

Response to <u>NDIS Planning Inquiry</u> (by the Joint Standing Committee on the National Disability Insurance Scheme, Parliament of Australia)

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1. About ADACAS

The ACT Disability Aged and Carer Advocacy Service (ADACAS) has been delivering advocacy for and with people with disability, people experiencing mental ill health (or psychosocial disability), older people, and carers in the ACT for 28 years. ADACAS has provides free advocacy and information to people with disability in parts of NSW: specifically, in set areas of Shoalhaven, the Eurobodalla Hinterland, Batemans Bay, Broulee – Tomakin, Moruya – Tuross Head

As an advocacy service, ADACAS is frequently working with people who are "falling through the cracks" in current service systems. We advocate on many topics: on housing, quality of service issues, NDIS appeals, at psychiatric treatment order tribunal hearings, on child protection matters, on restrictive practice/restraint/seclusion. ADACAS advocates also visit clients at their homes or places of the clients' choosing. ADACAS additionally offer NDIS support coordination to a small number of NDIS participants in the ACT, and have a Projects/research team, who are currently conducting action research looking at Supported Decision Making in Healthcare. We have recently commenced delivering Redress Scheme support services to people who were victims of institutional child sexual abuse.

Throughout this submission we seek to highlight both the issues that advocates have observed, and also issues that our clients have raised with us, and will use case studies to demonstrate circumstances. We value the opportunity to provide this feedback.

ADACAS acknowledges the Ngunnawal people as the traditional owners of the land on which we work, and pay our respects to their Elders, and to all Aboriginal and Torres Strait Islanders in our community.

2. <u>Responses to NDIS Planning Inquiry topics:</u>

a) The experience, expertise and qualifications of NDIS planners

The bulk of this submission addresses issues and problems with the planning process as it is currently operationalised within the NDIS, and offers constructive criticism. It does, however, identify that the process that was established may not have been ideal, and that some solutions may be possible if the overall architecture of the system was reconsidered and remodelled.

ADACAS advocates attend planning and annual review meetings with NDIS participants and planners who are external Local Area Coordinators (LACs) and also NDIS participants and planners from the NDIA on a frequent basis (multiple times a month). It is our experience that whilst there are some planners (both in LACs and within the NDIA) who have strong qualifications, strong communication and interpersonal skills, we have also witnessed a number of situations (both with LAC and NDIA planners) where planners have demonstrated a lack of skills/expertise, making (negative) assumptions or (negative) statements about participants, and their supports. There are also multiple situations where both sets of planners have demonstrated a lack of training, but also of tact and sensitivity as is illustrated with this participant's experience:

Participant experience 1:

A participant was horrified (and very distressed) to be told by a planner as part of their planning meeting: "I'd never heard of your disability before, so I looked it up on Wikipedia before this meeting")

We are aware that there are criteria that help to determine whether NDIS planning occurs with a LAC, or with the NDIA, and that in general the NDIA tends to assist where the planning process is likely to involve more complexity. We have been advised that the exact criteria to determine whether a person sees a LAC or the NDIA for planning is not currently public.

When a LAC is involved with a planning meeting, the LAC prepares the NDIS plan, and then it sent to the NDIA for consideration/approval by an NDIA planner/delegate (in the current structure we have been advised that LACs cannot approve plans). When an NDIA planner prepares a plan, they might approve it or it may also need to go to higher level delegates for approval (especially if there are aspects to the plan that are more complex, or involve higher levels of funding). Whilst NDIA staff tend to have more expertise with planning, both the NDIA and LAC services have had difficulties with staff recruitment and retention, and we have seen "suitable" and at other times "inadequate" plans come from both avenues.

Our primary concern with LAC involvement with the planning process is that by requiring LAC involvement with planning, LAC time is drawn away from other vital tasks that were originally intended (in the Productivity Commission's view) to be the focus of the LAC role ("NDIA local area coordinators would provide case management services, connect people to the community, liaise with the NDIS and

other government services" ¹ and also provide support for both participants and people with disability who are not NDIS participants).

We note also that there can be considerable drawbacks when there is not a direct relationship formed between NDIS participants and the NDIA planner who is either approving the plan (or involved in the approval process if the plan is being considered by a delegate at a higher level), in that it is easier for misunderstandings to occur or for things to be missed.

Planning process

Successful planning and annual review relies on a number of factors, including:

- Experienced, expert and qualified planners able to take a person-centred approach (and to support participant-led planning)
- The quality of the assessment tools that the NDIA are using, and
- The level of support (of the participant's choice) and preparation that a participant has available to assist with preparing for, and engaging with that planning meeting
- The timing and duration that suits for the participant
- A suitable environment for the planning or annual review meeting to occur.

Further below in this submission (at e) Participant involvement in planning processes and the efficacy of introducing draft plans) we will address what we believe to be fundamental flaws in the design of the NDIS which has led to both a denial of entry to the scheme and to a fundamental lack of respect for the ability of of individuals to understand and articulate their aspirations and to value their expertise with regards to what they need. Inadequate attention to this aspect is also currently resulting in planning processes that do not always provide the supports required to address these needs, such that the scheme can meet its goals of assisting people to lead inclusive and productive lives in the community.

The current planning process has, to a large extent, been reduced to a formulaic screening process, where planners are reliant upon algorithms to determine whether or not a person's expressed requirements "fit" within what the NDIA deems to be eligible for its funding. This has led to potential and actual participants having to precisely word their individual and unique experience of disability in terms that meet the requirements of the NDIA and the computer system that affects the options and funding levels funding available based on pre-determined formulae. Documentation that backs up claims for funding is also being required to a specific standard by the NDIA, and it is not individualised to support the unique application of the individual. Perversely this has led to a significant amount of time and energy being spent at times by people with disability and families seeking guidance and assistance from others about how exactly to word claims to seek to maximise funding available, instead of focusing intently upon the detail of their own situation, and coming up with a plan that seriously addresses a positive future using whatever

¹ Productivity Commission (2011), Disability Care and Support, Report no. 54, Canberra. Volume 1, Page 40 as accessed via: <u>https://www.pc.gov.au/inquiries/completed/disability-support/report/disability-support-volume1.pdf</u> in September 2019.

resources may be required in the short, medium- and long-terms. This represents little change to the situation that people were in before, where the end goal has become the securing of financial resources, given the understandable fear that many have of having to go without supports and an overall lack of security. To a large extent the current experience of the planning process is serving to pervert to intent and operations of the entire scheme, as the goal becomes to achieve security of resourcing rather than focusing on the outcomes that are required and the use of resources as a means to that end.

Planning occurs after a participant has been accepted into the NDIS, but to a large extent the limited assessment criteria, which serves to limit the scheme from people who are manifestly in need of support, also impact negatively on the options that are deemed acceptable to the NDIA for funding. The basis of assessment, on functional ability, severely limits the options that can be deemed fundable under the NDIS, significantly impeding the principle of choice and control and frequently denying the agency and expertise of the person with disability. This will be dealt with further at m), but in short ADACAS believes that the NDIA is ignoring the requirement to utilise the framework of the International Classification of Functioning (ICF) as the basis of assessment, which acknowledges the social, economic and environmental impacts upon a person's disability. It was clearly a recommendation of the Productivity Commission Report² that the ICF be used as the framework for assessment, which requires therefore that eligibility and the claims made by (potential) participants in their plans take into account the social, economic and environmental circumstances in which the person both lives now and in which they are seeking to lead their inclusive life into the future.

With the exception of the relatively small number of situations where an adult participant has excellent knowledge of the NDIS and their rights, and are also in circumstances where they can confidently prepare and self-advocate as needed, we have observed that it is frequently impossible for participants to get a fair outcome from a planning meeting if they have not had support (to the level that they have chosen, from people that they have chosen) available to them.³ Given all of the above – we emphasise the need for independent support to be made available for any participant who wishes or needs to access it. This support should be from very skilled staff, with excellent knowledge of the NDIS and how best to prepare, but also staff need to have the ability to assist with supported decision making (when appropriate), and also capacity building around how to prepare for a planning or review meeting. This topic will be addressed further at e).

In addition to the above, planners need sufficient experience, expertise and qualifications to seek to make it more possible to achieve equitable outcomes for all participants. Whilst the scheme needs to be able to tailor responses to individuals (and thus there should be variation between plans of people in similar life circumstances), there should not be situations where two people, in similar situations, asking for the same things, receive wildly different outcomes, depending

² Productivity Commission 2011, Disability Care and Support, Report no. 54, Canberra. (See Recommendation

on which planner is assisting. This level of consistency needs to be achieved, though, by constant review of participant outcomes and packages, so that a broader understanding can be made of why and in what circumstances people with essentially similar functional needs may be provided with different types and level of package.

Participant experience 2

A participant told us of an experience where a planner made assumptions about their disability (they have a physical disability of a type that is not visible) and where the planner's wording betrayed (negative) value judgements.

The participant explained "it was as though she didn't believe all the documentation by all the specialists and experts and the people who know me well. Just because my disability is not visible does not mean that it does not affect me. Does [the planner] realise how much it hurts when I leave a planning meeting feeling like <u>not</u> even the NDIA believe me, despite all the information they have about how hard my life is, and how my disability affects me?".

In that instance, the participant chose not to lodge a complaint due to fears about backlash/the impact on their relationship with the local NDIA office if they made a complaint.

ADACAS provides general feedback regularly to the agency re training needs.

The above is an example of what can occur when a planner does not have adequate experience, expertise and skill in working with people with disability, and the pivotal role that an inexperienced planner has in determining the future life circumstances of someone with disability whom the scheme has promised previously to respect as an expert in the articulation of what they need and what their reasonable aspirations are.

b) The ability of planners to understand and address complex needs

In attending planning meetings with participants, ADACAS advocates have observed that the ability of planners to understand and address complex needs is very variable. There are some planners with very strong skills, but others who need a lot more training and support to ensure better outcomes for people with complex needs.

ADACAS has observed that the planning experience needs to be based more closely around functional impact for participants (as opposed to medical diagnoses), as was the intent of the scheme⁴, and that the presenting life circumstances of individuals must also be factored in. People with disability overwhelmingly want this scheme to facilitate their good life in and of the community, so the social context is vital to consider, both current and projected,

⁴ Productivity Commission 2011, Disability Care and Support, Report no. 54, Canberra as accessed via: <u>https://www.pc.gov.au/inquiries/completed/disability-support/report/disability-support-volume1.pdf</u> in September 2019.

when determining the quantum and type of the goods and services required to deliver the participants' aspirational futures.

It also continues to be imperative that all planners recognise that there is typically both a cumulative but also a compounding impact where a person has multiple disabilities and/or health issues/ and/or other stressors, and that planners work with participants to look at the consequent impacts on functionality of having compounding impacts and are able to respond accordingly.

In October 2018⁵, the NDIA announced a psychosocial disability planning stream, recognising and acting on the need for planners assisting participants with psychosocial disability to have specialist expertise. This initiative is vitally needed and we call on the NDIA to expedite and continue the roll out, and the skill and training and support to approach the planning process in a consumer led way, whilst also maintaining a recovery mindset.

Planning needs to become much more participant-centred, and participant led, and currently there is a growing culture of authority by the NDIA, such that it has become similar in nature to the large state bureaucracies which presided over the "inequitable, underfunded, fragmented and inefficient" systems that the NDIS was established to replace⁶.

In terms of more general systemic issues re responding to complex needs:

Family plans: when there are families where multiple family members are NDIS participants, coordinated options need to be offered to families.

Depending on the wishes of the individuals involved (and the family structure/politics), this might mean approaches such as:

- having the same planner working with each different family member,
- having planning meetings at the same time of year or in a structured setup • (within a time period that works best for that family - i.e. a planning meeting a week for three weeks).

ADACAS is aware both of situations where a coordinated approach occurred (but also situations where a coordinated approach was requested by a family but where the NDIA declined to offer it, without adequate explanation or cause). We applaud initiatives to work with each family as to the approach that works best for them.

Recommendations:

- 1. that the NDIA staffing cap be abolished such that the agency has more flexibility to employ sufficient staff to meet participant needs, appropriately manage workload pressures and ensure adequate staff support.
- 2. That the NDIA ensure there is a focus within both recruitment and retention processes in ensuring the suitability of prospective and

⁵ NDIA (2018), Media release, as accessed online at: <u>https://www.ndis.gov.au/news/400-government-announces-</u> improved-ndis-mental-health-support, in September 2019.

⁶ Productivity Commission 2011, Disability Care and Support, Report no. 54, Canberra, p.5

current NDIA planners and managers in terms of qualifications and experience.

- 3. That the psychosocial participant pathway efforts be progressed, such that participants with psychosocial disability can have planners with specialist knowledge and expertise, and such that related initiatives to improve NDIS experiences of people with psychosocial disability occur.
- 4. That the NDIA focus on ensuring as many planners as possible have excellent skills in understanding and responding to and conducting planning meetings in situations where participants are in complex circumstances.
- 5. That the NDIA routinely offer <u>coordinated</u> planning arrangements for families where there are multiple family members who are NDIA participants.

c) The ongoing training and professional development of planners

Whilst ADACAS affirms the need for additional training and professional development for planners, we are aware that better knowledge alone does not automatically translate to improved performance"⁷. One-off training is insufficient for behaviour change, and we thus emphasise the need for ongoing mentoring that is both external to and inside the agency to achieve the quality improvement that is required.

The issue of staff capability is not just one of training, it is also about having a sufficient quantum of staff to be able to respond well to the diversity of request generated by this large and unique system. Frontline staff need to possess and exercise skills to be able to facilitate the expertise of the (potential) participant, and scrutinises her/his claim for funding based on their actual and project life circumstances, and so there is a need to adequately resource the cohort of staff who work on the frontline to facilitate entry to the NDIS and to approve the plans that will assist people to live inclusive lives. To this end ADACAS strongly advocates for the abolition of the current cap on the number of NDIA staff, specifically those employed to engage directly with clients, if necessary at the cost of reducing the overblown and ineffective management structures and the various task forces that have been set up within the NDIA to address issues and problems of its own making, which are better solved by resourcing and building the capacity of the community sector.

Participant experiences 4:

ADACAS advocates recently advised that four different participants left a planning meeting (with different NDIA planners within a four week period) feeling like the respective planners had accused each of them of fraud (despite there being no

⁷⁷ Batalden P, Leach D, Ogrinc G. Knowing is not enough. Executives and educators must act to address challenges and reshape healthcare. *Healthcare Executive*. 2009;24(2):68-70.

evidence of same in any of those instances), and despite each of the participants having acted in good faith.

Whilst we are conscious that NDIA's fraud team had been actively pursuing agencies where fraud had occurred, or was occurring, the approach that each of the various planners had taken in seeking to ask questions on topics that were related to this demonstrated a lack of adequate training, and the impact for the four participants was both negative and considerable.

Recommendations:

- 6. That planners be provided with high quality training, professional development and ongoing mentoring (internal and external to the agency), in order to achieve high quality outcomes for clients.
- 7. That there be an improved way to assess participant satisfaction of their planning experience and new plan.

d) The overall number of planners relative to the demand for plans

ADACAS advocates advise that there are sometimes very significant delays before a planning meeting is made available – and that the most commonly quoted reason for delay is a lack of planners available.

As expressed above at c) we support an increase in the number of planners made available such that planning, and annual review meetings can occur in a more timely way.

Recommendation:

8. That the numbers of planners be increased such that it is possible for planning and review meetings to happen in a more timely way.

e) Participant involvement in planning processes and the efficacy of introducing draft plans

As indicated above, there is a strong need for independent support to be made available to assist participants who want or need assistance with pre-planning, planning meetings or annual review processes.

Within the current system as it has been established ADACAS also strongly supports efforts to introduce draft plans. In our NDIS appeals work, we have seen countless examples of situations where a plan is riddled with incorrect information or errors. The opportunity to see and work with a draft plan means that participants and their supports can check and work with a planner to seek to ensure that final plans meets the clients' needs. We would expect that this would also mean more accurate plans, improved client satisfaction, leading to fewer internal reviews and external appeals.

ADACAS does not accept, however, that the NDIS has yet achieved a set up to allow it to adequately address the individualised nature of the support that it intends

to deliver to its participants, and that important lessons from successful overseas models of individualised funding schemes were ignored when the scheme was first established in 2013. In particular we refer to the critical supports that need to be in place to assist people applying to the scheme for assistance to accurately identify both their needs and how they intend to improve their lives with the goods and services that the scheme will fund. Two submissions to the Productivity Commission inquiry (those from People with Disability Australia and from In Control Australia, both referenced below) described in detail a level of support to people with disability and families that should be made available to enable them both to understand their circumstances and the external factors additional to the functional aspects of disability which are limiting their opportunities currently and to help them envisage and articulate a positive future and how this might be reached with assistance⁸⁹. Based on evidence both of these submission articulated the need for (potential) participants to have independent planning supports available to them, separate from their service providers, and also separate from Advocacy. The role of this support would be to ensure that participants were well-prepared for their planning meeting, and had the opportunity to articulate what was important to them. It was based on the principle that ability to articulate needs, wishes and aspirations are not mediated solely by functional cognitive capacity, but to a great extent by the a person's life experience and the strength or otherwise of the supports and other influences in their lives. To this extent all people with disability are not equal, and in order to satisfy the empowerment underpinnings of the NDIS (choice and control) whereas the ideal situation is for the person with disability to utilise their expertise and articulate their requirements, many people with need assistance in doing this. This type of assistance, which can be regarded as a facet of "service brokerage", needs to be delivered by an experienced and skilled person who is working for the person with disability and is not an agent of the NDIA.

The provision of a community-based resource that has the capacity to assist (potential) participants in their planning (and to continue the relationship if required to cover regular planning reviews and assist with new plans etc.) would create a more equal footing on which the NDIS could address the needs of those people who are eligible for funding to purchase goods and services. It also leaves the planners with the important role of determining the merits of the claims made by people, with a greater certainty that these claims have been made with a level of expertise that is currently missing in the current process. It will have the effect of building the capacity of participants to better understand the intended impact of NDIS supports, and to see the goal as not merely to gain as many resources as possible, but to seek customised supports and equipment with the intention of addressing their real dreams and aspirations.

⁸ In Control Australia 2010, Submission to the Productivity Commission inquiry into disability care and support, Submission No. 570, available: <u>https://www.pc.gov.au/inquiries/completed/disability-support/submissions/sub0570.pdf</u>

⁹ People with Disability Australia 2010, *Inquiry into Long Term Disability Care and Support: People with Disability Australia (Inc) Submission to the Productivity Commission*: Submission No. 524, available: https://www.pc.gov.au/inquiries/completed/disability-support/submissions/sub0524.pdf

At the present time, some participants receive planning (and/or pre-planning) support from an advocate (if there is an advocacy issue related to the plan), some receive it from a support coordinator (if they have an experienced support coordinator (with whom they have a good relationship) and also adequate support coordination funds available to assist with this), some receive it from chosen family/friends. However there is a significant group who are not receiving any support with planning and review processes. ADACAS receives a number of requests from people who require help to apply for the NDIS, which we are not always able to offer, unless a person has made previous attempts to apply (or there are factors which create an imminent risk if an application is not urgently submitted), if it appears that the person will be eligible and obviously requires some support to be able to re-apply perhaps with a more focused emphasis on their needs and on what they intend to achieve with NDIS funding. This demand demonstrates a fundamental problem with the process, which should always have been driven by claims for support being made by individuals in the form of their plan, which needs to be developed outside of the formal eligibility assessment process, with the NDIA working to accommodate a well-articulated individual plan within the funding guidelines of the scheme.

Whilst it may have been envisaged that Local Area Coordinators would take on the role of facilitating the articulation of needs and aspirations of (potential) participants, they are often acting as planners, and given their contractual responsibilities to the NDIA they are unable to be independent in this role. Additionally, there are circumstances where it can be problematic to have a family member/friend or a service provider present, if the person has vested interests in outcomes different from what the participant is seeking, especially if the planner is not skilled at establishing that this is the case, and managing the different perspectives.

Recommendation:

9. That DSS create a structure whereby independent assistance (not from the NDIA or LAC) can be made available to assist any participant who wants or needs assistance with pre-planning, planning meetings.

f) The Incidence, Severity and Impact of Plan Gaps

As an advocacy service, ADACAS is approached most weeks (and sometimes many times a week) by people seeking advocacy support to seek to challenge unsuitable NDIS plans and with regards to plan gaps that are having a profound impact. These changes vary from a need for urgent support coordination funds, to need for behaviour support, to a need for urgent respite options or more. Sometimes change can be achieved by lobbying the local NDIA office directly. At other times, due to the nature of the complexity and urgency of situations, ADACAS is working together with government departments and other services to find solutions.

The ACT Government's Office for Disability established an Integrated Service response team to provide urgent coordination assistance or funding in situations where an NDIS participant (or a person who is likely to be eligible for the NDIS) is in a crisis or critical situation. In conversation with staff from that office recently – they advised that they have received over ninety referrals since November 2018. The ability of that office to respond very promptly (and fund, for example emergency support from disability carers whilst a plan review is requested) can make an immediate difference to a client experience.

Whilst there is a similar service in NSW (the Integrated Service Response), this service does not have funding available to assist participants or potential participants.

Recommendation:

10. That all states and territories have an Integrated Service Response service equivalent, and that brokerage funding (to assist in resolving crisis situations) is made available for each of those services to be able to assist when needed.

g) The Re-assessment process, including the incidence and impact of funding changes

It is ADACAS' experience that in most cases where an NDIS internal review occurs, the outcome from the re-assessment is usually more suitable for the participant. Whilst every case is different, re-assessments will often have a considerable (and positive (in the participant's eyes)) impact on funding levels.

This perhaps indicates that there are fundamental flaws with the initial assessment process, and we address this more fully below at m).

h) The Review process and means to streamline it

We encourage the NDIA to actively intervene much earlier to seek to reduce the number of reviews that are needed. (We envisage that making draft plans the norm should assist with this).

We reiterate again the need to abolish the staff cap, such that the NDIA can employ adequate staff numbers to seek to do the above, and to respond to reviews.

As also mentioned above, the need for reviews could also be reduced if more support was available to assist people who are seeking entry to the NDIS (and/or preparing for NDIS planning meetings) and if the quality of the documentation available was improved.

In many instances (as was articulated earlier) people need support to put forward a good application for entry to the NDIS and also need strong medical documentation (and strong documentation from allied health and other services) both when entering the scheme, and also through the planning and planning review processes. At the present time, GPs and specialists are not typically funded for the time needed to produce this documentation (funding also can be limited for allied health support before people enter the scheme). GPs and Specialists also have very varying levels of understanding of the NDIS and how to write useful support documentation. Additionally, at this stage, many NDIS National Access Team assessors (who assess applications to enter the scheme) do not take an active approach in supporting participants to ensure that their circumstances are fully considered very early in the process.

Recommendations:

- 11. That independent and expert support is funded to assist all applicants applying to the NDIS to obtain any needed documentation and put forward a thorough application. (Note – in our experience LACs are unable to fulfil this function due to workload demands, instead usually only being able to provide information on how the process works (rather than concretely assist potential participants to obtain the documentation needed from a variety of sources)).
- 12. That new Medicare line items be created to allow for GPs and other medical specialists to be paid for the time needed to put together stronger supporting documentation for NDIS applications and reviews, and that additional training be provided in an ongoing way for GPs and specialists on this topic.
- 13. That National Access Team assessors are recruited with suitable levels of experience, expertise and qualifications, and that ongoing training, mentoring and professional development is made available to them.
- 14. That National Access Team assessors (and internal reviewers) each adopt an outreach model whereby they work with potential participants and their supporters (formal and informal as per the potential participants wishes) to explain and support people to obtain any additional information needed for an application to be thoroughly considered as early as possible in the process.

i) The Incidence of appeals to the AAT and possible measures to reduce the number

Over the last few years, ADACAS advocates have worked together with our colleagues at Legal Aid ACT and Legal Aid NSW to support over 100 people who were either contemplating and/or choosing to engage with the external appeals process through the AAT. Fifty three of those cases were active during the financial year 1 July 2018-30 June 2019.

Most of these appeals relate to entry to the scheme, although there are still a reasonable proportion of appeals that were by current participants in relation to the level of supports in an NDIS plan. Most were ultimately resolved in the appellant's favour. Only a small proportion (approximately 5%) have reached and had a full hearing after which outcomes are published (the final step in the appeals process).

In the earliest days of NDIS AAT appeals, many of the appeals were taking 1 to 2 years or more. More recently, whilst there continue to be some appeals that are still taking significantly longer, more of the appeals are being resolved in 6-8

months. We commend the NDIA on the introduction of the Early Resolution team (AAT applications and decisions) which has been acting in a proactive way as soon as an AAT appeal is lodged, to seek to resolve points of contention and to speed up the AAT appeals process.

In addition to reducing the number of AAT appeals, the need to improve the quality of experience that people with disability face throughout the appeals process. There have been many situations over the last few years where ADACAS staff have observed NDIA representatives (and the lawyers representing them in tribunal) act in ways that have caused harm to appellants instead of acting as a model litigant, as is their duty as a government agency:

Participant experience: 5

A person with disability was seeking access to the NDIS: this person had been told (twice) (from their initial application and internal review) that they <u>met</u> the requirement for substantial reduction of functional capacity, but <u>did not meet</u> the requirement for permanency of their disability.

There was then an approximately 18 month contest in the AAT about the topic of permanency of disability. The agency finally conceded on permanency (after an extremely-difficult-to-obtain specialist report became available). At this point, they then informed the person with disability that they had also reconsidered their position, and now (despite the decisions at initial application and internal review) that they no longer agreed that the applicant met the criteria re substantial reduction of functional capacity.

This decision caused immense distress to the applicant: "how can they decide twice that I meet this criteria, and then just change their mind when I have proved that I meet the permanency criteria? If they really thought I didn't meet this criteria, why didn't they tell me this at the beginning?"

It took an additional 6-8 months for the NDIA to return to their original position that the applicant met the substantial reduction of functional capacity criteria, and before the person was accepted into the scheme. During this time, the toll on the person and their family was immense: having both an emotional toll and a strong financial impact.

In terms of legal representation by the NDIA - we understand that there have more recently been changes with the approach that the NDIA is taking, to seek to ensure that the NDIA and any lawyers representing them are ever conscious of their responsibility to act as model litigant. It is imperative that efforts continue in this area.

On a separate topic, a number of people with psychosocial disability in contact with ADACAS have found themselves unable to go through the AAT appeals process: they have started and then withdrawn, or not felt able to start the process, even with support. Clients have told us that the process is too overwhelming, that it takes too long, and that the level of stress that the process can create (even with support) is too great to bear. We urge the NDIA to urgently investigate alternatives or more streamlined approaches that can make appeals processes more accessible for everyone.

We additionally encourage a close analysis of the profoundly negative impacts that various aspects of the current process have for appellants, with a view to finding ways to improve the quality of appellant experience (and reduce the chance that harm will occur to the often vulnerable individuals at the centre of the process).

As indicated by the example provided above, it is the view of ADACAS that many of the AAT reviews could have been avoided (or considerably shortened) if:

- in the case of applications to the NDIS, the applicant had had support with their initial application to the scheme, and;
- in relation to all appeals assessors with added training and expertise (and taking an active outreach approach) had been involved earlier, when possible with initial applications but also definitely with the internal review stage of the process.

Recommendations:

- 15. That the NDIA continue the Early Resolution team (AAT applications and decisions) approach which is engaging and pro-actively communicating early in the AAT appeals process, to seek to resolve matters.
- 16. That funding for expert reports be made available also via another channel, for the situations where expert reports are needed, but the appellant feels unable to connect with legal assistance.
- 17. That the NDIA both improve the AAT appeals processes (but also find alternatives) such that the external appeals processes are more accessible for all participants (including people with psychosocial disability).
- 18. That the NDIA finds a way to better seek participant feedback on the review process and the quality of experience of NDIA participants and potential participants through the internal review and AAT processes with a view to improving the quality of the review and appeals experiences
- 19. That the NDIA and the lawyers representing them act as model litigant before and during external appeals on NDIS matters to the AAT.
- 20. That the NDIA invest in systemic analysis of all reviews submitted to identify themes (and points of systemic improvement) that can help in reducing the number and duration of review processes

j) The circumstances in which plans could be automatically rolled-over

If a participant's plan met their needs the previous year, and if the participant's circumstances have not changed (and are not expected to change) and if the participant feels that the same plan would continue to meet their needs in the coming year, then there should be an option offered to that participant to have their plan "rolled over". Goals and objectives, and steps toward these, do not often fit neatly into an annual planning cycle, especially when they involve

moving toward radically different lives and circumstances. The nature of a scheme such as the NDIS is that it will require regular (annual) reviews of progress, so these should occur, but there should be no pressure to radically change course or levels of funding if the majority of goals are still in train at the time of the review.

k) The circumstances in which longer plans could be introduced

Longer plans might be suitable in situations where a participant's needs are likely to remain stable, where the person is happy with the content of the proposed plan, and where the person wishes to have a longer NDIS plan. Whilst all plans will be aspirational in nature, the particular living conditions of some participants will be such that the goods and services delivered through the NDIS will be of a constant and repetitive nature, and will only require review to ensure the quality is adequate and that the participant's needs are being met in the way that was articulated in their plan.

I) The adequacy of the planning process for rural and regional participants

ADACAS is aware of the shortcomings of the NDIA's reliance upon market forces to increase and improve service delivery to NDIS participants, and that this impacts significantly on a process of planning which encourages people to aspire to a better life without any guarantee of there being the services available to deliver the supports required¹⁰.

Since late 2018 ADACAS has delivered Advocacy to people with disability and families in the southern part of NSW, but at this stage has not received referrals which are directly relevant to the issue of NDIS planning in regional and rural areas. We have established links with regional networks who have indicated to us that they receive a significant number of enquiries about the NDIS generally, so further discussion with our colleagues in the networks will inform our understanding of how planning is being experienced by participants in the area.

m) Any other related matters

Section 2a) above has indicated that ADACAS believes there is a problem with the narrow understanding of "disability" when determining eligibility for the NDIS and in identifying "reasonable and necessary" supports that may be funded in a participant plan. The Productivity Commission Report has both recommended using the International Classification of Functioning (ICF) as the framework for assessment under the NDIS (Recommendation 7.1) and that the assessment

¹⁰ See for example Mavromaris, K, Moskos, M, Mahuteau, S, Isherwood, L 2018, *Evaluation of the NDIS: Final Report*, National Institute of Labour Studies, Flinders University, Adelaide, available: https://apo.org.au/sites/default/files/resource-files/2018/04/apo-nid143516-1215586.pdf

tools be subject to evaluation against best practices including the ICF, and recalibrated if necessary (Recommendation 7.9)¹¹. The ICF is the internationally accepted framework for describing disability, and was developed over a period of years in the 1990s and early 2000s to bring together earlier, mainly medically focused classification systems with the concepts of the "social model of disability", which has widely been adopted as an underpinning principle for the UN CRPD and the National Disability Strategy. At its heart the social model of disability accepts that the disadvantage experienced by people with disability is not inherent to their impairments or conditions, but instead an expression of the many and various barriers that they experience which people without disability are not subject to, and the social and economic impact this has on them and the further disadvantage they experience as a result. The ICF has translated this into its four domains, described thus:

- the body functions and structures of people, and impairments thereof (functioning at the level of the body);
- the activities of people (functioning at the level of the individual) and the activity limitations they experience;
- the participation or involvement of people in all areas of life, and the participation restrictions they experience (functioning of a person as a member of society); and
- the environmental factors which affect these experiences (and whether these factors are facilitators or barriers)¹².

This suggest that focusing solely on the first two domains, which appears to be the case currently within the NDIS, will significantly limit the effectiveness of the scheme, as it will not recognise and address the barriers in society that individuals need to overcome if they are to enjoy a fully inclusive life. This applies to assessment of eligibility and also to the range of supports that may need to be purchased or financed, given a participant's particular life circumstances. The narrow way in which is disability is understood in the planning process, together with the configuration of the NDIA systems that deny funding for non-specialist goods and services, is ignoring the broader systemic barriers that the NDIS was set up to help people with disability overcome. Given this is vital that the full scope of all domains of the ICF be adopted within the assessment and planning frameworks of the NDIS.

¹¹ Productivity Commission 2011, Disability Care and Support, Report no. 54, Canberra, available: <u>https://www.pc.gov.au/inquiries/completed/disability-support/report/disability-support-overview-booklet.pdf</u>

¹² Recommended in the People with Disability Australia submission to the Productivity Commission, see People with Disability Australia 2010, *Inquiry into Long Term Disability Care and Support: People with Disability Australia (Inc) Submission to the Productivity Commission*: Submission No. 524, available: https://www.pc.gov.au/inquiries/completed/disability-support/submissions/sub0524.pdf

3. Conclusion

NDIA planning processes and cycles have a profound impact on participants' experiences of the NDIS, and also on the effectiveness of the scheme. We urge sustained effort to address the current issues occurring, including consideration of a wide scale reform of the process as it stands, particularly the level of control exerted currently by the NDIA, so that participants are able to achieve what it was envisaged that the NDIS would offer: choice, control and a chance to live their own ordinary (good) life.

*All participant experiences have been de-identified and consent granted to include the examples provided.