National Disability
and Carer Alliance

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Australia

National Disability and Carer Alliance

Submission to the Tune Review

October 2019

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 Carer 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.

Having played a critical role in securing the introduction of the NDIS, the members of the Alliance are unwavering in their support for the scheme. All have had the opportunity to see the incredible difference it has made to the lives of participants and their families. We are also aware, however, of the significant implementation challenges in rolling out a scheme the size and complexity of the NDIS. We are all too aware of the impact some of these challenges have had on people with disability, their families and carers, as well as providers. We are anxious to make a constructive contribution to their resolution. The strength of the Alliance is its ability to articulate a coherent, common view across the disability sector and provide meaningful and practical advice and assistance to both the NDIA and governments. 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 Ms Leah van Poppell. Ms van Poppell is also CEO of Women with Disabilities Victoria.

Introduction

The Alliance believes the NDIS Act is, for the most part, sound and requires limited change or amendment. At the time the Act was drafted, the disability sector was consulted and involved (although somewhat constrained by the tight timeframes required to ensure the scheme was operational on July 1, 2013). Even given these limitations, the legislation for the most part strikes an appropriate balance between providing strong foundations for the effective operation of the scheme and being so prescriptive as to hamper flexibility and responsiveness. The Alliance would therefore be particularly concerned about any amendments that would weaken important principles or critical protections offered participants and their families. These were carefully considered at the time of drafting, have offered critical protections as the scheme has rolled out and should not be revised.

It is our collective view that the problems experienced by people with disability, their families and carers as well as providers are not the result of inherently flawed legislation but are instead a product of the way the scheme is being implemented on the ground.[1] The problems lie in the way the Act and Rules are being interpreted and the policies, procedures and practices that are adopted as a result. They are also in part a result of the way in which the National Disability Insurance Agency (NDIA) has been resourced.

Two examples to illustrate this last point. The first relates to the way in which NDIS participants may use their funding. The principles of choice and control are fundamental to the scheme. They are supposed to be central pillars, inherent in the very DNA of the scheme. And yet the way participant plans are currently constructed undermines these two core principles. At the moment funding is locked in three "buckets"- core, capacity building and capital. While core funding can be used more flexibly, capital and capacity building may not. And perhaps most importantly, funding cannot be moved between categories. This category construction is not a feature of the legislation. It is simply operational policy. And yet this lack of flexibility is one of the most important sources of stress, frustration and anger with the scheme. In our view this lack of flexibility is also one of the factors driving the high number of plan reviews.

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[1] There is one notable exception to this statement in the case of psychosocial disability. This is explained in the joint submission to this review from Mental Health Australia, Community Mental Health Australia and the Mental Illness Fellowship of Australia.

Another example is the NDIA's reliance on the concept of a "primary disability". There is no mention of the requirement for identification of a primary disability in the legislation. And yet the decision to base the operation of the scheme around this concept is one of the issues people with disability and their families and carers find most frustrating. The scheme was never intended to be based on diagnoses but always on functional impairment. The decision to require participants to identify a primary disability not only goes against scheme intent, it has a number of practical consequences. The first is that it forces people to choose – many participants have more than one disability. Which one is primary depends on many factors including timing, circumstances and environment. The one that has a greater impact on may vary from day to day, or from circumstance to circumstance. Identification of a primary disability also takes no account of the way multiple disabilities may interact. The decision to commit to primary disability means resulting reference packages and plans take no account of all of these important factors. It means people can miss vital support. Again this is an administrative issue rather than a legislative one, but its impact on participants and their families is significant.

You will note therefore that this submission contains very few recommendations to amend the legislation. It instead contains many recommendations about ways NDIS policies, procedures and practices could be improved to ensure good outcomes for people with disability.

We are sure the problems identified in this submission will be the same as the problems identified in many other submissions by individuals and organisations. We are also sure the solutions we identify will also be the same or similar to solutions identified in other submissions. People with disability, their families and carers and service providers have been the saying the same things for some time now – unfortunately with limited impact. The problems are well known. The solutions are well known. What has been missing is concerted and resourced action. We sincerely hope this review at last provides much needed impetus for change. Reform is desperately needed if the scheme is truly to achieve its original vision and deliver on its promise to people with disability and their families and carers.

Participant Service Guarantee

The Alliance supports the introduction of legislated timeframes for key NDIS processes. We note that at the moment the most significant process with a legislated timeframe is the access to the scheme. In the last several years the NDIA has routinely failed to meet this deadline. We do note however that in recent months the NDIA has made a significant effort to improve wait times and now has formally reported there is no longer a backlog of access requests waiting to be reviewed. This is welcome news.

We also note that, unfortunately, legislated timeframes are only being considered at the end of scheme transition – when the vast majority of participants are already in the scheme. Nevertheless, the Alliance believes their introduction will serve future participants well – as well as give current participants more certainty about the way the scheme will operate in the future.

PSG principles

In addition to legislated timeframes, the Alliance supports the introduction of principles to underpin the Participant Service Guarantee.

Before we move onto suggested principles, we note that the language used to describe these principles is neither plain nor simple. Once again the language used reflects the overly bureaucratic nature of the NDIS. If principles are to be introduced they should be described in accessible, everyday language that everyone can understand. How can people decide if the NDIA is living its principles and delivering on its promise if the principles cannot be easily understood?

Therefore, while we support the majority of the principles outlined in the discussion paper, we would respectfully suggest that before they are legislated they are rewritten in plain language. The selected terms should then be tested with people with disability and their families for accessibility and understanding. Given the very short nature of this consultation period, we have not had an opportunity to do this kind of testing within our respective membership groups. We would however be very pleased to do so once terms have been selected.

Timely

The Alliance supports this as a principle. Lack of timeframes and the length of time it takes for many of the Agency's decisions to be made is one of the principle sources of frustration and disappointment with the scheme in its current form. While acknowledging the significant efforts the NDIA is making to clear someone of the current backlogs, we feel compelled to say it is not before time. There is, for example, now a workaround for children who have been waiting for early intervention for longer than 50 days. While this represents a practical interim measure and reflects the importance of the early part of early intervention, it is an inferior substitute for a comprehensive planning process. Unfortunately wait times for that process are still lengthy. Although the NDIA are working through the considerable backlogs in approvals for equipment, for most people the wait has already been too long.

We also feel compelled to say that one of the most important ways to make things quicker would be to simplify complicated, complex and lengthy processes. We note that simple, easy, straight forward, uncomplicated, easy to navigate processes and procedures is not one of the principles suggested in the discussion paper. And yet we think simple and quick are both equally important and interrelated. Ease of use is a principle that should be considered in any PSG and is conspicuous by its absence here.

Engaged

Again here we note that while the term “engaged” is regularly and routinely used in NDIS land, it is not a term people routinely used in the real world. Who, for example, describes a trip to the movies as “engaging in the community” or “accessing the community”? That is however how it is routinely described within the NDIS.

And again whichever way you describe it, the track record of the NDIA is poor. Engagement has been patchy and flawed on two levels – both for participants and their families and carers as well as with organisations in the disability sector. At times it has represented best practice – and at other times been non existent. And everything inbetween.

People with disability and their families and carers routinely report that despite the rhetoric, the scheme does not appear to be built around them, their experiences or their needs. In stark contrast, the scheme appears to be driven by the dictates of bureaucracy. People with disability and their families report that they are not engaged with – they are talked to or at. They are not part of the process of implementing the scheme – they feel little more than numbers to be processed, KPIs to be met. They are beyond frustrated that their valuable experience and expertise is routinely ignored while highly paid consultants deliver “solutions” that will not work for them. People with disability and their families feel a strong sense of ownership of the scheme. They fought hard for it. They built the political and public support for it from the ground up. They want to be partners in its delivery. But they feel sidelined by government and corporate priorities that do not align with their own.

We acknowledge that the NDIA’s mechanisms for talking with people with disability and their families have been increasing over time. There are, for example, many more reference groups than during the early years of the scheme. But unfortunately we feel compelled to say that their addition appears to be ad-hoc rather than planned, often in response to pressure, and their selection processes for inclusion opaque in nature.

People with disability and their families and carers as well as service providers want and expect the NDIA to commit to true co-design. People want and expect the scheme to be genuinely delivered in partnership. They are not satisfied with consultations once decisions have already been made elsewhere however well intentioned.

This principle should be true both of people with disability and their families and carers as well as the organisations that represent them. The NDIA makes much of the fact that during the pathway review they spoke to 1000 participants and/or family members of participants. We hasten to point out that review was more than 12 months ago. The members of the Alliance and Every Australian Counts speak to thousands of people across the country day in and day out. As a result, our organisations have valuable on the ground experience and expertise to draw on that we would be more than happy to share in the interests of improving the operation of the scheme and improving outcomes for people with disability.

Expert

The members of the Alliance would like to acknowledge the many passionate, dedicated and skilled staff at the NDIA who are doing their absolute level best to roll out a new scheme under extremely difficult circumstances. Our acknowledgement would also extend to some stellar Local Area Coordinators and Early Childhood Early Intervention (ECEI) partners who routinely go well and truly above the call of duty to assist people and their families.

But unfortunately the members of the Alliance also routinely receive feedback from people with disability, their families and carers about experiences with LACs, planners and NDIA staff which range from poor to simply appalling. While much is made of the number of staff required to implement the scheme, people would like to much more attention paid to recruitment and training. People with disability and their families and carers suggest training should give staff a solid foundation of disability knowledge, including different kinds of disability, an understanding of disability rights and the social model of disability as well as development of key skills such as active listening, developing rapport and how to have an empathetic conversation to elicit key information. They would like the training to help LACs and planners understand the significant power imbalance that exists during the planning process and to understand better how the process is experienced from the other side of the table.

People with disability and their families and carers understand that LACs and planners cannot reasonably be expected to know everything about every kind of disability. But they do expect them to have a good baseline knowledge, as well as access to up-to-date specialised help and resources to assist them when they need it. LACs and planners need more than their instincts and Google to assist them in the incredibly important task they have been entrusted with.

And while the Alliance members agree that staff need to be appropriately qualified, have relevant experience and receive comprehensive training to support them in their vital role, we do not support use of the word “expert” to describe these qualities. In our view the positioning of LACs and planners as “experts” is one of the reasons the scheme has become so adversarial.

People with disability, their families and carers consistently report that they feel their experience is dismissed, that they are not listened to and their perspective is not respected. They feel that their judgement is substituted for the judgement of others – others who do not live in their world or walk in their shoes. At worst they are completely disbelieved or treated as if they are attempting to game the system. People strongly feel this fundamental lack of respect for their experience and authority is one of the reasons the planning process has become antagonistic and adversarial. We are concerned use of the word expert will only further reinforce this approach rather than act to counter it.

Valued

People with disability and their families and carers judge the success of the scheme by two measures – the outcome they were able to achieve with the funding with which they were provided as well as their experience on the way through. Unfortunately even those who are delighted with the outcomes they have been able to achieve report poor experiences on the way through. Far from being valued, experience of interactions with the NDIA vary significantly with people reporting not being listened to, dismissed, ignored and disrespected. Worse still, many report that they were made to feel like they were somehow greedy or even lying in an attempt to receive more than was really necessary. The process of describing yourself or your family member in the worst possible of terms in order to secure support is one of the reasons people fought so hard for the introduction of the NDIS. For many to find themselves here again is a profound disappointment and a source of deep resentment and anger.

The members of the Alliance would therefore respectfully suggest that the word “valued” is not an accurate reflection of the way in which people want and expect to be treated. What people want is to be listened to, to be treated fairly and to be respected. This is not captured in the word “valued” which appears unfortunately to be more than a little patronising.

Connected

Again, unfortunately this is an area where the NDIS has a poor track record. Six years into implementation and we are still trying to figure out how the scheme works with other systems. And like a number of other areas in the scheme, this area has not been served well by the complicated governance arrangements for the scheme. We would like to acknowledge however that there is now considerable work now underway and that there have been some very welcome announcements recently – for example in the areas of justice and health and the recently announced work to address issues between the NDIS and mainstream mental health systems.[2] Unfortunately in a number of other areas – such as transport – much work remains to be done.

And while we are pleased to see that progress is being made, we wish to sound one note of caution about recent announcements. We would be very concerned that in order to expedite resolution, costs may be transferred to the NDIS which should be more appropriately met by other levels of government. If this were to happen it could jeopardise the future sustainability of the scheme.

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[2] See Communique for Meeting of the COAG Disability Reform Council – Sydney – 9 October.

The NDIS is but one stream of the National Disability Strategy which outlines a vision for Australians with disability to be included in as equal citizens in every aspect of social economic, cultural and civic life. If we are ever to close the gap in life outcomes between Australians with disability and those without, it is absolutely essential that every level of government fulfil its obligations to people with disability as equal citizens. The NDIS was never intended to work in isolation. Nor was it intended to meet every need a person with disability might have. Nor was it intended to be a mechanism for cost shifting. While we are anxious for boundary issues to be resolved, this should not be at the cost of proper consideration of roles and responsibilities (no pun intended). The principle should be that the scheme remains person centred and the person receives the support they need – the administrative wrangling of who pays for what should be done back of house. But it should be done nevertheless.

Decisions made on merit

Lack of consistency and transparency are two of the most common complaints received about the operation of the scheme. In fact it is almost impossible to tell if decisions are made on "merit" as the Agency is not compelled to give any detailed explanation for their decisions. If explanations are offered – for example in a letter to notify a person that access to the scheme has been denied – they are general in nature only. It should not take an FOI request to uncover why decisions have been made and the reasons for them. Participants and their families and carers routinely report that unless a helpful LAC is able to shed some light, they remain in the dark about which requests were approved, which were not, and what the possible reasons may be. This is crucial information as it informs what a participant may choose to do next. Was a request refused because it was not considered reasonable or necessary or because there was insufficient evidence to make the decision?

The inconsistency and lack of transparency extends beyond participant plans to decision making processes and procedures within the Agency itself. For example, it is not always clear that the NDIA modifies or amends their own procedures and processes to take account of specific AAT decisions. This suggests that decisions that were made on their "merits" at the AAT do not always result in change beyond an individual participant.

It is also worth noting that the NDIA has only begun to release more comprehensive data on outcomes for participants in the last year. And again while this has been a very welcome development, the data that has been made available is limited in its use. It is aggregated in ways predetermined by the Agency and cannot be "cut" in different ways to ensure more comprehensive analysis.

Accessible

Again, we would like to acknowledge the considerable efforts the Agency has gone to, particularly recently, to improve accessibility. But we also note six years on we are still trying to get to the bottom of why the Agency continues to send letters to people who are vision impaired in formats they cannot read.

There is unfortunately no way the scheme in its current form could be described as accessible. In fact, as people with disability and their families and carers routinely report, even those who are well educated, well resourced, experienced in navigating bureaucratic systems and have someone giving them a hand, struggle to make their way through the complicated maze the scheme has become. For those who don't have those advantages – who don't have family in their corner, or who have complex needs, or who come from non-English speaking background or from an Aboriginal or Torres Strait Islander background, or who have good reason to be suspicious of government, or who don't have access to an advocate to assist – these are the people for whom the NDIS is failing. In fact in many cases it does not even make it out of the starting blocks.

Again, we feel compelled to make the point about the benefits of accessible universal design – simple, uncomplicated, easy to navigate processes would improve the experience for everyone, including those who are most disadvantaged. And we would be quick to add, the Agency's own staff and partners.

So what should happen if NDIA does not meet its own standards?

The Alliance acknowledges how difficult it is to legislate for values and principles. It is even harder to enforce. As we noted in our introduction, it is difficult to legislate and enforce culture. Reporting to the public or to Parliament is helpful for transparency but so far has proved reasonably ineffective in driving change. We note that in fact the Agency already regularly reports – it provides Quarterly Reports, Annual Reports, reports to the Disability Reform Council, and is required to appear before Senate Estimates. It is scrutinised by the Commonwealth Ombudsman's office and the Australian National Audit Office. It now also regularly releases data on its website. There have been pricing reviews and a capability audit. There has been a comprehensive Productivity Commission review. All this public scrutiny – and still change has been extraordinarily slow.

We note that the discussion paper questioned what should be regarded as appropriate sanctions for failure to meet standards. There appear to be few sanctions that are effective in publicly funded bureaucracies. We would in contrast rather see a focus on remedies for those affected. Don't get a plan in a legislated timeframe – then get access to a standard $10,000 to get going in the intervening period while you wait for an individualised plan. Don't get a review in the legislated timeframe? Then you can have the option of going straight to the AAT for resolution. We would suggest that resolution and recourse are far more appropriate responses in a truly person-centred scheme.

And finally, the discussion paper asks the critical question as to how progress should be measured. We have but one very simple answer – ask. Ask the people who know – people with disability, their families and carers, their advocates, the organisations that support them.

And ask in a range of ways to ensure an accurate and comprehensive answer. It is important, for example, that the Agency collects its own data. But there will always be difficulties in the NDIA asking people if they are satisfied, even anonymously. When people are reliant on the support provided, they are often reluctant to tell the truth for fear their honesty will come back to bite them.

That is why it is also important to ask trusted independent organisations to regularly collect feedback and data and then compare for a comprehensive picture of how the scheme is tracking.

But – and it is important but – if the NDIA and/or the government is going to ask the question they will need to be prepared to listen to the answer. And then be prepared to change. Part of the principle of transparency must be for the NDIA and the government to demonstrate how the data and feedback has resulted in change in policies, processes or practices.

Scheme implementation issues

We note with some frustration that many of the questions asked in the discussion paper about access, planning and reviews cover territory that has already been examined in a number of other inquiries and reviews. And as we noted in our introduction, we offer our responses in the sincere hope that this review will provide the impetus for change which to date has been slow to occur.

Eligibility and access

What are some of the significant challenges faced by participants in the access process?

Limited active outreach

With the notable exceptions of Queensland and Western Australia, the transition for people who previously received support through state disability systems is slowly drawing to a close. The focus now shifts to people who have not been identified through the transition process or who have not previously received support. There is a significant percentage of people who have been on waiting lists for many years who will find their own way to the door of the NDIA. While the process may not be easy or straightforward, they will find their own way to at least begin the application process.

In stark contrast however there is a sizable group of people who may not even realise the NDIS exists and that they may be eligible for support. They are likely to have other forms of social disadvantage and may have limited interaction with other government systems. They may be people who have good reason to fear government bureaucracies. This group of people will not be able to find their way through the maze that is the NDIS without significant support.

We note too that the number of people with disability from a Culturally or Linguistically Diverse background or from an Aboriginal or Torres Strait Islander background in the scheme remains persistently lower than expected.

All of this suggests that much more needs to be done to actively seek people out and provide them with significant support to not only apply for the scheme but throughout the planning process and beyond. We note with interest the announcement by the government during the federal election campaign to fund community connectors to assist people with disability from an Aboriginal or Torres Strait Islander background to access and navigate the scheme. We also note that the acting CEO of the NDIA recently told senate estimates that the early feedback on the connectors was positive. We would be keen to hear more about the progress of this program and any lessons learned that might be relevant for other population groups.

We would also note that there are many organisations that are already independent and trusted and have valuable existing networks that could be utilised to help locate people and assist them through access and beyond.

Poor guidance on the Access Request Form

While the focus of the scheme has, from the beginning, rightly been on functional impairment rather than diagnosis, this message has unfortunately not been effectively communicated to those applying or the medical professionals who are asked to complete the Access Request Form. We are aware of participants who were initially rejected but ultimately accepted – all as a result of the way in which the Access Request Form was completed. Training of medical professionals focuses on diagnosis – which explains why many simply scrawl a diagnosis rather than explain what impact the person's disability has on their daily life. We are aware that the Royal Australasian College of General Practitioners now offers training and the Royal College of Physicians has developed some resources to support completion of the ARF. A Primary Health Network in Queensland has partnered with a user-led advocacy organisation to produce an easy to use guide complete with case studies. The Agency itself has a short fact sheet for medical and allied health providers. But these are relatively recent developments in the life of the scheme.

One of the reasons medical professionals may not focus on the impact disability has on a person's daily life is because … they may not know. Like many other application processes, the access process for the NDIS privileges those who have regular health care and regular providers delivering it. It is extremely challenging to get the form to accurately capture functional impact for those who rely on a revolving door of bulk-billed GPs, however skilled.

Even for those who have regular health care, the one month turn around for access requests acts as a further impediment. This is insufficient time for people who need to book specialist appointments for assessments and reports.

Cost of assessments

And finally there is the significant costs of required assessments. The Alliance is aware of people who have paid hundreds and even thousands of dollars for assessments and reports, sometimes even going into debt to pay for them. For those who cannot afford to pay, the only alternative is long public waiting lists to see specialists or allied health professionals. Again, the process privileges those with regular health care providers who can afford to pay.

We are aware the NDIA has trialled an independent assessment process in New South Wales between November and April this year. We cautiously welcomed the trial, noted some potential issues but were keen to see how the trial panned out. Unfortunately no information is publicly available about how the trial went, what it found or what the next steps might be.

What do you think the NDIA could do to make it quicker and easier to access the NDIS?

- Fund active and assertive outreach by trusted organisations to reach people with disability and their families who may be eligible and who will need assistance through the application and planning process.
- Allow people to request or download the ARF so they can begin preparation without the clock running.
- Provide more comprehensive guidance on what evidence the NDIA requires for access – for both participants and medical professionals.
- Provide more information, training and resources for medical professionals to complete the Access Request Form.
- Establish a Medicare line item to cover the time required to complete the Access Request Form.
- Provide independent assessment of functional impact where required or provide funding to participants to cover the cost of assessments with specialist professionals of their choosing.
- Allow applicants to track progress of their applications.
- Provide more detailed information when access is denied as to reasons and what further evidence may be required to demonstrate eligibility.

Planning

What are some of the significant challenges faced by NDIS participants in the planning process?

Complicated processes

The resounding message from people with disability, their families and carers as well as providers is that people still find NDIS processes too complicated, too confusing and too difficult to navigate. As one participant recently told Every Australian Counts – “the NDIS is like playing a game without knowing the rules”. There are multiple steps for everything – which means everything takes a very long time and there are multiple ways for it to go pear-shaped.

Poor communication

We acknowledge the additional effort and resourcing the NDIA has dedicated in recent times to improving communication. The introduction of planning booklets and a self-management guide as well as the greater use of videos are just a few examples that reflect the NDIA’s commitment to trying to get information to people with disability and their families in a format that works best for them.

However … it also remains true that the complexity of the communication and the language used by the NDIA is one of the most common sources of frustration with the NDIS. Everyone agrees trying to navigate NDIS bureaucratic speak is like learning a completely new language without a guide. Often critical things that people with disability and their families and carers need to know is lost in complicated jargon. And if you don’t use the “magic words” you might miss out on what you need to know or, even more importantly, support you really need.

Communication is not only unclear, it is often inconsistent. The same terms can be used to describe different processes – for example the word review. It could mean an annual review, an internal review, a light touch review or a review of a reviewable decision. In contrast, sometimes different terms are used for the same concept depending on which channel they appear – the website, the plan, the portal or the price guide. This is so common that a number of guides have been developed in the sector to outline what the concepts are and what the different terms are in each of the channels. This is so people can manage their funds effectively.

Communication is not only inconsistent it is often poorly timed. The NDIA is also guilty of releasing information for providers but not releasing the same information developed for or targeted at participants. For example, the NDIA released a new price guide earlier in the year with information for providers but none specifically for participants. Just this week the Minister announced important changes to Specialist Disability Accommodation (SDA) – but the information was located on the provider section of the NDIS website. The scheme is for participants – they should always be first point of call. Providing different information and at different times to participants and providers also has the potential to damage what should be constructive working relationships.

And while there have been significant improvements to both the NDIS website and the portal, both require further changes if they are to become more user-friendly and easier to navigate. The overreliance on online channels of communication also creates an insurmountable barrier for people who have no or limited internet access or limited access to computers or mobile devices.

This overreliance on on-line communication becomes even more critical in the face of continuing problems with the NDIS call centre. While wait times for calls have decreased considerably in recent times, there does not appear to have been a corresponding increase in usefulness. The NDIA has not released data on the volume of calls. Informally people report that they have ceased calling the centre for all but the most basic of requests because they cannot speak directly to anyone who can resolve their issues.

Finally it should go without saying that people with disability and their families cannot become the informed resourced engaged consumers the NDIA assumes them to be without good access to clear simple and timely information.

Improved training

Again we acknowledge the sometimes heroic efforts of LACs, planners and NDIA staff who are working under very difficult circumstances. But, again, people with disability, their families and carers consistently report both poor outcomes and poor experiences with NDIA and partner staff. Good intentions are no substitute for the experience and knowledge necessary to work effectively and respectfully with participants and their families. Navigating complex processes is heard enough – but poorly trained and inexperienced staff who are unable to answer important questions or who treat people badly just make things even tougher.

Participants and their families understand that LACs and planners cannot be expert in every single type of disability – but they should have information they can refer to their fingertips or experts they can call upon to make sure they make informed decisions. In trial for example there were specialist planners who built up expertise in particular population groups or disability types.

The Alliance also believes that greater use could be made of organisations in the sector with specialised expertise. Organisations that specialise in particular disabilities have invaluable experience and expertise that currently remains under-utilised by the NDIA. The NDIA could 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 developing further guidance on “reasonable and necessary” in operational guidelines, or in effective communication to particular groups of participants.

Draft plans

People with disability and their families would like the opportunity to review their plan before it is submitted for approval. Draft plans have been much discussed, much mooted – but are still yet to be seen. Many people with disability and their family members also report they would like the opportunity to build their plans outside the NDIA with trusted individuals or organisations. These plans could then be submitted to the NDIA for approval. This would be particularly useful for people on their second and subsequent plans when they have more experience with the scheme.

Most people also like the concept of longer plans. Most find yearly reviews stressful, time consuming and unnecessary. They also come to the annual planning process with a fear of a reduction in support. But while people are generally supportive of the idea of longer plans, many are also concerned that they must be accompanied by the introduction of an effective triage process. People are only happy with longer plans if they are confident there is a clear and simple emergency triage process which allows participants to fast track their requests if circumstances change. It would be something of an understatement to say this confidence does not exist at the moment.

Primary diagnosis

As noted earlier, the NDIA requires identification of a primary diagnosis. This reliance on primary diagnosis does not reflect the reality of many people's lives. Using primary diagnosis to identify a Typical Support Package (TSP) for a participant and determine funding and support means that many people are not receiving plans that reflect their individual needs.

Consistency

People also report they are frustrated by the apparent inconsistencies between plans. People note that people who, from the outside, appear to have similar needs can receive wildly different plans and funding packages. People want to know that the scheme is fair – and is truly individualised.

We know the NDIA has developed Typical Support Packages to guide the development of plans and funding packages. We understand that LACs and planners are strongly discouraged from deviating from the TSPs and must justify any deviation.

It appears to people that the NDIA is therefore having a bet each way. They insist the planning process is truly individualised – and yet it is difficult to deviate from a TSP. And if TSP is really dictating plans and funding then the NDIA has an obligation to be more transparent about the process – particularly in how the TSPs themselves are constructed and the assumptions which underpin them.

Professional reports

People with disability and their families and carers go to considerable effort and expense to obtain professional or specialist reports – only to find they are not read or dismissed in preparation of plans. While this has been reported in all areas of the planning process, it appears to be particularly evident in the preparation of reports for assistive technology. Participants and their families and carers expect the reports of experts should be read and accepted – decisions should be made based on their considered professional opinion rather than the outcomes of Google searches by planners or LACs or their general "feeling" about what is reasonable or necessary. At the very least, if expert evidence is provided by the participant, the Agency/LAC should be able to provide its own evidence to demonstrate the basis for its decision.

More help!

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 is impossible to believe this will happen without a 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. While acknowledging recent efforts to build this capability through Information Linkages and Capacity Building grant rounds, this is an investment that has yet to be made in a coordinated or consistent manner. As a result people with disability and their families and carers consistently request in all forums that they need more help at all stages of the NDIS process – before access, during planning and beyond to get the plan off the page and into action.

The Alliance believes that disability support organisations could play an important role in capacity building. We would further suggest that 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.

Timeframes

The most complex decision the NDIA is required to make is granting access to the scheme. The timeframe established for that decision in the Act is 21 days. With the bulk of transition complete, the NDIA has indicated they are now able to meet that timeframe. The next most complicated decision is the development of an appropriate plan. We note that while there is a wide diversity of opinion amongst people with disability and their families, the 21 day timeframe appears to offer a reasonable guide.

What should be done to make the planning process easier?

- Improve training for LACs, planners and NDIA staff.
- Engage people with disability, families and carers in the development and delivery of training programs.
- Provide tracking of planning processes so individuals can see where they are in the "queue".
- Simple, plain, and timely communication in language everyone can understand.
- Removal of the "no caller ID" and ability to call LACs and staff directly.
- Ability to book call back times so participants and families can resolve issues at times convenient to them.
- No announcements or changes made without clear, simple information for participants to explain what has changed and what it will mean for them.
- Participants able to view a draft of their plan before being submitted for approval.
- Participants able to develop their plans with an independent individual or organisation and submit for approval by NDIA.
- Greater funding for user led and peer support organisations to support and assist people through access and the planning process.
- Removal of the need to identify a primary diagnosis.
- Professional reports to stand when submitted.
- Participants to be offered the opportunity to roll over plans without the need for review if circumstances have not changed.
- Development of simple effective triage process to escalate requests for reviews when necessary.

Plan utilisation

What are some of the significant challenges faced by NDIS participants in using the supports in their plan?

Lack of explanation

The Alliance notes that once the plan is completed, participants are expected to be offered a follow up meeting with their LAC to explain the contents of the plan and provide some assistance in getting underway. In practice this happens inconsistently. This helps explain low utilisation rates – people often report that they were not sure what to do next once the plan arrived because no one explained it to them. In some cases, people were even unaware a plan had been allocated to them or that they needed to formally activate it.

Beyond simply explaining what is in the plan, people with disability and their families need a clear understanding of what has been funded, what has not and the reasoning behind the decisions made. They need to know what assumptions have been built into the plan. For example – how many hours of support and at what rate. While they may not need to know this line by line, they do need to know on a global level to understand better how they may use their funding. Even agency managed clients need to understand in order to inform their decision making and contracting of services. It is even more important for the increasing numbers of plan and self-managed participants.

Understanding the assumptions built into the plan is even more important in the face of limited flexibility in use of funding. People want to be able to use their funds in a way that works for them. They also want to use them in a way they believe will be most cost effective. Evidence from models and programs in other countries consistently demonstrate that when people have genuine control over their funds, they use them in economical and efficient ways, often requiring less, rather than more, support.

At the moment, however, the fundamental principle of choice and control is being undermined by poor policies and processes and inflexible rules that just don't make sense to people. There are too many stories of people running out of funds in one area, having funds remaining in another area, and no capacity to move things around. While core funding is more flexible, capacity building funding is not and there is no capacity to move funds between them.

Self-management offers the greatest flexibility to participants. But given the complexity of the scheme, many people and their families are unwilling to take it on without additional support. It requires considerable time and resources to manage which not all participants have the capacity for, particularly when they feel there is little additional support available.

Lack of help … again

People with disability and their families and carers consistently report they believe all participants and their families would benefit from support coordination in at least their first few plans while everyone adjusts to the new system. While this would pose a significant challenge given the relative scarcity of support coordinators, it points to the fact that most people believe they would benefit considerably from more assistance in getting their plan up and running.

Difficulty in locating providers

Many people with disability and their families and carers report difficulty in locating providers – again with little or no assistance. The Provider Finder on the NDIS website is of limited assistance, spitting out a long list of providers with little guidance or useful detail. If people have not been previous recipients of service or are not linked in to good peer networks, it can be difficult to find out simply what services are available in any given area let alone assess their suitability.

People with disability and their families and carers also report a lack of services in all areas, but particularly in rural and remote. This scarcity of support is also true for particular population groups in metropolitan areas. Families with a son or daughter with complex needs, for example, frequently report that there are limited services available and equipped to deal with the complexity of the participant’s life. Families also consistently report shortages of allied health therapists.

While there has been much discussion about the need for market development and market stewardship, there has been much more limited action. As the Productivity Commission identified, the complex governance arrangements for the scheme has not facilitated action on this critical issue, with market stewardship a shared responsibility between the NDIA and the Department of Social Services. The concept of an emarketplace, to support people to make informed choices about those providers and supports they wish to use, is one which has been discussed for several years, without ever moving to the point of implementation.

We also note that despite the issue being identified as pressing before the NDIS even got underway, there has been a lack of concerted and coordinated effort to develop a workforce sufficient in size and possessing a diversity of skills and experiences to meet the needs of people with disability. Again, it appears the complex governance arrangement and shared responsibilities for this particular area have contributed to a lack of consistent and coordinated effort.

Lack of transport

Lack of funding for transport is consistently reported to Alliance members as one of the critical reasons why participants are unable to make the most of their NDIS funding. Many report that they have funding and support for activities – but not the transport to get there. As a result, the funds remain unspent. The recent decision by the NDIA to no longer allow participants to spend core funding on transport if they receive a transport allowance is exactly the opposite of what people with disability and their families consistently call for. People would like the flexibility to manage their funding in a way that works for them, including devoting additional funding for transport.

Assistive technology and home modifications

The process for approving equipment and home modifications is complex and confusing, and very often lengthy. People are waiting months, even years, for vital equipment and even longer for home modifications. Often the process takes so long that quotes "expire" and the process must start again. People are also increasingly concerned that valuable and much needed NDIS funds are being spent on expensive assessments for simple pieces of equipment or equipment that has been needed and used for many years. We welcome the changes the NDIA has made recently to allow direct purchase of low cost low risk equipment and the decision to allow purchase of "like for like" without the need for further assessment. We look forward to future changes to streamline processes even further.

What should be done to increase plan utilisation?

- Give people more help and assistance to understand their plans. Explaining the plan and the assumptions behind it should happen with every plan.
- Give people more help and support to get their plan up and running. Support coordination is one form of help but there are other ways to help people make the most of their funding. Training, resources, workshops, funding for one-on-one help are just some of the methods that should be considered.
- If plans are not being ultilised there should be a trigger in the IT system for LACs to contact participants and provide support – or arrange for support to be provided.
- Develop more effective, targeted and simple provider finders to help participants locate services in their area.
- E-market. Much talked about but still yet to become a reality. While an on-line platform would not suit everyone, it would be a good place to start for many.
- Fund disability led organisations to help people get their plans into action and learn about new different and innovative models of support – and how it can be done. Practical targeted resources and training led by peers.
- Tracking of approval processes so participants can see where they are in the "queue".

- Simplify process for approval of assistive technology and home modifications.
- Removal of the need for multiple quotes for equipment.
- On a macro scale much greater attention to the development of market and workforce to ensure there are diverse range of services for people to purchase.
- More attention to development of market for services for people with complex needs.

Plan reviews and appeals

What are some of the significant challenges faced by NDIS participants in having their plan reviewed (by planned or unplanned view)?

Like much of the rest of the NDIS, people with disability, their families and carers find the review process complicated and confusing. There are too many processes that sound like each other but which actually mean completely different things.

Participants and their families and carers consistently report they would like the opportunity to change simple things in their plan without triggering a full blown review. At the moment this can sometimes be done when the plan first lands with a “light touch review” but it appears to be inconsistently applied. Further, current NDIA processes mean that when a plan review is initiated, this is also triggers the need for service providers to reinsert service bookings for all services under the plan.

Many people who would like to seek a review of one part of their plan are warned the review will look at all areas in the plan. To many participants and their families and carers, that warning can actually sound much more like a threat. As a result, this can deter some from challenging decisions they do not agree with. Participants and their families and carers strongly believe reviews should be confined to the part of the plan which is being challenged – it should not trigger a wholesale review of the entire plan. This is one area where a change in the legislation to would offer participants important protection.

It is apparent the high number of reviews is a result of difficulties in the planning process and the lack of flexibility in using existing funding. As a result there is a considerable backlog of reviews which are still yet to be resolved.

The long wait for reviews leaves many participants between a rock and a hard place. If you are seeking a review because you believe you have insufficient funding what should you do? Spend your funds as you believe you need them and risk running out before your review is resolved? Or stretch them out slowly and risk that being taken as evidence that you do not require the support?

As with other areas in the NDIS, it would be helpful to establish fixed timeframes and tracking so people are not left to make this choice. And again as with other areas in the NDIS it would be helpful to provide participants and their families with greater support and assistance during the review process – particularly advocacy and legal support. At the moment participants feel strongly that they are "outgunned", particularly during AAT hearings. They feel the NDIA has unlimited resources to fight cases while they are left to struggle with limited help.

Given the experience of many people with disability and their families as applicants in AAT cases, we think it is important the Participant Service Guarantee include a commitment that the NDIA will be a Model Litigant, as required by Appendix B of the *Legal Services Directions 2017*.

Based on the experiences of participants who have appealed a decision to the AAT, the Agency has, for example, been criticised in the past for its failure to deal with claims promptly, belatedly making an assessment of the merits of a participant's case or even requiring the participant to prove a matter which the Agency already knows to be true.

Further, in instances where the Agency has not been successful before the AAT, the NDIA has not always reflected that decision in revised guidance, directions or advice to planners, Local Area Coordinators and Partners in Community. This is even in situations where there have been a number of cases with similar facts and judgements.

The inclusion of a clause in the Participant Service Guarantee stating that in all proceedings under the NDIS Act, the Agency will act as a Model Litigant and abide by Model Litigant principles, is both appropriate and necessary.

How could the NDIA improve the decision review process?

- Clarify terminology so each type of review has its own term.
- Allow participants to make small changes to a plan without requiring a full plan review.
- Allow participants to seek a review of one aspect of their plan while the rest of their plan remains the same.
- Ensure providers are not required to reinsert service bookings for all services every time there is a plan review.
- Greater funding for advocacy.
- Additional funding for legal support for participants involved in AAT hearings.
- Participant Service Guarantee to provide that NDIA will act as a Model Litigant in accordance with the *Legal Services Direction* 2017.