

Australian Federation of Disability Organisations

Submission to the Productivity Inquiry into the National Disability Insurance Scheme Costs position paper

July 2017

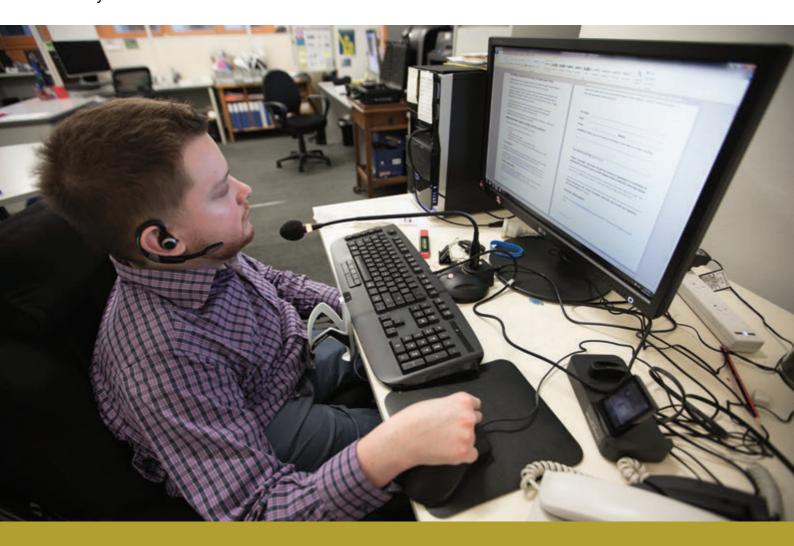


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Who is AFDO?

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

Brain Injury Australia

Deaf Australia

Deafblind Australia

Autism Aspergers Advocacy Australia

Down Syndrome Australia

Physical Disability Australia

Disability Advocacy Network Australia

Disability Justice Advocacy

Disability Resources Centre

People with Disability ACT

Enhanced Lifestyles

Deafness Forum of Australia

People with Disability WA





























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 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 the 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 of 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.

1. Draft recommendations

AFDO supports the following draft recommendations from the Productivity Commission Position Paper.

Draft recommendation 4.1

The National Disability Insurance Agency should:

- implement a process for allowing minor amendments or adjustments to plans without triggering a full plan review;
- review its protocols relating to how phone planning is used;
- provide clear, comprehensive and up-to-date information about how the planning process operates, what to expect during the planning process, and participants' rights and options; and
- ensure that Local Area Coordinators are on the ground six months before the scheme is rolled out in an area and are engaging in pre-planning with participants.

Draft recommendation 4.2

The National Disability Insurance Agency should ensure that planners have a general understanding about different types of disability. For types of disability that require specialist knowledge (such as psychosocial disability), there should be specialised planning teams and/or more use of industry knowledge and expertise.

Draft recommendation 5.1

Funding for Information, Linkages and Capacity Building (ILC) should be increased to the full scheme amount (of \$131 million) for each year during the transition. The funds that are required beyond the amounts already allocated to ILC to reach \$131 million should be made available from the National Disability Insurance Agency's program delivery budget.

The effectiveness of the ILC program in improving outcomes for people with disability and its impact on the sustainability of the National Disability Insurance Scheme should be reviewed as part of the next COAG agreed five-yearly review of scheme costs. The ILC budget should be maintained at a minimum of \$131 million per annum until results from this review are available.

Draft recommendation 5.2

The Australian, State and Territory Governments should make public their approach to providing continuity of support and the services they intend to provide to people (including the value of supports and number of people covered), beyond supports

provided through the National Disability Insurance Scheme. These arrangements for services should be reflected in the upcoming bilateral agreements for the full scheme.

The National Disability Insurance Agency should report, in its quarterly COAG Disability Reform Council report, on boundary issues as they are playing out on the ground, including identifying service gaps and actions to address barriers to accessing disability and mainstream services for people with disability.

Draft recommendation 5.3

Each COAG Council that has responsibility for a service area that interfaces with the National Disability Insurance Scheme (NDIS) should have a standing item on its agenda to address the provision of those services and how they interface with NDIS services. This item should cover service gaps, duplications and other boundary issues.

Through the review points of National Agreements and National Partnership Agreements under the Federal Financial Relations Intergovernmental Agreement, parties should include specific commitments and reporting obligations consistent with the National Disability Strategy. The Agreements should be strengthened to include more details around how boundary issues are being dealt with, including practical examples.

Draft recommendation 7.1

The roles and responsibilities of different parties to develop the National Disability Insurance Scheme workforce should be clarified and made public.

- State and Territory Governments should make use of their previous experience in administering disability care and support services to play a greater role in identifying workforce gaps and remedies tailored to their jurisdiction.
- The Australian Government should retain oversight of workforce development, including how tertiary education, immigration and aged care policy interact and affect the development of the workforce. In doing so, the Australian Government should pay particular attention to immigration policy to mitigate workforce shortages over the transition period.
- The National Disability Insurance Agency should provide State and Territory
 Governments with data held by the Agency to enable those jurisdictions to make
 effective workforce development policy.

Providers of disability supports should have access to a clear and consistent mechanism to alert those tasked with market development about emerging and persistent workforce gaps.

Draft recommendation 7.2

The National Disability Insurance Agency should publish more detailed market position statements on an annual basis. These should include information on the number of

participants, committed supports, existing providers and previous actual expenditure by local government area.

The Australian Government should provide funding to the Australian Bureau of Statistics to regularly collect and publish information on the qualifications, age, hours of work and incomes of those working in disability care roles, including allied health professionals.

Draft recommendation 7.3

The National Disability Insurance Agency's (NDIA) guidelines on paying informal carers who live at the same residence as a participant should be relaxed for core supports for the period of the National Disability Insurance Scheme (NDIS) transition. Such payments should be:

- accessible under clearly defined and public guidelines, which make reference to worker shortages in the relevant market using the NDIA's information about providers and supports in the participant's region;
- set at a single rate determined by the NDIS price regulator in a transparent manner; and
- reviewed by the NDIA as part of plan reviews.

Draft recommendation 8.1

The National Disability Insurance Agency should implement the eMarketPlace discussed in the Integrated Market Sector and Workforce Strategy as a matter of priority.

Draft recommendation 9.1

The requirement that changes to National Disability Insurance Scheme Category A Rules have unanimous agreement from the Australian Government and all host jurisdictions should be relaxed.

Draft recommendation 9.2

The Western Australian Government and Australian Government should put in place arrangements for Western Australia to transition to the National Disability Insurance Scheme. Any decision to join the national scheme should be made public as soon as possible.

Draft recommendation 9.3

The National Disability Insurance Agency should publicly report on the number of unexpected plan reviews and reviews of decisions, review timeframes and the outcomes of reviews.

Draft recommendation 9.4

The performance of the National Disability Insurance Scheme (NDIS) should be monitored and reported on by the National Disability Insurance Agency (NDIA) with improved and comprehensive output and outcome performance indicators that directly measure performance against the scheme's objectives.

The NDIA should continue to develop and expand its performance reporting, particularly on outcomes, and Local Area Coordination and Information, Linkages and Capacity Building activities. The NDIA should also fill gaps in its performance reporting, including reporting on plan quality (such as participant satisfaction with their plans and their planning experience, plans completed by phone versus face-to-face, and plan reviews).

The *Integrated NDIS Performance Reporting Framework* should be regularly reviewed by the NDIA and the COAG Disability Reform Council and refined as needed.

Draft recommendation 10.1

At full scheme, the annual operating budget for the National Disability Insurance Agency should be set within a funding target of 7-10 per cent of package costs with the expectation that, on average, it would sit at the lower end of the band.

The National Disability Insurance Agency should be required, in its annual report, to state reasons why it has not met this target in any given year.

Draft recommendation 10.2

The Australian Government should reconsider the staffing cap on the National Disability Insurance Agency, given the importance of developing internal capability and expertise.

Draft recommendation 10.3

In-kind funding arrangements should be phased out by the end of transition and should not form part of the intergovernmental agreements for full scheme funding. Should inkind funding persist beyond transition, jurisdictions should face a financial penalty for doing so.

2. How is the scheme tracking?

The benefits of the scheme are more than apparent to all AFDO members who remain fully committed to the aspirations of the scheme – providing choice and control for people with disability whilst increasing the breadth and depth of the disability supports available.

Never before in Australia's history has the experience of disability held such a focus for the Australian community. The NDIS reforms have shone a light on disability and it will never be the same again. People with disabilities, their families, friends and community and governments at all levels are thinking about disability in a new way. This is unprecedented in Australia's history. There will be challenges arising out of that new thinking and these challenges are both sticky and delicious.

Taking the analogy of NDIS experience as 'being like a plane that had taken off before it had been fully built and is being completed while it is in the air' (Whelan, Acton and Harmer, 2014) judging the experience from the perspective of 'smooth flying' and then making changes to the flight plan seems unreasonable. As the Productivity Commission itself states in its June 2017 Position Paper, "A long term focus, both within and outside of the NDIS, is therefore important."

The experience of the AFDO membership is that some plans meet the needs of people with disability and have a life changing impact. Whilst for others the plans do not deliver better outcomes, seem to have no connection to the lived experience of the person with a disability and create more problems for the families and communities and the agencies providing a service.

The impact of the rollout schedule as outlined in the bilateral agreements with their associated financial implications is complex. This complexity is having an impact across as aspects of the experience of disability. People with disability are worried because they hear that some people have received less supports and that people with disability are struggling in the absence of any supports. Disability support providers have had to completely re-organise their service systems with the added financial implications for doing so. The NDIA is struggling to implement much needed key reforms and policies. Members of the Federal Government are worried hat there will not be enough money. The complexity associated with the roll out has exposed the lack of capacity in the disability service system.

4. Scheme support

AFDO believe there is sufficient clarity around how Section 34 (1) relates to the consideration of what is reasonable and necessary.

It is appropriate that decisions from courts and tribunals continue to shape the breadth, scope and application of what is considered 'reasonable and necessary'. In the process of determining 'reasonable and necessary', where there may be differences of opinion and interpretation between people with disability and the NDIA is appropriate to turn to an independent player who can adjudicate. Court rulings also set precedent which can in turn be embedded in legislation.

Confusion may occur for participants in the planning space where the application of the financial value relating to 'reasonable and necessary' is made during the planning approval phase. The process of placing a financial value on 'reasonable and necessary' during the planning approval phase occurs within the agency without the participation of people with disability. Access to the plan once developed but prior to approval no longer seems to occur within either the Agency or with Local Area Coordinators. People with disability are able to participate in discussing what they need but the decision to fund one item but not another lay with the NDIA.

The tension between the NDIS fulfilling the dreams and aspirations of a person with a disability and the availability of funding for those dreams and aspirations is inevitable. Whilst the task of ascribing a dollar amount is the role of the NDIA the fact that people with disability are not provided with the opportunity to understand this task can lead to poor planning outcomes and locks people with disability out of the full process of what is in fact a plan about them.

The more transparency regarding this tension from the NDIA the better informed people with a disability will be - allowing for more choice and control and better planning outcomes. The better informed people with a disability are, the more they are included, the greater the degree of equity they are afforded, the more likely they are to understand the bigger picture and the greater the opportunities for choice and control.

AFDO remain concerned about the access and implementation issues associated with the planning process and the quality of the plans. Whilst the AFDO membership does not wish to see a slow-down in the roll out for transition to full scheme it is clear that the pace of the rollout is having an impact on the quality of both the planning process and the quality of the plans themselves.

People with cognitive impairments and complex care issues, including psycho-social impairment their families and carers are particularly vulnerable in the context of the impact on the planning process. For example people with cognitive impairments form the largest group of scheme participants but on the whole do not fare well in a telephone planning conversation. Given the history of abuse, neglect and exploitation that people with disability have experienced historically, there is no way of being certain

that people are not being coached, harassed or bullied when planning is planning is completed over the phone. Generally speaking for people with a cognitive impairment and complex care issues it is important that they are supported to participate in the planning process and that the planning occurs face to face. These complexities add to the problem faced by the NDIA is adhering to roll out schedule whilst ensuring quality planning can occur. It seems reasonable on the face of it given these pressures that the Agency may be looking at strategies where they could continue the roll out schedule and diversify responsibility for Plan approval.

AFDO does not believe that it is time to extend the responsibility for planning approval to Local Area Coordinators. It does make sense that the people engaging in 'Getting Plan Ready' and the 'Planning Conversation' also have the capacity to sign off on the Plans. It is important that a reservoir of experience, skill and oversight in relation to all aspects of the planning process continue to be built up within the Agency. The Agency, having held the experience of planning and planning approval can then develop an informed position on whether Local Area Coordinators are the right group of people to be providing Plan approvals.

5. Boundaries and interfaces with the NDIS

AFDO continues to support the original intention of the Information, Linkages and Capacity Building (ILC) program and the five streams outlined in the ILC Policy Framework (NDIA 2015). Those being:

- 1. Information, Linkages and Referrals
- 2. Capacity Building for Mainstream Services
- 3. Community Awareness and Capacity Building
- 4. Individual Capacity Building
- 5. Local Area Coordinators

Improving access to and the capacity of mainstream services to respond to the needs of people with disability for scheme participants as well as those people with a disability who will not be eligible is a long overdue necessity in making Australia a more inclusive society: and the NDIS reform is an excellent opportunity to ensure a more inclusive society. Implementing this goal responds to a key observation by the Committee for the Convention on the Rights of People with Disability that Australia could do more to include people with a disability in the civil, political, economic social and cultural life of the community.

AFDO believe that the budget for the ILC needs to be increased and that full funding should be made available each year during the transition phase. If the ILC is to meet its commitments in the five streams to the diversity of need for the approximately 3.8 million people with a disability who will not be eligible for a funding package through the NDIS then consideration needs to be given to increasing the ILC budget.

AFDO supports the Productivity Commission's view in the Position Paper that that ILC is a key component of the NDIS and that it is a false economy to have too few resources for ILC activities. AFDO is also worried that the scope of activities is greater than current budget allocation would allow and that there are insufficient funds to meet the policy intent outlined in each of the four areas. One example AFDO would highlight would be the higher costs of delivering services in rural and remote areas.

Continuity of support arrangements set out in the state and territory bilateral agreements must ensure that people with disability are not disadvantaged during the transition to full scheme. AFDO members however are reporting that state and territory disability services are winding down and that there is a lag time between the wind down at the state and territory level and full access to the NDIS for people with disabilities. AFDO are concerned that there is not a clear framework for continuity of support arrangements. This is particularly affecting people with disability who are not eligible for the NDIS, people with disability who have complex care issues, people with disability who have no family or advocate and are vulnerable and people with disability who have significant contact with other mainstream service system such as health, transport, justice, employment and particularly people with psycho-social impairments. AFDO

supports the statement from National Disability Services in the Submission to the Productivity Commission that, "Continuity of Support Arrangements for other people receiving disability support but who will not become eligible for the NDIS need to be released as soon as possible."

AFDO would like to see more transparent reporting for continuity of support against the Focus Areas of the National Disability Strategy and that such reporting occur not just through the COAG process but also through regular reporting from the NDIA. This would be consistent with the 2016 commitment by the Disability Reform Council to the National Disability Strategy.

6. Provider readiness

It is stating the obvious to say that the success of the NDIS is dependent, among other things, on the capacity of the disability support sector to provide disability supports. AFDO remain concerned about a range of issues related to provider readiness. Particular concern relates to:

- 1. The need for rapid growth of provider capacity in an unclear policy and financial environment
- 2. A lack of transparency around the assumptions underpinning the NDIA Reasonable Costs Model
- 3. A perceived conflict of Interest for the NDIA regarding being the funder and purchaser
- 4. Financial viability and certainty in the transition to a fee for service system
- 5. Recruitment issues for disability support workers including a largely female ageing workforce
- 6. A lack of disability support providers in rural and regional Australia for hard to reach populations, people with disability who experience complexity when seeking services, people with disability who are a risk of harm to others due to behaviours of concern, Indigenous Australians with disabilities
- 7. A lack of specialist allied health professionals
- 8. Preparatory work supporting NDIS implementation has slowed

The membership of AFDO support the immediate introduction of an independent price monitor to address the perceived conflict of interest issue relating to the NDIA being the funder and purchaser. AFDO would like to see independence and transparency for such issues as setting the pricing cap that an independent pricing regulator would enable. This is vital in the context of providing a degree of financial certainty for agencies which may allow for more providers to enter the marketplace or existing providers to develop sustainable business models. As well, as the Commission notes, it also affects who providers choose to supply.

Given the NDS portrait of a disability service sector where the majority of agencies have a workforce of ten or less and a limited budget AFDO is aware of sector wide concern that the financial realities of disability service provision are not given the weight they should.

Whilst AFDO members are unanimous in their support of an Independent Pricing Regulator they are divided in strategies to address the issue of thin markets particularly the idea that family members could be employed by scheme participants.

Those AFDO Members opposed felt that a better solution to thin markets would be a return to limited block funding. One Member organisation felt that a return to block funding with the institutional support and oversight of the NDIA could address key issues affecting particular disability populations such hard to reach populations or

| people living in rural or remote areas of Australia as well as ensure access to Provider of Last Resort. | |
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7. Workforce readiness

AFDO is worried that the level of workforce demand is outstripping the workforce capacity and supply. This barrier to the provision of disability support will be particularly felt in vulnerable groups including people with disability living in rural and remote communities, Indigenous Australians with disabilities, people with disability experiencing complexity around having their needs met and people with disability who are vulnerable and living on the fringes.

The Productivity Commission has identified the relaxing of operational guidelines to allow for the payment of informal carers through NDIA managed plans. Consultations with the AFDO membership revealed differences of opinion in response to the possibility of this option.

Half the membership supported the relaxation of the operational guidelines to allow for the payment of informal carers citing it as an expression of the principle of choice and control. Member organisations from this group stated that in rural and regional areas informal carers may already be providing disability support in the absence of available disability support providers. This option would acknowledge that relationship, resource it and may allow for the person with a disability to continue to live at home with family rather than having to move away from all that they know and trust in order to receive disability support.

AFDO members who supported this idea all went on to identify a number of issues that would need to be addressed for this option to be safe and successful. Issues identified included:

- The need for a code of conduct to be developed that would outline expectations regarding behaviour, obligations and responsibilities
- The need for financial oversight to be retained by the Agency
- The opportunity to have access to conflict resolution processes
- Being linked into disability support peer networks

Another significant group of AFDO members do not support relaxing the guidelines to allow for the payment of informal supports calling instead for the return of block funding to agencies in certain circumstances where there may be thin markets in rural and remote areas or the requirement for specialist disability support for particular group such as Indigenous Australians with disability.

AFDO Member agencies in this group were particularly concerned about the possibility of paying family members given their lived experience of disability was that it was family members who acted as significant barriers to the realisation of the dreams of a person with a disability. One AFDO member cited the issue that people with acquired brain injury often have co-morbidities around mental health, drug and alcohol and criminal justice. These co-morbidities add to the complexity of supporting a family member and could place intolerable burdens on family relationships.

Finally one Member organisation suggested that the two positions were not mutually excusive and that both block funding and a relaxation of the rules to allow for informal carers to be paid was needed to respond to the complexity of the situation particularly in rural and regional remote areas of Australia.

Finally AFDO supports the National Disability Services call for industry development plan and that the development of such a plan includes people with disability, their families and carers. An industry development plan needs to include actions, timeframes, accountabilities and monitoring arrangements.

8. Participant readiness

People with disability are the heart and soul of the National Disability Insurance Scheme – they are the schemes touchstone. It is because of people with disability, their patience, their trust and their confidence in the community to do a better job in providing disability support that this chance cannot go by without involving them in every aspect of the design, implementation and use of the NDIS. As such participant readiness is a central to its success. Indeed it seems somewhat a 'stating of the obvious' to say so.

AFDO supports the statement by the National Disability and Carers Alliance in their submission to the Productivity Commission that "insufficient attention has been paid during the transition years to building the demand side of the market".

Exercising choice and control is built on the experience of the opportunity to do so. The Disability Reform Council acknowledged in 2015 that people with disability may require additional support to do so. AFDO believe that this is especially so for those who are vulnerable, those who live on the fringes of society and those who's lived experience of disability is complex. People with disability are likely to turn to those that they trust whether, that is an individual or an agency. Consequently the Commission is right in stating that Disability Support Organisations could play an important role in capacity building around participant readiness. AFDO would extend that to include both individual and systemic advocates and informal supporters.

Building the capacity of people with disability to exercise choice and control can take many different forms and AFDO note the development of the eMarketPlace as a good example of that. AFDO also believes that NDIS information in accessible formats is crucial: accessibility could include Easy English or access to captioning. Peer led advocacy is another key strategy and has the added benefit of involving people with disability as providers not just participants of the scheme. AFDO remain concerned about how the funding for this work will occur and from where the funding of peer led advocacy will come from.

"It has made me feel much more confident about dealing with the NDIS"

Participant from an AFDO NDIS Disability Loop Workshop

Support Coordination is an effective mechanism by which people with disability can exercise choice and control, particularly people with a cognitive impairment. The aims of support coordination are also appropriate; that is to provide targeted support but to provide support in a manner that increases independence and capacity. Some people with cognitive impairment may always require support coordination but many people with a cognitive impairment are quite capable of undertaking tasks to enable their exercising of choice and control once shown how.

AFDO are alarmed by the news that New South Wales will cease funding to disability advocacy agencies and programs in this financial year. In the absence of a clearly

articulated National Disability Advocacy Program alongside the clearly understood need that some people with disability will require extra support to access and navigate the scheme such a move seems unreasonable. Continuity of support regarding advocacy must continue particularly in the absence of implementing the Quality and Safeguarding Framework.

"We have become more aware of our rights, responsibilities, and needs"

Participant from an AFDO NDIS Disability Loop Workshop

AFDO supports the view by the National Disability and Carer Alliance that disability support organisations could play a greater role in capacity building. Advocacy will continue to be crucial in ensuring access to the scheme and financial and programmatic certainty needs to be provided in order for organisations to fulfil this task. Individual advocacy and systemic advocacy are both fundamental to the success of the scheme.

9. Governance

AFDO would like to see a national scheme which includes Western Australia

The plethora of issues facing the NDIA particularly and the disability sector generally cannot be underestimated. People with disability live day to day with the impact of those issues. Appropriately funded and resourced work needs to continue in order to roll out of NDIS to ensure that the impact of issues on those who are participants of the scheme and those who are still waiting to access the scheme is addressed.

AFDO does not support a slow-down of the scheme. AFDO believe the NDIA needs to be appropriately funded and resourced to do the job it was designed to do. Initial reports from people with disability are that the NDIA is life-changing. How can it be justified at this stage that some people with disability can have that life-changing experience whilst others will have to wait longer than expected.

The Productivity Commission has identified a range of recommendations and strategies that should be adopted and implemented before consideration is given to any possible slow-down of roll out. AFDO believe that with the right amount of funding and resourcing these strategies and recommendations address many of the concerns raised and prevent any need for slow-down.

AFDO believe that people with complex needs do require more attention and a more nuanced approach to planning for that group needs to occur. But such focus should not mean that transition has to be slowed in order to achieve that. Appropriately funded and appropriately resourced, targeted interventions are what is needed.

The NDIS is a shared national resource and as such AFDO supports the current COAG governance arrangements.

10. Funding arrangements

AFDO support the view that the NDIA should be given greater flexibility on how it allocates resources including supporting the recommendation that the staffing cap on the NDIA should be lifted

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.

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 be held to account for the operation of the scheme and appropriate action taken.

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.