ADACAS Response to the Productivity Commission's Issues Paper on National Disability Insurance Scheme (NDIS) Costs

1. Introduction

About ADACAS

The ACT Disability Aged Carer and Advocacy Service (ADACAS) has been providing advocacy to people with disability, older people, people with mental health issues and their carers for over 25 years. We are an independent, not for profit organization. ADACAS provides support for people appealing National Disability Insurance Agency (NDIA) decisions (both internally, and also at the Administrative Appeals Tribunal (AAT)). ADACAS also delivers support coordination (with an advocacy style approach) to NDIS participants. Additionally, we deliver a range of supported decision making and other community capacity building activities. ADACAS is a member of the Disability Advocacy Network of Australia (DANA), as well as ACT and NSW disability advocacy networks.

We will seek to answer many of the questions raised in the Productivity Commission's Issues paper on NDIS costs throughout this response.

NDIS and Context

The NDIS is monumental reform for Australia: a grand scheme (akin to the introduction of Medicare) that has the potential to make vast differences in the life experiences of an array of people with disability, their families and carers both now and in decades to come. It also acknowledges the human rights of people with disability (and seeks to fulfil Australia's obligations under the United Nations Convention on the Rights of Persons with a Disability (UNCRPD)).

Given the early rollout of the NDIS in the Australian Capital Territory, ADACAS has already seen some of the life-changing difference that an appropriate NDIS plan can make to people with disability and their families. We strongly support the NDIS and the opportunities it offers for people with disability in terms of choice and control over their lives, and to be able to find employment, study and in increased opportunities for social engagement or community participation.

With such significant and important change, come also the challenges in realising the vision of the NDIS. Challenges of governance, of implementation, of financial sustainability of the scheme are inevitable. It is imperative however that these challenges are managed and solutions identified to enable the vision of the NDIS to be realised. We urge a focus on the long-term, on what can be achieved over time, by investing now and partnering with people with disabilities, their families, and community organisations in the future for people with disability and this scheme.

2. Overarching recommendation:

We recommend that the NDIS be adequately funded such that questions of current costs not do not undermine the longer term vision and aims of the NDIS and what it can achieve with and for people with disability.

3. Summary of Specific Recommendations:

NDIS Plan Utilisation and Implementation

1. We recommend that the NDIA improve the information, resources and training available to assist new and ongoing participants in the NDIS implement plans. We recommend also that more information on this and other NDIS topics be made available in easy English.
2. We recommend that the NDIA also improve the information that they provide about the list of NDIS registered providers in each state, so that participants can clearly see which provider offers which exact service and which providers are actively operating in their immediate town or area.
3. We recommend that there be academic research into the barriers that are affecting plan utilisation in different areas and that there be a concerted approach to address any barriers that are affecting plan utilisation.
4. We recommend that the NDIA offer (and pay for support coordinators and support connectors across the various organisations to attend) good quality training about the role and expectations of support coordinators, and that update training be provided periodically.
5. We recommend that the NDIA offer (and pay for support coordinators to attend) regular meetings with the NDIA, and that this also be a two-way communication process.
6. We recommend that the NDIA assist participants to connect to support coordinators when this is required.
7. We recommend that the NDIA analyse and seek to proactively address gaps in the disability services market in the different states and areas.

Access Eligibility and Scheme Boundaries

8. We recommend that the NDIA reinstate funding for set organisations in the ACT (and elsewhere) to support people with disability who have not yet entered, to enter the NDIS;
9. We recommend the development of a fully bulk-billed Medicare code that GPs or specialists can use when a long medical appointment (or additional time outside appointments) is required to complete NDIS entry paperwork;
10. We recommend that there is improved training for GPs on the NDIS access and entry processes;
11. We recommend that the NDIA continue to develop alternative entry forms for people experiencing psychosocial disability only - (for example those developed by ACT Mental Health in conjunction with the NDIA);
12. We recommend that the NDIA provide additional and more targeted assistance to ensure that people with disability from CALD backgrounds have the necessary information and support to enter the NDIS.
13. We recommend urgent research, analysis and investment to seek to appropriately resolve the interface issues between the NDIS and other sectors (Health, Mental Health, Education, Housing, Employment etc.), especially those interface issues having a significant impact on the wellbeing and experience of people with disability.

14. We recommend increased funding and focus on seeking to ensure that the rights and needs of people with mental health issues are met by the service system (both people eligible for the NDIS and those who are not).
15. We strongly recommend that the cap on NDIS staff numbers should be removed, such that the NDIA is able to employ the needed numbers of ongoing staff to allow the scheme to operate efficiently and effectively.
16. We strongly further recommend that Local Area Coordinators be permitted to cease involvement in NDIS planning and plan approvals, and instead return to their original designated function of supporting both NDIS participants and people with disability without an NDIS plan to understand how the NDIS works, build their skills and to connect to necessary services.
17. We recommend that the processes by which people with disability are referred back to mainstream services for support (when appropriate) be reviewed and significantly improved.

NDIS Planning Process

18. We recommend that the NDIA directly employ more NDIS planners, that they be employed in ongoing roles, and that the NDIA ensure that they are provided with good quality training and support.
19. We recommend continued (but careful) work on improving, streamlining and simplifying the assessment tools and the planning process. We note the urgent need to partner with people with disability, advocacy and community organisations to work through issues and decisions in this space.
20. We recommend that the NDIS take a transparent approach with regards to efforts to benchmark and/or develop reference plans, and that they partner with people with disability and work very closely with advocacy agencies, disability services and the community again in these efforts.
21. We recommend an urgent review of benchmarked costs/ reference plans for people with multiple and complex needs living in shared social housing, as we have observed that the support costs for people living in those settings seem frequently to be considerably underestimated.
22. We recommend also careful investigation and review of the impact of benchmarked plans and reference plans on people with multiple co-occurring forms of disability to ascertain and address any negative and systemic issues that a reference plan/ benchmark approach is having.
23. We recommend their be academic research into strategies for ensuring that there is sufficient flexibility, individualised attention and a continued focus on participant choice and control and person-centred planning through the planning process (especially if there is a context of benchmarking and reference-plans).
24. We recommend that the NDIS fund additional pre-planning and decision support for people with intellectual disability, or other cognitive impairments, who need support to exercise choice and control in the planning process.
25. We recommend a return to face-to-face planning meetings (except in the circumstances where planning by telephone is requested by the participant).
26. We recommend that the NDIA return to the "team of planners" model used in the ACT Trial site, where teams of planners were specialising in different areas (e.g. psychosocial disability, highly complex care coordination etc.) and assisting specific participants with the planning process.
27. We very strongly recommend that the NDIA fix their IT system such that it is possible for NDIA planners to amend NDIS plans when errors or accidental omissions occur, also such that quotes for pre-approved equipment items can be much more quickly approved.
28. We recommend that the NDIA take a proactive approach to seeking to ensure that there are equitable (yet still individualised) outcomes for participants from the NDIS planning process.

29. We recommend that the performance of planners be monitored via direct participant feedback on the quality of their experience and (post plan provision) on the adequacy of their NDIS plan. We recommend also that feedback from other stakeholders (family, guardians, community agencies etc.) also be taken into consideration.

Market Readiness

30. We recommend an increase in the fixed payment rate for disability support workers in the NDIS Price guide and considerably higher payment rates for disability support workers working with participants with complex health and behavioural support needs in recognition of the considerably higher level of skills needed.
31. We recommend that there be a focus on improving knowledge of the NDIS amongst allied health professionals, and that the registration and administrative processes for allied health professionals be streamlined and simplified.
32. We strongly recommend that there be increases in the funding available outside of the NDIS, to support carers.

Governance and Administration

33. We recommend that (more) people with disability be included and represented in governance and at the highest levels of both the NDIA and other governance structures that affect the NDIA.
34. We recommend that the NDIA should be measuring costs in the much longer term (as opposed to taking a year by year approach.
35. We recommend that responsibility for the management of the IT system and portal be moved away from the Department of Human Services (and instead undertaken by others with additional expertise/experience in addressing IT and IT implementation issues).
36. We recommend the NDIA address the excessive wait times for people calling their 1800 number by employing (and training) more staff to be able to assist.
37. We recommend a change such that service providers and participants can have direct email contact with NDIA officers working on cases (rather than being required to email a generic inbox).
38. We recommend the NDIA develop an improved communication strategy for keeping NDIS participants, service providers and the public informed as needed re changes and updates.
39. We recommend there be a separate and direct phone number to give feedback/lodge complaints with the NDIA.
40. We recommend there be a separate and direct phone number to reach the National Access Team
41. See recommendation 27.
42. We recommend that the NDIA make continuing and active efforts to seek to identify provider practises that are unduly and negatively affecting participants and that they address these issues as early as possible.
43. We recommend that there be timeframes set for the NDIA to respond to requests for internal reviews of decisions.
44. We recommend that there should be tender process/es to appoint a suitable and qualified provider of last resort for participants unable to access other supports.
45. Even with a national approach to quality and safeguards, we strongly recommend that there continue to be local staff with local expertise and knowledge, with the authority to be able to act on complaints and respond to and address issues in the local community, and to follow-up to ensure that changes are implemented and maintained.

46. We recommend that all national safeguards processes focus on safeguarding a good life for a person, as opposed to focussing purely on keeping a person safe.
47. We recommend that the NDIA set "the extent to which the NDIA and the service system is capable of safeguarding a person's right to have a good life and participate in the community" as a fundamental measure of its success.
48. We recommend that the NDIA continue to be mindful of the need to build appropriate safeguards into the systems and the ways in which the NDIS operates.
49. We strongly recommend the continued recognition of the importance of independent advocacy for people with disability.
50. We further recommend the need for urgent increases and stability in the funding available for all types of disability advocacy and organisations promoting capacity building in this space.

4. NDIS Plan Utilisation and Implementation

A. NDIS plans and Low Utilisation Rates

Why are utilisation rates for plans so low? Are the supports not available for participants to purchase (or are there local or systemic gaps in markets)? Do participants not require all the support in their plans? Are they having difficulty implementing their plans? Are there other reasons for the low utilisation rates?

It is likely that there are a number of reasons contributing to low utilisation rates for NDIS plans.

The most common reasons that we at ADACAS are hearing from participants experiencing difficulties in plan implementation include:

- Difficulties in understanding what the plan means and knowing how to implement it;
- Difficulties in finding and retaining suitable supports;
- Supports not being available for participants to purchase (for example: specialist support coordination for clients with multiple and complex needs can be very difficult to access in the ACT);
- Difficulties in navigating the service system: it can at times be so complex that managing this on top of managing impacts of disability (or informal care) can mean that participants and/or families/guardians become overwhelmed and give up on trying to implement the plan;
- Difficulty in accessing information about services in easy to read formats and language;
- Changes of circumstances, or significant life events (deaths, unexpected illness) of participant or family members/guardians taking precedence over plan implementation;
- The speed and complexity of change with both the NDIS, but also in the service sector (one year's NDIS plan looks very different to the next, services changing or disappearing);
- In NDIS plans where transport costs have not been provided, we are also hearing of situations where participants can't afford to attend and participate in desired activities;
- Additional challenges for participants (and families) from culturally and linguistically diverse communities due to language and cultural differences;
- Lack of support for people to understand what their plan means and how to implement it (low availability of support from Local Area Coordinators, ECEI partners or support coordination not being included in plans where it is needed).

In addition, plan implementation can be affected by the approaches taken by service providers and the experience or lack of experience of a support coordinator or Local Area Coordinator.

Do participants not require all the support in their plan?
It is our experience that the greater majority of participants **do** need all the supports in their plans, (that often that they need more support than is included in a plan).

B. Information Gaps that Affect Plan Implementation:

When an NDIS plan is sent out to a participant, there is often limited (if any) information provided with the plan about what the different funding categories mean, and how to start implementing the NDIS plan. This can have a significant impact on a participant's ability to implement their NDIS plan.

> **Case Study:**
> A participant new to the NDIS has received her first NDIS plan. Her plan includes funds for support coordination, for improved daily living, for improved health and wellbeing, for improved relationships, for transport, and for core supports.
>
> The participant reads the information, but it uses unfamiliar terminology, and she does not understand. What is support coordination? What category of funding will cover cleaning the house?? Where do they start to try and access the money? (Or as per an earlier question we received from another participant – if I don't use the funds, can I put those funds in my bank account and save this money??)
>
> The participant asks a service provider that she knows – the role of support coordinator is explained, and she is encouraged to start by trying to find a support coordinator. She is shown where on the NDIS website to find a list of all the registered providers of support coordination in the ACT. There is a general discussion about the difference between different styles of support coordination, how to go about interviewing potential services.
>
> The participant called and left messages with multiple support coordinators but found that service providers were not returning her calls. She eventually connected to a support coordinator approximately 2 months into her plan. Whilst the time of year (December), and workload issues for providers may have affected her experience, it should not be that difficult to connect with a support coordinator, and commence an NDIS plan.
>
> A few months down the track, the participant advises: "if the NDIA had just provided information in plain English about what to do, and where to start, it would have made it so much easier".

The NDIS Quality and Safeguards framework notes that "to facilitate choice and control in the NDIS market, information must be comprehensive, reliable and accessible to all people with disability and their families"[i]. We note that the factsheets and resources available for new participants needs to be significantly improved. We also note that the information about the list of registered providers available in each state needs to show which providers offer which exact service, which providers are actively operating (not just registered), and which are operating in which areas of the state.

Recommendations:
1. We recommend that the NDIA improve the information, resources and training available to assist new and ongoing participants in the NDIS implement plans. We recommend also that more information on this and other NDIS topics be made available in easy English.
2. We recommend that the NDIA also improve the information that they provide about the list of NDIS registered providers in each state, so that participants can clearly see which provider offers which exact service and which providers are actively operating in their immediate town or area.
3. We recommend that there be academic research into the barriers that are affecting plan utilisation in different areas and that there be a concerted approach to address any barriers that are affecting plan utilisation.

C. Support Coordinator and Support Connection Roles

We note also the importance of the role that support coordinators can play in supporting participants to implement their NDIS plan, achieve their goals, and also to respond to and manage the challenges of services being delivered across multiple providers. We are aware that it can be difficult for participants to find an experienced support coordinator who also has the time/capacity to assist. We also note that the quality, experience and expertise of support coordinators (and support connectors) seems to vary considerably.

We note that given the nature of the support coordinator role, a powerful way to impact the quality of NDIS participant experience would be to work closely with and continue to upskill support coordinators.

Case Study:

A participant aged in his 20s has an intellectual disability, is on the autism spectrum and has complex health and behavioural needs. Due to health reasons, he needs 24 hour care. He speaks few words verbally, but communicates using communication aids. His guardian (who is also his parent) advocates strongly for the participant's rights. Due to the complexity of his care, communication and behaviour needs, it is important that this participant has a consistent group of staff who support him day to day. The participant's guardian has tried working closely over time with many service providers in an effort to achieve this, but due to the complexities of the participant's circumstances (and the systemic difficulties that occur with service providers and the casualization of the disability support worker workforce), this has proved difficult to achieve. There are multiple providers involved in supporting this participant, and the family has also experienced the challenges of coordinating with many different service providers.

The role of the family in advocating for this participant has been critical to achieving positive outcomes for this participant. The role also of the support coordinator has proven to be especially pivotal in this situation, in assisting the family to learn about how the service system and NDIS works, supporting them in having issues addressed and as the participant and his family continue to seek creative solutions to support the participant to achieve his goals.

Recommendations:

4. We recommend that the NDIA offer (and pay for support coordinators and support connectors across the various organisations to attend) good quality training about the role and expectations of support coordinators, and that update training be provided periodically.
5. We recommend that the NDIA offer (and pay for support coordinators to attend) regular meetings with the NDIA, and that this also be a two-way communication process.
6. We recommend that the NDIA assist participants to connect to support coordinators when this is required.

D. Participant numbers:

Why are more participants entering from trial sites than expected?

It is our understanding that the initial estimates of people who might need to enter the NDIS were based on the numbers of service users of existing services at that time instead of measuring the level of need in the community.

We also note that the introduction of the NDIS may have also importantly raised awareness in the community regarding the rights of people with disabilities to access supports.

We note it has also likely ignited ambitions of people with disability who are wanting to experience greater social and economic participation, and thus can be seen as a mark of community acceptance of the NDIS vision.

8

E. Gaps in the market
What are some of the key gaps in the market in the ACT?
- Allied health and therapies: limited numbers of services are registered with the NDIS
- Availability of experienced support coordinators
- Specialist support coordination: ADACAS was searching for specialist support coordination for a client with very high and very complex needs. Despite sustained efforts, and enlisting the NDIA directly to assist, it took an excessive amount of time to find an agency to meet the participant's needs.
- Assistance to support a number of vulnerable people who are living in shared accommodation to move from one provider to another
- Support for clients needing assistance to apply for entry to the NDIS
- Difficulties in finding 24hour clinical nursing level of support for clients with the most complex of medical needs.
- Specialist culturally and linguistically diverse (CALD) organisations and bilingual workers
- Availability of support workers willing to assist clients who have complex health needs, and/or need a complex behaviour support approach

Recommendations:
7. We recommend that the NDIA analyse and seek to proactively address gaps in the disability services market in the different states and areas.

5. Access, Eligibility and Scheme Boundaries

A. Importance of improving access to the NDIS:
At the present time, within the ACT, there are a considerable number of people that should be eligible to receive an individual package of NDIS supports, however, who are not yet entrants to the scheme. There are a variety of aspects of the eligibility criteria and entry process that are making it more difficult for people who need NDIS supports (and should be eligible for entry) to enter the scheme.

Difficulties include:
- The NDIS access request form has a section that needs to be completed by doctors. As a long appointment is generally needed, this can mean gap fees or additional cost to participants (which can in many instances create a financial barrier to entry). There can also be significant costs in obtaining any additional medical and other supporting documentation from medical specialists or allied health therapists;
- Lack of GP training and familiarity with NDIS access request forms, means that sometimes GPs do not adequately complete NDIS access request forms. If an NDIS application is submitted without adequate medical supporting documentation / evidence of the impact of disability, this usually means that the application is unsuccessful. Being denied entry can have a profound psychological impact for the person with disability, and creates added work for the participant, any organisations able to offer support to that participant, and to the NDIA in the need to complete NDIS appeal processes;
- The increasing focus from NDIS planners on the inclusion of more specific diagnostic and supporting information from medical specialists and/or allied health therapists also adds cost and time barriers;
- Other aspects of life – for example, if a client is at present experiencing family breakdown, and involved in protracted court proceedings with regards to access to his children, he may not have the time or energy to also investigate/learn about NDIS entry processes during this period;
- Fear and anxiety about the process and scheme cause people also to delay entry;

- Also people who are unaware of the existence of the scheme. (For example ADACAS recently became aware of a family where two adult children have profound psychosocial disability, however because the family are isolated, and not in contact with services, and did not access media, they were completely unaware of the assistance available via the NDIS);
- Additionally, there are some eligible people who have opted to delay entry due to wanting the scheme to be up and running (and have any initial implementation difficulties or issues resolved first);
- Inadequate support and information available for people with disability from culturally and linguistically diverse backgrounds to enter the NDIS. At the NDIS Symposium: NDIS & CALD Communities: Aiming high for equitable access at Griffith University (11 October 2016), it was noted by Meagan Price from Diversitat in Geelong that whilst "estimates of numbers of people from CALD backgrounds with disabilities vary", that "current estimates are that approximately one in four people with disabilities in Australia are either first or second generation CALD". At that same conference, the Steph Gunn, General Manager of Community Linkages, NDIA, advised that as at 30 June 2016, 4% of NDIS participants from trial sites were of CALD backgrounds. Given this gap - there is considerable work needed to ensure that people with disabilities from CALD backgrounds receive information about the NDIS in ways that are understandable and meaningful, understand their rights and can access supports via the NDIS accordingly. Targeted face-to-face outreach to CALD communities is needed. Awareness raising activities must use networks and information sources commonly used by CALD communities, for example radio, and ethno-specific social and activity groups. This should be supplemented by information produced in other languages, and support from bilingual workers with NDIS access request forms.

Until the end of 2016, there was a consortium of organisations in the ACT who were funded to support people who needed assistance to enter the NDIS. That funding has now ceased. There continue to be significant numbers of people who have not yet entered the NDIS, but need support to gather the information and to enter the scheme.

Recommendations:
8. We recommend that the NDIA reinstate funding for set organisations in the ACT (and elsewhere) to support people with disability who have not yet entered, to enter the NDIS;
9. We recommend the development of a fully bulk-billed Medicare code that GPs or specialists can use when a long medical appointment (or additional time outside appointments) is required to complete NDIS entry paperwork;
10. We recommend that there is improved training for GPs on the NDIS access and entry processes;
11. We recommend that the NDIA continue to develop alternative entry forms for people experiencing psychosocial disability only - (for example those developed by ACT Mental Health in conjunction with the NDIS);
12. We recommend that the NDIA provide additional and more targeted assistance to ensure that people with disability from CALD backgrounds have the necessary information and support to enter the NDIS.

B. **Eligibility for the NDIS**
The NDIS issues paper enquires as to the reason for the "higher than expected numbers of children (especially in South Australia, Victoria and the ACT trial sites" (Issues paper page 11). It is our impression that the addition by the Productivity commission of NDIS entry criteria related to learning has increased the numbers of children entering the NDIS.

C. Intersection with Mainstream Services

The current split between the services agreed to be provided by the NDIS and those provided by mainstream services is not efficient nor sufficiently clear. The response to interface issues is also inconsistent. There are especial difficulties where multiple service systems interact – for example – people with disabilities who find themselves in hospital, but need increased health and disability supports (and changes at home (home modifications) or changes in pre-existing housing arrangements) in order to be discharged.

> **Case Study:**
> A participant aged in his early fifties has a degenerative disorder that is having increasing impacts on his cognition and mobility. Due to a related health issue, the participant finds himself in hospital. Before hospital, he was living at home, and he very much want to be discharged from hospital and to return home. Unfortunately, due to changes in his mobility, major home modifications are now needed to make the participants home (especially kitchen/ shower/bathroom) accessible, and before the participant can return home. The participant has an NDIS plan, an urgent review is requested and the reports to arrange the modifications ordered, but there is at least a six month wait for a service that is able to do the changes. As there are no suitable longer term respite options that he is eligible for, and that can meet his complex health needs, he ends up needing to remain in hospital for a much longer period than is desirable while these home modifications occur. Hospital is very unsuitable place to live during a period when he doesn't need urgent healthcare attention himself: he is in a shared room, is at increased risk of illness, and also has traumatic experiences in observing others in health crisis during this time.

Recommendations:

13. We recommend urgent research, analysis and investment to seek to appropriately resolve the interface issues between the NDIS and other sectors (Health, Mental Health, Education, Housing, Employment etc.), especially those interface issues having a significant impact on the wellbeing and experience of people with disability.

D. Intersection with Mental Health Services

Given what has been forecast so far in relation to funding and approach to mental health services, we hold grave concerns for the impacts of NDIS rollout on the mental health services sector, and more importantly for people with mental health issues (both those who will be eligible for NDIS funded supports, and those who will not). We are already seeing emerging in the ACT significant gaps in needed services.

Please see attached our recent submission to the Joint Standing Committee on the National Disability Insurance Scheme on "the provision of services under the NDIS for people with psychosocial disabilities related to a mental health condition" for additional information on this topic.

Recommendations:

14. We recommend increased funding and focus on seeking to ensure that the rights and needs of people with mental health issues are met by the service system (both people eligible for the NDIS and those who are not).

E. Information Linkages and Capacity-Building (ILC) and Local Area Coordinators (LAC)

Is the range and type of services proposed to be funded under the ILC program consistent with the goals of the program and the NDIS more generally? What, if anything, can be done to ensure that the ILC and LAC initiatives remain useful and bridging tools between services for people with disability?

While the aims of the ILC model are worthy, at the present time, implementing the ILC model of funding via shorter-term grants and contracts increases insecurity and the already speedy pace of change within the community sector and risks leading to a decrease in the capacity of community organisations to be strategic and plan for the longer-term. Sector development via grants cycles also increases the risk of a scattergun rather than strategic approach to decision-making, in this space.

The model originally proposed (by the Productivity Commission in their 2011 Report into Disability Care and Support report) in relation to the role of Local Area Coordinators is **not** being implemented as designed[ii]. Instead, the proposed model has LACs taking on an NDIS planning and plan approval function with participants. It appears that this is occurring because the cap that has been imposed on NDIA staff numbers is meaning that the NDIA does not have enough ongoing staff to fulfil standard operating procedures around NDIS planning, review and plan approval functions.

Strategies to deal with the cap on staff numbers by relying on staff from partner organisations (who have more limited training than ongoing NDIA staff) and also co-opting LACs into assisting with NDIS planning, review and plan approval functions are short-sighted and risk causing significant damage to the scheme in the longer term. We also note that the people experiencing the strongest impact of this change are people with disability, who are being left without the supports needed to connect to services.

We strongly recommend that the cap on NDIA staff numbers should be removed, such that the NDIA is able to employ the needed numbers of staff to allow the scheme to operate efficiently and effectively. While this might mean added investment now, we note that we would expect that in the longer term this would improve the quality of NDIS planning and plans, (reducing the number of appeals (and both participant, staff and community organisation time in writing appeals, and NDIA efforts to respond to appeals). We note that it would also likely improve NDIA staff motivation, allow for the development of deeper staff knowledge and expertise, and enable better outcomes for participants.

Recommendations:
15. We strongly recommend that the cap on NDIA staff numbers should be removed, such that the NDIA is able to employ the needed numbers of ongoing staff to allow the scheme to operate efficiently and effectively.
16. We strongly further recommend that Local Area Coordinators be permitted to cease involvement in NDIS planning and plan approvals, and instead return to their original designated function of supporting both NDIS participants and people with disability without an NDIS plan to understand how the NDIS works, build their skills and to connect to necessary services.

F. **Referrals Back to Mainstream Services for People Who are Not Eligible for NDIS Individual Funding Package Support**
Is the way the NDIS refers people who do not qualify for support under the scheme back to mainstream services effective? If no, how can this be improved?

The way that the NDIA refers people who do not qualify for support under the scheme back to mainstream services is not currently effective.

Our experiences have been that potential participants are typically very disheartened by the news that their NDIS application had been unsuccessful. In most situations, potential participants received a letter (only) from the National Access team to advise of the outcome and referral pathways. The referrals provided by the National Access Team in these letters were usually either too generic to be of assistance ("that the health system can meet your needs") or unhelpful/ incorrect: (for example, advising a person that they can't access the NDIS but can instead access adequate support from the Pain Management

Unit at the Canberra hospital, when the Pain Management Unit had referred them to the NDIS as their level of need was higher than what the Pain Management Unit could assist them with).

Referrals could be improved by:
- A thorough approach to the initial assessment (the National Access Team staff member ensuring that they have all the information needed such that accurate decisions regarding entry can be made);
- If the person is found ineligible for support to the NDIS, providing the opportunity for the person with disability to discuss the outcome, appeal avenues and/or referral paths, as needed, with an NDIA staff member* who has excellent knowledge of service levels and referral pathways;
- Ensuring that when clients are to be referred to other services for support, that these referrals are specific, accurate and appropriate to the individual client's needs (and that they take account of avenues that clients have already tried).

*I note that it has been considered that LACs may take on this referral role, however also that in the ACT experience, the workload for LACs was so high that they were unable to assist <u>current</u> NDIS clients with plans or connecting to supports (it would not have been possible for them to take on this additional role).

Recommendations:
17. We recommend that the processes by which people with disability are referred back to mainstream services for support (when appropriate) be reviewed and significantly improved.

6. NDIS Planning Processes
QUESTIONS • Is the planning process valid, cost effective, reliable, clear and accessible? If not, how could it be improved? • How should the performance of planners be monitored and evaluated?

A. NDIA Planners:
The skills, experience and expertise of the NDIA planner make an immense difference to the quality of the planning process and the outcomes for NDIS participants. It is crucial that the NDIA continue to recruit planners with the right combination of skills, experience and passion, that they offer good training and that workload pressures for NDIA staff are managed. Planners need the skills to be able to tailor the planning approach, and their communication style to participants with different needs (e.g. a participant with an intellectual disability, OR a participant who finds maintaining attention/ concentration very difficult OR a participant with memory difficulties).

When planners with less experience, skill or training (e.g. some of the planners brought across from other areas of government) have been assisting participants with the planning, we have observed that experiences for participants are less positive and the likelihood of unsuitable or inaccurate NDIS plans considerably increases.

B. Assessment Tools:
The current first plan assessment tool/s include a series of automated questions, the answers for which then assist the planner to determine funding levels and options. Whilst we understand that the World Health Organisation Disability Assessment Scale (WHODAS) forms one part of the questions, our understanding is that the exact decision-trees, rationales behind funding limits and full sets of questions are not public documents. We rely upon seeing participant outcomes to seek to ascertain what assumptions are being made and what limitations imposed.

ADACAS has observed a variety of situations where a planning meeting has seemed to capture very inaccurately a participant's actual level of need. We have concerns that the tools in some situations are not reliable, due to inconsistency of outcomes for people (beyond what individual difference and choice/control should warrant).

The impact for a participant of not receiving funding for needed supports can be profound and considerable. In many cases a review of decision will then be needed, which creates considerably more work and stress for participants, community organisations and the NDIA.

While a good planner can sometimes work around the limitations of the assessment tools to negotiate appropriate outcomes, a less experienced planner struggles. There is continued work needed on seeking to refine and improve these tools. We encourage the NDIA to partner with people with disability, advocacy and community organisations to work through decisions in this space.

C. Benchmarking / reference plans:
We are also aware that the NDIA has been starting to benchmark funded supports and develop reference NDIS packages. Whilst we appreciate these are efforts to improve the accuracy of plan outcomes, we note that additional difficulties are emerging. We would encourage a transparent and rigorous approach to consideration of benchmarking and reference plan topics.

We note also that taking a prescriptive (top-down) approach also carries inherent risks that planners (and assessment tools) will overly rely on reference plans as opposed to taking a person-centred approach - focusing on each individual participants situation and goals, and what each person individually needs in their individual circumstance.

Additionally, we note that recent NDIS benchmarked costs for <u>participants living in shared supported accommodation</u> seem often to be significantly underestimating the costs involved in supporting these participants. Given that participants living in these settings tend to have multiple and very complex needs and are additionally vulnerable as a result, underfunding needed supports can have profound impacts for quality of care that participants are receiving, and can significantly increase the risks of harm to people living in those settings. We urge further analysis and an increase in the benchmarked costs for people living in these settings accordingly.

It has been our observation as well that NDIS participants with multiple co-occurring forms of disability (for example, both physical and psychosocial disability) are at times having their needs significantly underestimated, and thus plans being considerably (at times) underfunded. It is unclear if this is occurring due to lack of planner awareness of about the compounding impact of multiple disabilities and the increased level of funding for supports needed, or if it is a systemic issue and linked with the assessment tools and benchmarked plans. We urge the need for a careful investigation and review in this area.

D. Need for Support for Decision Making
For people with intellectual disability (or other cognitive impairments), providing support for decision making in advance of and during the planning process would make planning more efficient. The current process does not recognise that people with decision making disabilities may need decision making support to exercise choice and control. Decision support could stream-line the planning process, ensuring people are working toward self-nominated goals to ensure that plans are able to provide for the best supports.

E. Planning by Telephone

The recent development whereby NDIS planning meetings are being conducted over the phone (sometimes without the participant realising that it is a planning meeting) is counterproductive and ineffective. Participants who are unable to outline clearly their needs (or who are not supported by someone able to do this on their behalf) are significantly disadvantaged. The NDIS Quality and Safeguarding framework highlights the importance of the planning meetings also as

Whilst ADACAS is aware that participants who are offered a telephone planning meeting can request a face-to-face planning meeting, participants are not always aware of this fact. On some occasions, participants have told us that time factors have affected their choice (we are aware of participants who were advised - we can offer a planning meeting by phone this week but that the next face-to-face meetings were not available for a considerable period (six-eight weeks)). Unless a participant has specifically requested a phone-planning meeting, we would continue to advocate for the need for in-person planning meetings.

F. Specialist team approach:

In the ACT, for a period, there were NDIA teams specialising in different areas (psychosocial disability, highly complex care coordination, early intervention plans with children etc.) who were undertaking planning for the relevant groups of clients. It was our experience that having a planner who specialised in the correct area (for example: planning with clients with psychosocial disability), resulted generally in significantly more accurate and appropriately funded plans.

G. Ability to amend plans / Quote approval timeframes:

Under the previous IT system for the NDIS, there was the ability to amend plans when errors or accidental omissions occurred. With the new IT system, this option was removed, which means that if an error occurs during the planner process (for example, if an incorrect equipment quote was provided, or if a participant becomes aware later that due to a lack of NDIS registered providers, that they need to change the way that funds are managed from NDIA managed to plan managed), an internal review now needs to be completed. This process adds significant and unnecessary work and time for participants, agencies assisting them, and the NDIA. In addition, there should be an IT solution such that quotes for pre-approved equipment items can be much more quickly approved.

H. Impact of Perceptions around Costs and Cost Pressures:

It is our experience that perceptions around NDIS cost pressures also from time to time seem to be affecting planners, introducing expectations that an NDIS plan will reduce from year to year, which is not realistic in many circumstances where instead it is expected that cost gains will be achieved in the longer (not shorter) term.

We note as well that there are some participants where due to the impact of disability there will always be a need for a level of coordination and administrative support throughout the participant lives, and it is not reasonable to expect otherwise.

I. Inequities

As advocates, we are also very concerned at the inequities emerging in the way that the planning process and plan outcomes are occurring for participants who understand and are informed about NDIS processes (or who have families, friends, guardians, support coordinators or access to advocates who are) as compared with NDIS participants who do not understand their rights or the processes (or how best to prepare for them), and do not have people supporting them to do so. The NDIS planning process should be sufficiently robust that it can generate fair and equitable outcomes and appropriately funded NDIS plans for all eligible people with disability.

J. Monitoring Planner Performance:

The performance of planners needs to be monitored through feedback from participants with regards to the quality of their experience, and the suitability of the information provided and the plan issued. Feedback from other stakeholders (community agencies, if appropriate, participant family members, guardians etc.) also needs to be taken into consideration.

K. Recommendations:

18. We recommend that the NDIA directly employ more NDIS planners, that they be employed in ongoing roles, and that the NDIA ensure that they are provided with good quality training and support.

19. We recommend continued (but careful) work on improving, streamlining and simplifying the assessment tools and the planning process. We note the urgent need to partner with people with disability, advocacy and community organisations to work through issues and decisions in this space.

20. We recommend that the NDIA take a transparent approach with regards to efforts to benchmark and/or develop reference plans, and that they partner with people with disability and work very closely with advocacy agencies, disability services and the community again in these efforts.

21. We recommend an urgent review of benchmarked costs/ reference plans for people with multiple and complex needs living in shared social housing, as we have observed that the support costs for people living in those settings seem frequently to be considerably underestimated.

22. We recommend also careful investigation and review of the impact of benchmarked plans and reference plans on people with multiple co-occurring forms of disability to ascertain and address any negative and systemic issues that a reference plan/ benchmark approach is having.

23. We recommend their be academic research into strategies for ensuring that there is sufficient flexibility, individualised attention and a continued focus on participant choice and control and person-centred planning through the planning process (especially if there is a context of benchmarking and reference-plans).

24. We recommend that the NDIA fund additional pre-planning and decision support for people with intellectual disability, or other cognitive impairments, who need support to exercise choice and control in the planning process.

25. We recommend a return to face-to-face planning meetings (except in the circumstances where planning by telephone is requested by the participant).

26. We recommend that the NDIA return to the "team of planners" model used in the ACT Trial site, where teams of planners were specialising in different areas (e.g. psychosocial disability, highly complex care coordination etc.) and assisting specific participants with the planning process.

27. We very strongly recommend that the NDIA fix their IT system such that it is possible for NDIA planners to amend NDIS plans when errors or accidental omissions occur, also such that quotes for pre-approved equipment items can be much more quickly approved.

28. We recommend that the NDIS take a proactive approach to seeking to ensure that there are equitable (yet still individualised) outcomes for participants from the planning process.

29. We recommend that the performance of planners be monitored via direct participant feedback on the quality of their experience and (post plan provision) on the adequacy of their NDIS plan. We recommend also that feedback from other stakeholders (family, guardians, community agencies etc.) also be taken into consideration.

7. Market Readiness

A. Disability workforce

Will the workforce and providers be ready?

There is a considerable undersupply of disability support workers available in the ACT. Factors likely to be affecting this include that the general disability support worker wage is low, most of the workforce seems to be in casual roles and especially when a participants needs are complex, there seems to be high expectations in terms of responsibility, but at the same time, due to cost necessities of the various organisations, at times limited support available for staff. We agree that it seems that the perception is there that caring roles are poorly valued. We have observed as well that there can be particular difficulties in finding and retaining workers for participants who have complex health and behavioural support needs.

In terms of allied health professionals in the ACT: despite the NDIS rollout being considerably progressed, there continue to be many providers with a general lack of knowledge and awareness about the NDIS. From allied health providers who have explored registering with the NDIS, we are hearing that the initial registration process for the NDIS is too complex and time-consuming (and of significant time delays) also that the amount of additional bureaucratic work that engaging with the NDIS requires is excessive. Perceived issues in obtaining payments from the NDIS have also proved to be a disincentive to registering for some providers.

Recommendations:

30. We recommend an increase in the fixed payment rate for disability support workers in the NDIS Price guide and considerably higher payment rates for disability support workers working with participants with complex health and behavioural support needs in recognition of the considerably higher level of skills needed.
31. We recommend that there be a focus on improving knowledge of the NDIS amongst allied health professionals, and that the registration and administrative processes for allied health professionals be streamlined and simplified.

B. Support for informal and family carers

At present there is not enough funding and support available for informal and family carers in the ACT. Insufficient support for informal/family carers is already having an impact on the ability of informal or family carers to continue to offer informal care, which increases the need for paid carer supports. We note as well that funding carers via NDIS plans is often ineffective (especially for carers of participants with psychosocial disability who do not perceive there to be a carer role, even though considerable carer support is provided).

Recommendations:

32. We strongly recommend that there be increases in the funding available outside of the NDIS, to support carers.

C. Participants and the NDIS

Will participants be ready?

Many NDIS-eligible individuals (and their families and carers) are not well-equipped to understand and interact with the scheme, to negotiate plans and to find and negotiate supports with providers.

Most NDIS-eligible individuals referred to ADACAS have very limited knowledge of how the systems work, and limited confidence in engaging with these processes. This is reflected in the low-utilisation rates for participants. As noted earlier, there is a strong and ongoing need funded assistance with pre-planning and access request processes.

8. Governance and Administration of the NDIS

A. Areas to be addressed

Existing governance and administrative arrangements definitely affect (and have the potential to affect) the provision of services, and can have a profound impact on scheme costs. (We cite the costs involved in the difficulties with the new IT system implemented for the NDIS as one example).

Governance issues to be addressed include:

- Representation: It is imperative that more people with disability are included and represented in governance and at the highest levels of both the NDIA and other governance structures that affect the NDIA. The voice and informed perspective of a variety of people with disabilities are needed to inform decisions that affect the NDIA and NDIS processes and strategic choices. In addition, it is part of the fundamental human right of self-determination, where people with disability are able to guide, direct and implement systems, policies and procedures that affect their own lives.
- Performance measurement: we contest that the NDIA should be measuring costs in the long-term (not taking a year by year approach). We note also that there should be the expectation of additional costs at the present time, whilst the scheme is rolling out and being established.

Other administrative issues that urgently need to be addressed include:

- Ongoing issues with accessing the portal/portal design flaws (both for participants and providers). Self-managed participants are consistently reporting difficulties in claiming / billing, and providers advise regularly of difficulties in logging on, and delays in receiving payments via the portal.
- Change in area responsible for management of the IT system and portal: we note that responsibility needs to be moved away from the Department of Human Service (We note that it seems that there are continuing and continual service issues throughout the time it has been managed within this area), that it seems that it is not being managed well through this area.
- Difficulties in communicating with the NDIA.
  - o By Phone: At present, in our experience, it usually takes a minimum of 30-40 minutes to get through to the NDIA via their 1800 phone number, usually closer to an hour. These delays are unacceptable, and unworkable as an approach to supporting people with disability and providers. In addition – the level of training of the staff at the communication who are responding, is often insufficient to be able to accurately answer the questions.
  - o By Email: there are also often considerable (and unacceptable) delays in response times to emails. We would encourage further monitoring of service standards in this area. We also request a change to the system of emailing a generic inbox – we need to have direct communications with NDIA officers working on cases, such as what occurs in interactions with other government services (Housing ACT).
  - o Communications from the NDIA: the NDIA also needs in general to improve its communications strategy and approach with NDIS participants, service providers and the public.
- Separate and direct numbers for feedback, also for the National Access Team: There needs to be a separate and direct phone line and number to handle complaints and feedback to the NDIA, and also a separate and direct number to reach the National Access Team.
- Ability to amend NDIS plans: as noted earlier, there is also a key need for NDIS plans to be able to be amended (immediately) by planners, when errors occur or smaller scale changes are needed, rather than requiring a full internal review process every time that an incorrect quote is provided, something is accidentally omitted, or a planner makes a mistake.

18

Recommendations:
33. We recommend that (more) people with disability be included and represented in governance and at the highest levels of both the NDIA and other governance structures that affect the NDIA.
34. We recommend that the NDIA should be measuring costs in the much longer term (as opposed to taking a year by year approach.
35. We recommend that responsibility for the management of the IT system and portal be moved away from the Department of Human Services (and instead undertaken by others with additional expertise/experience in addressing IT and IT implementation issues).
36. We recommend the NDIA address the excessive wait times for people calling their 1800 number by employing (and training) more staff to be able to assist.
37. We recommend a change such that service providers and participants can have direct email contact with NDIA officers working on cases (rather than being required to email a generic inbox).
38. We recommend the NDIA develop an improved communication strategy for keeping NDIS participants, service providers and the public informed as needed re changes and updates.
39. We recommend there be a separate and direct phone number to give feedback/lodge complaints with the NDIA.
40. We recommend there be a separate and direct phone number to reach the National Access Team
41. See recommendation 27.

B. Importance of effective quality assurance and of monitoring provider practises:

The move to national system of quality and safeguarding is a key element in the success of the NDIS. The extent to which the system is capable of safeguarding a person's right to have a good life and participate in the community will be a fundamental measure of its success.

We note the importance of effective quality assurance and monitoring also in addressing issues/constraints on participant choice and control that are arising from provider approaches and practices, and the growth of conflict of interest issues. For example, ADACAS is aware of instances where registered NDIS providers have advised participants as follows:

- A Supported Housing Provider that had been saying to participants that "if you wish to live in the property which we coordinate, we require you to accept support coordination from our service. If you choose to use a different support coordination service, we cannot offer you a place in this accommodation".
- A support coordinator service that has their own support worker staff offering personal care, domestic assistance etc. advising participants that "we can only assist you to connect with those services if you choose to have them from our service" (not assisting the participant to arrange them with other providers even if this is what the participant is requesting or needs).

In situations where there are limited availability of supported accommodation options, and at times difficulties for participants to find the right support coordination and support worker staff, such approaches limit choice and control for NDIS participants, and can have very negative and adverse impacts as a result.

Recommendation:
42. We recommend that the NDIA make continuing and active efforts to seek to identify provider practises that are unduly and negatively affecting participants and that they address these issues as early as possible.

C. Disputes with the NDIA

At the present time there NDIS legislation allows the NDIA to respond to requests for internal reviews of decisions "as soon as reasonably practicable"[viii]. This is not sufficient. The NDIA needs set timeframes for response. We would also note the importance that reviews and complaints are handled in a consistent manner.

Recommendation:

43. We recommend that there be timeframes set for the NDIA to respond to requests for internal reviews of decisions.

D. Provider of last resort

It is imperative that there be a provider of last resort, to assist NDIS participants unable to access support via other providers/where other options have been exhausted. Whilst this role was previously taken by government (in the ACT, it was Disability ACT) – given the focus and approach of the NDIS, we contend that this provider must not be the NDIA. We would instead recommend that there be a tender process to appoint a provider of last resort. We request that the selection criteria includes that providers must have the ability, experience and expertise to work with people in crisis, and those with varying types of disabilities and health issues. A provider of last resort must be able to work with participants with the highest and most complex of needs. Furthermore, the tender must also require prospective providers to meet criteria around best practice, and excellence in service provision.

Recommendation:

44. We recommend that there should be tender process/es to appoint a suitable and qualified provider of last resort for participants unable to access other supports.

E. NDIS complaints and complaint mechanisms

The availability and accessibility of independent complaints mechanisms which are able to use local knowledge and expertise in responding to complaints is crucial. Our experience with the national complaints system in the aged care sector demonstrates that a national scheme that does not have local presence is less effective than schemes with local staff able to respond to local complaint matters. Complaints processes must be able to act on complaints that come in any form, including anonymous complaints and must be able to offer both mediation and resolution, including follow-up of agreed changes to practice to ensure that changes are actually implemented and maintained not just proposed.

Complaints mechanisms should be able to respond to complaints about all supports used by a person not only those funded by the NDIS or within the specialist disability sector. Independent advocacy support to enable people to access complaints mechanisms is also essential.

Recommendation:

45. Even with a national approach to quality and safeguards, we strongly recommend that there continue to be local staff with local expertise and knowledge, with the authority to be able to act on complaints and respond to and address issues in the local community, and to follow-up to ensure that changes are implemented and maintained.

F. Safeguards and Quality Controls

To what extent do the existing regulations provide the appropriate safeguards and quality controls? Can these arrangements be improved?

The move to national system of quality and safeguarding is a key element in the success of the NDIS. The extent to which the system is capable of safeguarding a person's right to have a good life and participate in the community will be a fundamental measure of its success.

Traditionally the concept of safety revolved around physical safety, from abuse and neglect but also from perceived dangers in the community. A common response to these safety concerns has been to segregate people with disability, from a young age and continuing throughout their lives, so that a benevolent watch can be kept and they can avoid participating in activities which others perceive as risky. We now know that this approach to safety is fundamentally flawed and indeed has led to potentially greater risk to safety, and certainly to quality of life, than had such measures not been introduced. The current Royal Commission and inquiries are highlighting on a daily basis the very genuine risk which these approaches represented to people with disability and the consequent harm which they have suffered.

There are also risks associated with conflating quality and safeguarding into a single measure. The two are quite different and by their nature focus on different aspects of the system. Quality frameworks target the work of organisations in providing service; they are generally focused on system level activities such as policy and procedure, reporting, and check box methods of tracking service processes. While there will continue to be a role for quality frameworks, and these are useful triggers for continuous improvement of organizations' systems, they do not necessarily address the genuine experience of quality service to people with disability. Services which have ticked all the boxes and can proudly boast of quality certifications are at the centre of some of the current abuse cases which are under investigation. Clearly quality frameworks have failed in their ultimate measure and the intention to continue with essentially the same system under the new national framework does little to reassure individuals and families of change.

There is a real risk that the culture which led to the existing safety practices will carry over and that as a result the concept of safeguard will come to mean benevolent imposed safety measures and risk avoidance. Safeguarding however is not about that. Using the model of safeguarding described by Julia Farr in the Model of Citizenhood, means that the focus is not on protecting a person from risk, but enabling them to live an active, engaged, valued, visible life embedded within, rather than isolated from, their community and it is the very nature of this good life which acts to safeguard the person. All national safeguards process needs to take an approach of safeguarding a good life for a person, as opposed to focusing purely on keeping a person safe. Examples of safeguards in an NDIS context include – whilst being mindful of the importance of choice and control:

- Ensuring that no person's plan is fully implemented by a single service provider, rather that there are many paid and unpaid interactions built into their plan to ensure that the opportunity for one entity, or individual, to perpetrate abuse or neglect is minimised.
- Ensuring that people who continue to live at home with family, are actively engaging in a range of independent community activities so that they can develop a wider network of people to whom they are known and who will be alert for changes of concern in the persons behaviour, health or wellbeing.
- Responding to 'behaviours of concern' by recognising them to be communication by the person that all is not well with their world and investigating and resolving the triggers for the behaviours rather than focusing on managing symptomatic behaviour.
- Ensuring that individual capacity building activities are built into every plan so that the person continues to have opportunities to grow skills, learning and independence at the pace which is right for them.

Genuine change to risk management strategies is also crucial to a successful quality and safeguarding framework. Risk management is, all too often, focused on avoidance of risk which might vest with service providers; with government departments; or Ministers; rather than risk which might apply to the individuals themselves.

21

The concept of 'dignity of risk' is largely absent from existing risk management approaches. Dignity of risk enables a person to identify their appetite for risk and the level of risk which they are willing to accept. It needs to be central to any risk management policy and procedure which is applied to an individual. All risk management should include identification of the risk to quality of life and the risk to a good life, rather than focusing solely on the more traditional safety risks. We hope that the new Quality and Safeguards framework will spearhead the development of resources which support individuals, and those around them, to address and manage risk to a good life, as this would be a significant improvement on previous approaches.

Recommendations:

46. We recommend that all national safeguards processes focus on safeguarding a good life for a person, as opposed to focussing purely on keeping a person safe.
47. We recommend that the NDIA set "the extent to which the NDIA and the service system is capable of safeguarding a person's right to have a good life and participate in the community" as a fundamental measure of its success.
48. We recommend that the NDIA continue to be mindful of the need to build appropriate safeguards into the systems and the ways in which the NDIS operates.

G. Independent Advocacy as a vital safeguard

As an independent advocacy service we work with people with disability who are often unable to speak up for themselves. Advocates work with individuals on a range of issues including service quality, abuse and neglect, community participation and access to justice.

Being able to access free and independent advocacy is also an important safeguard. There is a significant body of evidence of the impact that the presence of an advocate in the life of a person has on the actions of others. There is a degree to which the behaviour of others is moderated by the knowledge that an advocate is alert to the needs of an individual and will be swift to act when required.

In addition, one outcome of high quality independent advocacy is to build capacity in the person. Capacity to self-advocate, knowledge of rights, knowledge of complaints mechanisms, experience being heard and speaking up, all build capacity of individuals to safeguard their own lives. The work of individual advocates, citizen advocates and self-advocacy services are particularly important as preventative safeguards for vulnerable individuals.

Advocacy services also do much to assist individuals to access their right to justice and other corrective mechanisms. Without advocates, many people with disability do not feel able to engage with corrective systems and lack the confidence to tackle the issue themselves.

All schemes, including the NDIS, are at times imperfect. Advocacy can assist in drawing attention to issues where attention is needed. Independent advocacy can also help to find and negotiate solutions to complex intractable issues.

There have been strong public calls for increased access to advocacy through social media and other mechanisms. The now almost 28,000 member NDIS Grassroots Facebook page, often includes comments about the vital nature of advocacy and the challenges faced by those who are unable to access it. Other inquiries have also recognised the increasing role for advocacy with the introduction of the NDIS. The Victorian Ombudsman stated:

"Without a strategy to embed the role of advocacy, a market-based model appears inaccessible for a large sector people with diminished capacity to make informed

decisions. It is not viable for advocacy to take a secondary position in the safeguards framework. I consider advocacy to be key in a framework for... people with disability who have no prospect of becoming empowered consumers and have no family or friends to voice their best interest." (Reporting and investigation of allegations of abuse in the disability sector: Phase 1 June 2015 p 90)

Given the magnitude of change that the NDIS is bringing, and the additional issues that are arising as a result of that change, we also urge there to be an increase in the funding available to independent advocacy services, to support people to raise concerns, and have issues addressed.

Recommendation:
49. We strongly recommend the continued recognition of the importance of independent advocacy for people with disability.
50. We further recommend the need for urgent increases and stability in the funding available for all types of disability advocacy and organisations promoting capacity building in this space.

H. **Does the current funding split between the Commonwealth and the States and Territories have implications for the scheme's sustainability?**
Yes. The dispute that arose between the Commonwealth and the Australian Capital Territory (ACT) government about funding participant numbers beyond 5075 (and which resulted in a decision to temporarily cease offering planning meetings to new NDIS participants, and to delays in the processing NDIS access request forms) is an example of the types of issues that can arise when funding is split between federal and state governments.

9. Conclusion

The NDIS is a scheme with the potential to revolutionise the lives of people with a disability. It has a transformative vision, and one that is shared: people with disability want it to succeed; their friends and families want it to succeed; organisations working with people with disability want it to succeed, as does the community at large.

The NDIS is an **investment** in the future of people with disabilities, their families and carers. It is not a welfare measure. It is a human rights based approach which aims to improve life experiences and to increase the power that people with disabilities have over their own lives. The NDIS is already making major improvements to the lives of many people with a disability and their families and has the capacity to positively affect so many more.

However it is vital that the NDIS vision is not compromised by the approaches being taken during the NDIS implementation and roll-out. An insurance approach means that there is a need to invest now and recognise that savings will come in the much longer term. Given this, it is imperative that the vision of the NDIS continues to be supported, and that the long-term view and success of the scheme is not undermined by short-term thinking, and by an excessive focus on current costs. Current NDIS costs (and the fear of same) are not the right factors with which to judge NDIS success.

It is also imperative that through this implementation time, that we do not lose sight of the vision of the NDIS: that more people with disability and carers will be in employment, that people with disability will experience greater social and economic participation and inclusion, that the rights of people with disability will be respected and that the likelihood that people with disability will experience abuse/harm will be greatly reduced.

The NDIS is a worthy scheme, and deserves ongoing support. We thus reiterate the need to focus on the long-term, on what can be achieved **together**, over time, by investing now and partnering with people with disabilities, their families, and community organisations in the future for people with disability and this scheme.

Comment re Case Studies: Please note that all case studies have been de-identified and adapted or merged so as to protect participant identities.

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[i] National Disability Insurance Scheme Quality and Safeguarding Framework (January 2017).
Available from: https://www.dss.gov.au/disability-and-carers/programs-services/for-people-with-disability/ndis-quality-and-safeguarding-framework
[ii] Disability Care and Support Inquiry Report, Productivity Commission, 2011. Available from:
http://www.pc.gov.au/inquiries/completed/disability-support/report (Accessed during March 2017)
[iii] National Disability Insurance Scheme Act 2013, Chapter 4, Part 6, Section 100. Available from
https://www.legislation.gov.au/Details/C2016C00934 (Accessed during March 2017).