



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

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 Disabilities ACT

Enhanced Lifestyles

Deafness Forum of Australia

People with Disability 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.