half of inactive youth are Commonwealth passive income support clients of whom the largest group receive disability support pensions”.

In 2011, less than 2% of people with disability were enrolled in an apprenticeship or traineeship, with people with disability also significantly underrepresented in the vocational education and training.

AFDO believe that a strong school to work system of support is one of the most effective strategies to address the low labour force participation rate of people with disability. The success of this strategy is dependent on an approach that crosses inclusive of a number of sectors and jurisdictions and spans income support, disability, health, employment and education and training portfolios.

Outcome 6: Health and wellbeing

People with disability attain highest possible health and wellbeing outcomes throughout their lives.

Forced sterilization

Women and girls with disability in Australia continue to be denied their human rights to make informed choices about their bodies and their reproductive lives. Women and girls with disability continue to be sterilised without their consent - a clear violation of their human rights, and an act of unnecessary and dehumanising violence which denies a woman's basic human right to bodily integrity and to bear children, which can result in adverse life-long physical and mental health effects.

In its Concluding Observations, the UNCRPD Committee raised significant concerns that the Senate Inquiry into the Involuntary and Coerced Sterilisation of Persons with Disability, released in July 2013, in effect, supports the continuation of these practices. The Committee has urged Australia to adopt uniform national legislation prohibiting the sterilisation of boys and girls with disability, and adults with disabilities, in the absence of their prior, fully informed and free consent.

The high incidence of violence against, and sexual abuse of women was also identified in the Concluding Observations of the UNCRPD Committee. The Committee has recommended (Paragraph 17) that Australia include “a more comprehensive consideration of women with disabilities in public programmes and policies on the prevention of gender-based violence”, to ensure access for women with disability to an effective, integrated response system.

AFDO supports these recommendations and calls for their immediate implementation.

Abuse and neglect

Long after there was an attempt to end institutional models of care for people with disability under the Disability Services Act (Cth), there are still many people with disability accommodated, educated and cared for in settings that segregate them from the rest of the community. Neglect, abuse and exclusion continue to be a common experience for far too many people. This issue was well documented in the *Shut Out* Report and has emerged in consultations AFDO have undertaken. While AFDO has welcomed the closure of institutionalised settings such as the Oakleigh Centre in Victoria, greater commitment is required by all levels of government to ensure that the intent of the Strategy reflects real commitment.

It is well known that women with disability experience high levels of physical, emotional and sexual abuse. Women with disability and their children in urgent need of emergency housing are often unable to find properties to meet their access needs. Access barriers to the legal system, as outlined earlier in this report, further exacerbate

the exclusion experienced. Women with a cognitive impairment are particularly vulnerable to abuse, with urgent action required to address this situation as recommended in Paragraph 17 of the UN Concluding Observations Report. As noted in Part 2 of this report, women from CaLD and/or NESB backgrounds with disability are also usually unlikely to use the justice system, especially in family and civil law. NEDA strongly suggests that this situation be addressed through programs specifically targeting women from CaLD and NESB backgrounds. AFDO supports this approach.

Paragraph 37 of the Concluding Observation makes specific reference to the high rates of violence perpetrated against women and girls living in institutions and other segregated settings with the UNCRPD Committee recommending that Australia “investigate without delay the situations of violence, exploitation and abuse experienced by women and girls with disabilities in institutional settings, and that it take appropriate measures on the findings”.

Children and abuse

In 2013, a Royal Commission into the Institutional Responses to Child Abuse was instigated. Through significant pressure by AFDO and other disability groups, attention was given to the abuse and neglect of children with disability; an area which has been largely ignored, trivialised and forgotten.

Our understanding as a sector of the levels of sexual abuse among children with disability is very limited, and the victims are left with few, if any, means to resolve their complaints and move on in their lives. Many inquiries are already revealing the high incidence of sexual abuse of children with disability. It is imperative that children with disability are afforded the same rights as children without disability.

AFDO is concerned that children with disability still largely do not have a voice and can therefore be subject to higher levels of abuse and neglect. Often children with disability use alternative modes of communication, such as non-verbal cues or communication aids, and police and other investigative mechanisms may be reluctant to accept the evidence related to their sexual abuse. Likewise, some children with disability, such as those with intellectual or psychosocial disability, are considered less reliable witnesses in formal prosecutions because they are disabled. It is because of this that it is possible that children with disabilities may, in fact, have been targeted by sexual predators.

Further, the distinction between family abuse and institutional abuse may be blurred in the case of children with disability. For example, the abuse may have occurred in an institutional setting but not spoken of in the family, as they were dependant on the institutional support for their family member and vice versa. Children with disability living at home may also experience abuse from carers or other professional staff from institutions in their family setting.

In its Concluding Observations, Paragraph 18, the UNCRPD Committee have expressed concern that there is no comprehensive national policy framework for

children, including children with disabilities, that articulates how the rights of children should be implemented, monitored and promoted. The Committee have recommended that Australia:

(a) Step up efforts to promote and protect the rights of children with disabilities, by incorporating the Convention into legislation, policies, programmes, service standards, operational procedures and compliance frameworks that apply to children and young people in general;

(b) Establish policies and programmes that will ensure the right of children with disabilities to express their views on all matters concerning them.

Restrictive practices, compulsory treatment and seclusion and restraint

Concerns continue to be expressed about ongoing practices in the disability support system where people with disability experience solitary confinement, being tied up, shackling, over use of medical restraints and control agents without recourse to more appropriate and effective contemporary expertise and practice in this area..

People with disability subject to restraint and seclusion have raised major concerns about the use of these practices in their lives, particularly among people with an intellectual disability, psychosocial disability and/or various dual and multiple disabilities. They have provided many examples of the abuses they've undergone or witnessed, and the subsequent loss of physical and emotional safety and security in their day to day existence.

Similarly, the rights of children with disability are also recognised in the UNCRPD as part of the population of 'persons with disability' whose rights are enshrined. Disability advocacy groups have highlighted the ongoing problem of the physical and psychological abuse of children and young people in schools in Australia. In discussion they cite numerous examples of abuse being reported to them which not only breach the UNCRPD, but also ignore the Convention on the Rights of the Child, the International Convention on Civil and Political Rights and the Convention against Torture. Abusive restrictive practices in schools continue to be reported across Australia. These include, but are not limited to, children and young people with disabilities being:

- regularly locked in a room for lengthy periods resulting in soiling of their clothes, and frequent physical restraint. This is not only physically and emotionally distressing, but also demonstrates a lack of respect for the child/young person and their dignity;
- tied to chairs;

- locked in isolation rooms;
- fenced off in outside areas; and
- subject to a range of other physical and mechanical restraints.

From the perspective of AFDO and its members, the location, age and gender of the person with disability is irrelevant. Whether it be a residential unit, a day program, a hospital or a school, the rights of a person with disability to be treated with dignity and respect, and to be able to participate in the decisions that affect their lives is non-negotiable. AFDO believes that a cross government, cross jurisdictional strategy is required to ensure that restraint and seclusion is not only prevented, but entirely eradicated. Further information regarding the experience of children in school settings is provided in Part 5 of this report.

One of the most concerning aspects of the current regime of restraint and seclusion is the lack of advocacy services for people with disability subject to, or potentially subject to, these practices of abuse. It is not good enough to have an 'independent' person to explain restraint and seclusion in an individual plan and/or the possible avenues of a right of appeal. This approach is almost a technical 'tick the box' which in no way addresses or supports the right of the individual to freedom of choice in decisions which affect their personal liberty, safety and health and well-being. A robust and appropriately funded advocacy program, independent of the service system, is a fundamental component of a truly rights-focused paradigm shift in models of support and care.

The use of restraint and seclusion is abhorrent, abusive and represents significant breaches of the UNCRPD which cannot be ignored. There is no evidence base to justify the use of these practices as therapeutic for individuals with disability. It is also imperative that 'environments of concern' (the systems of care and support, and the workforce within these) should be driven by the aspirations, hopes and dreams of people with disability, rather than the reality which is focused on systems of control and management at the expense of individual rights. For people with disability subject to restraint and seclusion this has led to a culture of fear, anxiety, intimidation, frustration, anger and a life where a sense of personal safety and security cannot be found at home, at school, in training or even when seeking healthcare in hospital.

Australia's commitment must be to totally eradicate the use of restraint and seclusion, not just to introduce strategies over time to monitor, prevent and 'where possible' eliminate these practices of abuse. Having consistent definitions and a national database may serve to demonstrate the size of the problem in states and territories across Australia, but whether it is abuse of 60, 600, 6,000 or 60,000 people the fundamental principle and right is unchanged.

In recent years, the Australian Government explored the introduction of a national framework to monitor 'acceptable' forms of restraint and seclusion. AFDO at the time noted that it was not acceptable and assumed a continuation of current practices in the

foreseeable future and hence implicit support for the use of restraint and seclusion during a set period of time. The proposal amounted to an acceptance of further abuse of the rights of people with disability, irrespective of what may or may not be the long term goals.

The UNCRPD Committee has made a number of recommendations in their Concluding Observations with specific reference to medical intervention imposed against the will of a person with disability, if the person is deemed to be capable of making or communicating a decision about treatment. In Paragraph 34, the Committee recommends:

34. The Committee recommends that the State party repeal all legislation that authorizes medical intervention without the free and informed consent of the persons with disabilities concerned, committal of individuals to detention in mental health facilities, or imposition of compulsory treatment, either in institutions or in the community, by means of Community Treatment Orders.

Freedom from torture and cruel, inhuman or degrading treatment or punishment (art. 15)

35. The Committee is concerned that persons with disabilities, particularly those with intellectual impairment or psychosocial disability, are subjected to unregulated behaviour modification or restrictive practices such as chemical, mechanical and physical restraints and seclusion, in various environments, including schools, mental health facilities and hospitals.

36. The Committee recommends that the State party take immediate steps to end such practices, including by establishing an independent national preventive mechanism to monitor places of detention — such as mental health facilities, special schools, hospitals, disability justice centres and prisons —, in order to ensure that persons with disabilities, including psychosocial disabilities, are not subjected to intrusive medical interventions.

Conclusion

Australia's ratification of the UN Convention on the Rights of Persons with Disability was a significant moment for Australians with disability. The nation's plan to enact the rights enshrined in the Convention is the National Disability Strategy.

The goals articulated in the Strategy remain sound. What remains necessary is an effective and resourced operational plan with timeframes and indicators of success to ensure goals are achieved. While AFDO is supportive of the areas of action identified in the Second Implementation Plan, we remain concerned that there are no clear actions articulated, no indicators of success outlined, no timelines identified and no resources allocated. While some reforms may be initiated, without these key factors, the large scale systemic change that is required is unlikely to be achieved.

Appendix A



Australian Federation of Disability Organisations

**Submission to the Productivity Inquiry into the
National Disability Insurance Scheme Costs**



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Who is AFDO?

The Australian Federation of Disability Organisations (AFDO) is the peak organisation in the disability sector representing people with disability. AFDO and its member organisations are run by and for people with disability. AFDO is the place for organisations that represent people with disability to work together to achieve common goals. AFDO's mission is to champion the rights of people with disability in Australia and support them to participate fully in Australian life. AFDO has strong relationships not just with its member organisations, but across the disability sector including peaks representing service providers as well as those representing families and carers.

AFDO's members include:

Blind Citizens Australia	Disability Advocacy Network Australia
Brain Injury Australia	Disability Justice Advocacy
Deaf Australia	Disability Resources Centre
Deafblind Australia	People with Disabilities ACT
Autism Aspergers Advocacy Australia	Enhanced Lifestyles
Down Syndrome Australia	Deafness Forum of Australia
Physical Disability Australia	People with Disabilities WA



Summary of Key Issues

1. **Continued support for the NDIS** - AFDO's support for the National Disability Insurance Scheme (NDIS) remains unchanged and unwavering. All constructive feedback provided to date – to the National Disability Insurance Agency (NDIA), to the Commonwealth and to State and Territory governments, to this inquiry – should be viewed as our contribution to ensuring the scheme fulfils its potential and its promise to people with disability. Comments should not be interpreted as a diminution of our support. We believe the NDIS is essential to improving life outcomes for people with disability.
2. **Greater attention on outcomes** - The focus of this review on the costs of the NDIS without corresponding attention to the significant outcomes achieved provides a lopsided view of the impact of the scheme. A focus on costs must not drive decision making without consideration of the impact on those the scheme is intended to assist.
3. **Capture return on investment** - Given the Productivity Commission's extensive expertise and experience in capturing return on investment, an expansion of the review to capture the economic impact of the scheme is warranted to ensure the full impact of the scheme is assessed.
4. **Resolve interface with mainstream systems** - Lack of access to mainstream services, poor service response and failure of communities to address issues of inclusion contributes to poor life outcomes for people with disability. It also results in cost shifting and is a major risk to the sustainability of the scheme. Responsibility lies with all levels of government.
5. **Reinvigoration of the National Disability Strategy** - to improve outcomes for people with disability and counter the significant risk of cost shifting.
6. **Rethink of ILC** - The successful implementation of Information, Linkages and Capacity Building (ILC) is critical to the overall success of the NDIS. But the ILC policy is too broad and the budget too limited to be effective. Without the

foundation of ILC to drive inclusion, outcomes will be poor and scheme sustainability will be threatened.

7. ***Terminate in kind arrangements*** - The arrangements for in kind contributions during trial and the transition to full scheme have compromised the vision of the NDIS and significantly curtailed the ability of participants to exercise choice and control. Plans should immediately be put into place to ensure arrangements do not continue beyond the transition phase.

8. ***Greater attention to building the demand side*** - Insufficient attention has been given to the role of demand in shaping and driving the market for specialist disability services. Greater investment must be made in building the capacity of people with disability and their families to become the kind of consumers that will demand change and ensure continuous improvement.

9. ***Ensure transition arrangements cease at the end of transition*** – the need to bring in a large number of participants into the scheme to meet bilateral targets has during transition led to practices which have not always been consistent the original vision of the scheme. While AFDO acknowledges the challenges and does not support a slow down in the roll out of the scheme, we are concerned that without continued vigilance, some of these less than ideal practices may become entrenched.

Introduction

As a founding member of the National Disability and Carer Alliance, AFDO played a key role in the campaign for the introduction of the National Disability Insurance Scheme (NDIS). As the NDIS has moved through the trial phase and begun the transition to full scheme, AFDO and its members have continued to work constructively with the National Disability Insurance Agency (NDIA) as well as Commonwealth and State and Territory governments to provide critical feedback and address implementation issues as they arise.

AFDO welcomes the opportunity to have input into the Productivity Commission's inquiry into NDIS costs. We want to begin, however, by emphasising our unwavering support for the NDIS. AFDO and its members regularly hear from people with disability and their families about the difference the NDIS is making to their lives. People who now have the dignity of appropriate and timely support, the opportunity to be more involved in their communities, the chance to move out of home, the economic freedom of a new job. These are the kinds of differences the NDIS is making.

AFDO and its members were all too familiar with the failings of the previous disability system, which the Productivity Commission infamously characterised as "inequitable, underfunded, fragmented, inefficient and gives people with disability little choice and no certainty of access to appropriate supports". AFDO and its members were highly critical of the previous system and its chronic failure to neither provide appropriate support to people with disability nor close the gap in life outcomes between those with a disability and those without.

And it is because of our deep understanding of the failings of the previous system that we are concerned about the focus of this current inquiry on the costs of the NDIS, without sufficient attention to the outcomes that have been achieved for people with disability as a result of the introduction of the scheme.

AFDO remains committed to the vision of the NDIS and is determined to ensure it is implemented in full. AFDO strongly opposes any attempts to deviate from the original vision and intent or to curtail its implementation. The comments that follow should therefore not be interpreted as lack of support for the scheme. They represent AFDO's thoughts about how to ensure the scheme is the best it can be, identifying issues and areas that warrant further attention, analysis and action. We want to see the scheme reach its full potential and improve outcomes for people with disability.

Finally, our comments should also be considered in the light of the importance of ensuring people with disability are at the heart of the scheme. A focus on costs should not be at the expense of a focus on outcomes for the very people the scheme is intended to support. Any decisions made in the interests of ensuring sustainability should also be consistent with improving outcomes for people with disability. We should

not put other interests – the interests of the system, the interests of governments, and the interests of service providers - ahead of the interests of people with people with disability. The sustainability of the scheme is of vital importance to people with disability – people with disability understand it is essential to the longevity of the scheme. But the focus on costs should not be at the expense of delivering good outcomes for people with disability. The scheme must always put people with disability first.

Focus of this review

The focus of this review is on the costs of the NDIS. It should be noted that, to date, the scheme has been delivered on time and within the given funding envelope. This cannot be said for other large government initiatives. Given the size and complexity of the NDIS, this fact should not be overlooked.

People with disability, their families as well as the organisations that support them are vitally interested in the sustainability of the NDIS. We want the NDIS to support generations of Australians to come. We understand that cost overruns jeopardise public and political support for any government initiated scheme. We are therefore interested in the effective and efficient administration of the NDIS to ensure its ongoing support throughout the wider community.

But government initiatives can be well managed and still not achieve intended outcomes. The scheme should be judged not only by how it manages costs but what outcomes are achieved. It is also true that the good outcomes delivered by the NDIS are often hard to capture and quantify. It is even more difficult to assign value in economic terms and measure return on investment. Some economic outcomes are easily captured and quantified – investment in capacity building or home modifications or equipment can reduce support costs in the long term. And if an NDIS participant is supported to move into employment, or a family carer re-enters the workforce, the economic impact of that change can be measured.

But other, just as important outcomes, are not only more difficult to capture, they are more difficult to assign value. What value can we assign, for example, to increased inclusion? To increased independence? To increased dignity? Through the development of an outcomes framework, the NDIA has begun the work of attempting to capture and document these outcomes. Because of their vital importance in assessing the full impact of the scheme on the lives of people with disability, we believe this work warrants further attention.

And we believe it is those outcomes which should also be the focus of this review. We would respectfully suggest that the focus of this review on the costs of the NDIS results in a lopsided picture of the impact of the scheme. We acknowledge the difficulty of capturing some of the more intangible and long term outcomes, and measuring return on investment. But given the particular skill set, experience and expertise of the Productivity Commission, it would seem appropriate that the Commission be asked to consider return on investment as well as costs.

We would also argue strongly for patience in examining outcomes from the scheme. We expect that return on investment will take some time to be realised. This is particularly true because previous system was under resourced and highly rationed that many people with disability arrive at the door of the NDIS with high and complex needs. We

would expect this to reduce over time as people receive more timely and appropriate supports. This is not the time for governments to lose their confidence in the scheme. The insurance principles which underpin the NDIS mean the scheme takes a lifetime view of an individual. So too should governments take a long-term view of the implementation of the scheme. This is particularly difficult in our current political climate but essential to good governance.

We acknowledge that there have been many issues during trial and the transition to full scheme implementation. But we also recognise that this is a unique period in the life of the NDIS. Never again will the scheme have to grapple with the multiple challenges posed by bringing in a large number of participants in such a short period of time. Once this period of transition is over, growth will be limited to a small number of new participants. AFDO understands that there are significant operational challenges in ensuring hundreds of thousands of people enter the scheme in a short period of time.

Some in the sector have responded by arguing for a slow down the roll out and to lengthen the transition period. To AFDO and its members, this would be completely unacceptable. For many people with disability, the wait has already been too long. For people who have had little or no support for many years, the NDIS cannot come quickly enough. Slowing down the roll out is therefore not an option. The only acceptable option is for partner governments and the NDIA to listen carefully to the feedback provided by people with disability, their families and carers and the organisations that support them, and to work constructively with them to address operational issues as they emerge.

This has been particularly evident in the planning space. The introduction of such responses as the “First Plan” and conducting planning conversations over the phone have clearly been designed to ensure large numbers of people with disability can enter the scheme in a timely fashion. It has however, compromised the commitment of the scheme to individualised responses and to choice and control. We are also concerned that some responses appear designed not only to ensure timely entry into the scheme, but designed to reduce operating costs, again at the expense of best practice and better outcomes for people with disability. We are concerned that without vigilance and commitment, poor practice and outcomes will become entrenched.

Cost Drivers

Mainstream Interface

The Issues Paper asks “what are the cost drivers of the scheme” and identifies a range of issues including eligibility, planning, plan implementation and service provision. But the paper also asks if there are drivers that have not been identified and further questions how they impact costs in the short and long term and how and to what extent governments can influence them.

The diagram on Page 9 of the Issues Paper entitled “What drives scheme costs?” details factors that impact costs in both the short and long term. This diagram makes no mention of the intersection of the NDIS with mainstream supports and services and the impact it has on scheme sustainability.

In theory, the COAG Applied Principles detail respective roles and responsibilities of the NDIS and mainstream services. The issue however, remains practice on the ground.

In the experience of AFDO and its members, lack of access to mainstream services, poor service response and failure of communities to address issues of inclusion contributes to poor life outcomes for people with disability. These three issues routinely feature in the complaints of members to their membership organisations and dominate the workloads of advocacy organisations.

These failures also place significant pressure on NDIS participants to include supports and services in their individual plans to meet needs which rightly should be met by mainstream services. It also means that people with disability who sit outside the scheme and who are not eligible for individualised support do not have their needs addressed. This in turn places pressure on these individuals to test their eligibility in order to try and receive appropriate support.

Sometimes the pressure to include supports more appropriately provided by the mainstream in NDIS plans comes from people with disability themselves. Desperate for support and for a resolution to the never-ending message “we are not funded to do that”, people just look for any means necessary to have their needs met.

In other cases the expectation of support from the NDIS has come from mainstream services themselves. In our view, there is an unrealistic expectation amongst many mainstream services that the NDIS would assume responsibility for meeting any need a person with disability might have. The idea that they have a universal service obligation to the community seems to have come as a surprise.

In other cases government itself has been responsible for creating boundary issues. This appears to be particularly true in the area of mental health. Funding for some community mental health services in particular has been diverted to the NDIS, with an

expectation that people with psychosocial disability would receive support from the scheme. This is despite the fact that only some people with psychosocial disability who currently rely on community mental health services will in fact be eligible for an individual NDIS plan. The rest will need to draw on activities funded through Information Linkages and Capacity Building (ILC) or remain unsupported. Demand on ILC already exceeds the budget allocated to it, and it is expected to provide assistance to people with a diversity of disabilities, not only those with mental health conditions. This is an issue which is beyond the remit of the scheme – it must be resolved by government.

During the trial phase, continuity of support arrangements appear to have “masked” some of the failure of mainstream services to meet the needs of people with disability. In combination with the smaller number of people supported by the scheme, AFDO believes the full impact of mainstream failures and a lack of community inclusivity is yet to be felt. Some of the boundary issues are still yet to fully emerge and it is probable that the impact on scheme costs is yet to be fully realised.

These “boundary” issues have been highlighted in an NDIS test case that was resolved just as AFDO was preparing this submission. A young man with an intellectual disability and living in a small town outside of a regional centre has been a participant in the NDIS during trial. His participation in supported employment and social activities in the regional centre were funded as reasonable and necessary supports in his plan. Initially all of his transport costs to and from these activities were also funded. But the NDIA attempted to reduce the amount of funding allocated to transport, and he and his family appealed the decision. The Federal Court this week upheld the decision. The NDIS will now be responsible for meeting all of his transport costs.

The first thing that must be said is that we are pleased this young man will be adequately supported to achieve his goals. We believe the policies underlying planning decisions must be transparent. But it should also be noted that the young man requires additional transport into the nearest regional centre because there is no public transport in his town. This is a failure of the public transport system – not the disability system. It should also be noted that this young man travels into the nearest regional centre for both supported employment and social activities. If employment was available closer to his home, and he was able to participate in social activities in his local town, then the need for transport into the regional centre would be reduced. This would be both a better outcome for this young man and his family, a better result for his town, and a better outcome for the scheme. This case provides a clear example of the ways in which failings in the mainstream are both directly and indirectly resulting in significant cost shifting to the scheme.

Reinvigoration of the National Disability Strategy

Responsibility for implementing the agreed National Disability Strategy sits with all three levels of government – Local, State/Territory and Commonwealth. All three should be responsible for driving an agenda of inclusion, which will ultimately close the gap in life outcomes for people with disability, improve economic and social participation. As community inclusion increases and more appropriate support is available from mainstream services, it will also in the long term reduce cost pressures on the scheme.

AFDO and its members also welcome the current review into the NDS. However, the strategy has been much neglected while the focus has been on implementation of NDIS, much to the dismay of people with disability, their families and carers and the organisations that support them..

We believe a reinvigorated commitment to implementing the aims of the NDS across all levels of government, will not only improve outcomes for people with disability, but reduce the significant current risk of cost shifting.

Operating Costs of the NDIA

People with disability and their families do not want to see the NDIS run by a complex, cumbersome and expensive bureaucracy. The scheme should be administered by an agency that is small, agile, and connected to the community.

We also expect representation of people with disability at all levels of administration – from the board, to senior management through to regional staff. One indicator that the scheme is being administered well is that operating costs are minimised – it is vital that the bulk of the funding is delivered to people with disability through their individualised packages and not diverted to administering the scheme.

But the target the NDIA has been given – 7 per cent – is a level well below comparable schemes. This seems particularly short sighted given the scheme has only just begun the transition to full scheme, and is responsible for bringing in large numbers of participants in a short time frame. In the corporate world, there is a recognition that start-ups require a high-level investment at the beginning, which is gradually scaled back as operations become well established. In our view, some of the less than desirable decisions that have been made during transition appear to have been driven by a determination to cut costs. It would be a perverse outcome if the NDIA did not appropriately administer the scheme and monitor and manage costs effectively because it did not have sufficient resources to do so.

It is also important that NDIA retain its status as an independent statutory authority. The independence of the agency responsible for administering the scheme was one of the key issues during the campaign for the introduction of the NDIS. An independent agency with its own board (including board members with disability) helps to ensure the

vision of the scheme is realised and it is not subject to the changing priorities of successive governments. It is also important that the independence of the agency's decision making is not compromised or undermined by interference in day to day operational issues. Structural and systemic issues lie with the governments who work in partnership to deliver the scheme – day to day operational issues should lie with the NDIA. And the NDIA should be held to account by its own board and COAG should they fail to administer the scheme efficiently and effectively.

Cost Overruns

The Issues paper questions “what should happen in the event of cost overruns”. But as the experience of the scheme in trial tells us, any response should be entirely determined by the nature and source of the issue. During the trial period, there were multiple issues that required entirely different solutions.

As the Productivity Commission noted in its original report, the historic paucity of robust data about disability has significantly hampered efforts to effectively target support or operate an efficient support system. The scheme had to be introduced despite the absence of comprehensive data. More than three years into the scheme, there is already more data than in any other period in history. This data should be constantly reviewed and refinements and adjustments made to the operation of the scheme as a result of this analysis as part of the good governance of the scheme.

This is an important point in the context of the underlying source of cost overruns. If the estimates provided by the Productivity Commission prove to be incorrect, and there are more people with disability who should be eligible for support or their support needs are greater than originally envisioned, this should not be a cause for cost cutting. It is the responsibility of Commonwealth and State and Territory governments to share the cost of meeting additional through the existing funding arrangements in the bilateral agreements.

But if the cost overruns are a result of cost shifting by other systems or the failure of mainstream services to adequately meet the needs of people with disability, then this must be addressed by State/Territory and Commonwealth governments individually and collectively.

If the cost overruns are a result of mismanagement of the scheme by the NDIA, then the NDIA must to be held to account for the operation of the scheme and appropriate action taken.

Information, Linkages and Capacity Building (ILC)

The Productivity Commission, in its original report into Disability Care and Support recognised that the provision of greater individualised funding alone could not achieve improved life outcomes for people with disability. The report argued that there would remain activities or supports that could not effectively and efficiently be individualised but were still essential to effective support. The report also recognised that there would be a group of people with disability who still required some forms of support but whose functional impairments would not meet the threshold established for the scheme. Tier 2 would therefore be both a population group and a collection of activities.

In July 2015 the Disability Reform Council renamed Tier 2 Information, Linkages and Capacity Building and released the agreed ILC Policy Framework. The policy described the kinds of activities that would be funded through ILC in the future, grouped into five areas – information, linkages and referrals, capacity building for mainstream services, community awareness and capacity building, individual capacity building and local area coordination (LAC). The NDIA has since made it clear that LAC will be implemented separately. The budget for the remaining four areas described in the policy is \$132 million per annum.

It would be an understatement to say that the policy intent of COAG has not been matched with the budget allocation for ILC. There are insufficient funds to meet the policy intent outlined in each of the four areas. The budget for ILC must not only be spread across all four activity areas, but also provide appropriate geographic coverage – particularly meeting the needs of people with disability and their families living in rural and remote areas, where the cost of delivering activities is likely to be higher.

The budget must also meet the diverse needs within the disability community and in particular, provide diagnostic specific support as well as meeting generalised information, support and referral needs. It is something of a “Herculean task” to expect \$132 million to effectively meet the diversity of need across the geography of the country. But it is not the only task ILC is expected to perform.

In addition, ILC has particular responsibility for people with disability who sit outside the scheme. For the scheme to operate efficiently and effectively, there should be minimal difference between those who are just eligible for the scheme and receive a small individualised package, and those who sit just outside the scheme and have their needs met by ILC. To do otherwise is to create an incentive to test eligibility and move into the scheme. This is a very important function of ILC and implemented well would make a significant contribution to scheme sustainability. Despite the importance of this function and the significance of this group, little is known about their characteristics, their likely

support needs and the quantity of funding required to ensure they are appropriately supported. This is an area of research and analysis that warrants further attention.

The effective implementation of ILC is of vital importance to AFDO and its members, as there is great potential for ILC to drive inclusion across the community.. For ILC to deliver on its promise, progress will have to be made in two areas –

1. Ensuring people with disability and their families have the knowledge, skills and resources they need to live the life of their choosing
2. Making sure mainstream services and community supports, programs and activities have the knowledge and skills they need to be accessible and inclusive.

Improved life outcomes for people with disability will not be achieved unless progress is made in both areas. Both will also make an important contribution to scheme sustainability – as people are engaged with and included in their communities and well supported by mainstream services, reliance on paid specialist disability supports will reduce over time.

The current budget allocated to ILC is unlikely to ensure significant progress in these areas – one may be possible, but not both. Given progress in one is linked to progress in the other, in our view the outlook for ILC is grim. As it stands, one of the very foundation stones of the scheme has been weakened by a broad policy, a limited budget and a lack of clarity about individuals who most need assistance and what support they might require.

There are four potential solutions to this issue;

1. Reduce significantly the scope of the ILC Policy so it better matches the current budget.
2. Increase the ILC budget significantly.
3. A combination of both 1 & 2.
4. Allow the NDIA greater flexibility in administering its funding envelope to meet both package costs and the demands of operating an effective ILC.

Given that an increased budget is highly unlikely in the current fiscal environment, it would seem a sensible approach to allow the NDIA greater flexibility in the way in which it apportions the budget it is currently allocated.

Market

There are others in the disability sector who will discuss at greater length and in more extensive detail what has been learnt during the last four years in the market for disability service provision. We will not attempt to duplicate that material here. We will confine ourselves to the perspective of people with disability and their families.

AFDO and its members remain concerned about the ability of State and Territory governments to continue to contribute to the operation of the scheme through “in kind” arrangements. “In kind” fundamentally compromises the ability of participants to exercise choice and control. Continuing to allow in kind during the transition years to full scheme has undermined the original vision of the NDIS. Complaints regarding in kind are common amongst participants and their families. AFDO and its members remain fundamentally opposed to in kind and expect to see a clear indication of how the arrangements will be phased out quickly once the scheme reaches maturity and is operating at full capacity.

AFDO and its members also routinely hear complaints from people with disability and their families about the lack of choice in rural and remote areas. In some cases, participants are unable to purchase support at all. It is not clear to AFDO and its members how the Market Sector and Workforce Strategy developed in partnership by the Commonwealth and State/Territory governments, or funds from the Sector Development Fund have resulted in progress in this important area.

While we acknowledge the importance of addressing issues with regard to supply, AFDO believes insufficient attention has been paid during the transition years to the importance of building the demand side of the market. Given the fragmented and highly rationed disability system of the past, few people with disability have had the opportunity to exercise either choice or control.

AFDO believes an investment in capacity building is required to ensure people with disability and their families have the knowledge, skills and experience required to make the most of the opportunities presented by the NDIS.

Effective and efficient implementation of the NDIS is dependent on well informed, well resourced and highly engaged consumers, able to clearly articulate their needs, search for an appropriate service and negotiate the terms of engagement. Given the striking lack of opportunity for choice and control in the past, it will take time to build the capacity of some people with a disability and their families to become those consumers.

But it is also precisely those consumers that will drive change in the market. In AFDO’s view the market cannot and will not respond on its own – consumers must come together to demand new and different services, encourage new entrants or demand existing providers offer alternatives. Without a significant investment in the demand side

of the market, AFDO believes it is unlikely the innovation promised by the scheme will be achieved.

Conclusion

The NDIS is complex social and economic reform. Given its complexity and sheer scale, implementation issues were to be expected.

It is AFDO's view that governments, in partnership in the delivery of the scheme, should accept responsibility for addressing systemic and structural issues, and the NDIA should address day to day operational issues. Each should be held to account for progress – or in some cases lack of progress.

AFDO remains concerned that the terms of this review focus exclusively on costs without addressing the outcomes achieved by the scheme. We remain equally concerned that a desire to reduce costs will result in compromises to the original vision of the NDIS, with poor outcomes for people with disability and therefore future long-term cost blow-outs the inevitable result.

People with disability must be at the centre of the scheme – and the centre of any decision making regarding its future implementation. The needs of others – of governments, of the NDIA, of providers – cannot override the needs of people with disability.

The vital need to ensure scheme sustainability must be balanced with the need to ensure life-changing outcomes for people with disability and their families.