

National Disability and Carer Alliance

Response to Productivity Commission NDIS Costs Inquiry Position Paper

July 2017

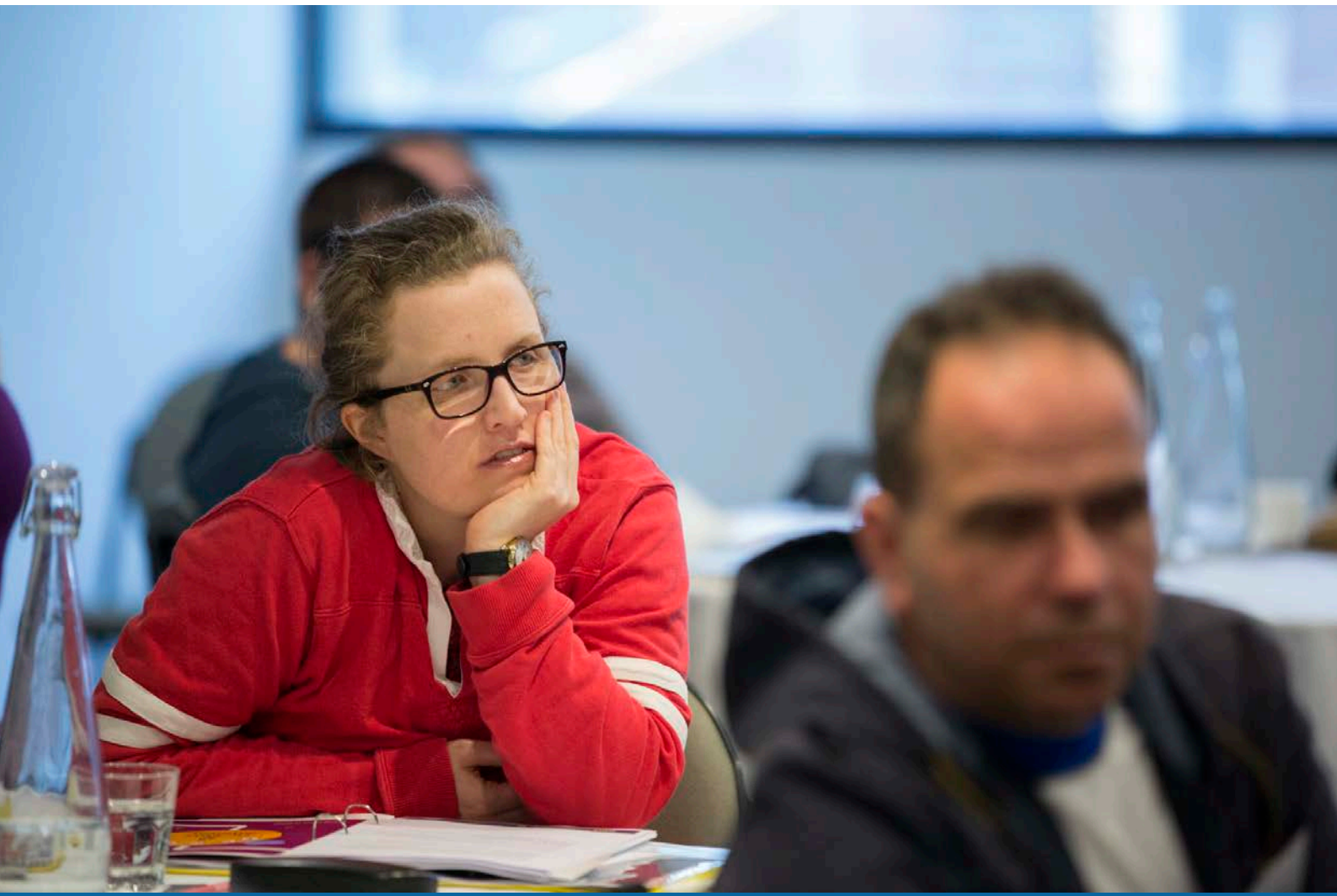


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Who are we?

The National Disability and Carer Alliance was established in 2009 by three peak organisations in the disability sector – the Australian Federation of Disability Organisations, representing people with disability; Carers Australia, representing families and carers; and National Disability Services, representing specialist disability service providers. These three organisations had for many years advocated for much needed reform of the disability support system. But they had done so from the perspective of their membership base, and had not worked collaboratively together to push for systemic change.

By 2009, the idea of the National Disability Insurance Scheme (NDIS) had come to public prominence. The three organisations realised the introduction of a social and economic reform the size of the NDIS would only be possible with a common voice and collective action. The three organisations began to meet to establish a common agenda, and the National Disability and Carers Alliance was born.

The primary activity of the Alliance in its early years was the creation of the Every Australian Counts (EAC) campaign. The campaign was critical in mobilising public and political support for the NDIS. Once Federal and State governments committed to the introduction of the NDIS, the Alliance moved into providing policy and implementation advice.

The three founding members of the Alliance have recently been joined by an organisation with specialist expertise in mental health, Mental Health Australia. This move has further strengthened the Alliance and reflects the ongoing challenge to ensure the scheme is responsive and effectively supports people with psychosocial disability.

As the NDIS moves towards full implementation, there are a number of outstanding policy and operational issues that require careful and considered attention and resolution. There is also renewed public debate about the operation of the scheme and its sustainability in the current fiscal environment. There is also a need to continue to build public and political understanding of the role of the NDIS within the National Disability Strategy. The strength of the Alliance is its ability to articulate a coherent common view across the disability sector to address all of these issues. Through its policy and implementation advice, the aim of the Alliance is to ensure the original vision of the NDIS is realised, and the scheme lives up to its promise to transform the lives of Australians with disability.

The members of the Alliance are:

- Australian Federation of Disability Organisations
- Carers Australia
- National Disability Services
- Mental Health Australia

The independent Chair of the Alliance is Mr Gerry Naughtin, CEO of Mind Australia.

Response to Recommendations and Requests for Information

How is the Scheme Tracking?

The Alliance would like to preface its remarks by restating its unwavering support for the National Disability Insurance Scheme. The National Disability and Carers Alliance was instrumental in the campaign for the introduction of the NDIS and remains convinced it is the only model able to deliver outcomes for people with disability in a sustainable manner. The Alliance remains committed to the vision of the NDIS and is determined to see it implemented in full. The commentary and suggestions that follow are offered in the interests of making sure the scheme achieves its full potential and delivers on its promise for people with disability. They should not be misinterpreted as any reduction in support for the scheme – in contrast, they are made in the hope the original intent of the scheme can finally be realised.

In public policy terms, the NDIS is still in its infancy. And despite the challenges that have been experienced over the last few years, it has already made a significant difference to many people's lives. The fact that it is broadly on time and on budget is noteworthy - even a passing comparison to other large government initiatives suggests this is no small achievement. Given the size and complexity of the scheme, implementation issues were always to be expected. And while many positive outcomes have been achieved, it must be noted that the implementation issues have compromised outcomes for the very people the scheme was designed to assist.

The short answer to the question of how the scheme tracking is that even in these early days, outcomes for many participants are significant. There is ample evidence that the scheme has delivered much needed support to many participants and is helping them to achieve their goals. This appears to be particularly true for people who did not receive any or received only limited support under the previous system. For this group of people, the scheme has already been transformational.

But positive experiences are not universal. Many participants report poor experiences of planning – both in their interaction with planners and with their final plans, which do not reflect discussions or accurately capture need. And as the Commission notes, many participants report feeling ill-prepared for both the planning process and the task of translating their plans into action once finalised. The Alliance is particularly concerned about the negative experiences and poor outcomes for three groups of people - people with psychosocial disability, people who have complex needs or who are hard to reach and people who have no one to assist them to navigate complex NDIS processes. For these three groups of people, outcomes have been much more mixed and require particular attention.

Scheme Supports

Information request 4.1

The Alliance agrees with the Commission that there has been inconsistency, and in some cases inequity, in the ways in which the guidelines around reasonable and necessary have been interpreted and implemented by staff involved in planning. We would therefore support any and all attempts to provide greater clarity in the NDIA's operational guidelines. The Alliance would also support improved training for planners – whether Local Area Coordinators (LAC) or National Disability Insurance Agency (NDIA) staff. And given the considerable reliance on LACs for planning and implementation, we would also support greater oversight by the NDIA of LACs to ensure consistency and fairness.

Draft Recommendation 4.1

The Alliance recognises that this transition period is a unique period in the life of the NDIS. Never again will large numbers of people be required to move into the scheme in such a short period of time. The Alliance understands that difficulties were to be expected given the numbers of people involved and the complexity of the task at hand. However it must be said that there continue to be serious implementation issues which, if left unaddressed, will compromise the vision of the scheme and leave some people with disability, their families and carers worse off. This is unacceptable and cannot be allowed to continue.

Collectively and individually, we are concerned that the only metric the NDIA is currently being judged upon is volume. In the headlong rush to meet both time and volume commitments outlined in bilateral agreements, insufficient attention appears to have been paid to quality. This is compromising the vision of the scheme and undermining public confidence in its effectiveness. The Alliance wants to see the scheme deliver improved outcomes for people with disability – not simply meet targets outlined in intergovernmental agreements. The scheme's success must be measured by how well it supports people with disability – not how well it serves governments. We are increasingly concerned that both the timetable and limited resourcing are dictating process, rather than the other way around. We want and expect to see an improved planning process deliver better outcomes for people with disability – and believe both these things can be achieved in a timely manner. We do not agree that time and quality are antithetical – with commitment and resources both can be achieved. We do not accept that there must necessarily be a choice between getting it right and getting it done on time – we expect all governments and the NDIA to step up and deliver a quality scheme in a timely manner.

We support the Commission's recommendations regarding planning. We agree that planners need improved training and greater oversight to ensure consistency and improved outcomes. We support the creation of teams of planners with specialist expertise. We believe this is particularly important for people with psychosocial disability, and people with complex support needs.

The Alliance also agrees that greater use needs to be made of organisations in the sector with specialised expertise. Consumer-led organisations that specialise in particular disabilities have invaluable experience and expertise that currently remains under-utilised by the NDIA. The NDIA should draw on this experience in both the development and implementation of training for planners. But beyond planning, this experience could be invaluable in resolving implementation issues more generally – such as the development of reference packages, in the development further guidance on reasonable and necessary in the operational guidelines, or in effective communication to particular groups of participants.

Specialist organisations could also provide invaluable assistance with pre-planning. While we agree with the Commission that greater attention needs to be paid to pre-planning, we do not agree that having LACs on ground six months in advance will help resolve the issue completely. There does need to be clearer communication with participants about what to expect from NDIS processes. But it also needs to be from trusted sources, needs to be in accessible formats and it needs to be in plain language that everyone can understand. In all of these things organisations with specialist expertise could be of assistance to the NDIA. Given the significant funding stress a number of these organisations are currently experiencing however, some attention would need to be paid to how this work would be resourced.

The complex and labyrinth governance arrangements currently in place for the NDIS have acted as a barrier to effective and timely two-way communication between specialist expertise in the sector and those responsible for implementing the NDIS. Consultations with people with disability, their families and carers and the organisations that represent them have been ad-hoc and inconsistent. While the NDIA has established some good mechanisms – such as the Mental Health Sector Reference Group or the Independent Advisory Council's Intellectual Disability Working Group – they are not consistent across all groups and their effectiveness is limited by their mandates. They can only, for example, consider implementation issues that rest with the NDIA and cannot consider broader policy issues which rest with government. This is an issue that the Alliance believes should be resolved as a priority.

Boundaries and Interfaces with the NDIS

Draft Recommendation 5.1, 5.2 and 5.3

Information Linkages and Capacity Building (ILC) is one of the foundation stones of the National Disability Insurance Scheme. ILC is expected to carry out three important tasks:

- Provide information, linkages and capacity building for people with disability regardless of whether they also receive a package of individual supports;
- Carry out capacity building in mainstream and community supports and services; and
- Provide support for people with disability who are not eligible for an individual package of support.

As the Commission has observed, the success of ILC depends heavily on the effectiveness of mainstream supports and services upon which all people with disability – whether eligible for an individual NDIS package or not - will continue to rely. The effectiveness of information and referral services funded through ILC is in turn dependent on the availability, quality and responsiveness of services to which people are referred. This interdependence is reflected that information and referral and capacity building for mainstream services are two of the five activity streams identified in the ILC Policy Framework.

An effective Tier 2 is key to good outcomes for people with disability, their families and carers. It is also key to the sustainability of the scheme. Without an effective second tier, people with disability will be forced to test their eligibility for the scheme in order to receive necessary support. This would be a perverse outcome.

The Alliance agrees that it is a false economy to ration ILC through transition years. We agree with the Commission that the full amount of funding should be made immediately available to support the transition to full scheme. But we would also argue that the funding for ILC is insufficient to properly support the effective implementation of the scheme. The policy intent of ILC far outstrips the budget allocated. There are insufficient funds to carry out the three expected tasks and meet all objectives.

We do however acknowledge that budgetary constraints will have an impact on any potential increase in funds for ILC. One possible solution is to allow the NDIA greater flexibility in how to use the total budget allocated to the scheme. This would allow the NDIA to determine the most effective and efficient use of resources allocated and ensure an appropriate balance between package costs and ILC.

The Alliance agrees that the outcomes from ILC should be monitored over time. This transparency would be particularly important in the event that the NDIA were given

greater budgetary control and were able to exercise greater flexibility in how it manages its budget allocation.

But beyond greater resources and improved monitoring, the Alliance would also argue there is a pressing need for greater research and evidence to determine who should be supported through ILC and what they need. ILC has a particular responsibility to meet the needs of people who are not eligible for an individual NDIS package but who nevertheless have support needs. But while this has been articulated many times in multiple documents both from COAG and the NDIA, there is a paucity of evidence about who this group is, what their particular support needs are and how they may be best met. Again this is another area where specialist organisations in the disability sector may have evidence and experience that may be invaluable in determining the size of the population, their support needs and how they may be best met. This important work will also determine the extent to which further funding may be required.

The Alliance agrees that there should be greater transparency around continuity of support. All organisations involved in the Alliance have previously argued that the lack of clarity about which programs have been transitioned into the scheme has left groups of people vulnerable and without support, has undermined and/or jeopardised existing providers and undermined public confidence in the scheme.

As the Commission notes, these issues have been most keenly felt in the mental health sector. But the Alliance is also concerned that a number of programs that currently support families and carers have also been transitioned into the NDIS without reference to what will happen to people if family members do not receive support from the NDIS.

The Alliance is dismayed that groups of people with disability have already been left vulnerable or without support as programs have transitioned into the scheme. We are further concerned that any attempt to slow down transition will exacerbate these issues and leave even more people without support. This would be completely unacceptable.

Greater transparency and improved reporting will assist in reducing the current confusion and improve planning, both for people with disability and for providers. It will also allow for a more timely response should further gaps emerge. But improved transparency alone is insufficient. We reiterate our call for greater evidence to understand who in particular is being impacted, what their needs are and how they may be best supported. This will allow governments and the NDIA greater clarity about which needs should be met through ILC and which remain outside the scheme and need to be met by Federal or State and Territory governments.

Beyond improved reporting, there also needs to be renewed commitment by all three levels of government to achievement of the goals outlined in the National Disability Strategy. Attention to the goals outlined in the NDS will improve outcomes for all people with disability, regardless of whether they are eligible for an individual funding package through the NDIS. Lack of access to mainstream services, poor service response and the failure of communities to address inclusion affect all people with disability. While

consistent reporting on standard indicators would ensure greater transparency and assist with comparison across jurisdictions, additional reporting alone would be insufficient. Commitment to timely action with appropriate resources is necessary to ensure there is finally some progress towards achievement of the Strategy's goals.

Provider Readiness

Draft Recommendation 6.1

The Alliance agrees with the Commission that there is an inherent conflict of interest in allowing the NDIA to continue to set prices while they remain responsible for scheme sustainability. The Alliance therefore agrees with the Commission's recommendation to establish an independent body responsible for price regulation.

Beyond establishing an independent regulator, the Alliance believes there must be greater transparency regarding the reasonable cost model which underpins the prices set for reasonable and necessary supports. The cost model must be based on evidence and the assumptions which underpin it grounded in the everyday realities of service provision. The NDIA to this point has been reluctant to be more transparent about the assumptions of the model or to test them against data collected from existing providers. Assumptions, for example, about allowances for leave, training and cancellations must all be further tested to ensure they are consistent with best practice. Greater collaboration with the sector must be a feature of any model of price regulation.

Workforce Readiness

Draft Recommendation 7.1

The Alliance shares the Commission's concerns that the fragmented nature of roles and responsibilities for market stewardship and workforce development between governments and the NDIA have hindered the development of a comprehensive and coordinated approach to the successful transition of the sector to the NDIS. The members of the Alliance therefore reiterate the call by National Disability Services for a clear and coherent industry development plan to support sector development. The stakeholders providing critical input into this plan must include not only governments but also providers and people with disability, their families and carers in order to ensure it reflects the needs and aspirations of all. Unlike current arrangements, the plan should also include actions, timeframes, accountabilities and monitoring arrangements.

Participant Readiness

Draft Recommendation 7.1

The members of the Alliance welcome the Commission's focus on participant readiness. The Alliance believes there has been insufficient attention paid during the transition years to building the demand side of the market. While the Commission's recommendation regarding the e-market is welcome, it alone is insufficient to ensure people with disability, their families and carers have the knowledge, skills and resources they need to make the most of opportunities presented by the NDIS and drive change in the market.

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 appropriate services and negotiate the terms of engagement. Given the striking lack of opportunity for choice and control in the past, it will take significant investment and a considerable period of time to build the capacity of people with disability, as well as their families and carers to become those consumers.

The Alliance agrees with the Commission's suggestion that disability support organisations could play an important role in capacity building. We would further suggest user-led organisations, with their unique blend of experience and expertise, could play a particularly important role. People with disability and their families and carers value the independence of these organisations and see them as a trusted source of information and support. The important role peers can play in working alongside people with disability and their families to imagine new possibilities and to make the most of new opportunities cannot be overstated. But while all are in agreement about the value and importance of this work, the question of how and where the funding for this work should be drawn remains unresolved.

The Commission also highlights the important role advocacy organisations could play in capacity building. It should therefore be noted that the future of the National Disability Advocacy Program remains unresolved. While funded organisations have been given an extension of funding for one year, the uncertainty over the future of the program has undermined forward planning and plagued the sector at a time when demand remains at extraordinarily high levels. The future of state based funding for advocacy programs also remains uncertain. In New South Wales for example, funding for information and advocacy services will cease next year. Advocacy organisations cannot be relied upon to carry out these important tasks if their future is in jeopardy.

Beyond the current limitations to individual advocacy, there has also been insufficient attention to the important role systemic advocacy can play in the successful implementation of the scheme. As Mental Health Australia highlights in their submission to the inquiry, neither the NDIA nor Federal and State governments appear to have given sufficient consideration to the broader eco-system in which the NDIS sits. The

members of the Alliance would expect this important part of system architecture to be considered by both governments and the NDIA as a matter of priority.

Funding Arrangements

Draft Recommendations 10.1 and 10.2

The Alliance does not want the NDIA to evolve into a complex and costly bureaucracy. The creation of an independent statutory body rather than having the scheme run within an existing Commonwealth department was a central feature of the campaign for the NDIS. The Alliance believes people with disability, their families and carers are best served by a cost effective, flexible and nimble operating agency that has the skills, knowledge and resources to respond quickly and effectively as they emerge.

Unfortunately at moment it is very clear that the NDIA has significant limitations in both capability and capacity. Both need to be addressed as a matter of priority. Capping of staff numbers and maintaining unrealistic expectations regarding the operating budget seem particularly short sighted given the size and complexity of the roll out of the scheme. It is also evident that some of the decisions made by the NDIA during transition have been driven by resource limitations. This is a perverse outcome in an insurance scheme. While the bulk of the NDIS funds should deliver support for people with disability and the NDIA should be held accountable for how funds are utilised, some flexibility in the early years of the scheme should be given to ensure this complex scheme is implemented effectively.

Draft Recommendations 10.3

The Alliance supports the Commission's recommendation that in-kind arrangements should cease during transition and should not be a feature of full scheme. The Alliance agrees that in-kind arrangements with State and Territory governments have compromised scheme flexibility, are inequitable for providers and have reduced choice and control for participants.