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When The Right Information Matters

HOW THE SYSTEM OF THE NDIS IMPACTS THE PROVISION OF SUPPORT COORDINATION

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EXECUTIVE SUMMARY

This report is an indepth analysis of the overall operational aspects of the NDIS that have a serious impact on the delivery of support coordination services provided to Participants. It discusses the period from when a person with a disability first tries to access the NDIS through to their first plan and subsequent plans.

Part 1 of this report discusses how support coordination services interrelate with other operational aspects of the NDIS. The report begins with an explanation of the history, aims and objectives of the NDIS, followed by a detailed discussion on the various aspects of the NDIS, including the expectations of Support Coordinators, defining the role of Support Coordinators, the difference between Local Area Coordinators and Support Coordinators, the problems that exist with NDIA Planners and Plan Reviews, the interface between NDIS and mainstream services, support coordination and capacity building, The Financial Sustainability of the NDIS, The complexity of the NDIS as a system, as well as a range of other topics.

Information for this part of the report has been derived from a range of resources including a report from the Joint Standing Committee on the National Disability Insurance Scheme, National Disability Services (the peak body for disability services in Australia), various Parliamentary Inquiry reports and a research report from Flinders University in Adelaide.

Part 2 of this report is based on a series of questions posed to NDIS participants, their families and some Support Coordinators, through social media, as well as some input from the author. This part of the report discusses what Participants expect from their Support Coordinator, the lack of clarity and consistency of the NDIS, the training of Support Coordinators, the burnout of Support Coordinators, the value placed on the role of Support Coordinator, the value Support Coordinators place upon Participants, Clearer Boundaries On What Are Billable Hours For Support Coordinators, Issues And Barriers In Providing Support Coordination Services To Participants, as well as a range of other topics.

This report finishes with a range of recommendations on ways in which the issues discussed wtihin the report could be addressed.

PART 1: THE PROVISION OF SUPPORT COORDINATION AND THE OPERATIONAL ASPECTS OF THE NATIONAL DISABILITY INSURANCE SCHEME (NDIS)

History, Aims and Objectives of the NDIS

The National Disability Insurance Scheme Act 2013 (the NDIS Act) was enacted to deliver the National Disability Insurance Scheme (NDIS) – a world first approach to the provision of disability support that puts people with disability at the centre of decision-making through the principles of reasonable and necessary supports and individual choice and control.

Since its inception, the National Disability Insurance Agency (NDIA) has been responsible for the once in a lifetime role of completely transforming the disability support sector, with the key focus over the last three years on transitioning people with disability from existing state and territory service systems to the NDIS. The nature and speed of this transition was highly ambitious.

For many of its participants, the NDIS is helping to improve their social and economic outcomes, increasing their ability to live an ordinary life and achieve their goals and aspirations. However, the implementation of the NDIS has not been smooth and it is evident that the pressure of rolling the scheme out across Australia has directly impacted the NDIA's ability to provide a consistent, effective and high quality service delivery offering.

The intent of the NDIS is supported by all levels of government and the Australian community. However, people with disability have reported frustrations about the administration of the NDIS by the NDIA. Transparency, consistency and timeliness in decision-making are critical issues and people with disability have reported poor experiences when working with NDIA staff and its Partners in the Community.

The NDIS service delivery response works well in general for adults with physical disability, but not so well for some other cohorts. In particular, the provision of services to people with psychosocial disability or those with developmental delay has been challenging, with the NDIA's operational response constrained by a lack of clarity in the legislation on appropriate service responses.

The Australian Government can support the NDIA to deliver better outcomes for these cohorts through legislating changes that:

- clarify when an impairment is considered permanent for people with psychosocial disability, appreciating that their needs may be episodic and fluctuate over time
- clarify that the determination of reasonable and necessary supports for people with psychosocial disability should be aligned with best practice recovery approaches
- give the NDIA more flexibility to support families to build their capacity in understanding the needs of their child and exercise informed choice and control

- move the concept of reasonable and necessary supports for children towards a family-centred planning approach.

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The concept of reasonable and necessary in the NDIS Act, while not being new to legislative frameworks across Australia, is subject to differing interpretations by people with disability and NDIA decision-makers. This is principally the result of the absence of a clear definition of what constitutes a reasonable and necessary support. This creates confusion around the role and purpose of the NDIS and drives a number of individual cases towards tribunals and courts.

All governments and the NDIA should take a greater role in defining reasonable and necessary in order to provide additional clarity on the services that will be funded by the NDIS.

Flexibility is key to positive participant experiences and the current implementation of the NDIS is impacted by excessive complexity. While this complexity is largely driven by NDIA operational procedures, there are some areas of the NDIS Act that are unnecessarily rigid or do not incentivise flexibility. The inability to amend a plan is one of the key frustrations for participants and one of the biggest weaknesses of the NDIS Act.

The objectives of the NDIS (as outlined in the NDIS Act) include:

a. supporting the independence and social and economic participation of people with disability
b. providing reasonable and necessary supports, including early intervention supports, for participants
c. enabling people with disability to exercise choice and control in the pursuit of their goals and the planning and delivery of their supports
d. facilitating the development of a nationally consistent approach to the access to, and the planning and funding of, supports for people with disability
e. promoting the provision of high quality and innovative supports to people with disability.

The NDIS Rules made for the purpose of the administration of the NDIS by the NDIA go to issues such as:

a. when a person becomes a participant
b. when a support is reasonable and necessary
c. when a person should be appointed as a nominee to act on behalf of a participant
d. when a person is responsible for undertaking actions and making decisions on behalf of children
e. how participants can manage the funding in their plan
f. how the NDIS works alongside other service systems
g. arrangements for the protection and disclosure of NDIS information.

The NDIS Rules made by the NDIS Quality and Safeguards Commissioner are in relation to the NDIS Quality and Safeguards Commission’s stated powers under the NDIS Act, including: the registration requirements NDIS providers must comply with, worker screening arrangements and reporting and oversight arrangements to reduce and eliminate the use of restrictive practices in the NDIS.

From 1 July 2016, the NDIA commenced the full-scale rollout of the NDIS across Australia, with more than 400,000 participants estimated to transition into the NDIS over four years through a mix of phasing arrangements. In some states and territories, participants phased into the NDIS based on the region they lived in and, in others, based on how old they were.

The NDIS transition period was a unique and the most complex period in the life of the NDIS. The transition was closely linked to the dismantling of existing state and territory disability support systems and transferring support structures towards a market-based system where eligible participants receive funding based on need and are supported to exercise choice and control in the planning and delivery of their supports.

A 2014 review stated the NDIS was “like a plane that took off before it had been fully built and is being completed while it is in the air” . Building on that metaphor, five years on, the plane is flying but the passengers are experiencing some turbulence. In order to ensure the NDIA is able to deliver an efficient and effective scheme, the next phase of NDIS implementation will need to have a focus on:

a. building the trust of participants, their families and their carers when engaging with NDIS processes
b. activities to support new people with disability to access the NDIS
c. expediting access to funded supports and reducing the number of unnecessary steps in the participant pathway.

However, the NDIS is already a large and complex system, meaning further improvements to support positive participant experiences will take time to embed within NDIA operations, including making the required changes to ICT systems. It is therefore reasonable to expect it will take several years before the NDIS is operating in a fully efficient and effective manner.

In addition, there are many policy and practice challenges that will need to be addressed to ensure the NDIA can fully deliver on its promise to people with disability, particularly in relation to:

a. fully overcoming delays across all decision-making processes, to ensure timely access to supports when people with disability actually need them
b. resolving ambiguity in the construction of supports so plans meet participant expectations and always have a clear link to the participant’s goals and aspirations
c. actively supporting people with disability to build their capacity to identify their support needs, goals and aspirations, self-advocate and navigate the market
d. improving the capability and capacity of the NDIA workforce, including Partners in the Community.
e. supporting the development of a robust marketplace of disability service providers that keeps pace with demand
f. ensuring disability service providers are acting in the best interests of participants.

What are the Expectations of Support Coordinators?

Support coordinators will help participants with different things depending on what the individual participant’s goals, needs and circumstances are. This should also consider what has been funded in the participant’s plan.

As with all NDIS providers and workers, support coordinators must promote and protect the safety and wellbeing of participants. This should underpin everything that a support coordinator does.

A support coordinator should:

1. Help participants connect to NDIS and other supports
2. Build a participant’s capacity and capability to understand their plan, navigate the NDIS and make their own decisions
3. Broker supports and services in line with a participant’s wishes and their plan budget
4. Monitor plan budgets and support effectiveness.

The NDIA expects support coordinators to understand service offerings available in a participant’s local market, and actively help participants to find service providers who meet their needs. The NDIA has observed instances where support coordinators have used their local market knowledge to drive quality participant outcomes. For example, when a service provider decides to exit the NDIS or withdraw their services, quality support coordinators are able to quickly source and connect participants to alternative service providers. This has been integral for participants to maintain continuity of supports and services.

Support coordinators should also link participants to mainstream, community and informal supports where appropriate. The NDIA has seen quality outcomes when support coordinators have a sound knowledge of service offerings – including mainstream, community and informal supports – and have strong provider networks in the participant’s local area.

Support coordinators need to be aware when their involvement moves beyond supported engagement into the role of a formal advocate. While there is no hard and fast line between supported engagement and formal advocacy, this is an important consideration for support coordinators in determining the scope of their service.

In addition to helping participants connect with NDIS and other supports, support coordinators should also help participants to explore the right mix of supports. Stakeholders generally agreed that this should involve helping the participants to trial options, design a suitable support approach and negotiate service agreements in line with the participant’s preferences and plan.

Support coordinators should regularly engage with participants to understand their individual circumstances, disability-related support needs and goals, including any potential changes.

In doing so, support coordinators should work with the participant to prepare for unexpected events or interruptions in supports. Preparing participants for unexpected events includes establishing supports to prevent crisis situations from arising, and ensuring a plan is in place should a crisis occur. When a crisis situation arises, support coordinators should help the participant to put the plan into action and to access the appropriate supports, including crisis or emergency services, where needed.

Support coordinators should also regularly track how the participant's plan is being used and ensure the participant will be adequately supported throughout the duration of their plan. As part of this, support coordinators should evaluate how effectively their supports are meeting the participant's needs. Support coordinators should regularly review whether the current support mix meets a participant's needs or whether alternate options may be more suitable. Part of this should consider emerging, innovative support options or service delivery models (e.g. telehealth) in helping participants pursue their goals.

Local Area Coordination vs Support Coordination role

The different terms used for people working under the may come across as confusing and their duties may even overlap. One area that may be a cause for confusion is the difference between a Local Area Coordinator and a Support Coordinator. Both are there to support participants and get you what you need, but they work in different ways.

If you live in an area with an partner organisation such as Maple, then you will work primarily with our who will help with the general identification and implementation of supports available to you. If you live in a remote area where there is no partner, the will provide additional funds for you to work with a Support Coordinator.

Additionally, a Support Coordinator focuses on more complex plans, specialist supports, and management of plans. Your or Support Coordinator can also work with you to make changes to your plan through reviews which usually occurs around 12 months after your plan is implemented. (This ia discussed further in Part 2, of this report)

Should Support Coordinators be independent from Service Providers?

Support Coordination is meant to support those participants with complex care needs who need support to set up their plan, assess their options and choose their service. A service provider who provides multiple services under the NDIS cannot, hand on heart claim to provide an independent and impartial Support Coordination service to participants. In fact for many service providers, their strategy of offering Support Coordination was driven by their want to gate keep and usher participants into their own services.

The NDIA should revert to their original position and only allow independent providers deliver Support Coordination. It's the best and fairest option for participants and their families.

When a Support Coordinator is employed by an organisation that offers a range of NDIS funded services, they have a conflict of interest. Most organisations expect staff members (whatever their role) to be ambassadors for the organisation. But it is a Support Coordinator's job to support people to make choices about what is best for them, without bias or receiving incentives.

A best practice approach to keeping information separate may involve separate management for Support Coordination and other service teams within the organisation with discrete lines of reporting from the executive level down to the front line. It is encouraged that providers have separate client database systems to make sure information on Support Coordination clients is only viewable within the Support Coordination team. It would also be advisable for Requests For Service (RFSs), that now come through to the provider's primary portal, to be diverted directly to the Support Coordination team and not via other service managers.

Comments extracted from the Tune Review (Review of the National Disability Insurance Scheme Act 2013, Removing red tape and implementing the NDIS Participant Service Guarantee, David Tune AO PSM, December 2019) specific to support coordination services also support this position:

"Importantly, support coordination should not be provided independently of other service providers if it is against the wishes of the participant or if that separation would mean the participant could no longer live in their community. Nevertheless, first principles would suggest that it is reasonable to expect that in most cases the provider of support coordination is not the provider of any other funded supports in a participant's plan."

'"It should also be noted that support coordination, like any other NDIS support, is subject to the provider registration and practice standards rules enforced by the NDIS Quality and Safeguards Commission unless the participant is self-managing and using an unregistered support coordination provider. The NDIS Quality and Safeguards Commission's requirements include ensuring participants receive transparent and factual advice about the support options available in their community and that providers have respect for the participant's rights to freedom of expression, self-determination and decision-making."

"Legislative amendments should not restrict, in any way, participants from having choice and control over their NDIS supports. On this basis, the legislation should not require support coordination to be independent of other service provision, but rather mitigate the risk of participants being exposed to inappropriate conflicts of interests. This could be achieved by requiring the NDIA to actively assess the risk to participants when supporting them through plan implementation. This would not be limited to participants receiving SIL but would be of particular importance for this cohort."

Outcome based Vs. Profit based

Setting benchmarks around Participants achieving goals is not in the spirit of the NDIS for the same reason NDIS are not allowed to incentivise staff. Moreover in practice, goal attainment is more likely to be delegated to other service providers such as community access, SIL or therapists, who works towards goals with Participants regularly.

Pricing cannot be determined based on the progression of participant goals and outcomes without ignoring the unique barriers and circumstances people face. This is especially relevant for people with psychosocial disability, whose lives are often complex and intersect with various mainstream services. For these reasons, support coordinators with monetary KPIS' based on outcomes is a slippery slope.

Effective support coordination is a critical enabler of good outcomes for all participants, including those with complex support needs. There are benefits in the NDIA engaging in the support coordination market more directly to ensure participants with complex support needs can access a skilled quality support coordinator who meets their needs and who may take on some additional responsibilities, for example around safeguarding. More actions are likely to arise for this participant cohort, as we consider the options available to engage more actively with this market.

There has been insufficient study and research into the focus of outcome-based assessment and its impact on efficacy, efficiency and cost. Much of the research conducted to date is based on small-scale evaluations of pilot programs and, in some cases, lacks methodological rigour (Goodwin, et al., 2013) .

There is an underlying assumption that the achievement of individual goals contained within a NDIS plan is in some way achieving positive participant outcomes, building capacity and over time, sometimes considered as one plan cycle by some NDIA planners, reducing the overall cost of funded supports for a participant.

At no point during pre-planning or planning with a participant are long term pathways, outcomes and support trajectory considered (i.e. if all of plan one goals are achieved what does that mean for plan two, plan three and so on). There is good reason why this does not happen because life is not easy, simple or one dimensional. Life for all Australians changes over time and presents obstacles, setbacks and challenges.

Outcome based pricing makes the assumption that such long-term planning and projections are undertaken. Given the current planning process, business system constraints on efficiency-based pricing approach, a transition to such a model is likely to be extremely complex and costly.

Further, achievement of a participant's goals or outcomes is dependent on all supports contained within a participant's plan creating a coherent package of supports which are appropriately funded to meet the desired outcome or goal. If supports required for a participant to achieve their goals or outcomes are not fully funded to the extent required to achieve a goal, this would significantly hamper the Support Coordinator's ability to support the participant and ultimately be paid for their work. As Support Coordinators are not decision makers in the planning reliant on other supports and plan funding.

Human Based Practice vs. Profit Based Practice

The main difference between human based practice and profit based practice is that human based practice is concerned with making the lives of individual NDIS participants better, while profit based practice is more concerned with service providers and independent support coordination businesses making a profit, than the welfare of participants.

While acknowledging that support coordination services need to make a profit, in order to remain viable, this should not be at the expense of participants and service costs should not be over-inflated, although this is some what controlled by the NDIS price guide . Some participants are being charged for services they don't receive. Sometimes service providers and support coordinators refer to support coordination funding as "their funding", thus, forgetting that the funding is allocated to the participant, not them.

Sometimes a participant is charged excessive billable hours- there are two main reasons why this happens, some support coordinators just bill participants excessively and the second reason is that some support coordinators are under pressure to meet KPI'S. Some service providers care more about making money, than the quality of service they provide to participants.

Another problem that seems to be emerging is that Participants are continously being billed, without deliverable outcomes being achieved. This is particularly prevalent in rural and remote communities, where there are very limited services available. Despite the absence of deliverable outcomes being achieved by support coordinators for participants in rural/remote areas, each year support coordination funding for such participants keeps rising, so essentially, the NDIS is paying support coordinators to do nothing. The NDIS need clearer boundaries on what is and isn't billable.

Some support coordinators are getting the job because they know someone within the organisation (jobs for mates) instead of based on merit. Some service providers and support coordinators are in the industry for reasons of pure greed, going so far to employ fraudulent practices, with no thought being given to participants

Justification of support coordination hours from support coordinators

While the majority of Support Coordinators act in the best interests of Participants, there are some rogue Support Coordinators doing the wrong thing. As mentioned above, some Support Coordinators have charged Participants for services they have not received.

Sometimes Support Coordinators have gone against the wishes of Participants, organising services that services that the Participant doesn't want or need, or services that don't suit the needs of the Participant. Worse still, some Support Coordinators have organise services for a Participant, before they have actually met them .

Some service providers and Support Coordinators have charged Participants absorbent fees for initial consultations, despite the fact that Participants have not yet decided whether or not to use their services. Some Support Coordinators take a very "ablestic" view when it comes to supporting Participants telling them what they need, instead of letting the Participant tell them what they need. As a result, a lot of time and money are wasted on things that are not beneficial to the Participant. Sometimes Support Coordinators are just not willing to listen to Participants.

In rural and remote communities, the support coordination funding of Participants keeps on increasing each year, despite the fact that some Support Coordinators are not actually doing anything to support Participants. Some Support Coordinators are still charging Participants for support coordination services- this means that some Participants are paying for services that they literally don't use.

Sometimes Support Coordinators are paying 10% commissions to their “mates” to do home modifications for Participants, instead of going through the proper channels. They are also not listening to Participants when it comes to hiring Support Workers, arranging Gardening/maintenance or cleaning services, or arranging meal delivery services. This has a detrimental affect on Participants-due to the fact that it is not what they want and is a poor use of precious support coordination hours.

If the NDIA reviewed all these factors, it would find that a lot of money could be saved in the area of support coordination.

Interface between NDIA Planners, Local Area Coordinators and Support Coordinators

Some NDIA planners (and support coordinators) lack clinical expertise, which can lead to a failure to incorporate key support recommendations in a participant’s plan. It is of concern that Local Area Coordinators (LACs) continue to undertake planning for clients with complex needs who require specialised support in disability or other mainstream interface areas, including health care. Participants generally experience better outcomes when the development of their plan is facilitated by a planner at the NDIA rather than a LAC, who may be less experienced and lack specialist expertise. It has been observed that mental health teams are insisting on NDIA planners do plan reviews for Participants with complex mental health needs, not LACS. Unfortunately, this mean delays in the Plan Review Process.

Despite this predicament, Support Coordinators and Participants have reported that both NDIA Planners and LACS lack knowledge and expertise, when it comes to planning for people with disabilities. Sometimes in planning meetings, they are totally dismissive of the needs of the Participant, even leaving some Participants totally traumatised. Support Coordinators have also reported that the have spent considerable time fixing the errors oif NDIA Planners, due to the fact that they haven’t listened to the Participant or their Support Coordinator.

Problems with Local Area Coordinators and NDIA Planners

Planners need to take into account the disabilities, circumstances, goals and wishes of participants and their support networks, the legislative and policy framework that provides guidance on what to include in a plan and the kinds of supports that would help to address participants’ goals and set them up for a better life in the future.

The Joint Standing Committee on the National Disability Insurance Scheme received a considerable body of evidence outlining Planner errors in plans. Some suggested that LACs were not passing on information to NDIA decision makers, or that NDIA planners were inputting incorrect information that did not reflect what was discussed in planning meetings. In some instances, the committee was informed, planners may be incorrectly listing participants’ names and their disability type.

An advocacy organisation commented that of several hundred plans that it had advocated for, only one had met the participant’s needs. In some instances, it reported, planners may not even be correctly identifying the participant’s disability in their plan.

The sibling of a participant, who attended a plan review meeting, reported that after the planner was asked to read back what they had typed, 'it was significantly different to what had been discussed with missing detail. If we hadn't asked for this we would not have had the opportunity to make corrections'.

Roundsquared, which provides mentoring, support and consultancy services to people with disability and their families, outlined examples of Planner errors that included:

- A participant's goal being listed as 'I would like to increase my capacity to complete writing my book', despite the participant's 'enormous difficulty reading' and the participant, according to his mother, never saying in the meeting that he wanted to write a book.
- Plan content being cut and pasted from other participants' plans, where the names of the other participant have not been changed in the new plan.

While the NDIA guarantees that participants can have a face-to-face meeting with a planner, 'planners have disclosed that they are being pressured into getting people to do plans over the phone because this allows them to do more plans per day'. It further argued that the pressures on planners meant that they did not have time to read evidence submitted to support participants' requests for supports.

The Community and Pubic Sector Union (CPSU) informed the committee that a number of negative impacts were arising as a result of performance pressures on planners. These included:

- LACs were forced to accept that many of the plans they developed would need plan reviews to correct plan details and supports.
- LACs did not have the time to explain plans in a way that would be understandable to participants.
- LACs did not have time to develop relationships with participants and their families.

Roundsquared reported that LACs were allocated 90 minutes for the planning process and 90 minutes to write up a plan. It argued that this would be possible if the participant's situation was stable and the nature of their disability was not complex, but much more difficult if the participant had significant changes to their living situation or functional capacity, needed home modifications or assistive technology, or if the LAC needed to call therapists or support coordinators to clarify information.

The committee heard that there is a high turnover of Planners and this has impacted plan outcomes and led to plan inconsistencies. For example, Leadership Plus argued that staff turnover in the NDIA 'has been endemic since the NDIS commenced. Enormous amounts of money and time must have been spent training people who have left'.

The Australian Services Union argued in relation to LACs that a 'system of poorly paid workers with no training opportunities cannot give each client the quality individualised plans they need'. Similarly, Carers Victoria also called for planners to be well remunerated, arguing that wages 'are the strongest motivator in attracting and keeping skilled workers'.

The NDIA argued that it 'does not have a high turnover rate for planners'. It reported that its turnover rate for a financial year for planners is 8.36 per cent, with the average separation rate for ongoing Australian Public Service planners being lower than the average turnover across the Commonwealth. Although this figure only includes government (NDIA) employees, the NDIA reported that the current rolling average separation rate for LACs is only slightly higher, at 9 per cent. This figure is impacted by contracts ending for some Partners in the Community.

Multiple submitters argued that an inadequate number of Planners has led to delays in organising planning meetings, developing plans and conducting plan reviews. For example, Carers Victoria suggested that the number of planners is so limited ‘that they are copying and pasting sections from other participants’ reports’ because of demand on their time.

Family Advocacy suggested that if more Planners were available, and if these Planners were ‘well-trained, good quality planners’, this could lead to more time allocated per participant, meaning planners could better understand participants’ needs, create better quality plans and lead to ‘far less applications for plans to be reviewed and cost the NDIA less in resources’.

Queensland Advocacy Incorporated suggested that because LACs may have very high caseloads, they may not have sufficient time to link and connect participants to services, perhaps leading to the number of requests from participants for support coordination.

The committee learned during the course of the inquiry that Planners’ expertise and backgrounds may vary considerably, including their understanding of disability and its impact on participants’ lives. It should be noted that the NDIA does not require Planners to have lived experience in disability or allied health or disability-related qualifications.

The committee was informed that some NDIA personnel, including those in managerial positions, had disclosed ‘personal views which are abhorrent and contradict NDIS principles’.

In one instance reported to the committee, a Planner asked a family whether Down Syndrome was a permanent condition. The Royal Australasian College of Physicians noted a similar example where a participant with Down Syndrome had been asked how long they had had Down Syndrome. In other instances, the Royal Australasian College of Physicians reported that Planners were asking participants’ families whether their child’s condition had improved, in cases where a condition was palliative, listed as degenerative or where an expert had stated that the disability would have lifelong impacts requiring therapy and care. The College argued that such questions indicated ‘a gap in knowledge and understanding of particular conditions on the part of NDIS Planners and Local Area Coordinators’.

Similarly, Kelmax Disability Services commented that it had often heard of Planners telling participants that ‘they will fully recover from treatment resistant schizophrenia...This is inappropriate and reflects in the plans with insufficient support based on assumptions’ rather than clinical evidence.

One participant with psychosocial disability argued that ‘tertiary qualifications and Government department work history is meaningless if Planners do not possess necessary skills like empathy, listening, self-reflection and the ability to imagine’. Similarly, Mr Sean Redmond from AEIOU Foundation suggested that Planners needed ‘to come from a very caring and understanding background, and you need to take the time to listen to the families’.

The committee learned that small teams of Planners may be working across large locations, meaning planners may have less capacity to develop expertise in particular areas of disability or to mentor other, less experienced Planners. Further, submitters also reported that planners in some instances were not aware of rural and remote locations services available in an area and the distances required for participants to access services.

The Queensland Office of the Public Guardian informed the committee that in its experience, participants had generally experienced ‘better outcomes’ when their plan was facilitated by a planner within the NDIA rather than a LAC, especially if the participant had complex needs and life circumstances. This was echoed by the Northern Territory Office of the Public Guardian, which suggested that external partners ‘have the same or higher skill deficiencies as the NDIA planners.

Roundsquared expressed its concern that the NDIA, in its position descriptions for planners, does not require applicants to have qualifications inthe areas of disability, early childhood development, mental health, rehabilitation or community/health education. It suggested that ‘the experience, expertise and qualifications of planners and LACs may well be suited to the bureaucracy’ but are not sufficient for planners and LACs to understand the range of disabilities, the functional capacity of particular disabilities, the inter-relationship of multiple disability types, and the impact of caring on families.

In some instances, the limited expertise of Planners may be ‘disheartening’ and ‘distressing’ for participants. According to MND And Me Foundation, families had reported that when they had asked their Planner if they had any direct knowledge or experience with Motor Neurone Disease (MND), a ‘common response’ was: ‘[n]o, not directly. But I have had a quick look online’. Without Planner knowledge or expertise, MND And Me suggested, plan gaps may arise because the Planner is unaware of the progressive and unpredictable nature of MND.

The impact of limited Planner expertise, Orthoptics Australia informed the committee, can lead to inadequate knowledge of what supports or equipment would be appropriate, and Planners giving incorrect information about the best interventions and supports to address participant needs.

Queensland Advocacy Incorporated called for ‘transparency and accountability regarding the requisite base level training Planners must undertake, along with the additional training provided’.

In some instances, the inquiry learned, providers may be spending ‘significant time, energy and resources in capacity building with planners who come to planning meetings very poorly prepared, with providers sometimes aware of new NDIA procedures before Planners were. Early Start Australia argued that that on ‘a regular basis we as providers are fulfilling an unpaid education and support role helping families navigate changes their Planners are not aware of’.

Multiple submitters called for more training for' Planners and LACs to help them understand the impact of disability. The Australian Services Union reported that its members had 'identified the lack of investment in training since the rollout of the NDIS as a key issue for the workforce', with LACs in particular calling for more training.

Multiple submitters and witnesses proposed that the NDIA consider increasing its sourcing of professional development from experts, including health industry peak bodies and the allied health professions.

The evidence provided to the inquiry suggested that a considerable number of Planner errors, as reported by participants, may be because of performance pressures on LACs in particular, staff numbers, limited Planner expertise and inadequate training for Planners.

Given the impact that Planner decisions can have on participants' lives, including whether the supports for which participants are funded are appropriate or clinically advisable, the 'committee considers that the NDIA should give greater preference in its recruitment processes for Planners to candidates who have experience or qualifications in allied health or disability-related areas.

The inquiry received evidence from multiple sources that expressed concern that some planners excluded participants from planning meetings. For example, Carers NSW reported cases where participants had been excluded from planning meetings, 'either because the Planner has told the carer that they do not need to be there, or because appropriate communication aides have not been implemented'. In other instances, carers had been excluded, while supporters and advocates, including practitioners and service providers, had been deterred from participating. Carers NSW argued that 'carers and participants should be considered experts in their situation and needs', and failing to include them in planning was likely to lead to increased need for plan review.

Leadership Plus expressed concerns that some participants with acquired brain injury were missing 'planning meetings due to their disability, and because of low Planner numbers, plans are simply developed without any input from the person'.

Even where participants are present at planning meetings, however, their involvement may be 'superficial and patronising', according to the Tasmanian Office of the Public Guardian. It called for planners to be 'mindful and skilled' when engaging with participants. The National Rural Health Alliance similarly noted that some participants were 'often not included in the plan and even when in the room, are not included in the conversation'. It reported that in some instances participants who were not verbal but able to use speech generated devices were often still excluded from the planning process. The National Rural Health Alliance suggested that 'some Planners were not aware or mistaken about the cognitive abilities' of some participants.

On some occasions, the committee heard, Planners did not involve other people who participants brought with them to planning meetings. Kelmax Disability Services noted that some LACs and Planners were refusing to allow a support coordinator to communicate on behalf of a participant.

In its response to questions on notice provided in October 2020, the NDIA stated that 'it is critical a participant attends a planning meeting, either in person or over the phone to ensure relevant information can be collected to support quality plan development'. The NDIA asserted that it 'does not have a policy to exclude participants, their carers, supporters or advocates from attending planning meetings' and acknowledged 'the important role families and carers play in the lives of people with disabilities, including their involvement in planning meetings.

Depending on the expertise of the Local Area Coordinator or NDIA Planner, Support Coordinators can be left dealing with traumatised participants and/or families due to the fact that a LAC or NDIA Planner has been totally dismissive towards the partcipant and/or their family, during planning meetings. It is also quite common for Support Coordinators to spend a lot of time fixing the mistakes of NDIA Planners. This means that either a lot of the Participant's funding is spent on fixing the errors of the NDIA Planner that developed their plan, or their Support Coordinatior is working a lot of unpaid hours-fixing their plan.

While it is acknowledged that some Support Coordinators do not research some of the disabilities of Participants assigned to their caseload, the same could be said for LACS and NDIA Planners. As a consequence, it is quite common for LACS and NDIA Planners to be unaware of how a participant's disability affects their life, and yet, they are charged with the responsibility of deciding the amount of funding the participant will receive to spend on supports and services, as well as any equipment they may need-participants and their families can rightly question what qualifies these persons to make such decisions.

Furthermore, LACS and NDIA Planners are sometimes dismissive of the lived experience of Participants and their families, arguing that they don't need certain inclusions in their plan (eg: a certain piece of equipment) or opting for a cheaper, often less effective option. Even though Support Coordinators are not meant to be be formally advocating for participants, they sometimes do so, due to sheer arrogance of LACS or NDIA Planners and their dismissive attitudes towards Participants. Sometimes LACS and NDIA Planners do enjoy power plays over participants and their families and Support Coordinators have had to be the ones to call out the imbalance of the equity in the situation.

Is The NDIA Acting In The Best Interests Of Participants?

Many participants and their families report feeling overwhelmed, confused and disempowered by the planning process as a result of too little time to build their understanding of the NDIS, the inability to view a draft plan, and the lack of communication and transparency regarding decision making. A 2016 audit by the Australian National Audit Office on the management of the transition to the NDIS found that the rate of unscheduled plan reviews and appeals to the Administrative Appeals Tribunal has far surpassed expectations, placing significant pressure on the NDIA and creating additional stress and frustration for participants.

Many Participants find the planning process disempowering , with very little communication or transparency between the NDIA, LAC/ECEI staff and participants and families.

NDIA planners often base decisions about the inclusion or exclusion of funded supports on TSPs (rather than the circumstances of the participant, resulting in participants receiving plans that do not match what they discussed with their LAC staff member. This creates significant confusion and distrust between LAC staff and participants, undermining the relationships that are critical to good planning outcomes.

Allowing participants to view a draft plan is critical to empowering them with choice and control—as consistently stated by advocates, participants, families and many others—and should be implemented immediately. Doing so would help reduce the incidence of issues , such as plan gaps and unscheduled reviews. However, draft plans need to be complemented by more opportunity for communication and collaboration between participants and their families, the LAC/ECEI staff member working with them, and the NDIA delegate approving their plan.

Planning needs to recognise not only any functional impairment experienced as a result of disability, but also the person's context – their family, friends and carers; the community they live in; and their strengths and interests, as well as any other challenges they may be facing.

Critically, plans are often too narrowly focused on the funded support needs of the individual alone, to the exclusion of what families need to build resilience and continue to support their loved ones. Given that the NDIS is predicated on families continuing to provide up to 60 per cent of care, family-centred planning is critical for not only good participant outcomes, but for scheme sustainability.

Understanding a participant's context as part of the planning process requires adequate time to build trust and relationships between participants (and their families), LAC/ECEI staff and planners. However, contractual KPIs for LAC/ECEI providers work against the development of these relationships. KPIs relate to the number of days elapsed between steps in the planning process, driving efficient throughput rather than quality planning. This is compounded by the overreliance on TSPs by NDIA planners to decide the components of participant plans, rather than an understanding of the participants.

Serious concerns have been raised within relation to exploitative actions by service providers in relation to provision of SIL arrangements. This includes examples where a service provider will allocate multiple people into independent living accommodation, but continue to charge each participant for private accommodation when it is a shared living arrangement.

Other processes relied on by service providers are presumably designed with a focus on service provider administrative convenience, rather than on facilitating the best living arrangement for the individual. For example, a participant is unable to seek a review or make changes to their accommodation arrangement without undergoing a full review of their plan.

Applications for an NDIA internal review of a SIL package are only permitted within the first months of the participant entering the accommodation, meaning that a participant is often 'locked in' to a SIL package that may not be suitable, for an extended period of time. Appeal pathways to the Administrative Appeals Tribunal are restrained to the limited jurisdiction of the Tribunal to make decisions on these issues.

There is some concern over the lack of monitoring and oversight the Quality and Safeguards Commission has shown to date with NDIS service providers. One particular concern which has been highlighted to the National Disability Insurance Agency and the Commission, is the lack of oversight, monitoring and investigation of service providers who provide ‘wrap around services’, such as accommodation, support workers, support coordinators and even their own therapist’s or medical professionals.

These service models are especially prevalent in Supported Independent Living (SIL), arrangements, hostels and other group home settings. Many participants living in SILs, hostels or group homes did so prior to the NDIS roll out. These participants have not been provided the opportunity to explore different housing options, different service providers or even different support coordinators outside of the service provider who provides both accommodation and support workers.

On occasion where a participant may voice their concern or request that an outside organisation provide support (such as support coordination), the participant is threatened with eviction, termination of support services and in some cases ‘reprimanded’. This results in participants staying quiet to ensure they have somewhere to live.

The processes involved in accessing the NDIS present many barriers for people experiencing disadvantage. From getting the form itself to through to completing each step, our members report the process is often inaccessible, intensive, invasive and long.

When people are in crisis or experiencing multiple layers of disadvantage, there is no dedicated avenue for their access request to be escalated or addressed with sensitivity. While the complex needs pathway has been established for the planning phase of the scheme, it has been reported that there is no equivalent specialised support available on the ground before or during the access stage.

This intensive support is usually provided by service providers, who are not funded to provide this kind of assistance, and advocates, who are equally stretched and underfunded. As providers complete the full transition of their business into the scheme, this unfunded work will not be sustained. Additional pressure will be placed on families, carers and advocates, who will not be able to sustain their efforts either.

Making the form easier to access, in a range of online and offline accessible formats, would provide greater opportunities for staff in intersecting services to support people through the NDIS access process.

There is a burning platform for change. Confidence and trust in the scheme – from the perspective of participants, families and carers, advocates, service providers, and the broader community – has been substantially eroded. Understanding, accessing and navigating the NDIS has become so complicated that the scheme is inaccessible for some of the very people who need it most.

All Participants should be granted support coordination funding within their first NDIS plan, to assist them to learn how to navigate the system that is the NDIS. It also should not automatically assumed that a participant’s support coordination funding can be decreased over time and there should not be a blanket ruling as such. In detemining a Participant’s eligibility for support coordination, their individual circumstances should be taken into account, as some Participants are more vulnerable than others.

The Financial Sustainability of the NDIS

The NDIS was designed as a social insurance model. A social model reflects that disability arises socially rather than medically. An insurance model means that services are guaranteed to insure people against long-term or ongoing risks.

Under a social insurance model, the NDIS would take the risk of disability support costs away from individuals and distribute it across the Australian community by pooling funding from the broader community. In essence, a social insurance model insures all Australians against the costs associated with long-term and significant disability.

A social insurance model was preferred over other options, such as private insurance and welfare. Private insurance policies are not suited to universal coverage of the population against the potential costs of long-term disability care and support. Further, the NDIS was intended to move away from previous disability welfare systems to one of providing reasonable and necessary supports for people to engage in education, employment and community activities.

The NDIS was intended to fund specialist disability supports. These are supports that would otherwise not be reasonably met without NDIS funding, or that are not more appropriately met by other systems.

The NDIS was not intended to respond to shortfalls in mainstream government-funded services such as education, health care, public housing, transport and employment services.

The financial sustainability of the NDIS is important to give people with disability certainty about receiving reasonable supports over their lifetime. The Productivity Commission envisioned financial sustainability would be guided by the following principles and parameters:

- **The NDIS was intended to supplement, not replace, existing income support programs: for example**, the Disability Support Pension which assists people whose incapacity for work is due to illness or injury including people without a lifelong disability. The PC envisaged that better economic, employment and independence outcomes for people with disability would result in substantial economic benefits.

- **The NDIS should focus on cost-effective early interventions:** a deficiency of previous disability support schemes was their crisis-driven approach to funding needs, which impeded a longer-term approach to achieving beneficial outcomes for people with disability and the community at large. The objective of early intervention is to fund supports that would over the long-term increase economic participation by people with disability and their carers. The PC was aware that insufficient early intervention outside of tier 3, could impact the sustainability of the NDIS.

- **The benefits of the NDIS would significantly exceed the costs:** benefits include improved outcomes for NDIS participants, their families and informal carers; increased economic participation for both NDIS participants and their informal carers; and efficiency gains and cost savings in the disability support system and savings to other government services. The PC calculated the NDIS would only have to produce an annual gain of $3,800 per participant to meet a cost-benefit test. Given the scope of the benefits to be achieved, the PC believed that test would be passed easily.

- **Financial sustainability is an obligation of the NDIA:** with the NDIA to oversee the administration of the NDIS, the PC recommended this obligation should be enshrined in legislation and should be a specific obligation of the board, management and the Minister. This is picked up in the NDIS Act which provides that the NDIA is to manage, advise, and report on the financial sustainability of the NDIS including by identifying and managing risks relevant to NDIS sustainability. 80 The PC also proposed the NDIA's oversight of the NDIS be subject to external monitoring and auditing.

- **Gathering and analysing data for continual improvement:** the PC considered that to achieve financial sustainability, a thorough and ongoing understanding of the short and long-term financial pressures and risks would be required. Data collection and analysis would provide critical feedback and improve sustainability by reducing inefficiencies, monitoring service providers and assessing the overall cost-effectiveness of particular services and interventions.

- **The Australian Government should be the single funder of the NDIS:** this was the PC's preferred funding option as this would be more efficient than coordinating funding from eight different governments and provide greater certainty of long-term funding. This would be more in line with an insurance-based scheme (see further above), which is designed to take a lifetime approach to disability care and support. Contrary to the PC's recommendation, in implementing the NDIS, the Commonwealth, State and Territory governments contribute funding to the NDIS.

Stakeholders reported that the NDIA has refused to fund supports, including support coordination, on the grounds that it would threaten the financial sustainability of the NDIS, but the lack of transparency in the NDIA's decision-making means that a participant is limited in their understanding of and their ability to challenge that decision. One stakeholder reported that some participants felt the onus was on them to prove that their support would not lead to financial unsustainability of the Scheme.

It was also reported that some participants, especially people with psychosocial disability, were so concerned about financial sustainability that they were worried about using the funding they had been allocated because of the fear that they would be a burden on society. Another stakeholder also reported similar concerns raised by CALD people with disability.

Some stakeholders noted that the manner in which financial sustainability was raised by the NDIA assumes that all participants with the same disability in similar circumstances will seek the same supports when drafting their plans, which undermines the choice and control that should be enjoyed by each individual.

The ambiguity of the phrase ‘have regard to... the need to ensure the financial sustainability of the NDIS’ is reflected in the lack of authoritative decisions on the matter, whether at the AAT or at the Federal Court. In McGarrigle, the Court expressly declined to decide on the role of considerations of financial sustainability in the NDIS, noting that it ‘is an important issue which should await determination in an appropriate case’

Decisions at the AAT on financial sustainability provide only limited guidance on the matter. More recent decisions tend to suggest that evidence from the Scheme Actuary would be required to raise financial sustainability as an issue before the Tribunal, and that the evidence must be specific and relevant. Deputy President Humphries in BIJD reasoned that financial sustainability involves the making of value judgments balancing, on the one hand, the cost of widening the NDIS’s scope, and on the other, the benefits conferred. Thus, if the benefits conferred by the requested support are significant, then a significant additional cost may be justified.

Given the need for value judgment, it is clear from this decision that actuarial analysis can only be an advisory tool to assist with determining the effect on costs to the Scheme, and not a determinative tool in deciding whether a person’s supports should be funded. Within this context of legal ambiguity and value judgment, stakeholders were firm in identifying financial sustainability as an issue that required clarity – both in its operation within the NDIS Act, and in how the NDIA applies financial sustainability considerations in its decision-making.

While the criterion relating to ‘value for money’ may suggest financial sustainability can and should be taken into account, in fact that criterion is narrow and individualised in its scope. The section requires the CEO to consider whether ‘each support’ being considered for a participant ‘represents value for money in that the costs of the support are reasonable, relative to both the benefits achieved and the cost of alternative support’.

The reference to ‘having regard to’ financial sustainability in the NDIS Act should be amended to clarify that considerations of financial sustainability are not an additional or separate criterion to be considered in determining whether a person meets the access criteria or whether a support is ‘reasonable and necessary’.

Many Participants who are in desperate need of support coordination funding, either receive no such funding or inadequate funding. The fact that some Participants are reluctant to use their allocated funding, due to being considered as a “burden to society” means that they might leave things until they escalate into a crisis situation. Thus ultimately needing an increase, not decrease in support coordination funding.

Support Coordination and Capacity Buliding

The Price Guide describes capacity building as a support that enables a participant to build their independence and skills. In practice, capacity building supports are time limited and outcomes focused. There is also a strong, if unwritten assumption, that the use of capacity building supports will reduce the quantum of core supports required.

Some participants, families and contemporary capacity building providers question the therapeutic approach to capacity building that focuses on eliminating functional impairment.

Many participants cannot eliminate functional impairment. They can however build capacity and independence by a range of non-therapeutic approaches that lead to greater inclusion and independence in their daily lives including greater efforts to introduce unpaid people into their lives in ways that promote informal support, belonging and inclusion. This approach suggests that the outcomes and measures of success of capacity building should be expanded to include strategies that harness informal support to reduce the level of paid support.

Many also question three key NDIA expectations in relation to capacity building:

- Expectations related to the time frames required to build capacity, especially for people with significant impairment

- Expectations that increased capacity can be sustained without some level of skilled support.

- Expectations that building capacity will always result in a reduction of core support.

Many argue that capacity building should be valued even where it does not reduce the need for paid support as it ultimately leads participants toward the intended outcomes of the scheme.

While it is acknowledged that it is important to build the capacity of Participants to ensure they reach their full potential and to live life as independently as possible, it is uncertain whether the NDIA has fully realised that this is only one part of the equation.

Unfortunately, no amount of capacity building on the part of Participants will make them more welcomed within mainstream society, using mainstream systems. For instance, a Support Coordinator can build the capacity of a Participant to use mainstream health services- but this does not mean that doctors and other hospital staff will be fully responsive and accepting of the Participant, a Child Participant might fully prepared to go to a mainstream school-but this does not mean that Principals are going to accept the Child at their school.

So, not only should there be capacity building when it comes to Participants, but there should also be capacity building when it comes to mainstream systems. While it is acknowledged that a magical wand can not be waved and people with disabilities will be accepted by everyone they meet on the streets, we can educate our mainstream systems on how they should treat people with disabilities. Mainstream Systems include Education, Employment, Health, Housing, Childcare and Justice systems.

Both NDIA and Participants have very little control over members of the community being disrespectful or rude to people with disabilities. However, when it comes to using mainstream services, people with disabilities should be treated as equals. When a Participant goes to see a doctor, the doctor shouldn't just talk to their Support Worker and completely ignore them, while trying to enrol in a course or trying to get something fix at home, wherever possible, the person with a disability should always be asked-not their Support Worker.

In one way, by having the NDIA only concentrating on building the capacity of Participants is quite ableist. While acknowledging that it is quite advantageous to build the capacity of participants, the NDIA needs to also play a role in building the capacity of mainstream systems in our society to have more appropriate interactions with people with disabilities. By only concentrating on building the capacity of participants, the NDIA is subscribing to the theory that was so entrenched in the old system predating the NDIS-that people with disabilities **are the problem!!**

It would be delusional to think that by just having the NDIA play a role in building the capacity of mainstream services to be more confidence in their interactions with people with disabilities, that all mainstream services across Australia will magically change their attitude towards people with disability. This is just not going to happen, but by having the NDIA being involved in the process of making mainstream services and systems more "disability confident" a small percentage of these service and systems may become more accommodating towards people with disabilities. While this may not solve the problem in the big picture, it's a start.

In practice, most providers of Support Coordination work as case managers, linking participants to services and assisting them to negotiate entitlements in mainstream and community services. There is little or no attention to building informal support, developing personal safeguards or building the participant's capacity to redesign support let alone to direct their lives.

Outcomes of Support Coordination are more likely to be achieved if the NDIA outlines the capacity building elements and reflects them in expectations and outcomes.

Support Coordination is a key tool in the NDIS to strengthen the capacity of participants. A key issue under discussion is whether the Support Coordination function is fundamentally about establishing the infrastructure for capacity building for the individual or whether the purpose includes direct work by the support coordinator to build capacity.

Interface Between NDIS and Mainstream Services

Six broad principles, agreed by COAG, determine the responsibilities of the NDIS and other services systems. Principle Two states that the NDIS will fund personalised supports related to people's disability support needs, unless those supports are part of another service system's universal service obligation (for example, meeting the health, education, housing, or safety needs of all Australians) or covered by reasonable adjustment (as required under the Commonwealth Disability Discrimination Act 1992 or similar legislation in jurisdictions).

Streamlining the NDIS with Education and Early Education was identified as a key area within the NDIS that remains inconsistent. Evidence provided emphasised the importance of Early Intervention Programs in supporting parents, as well as the child. Additionally, consideration of the capacity of educators in facilitating disability support services as also been raised as an issue.

Transportation is another key area of concern in which Participants have had to bear the cost of transitioning from State/Territory Systems to the NDIS. Previously, the transportation costs of Participants were subsided by State/Territory Governments, however with the introduction of the NDIS, most of these schemes have now been abolished. This shift in financial responsibility, as well as financial limitation has resulted in NDIS participants having to subsidise funding from other areas and subsequently missing opportunities to participate in the community.

A key issue noted by stakeholders was the gaps between the NDIS and other mainstream services provided by Commonwealth or State and Territory governments. Under the NDIS Act, there are two critical interface points between the NDIS and mainstream services. The first is in relation to eligibility. Under section 21 of the Act, a person meets the criteria for access to the Scheme if they satisfy the age requirements, residence requirements, and either the disability or early intervention requirements.

However, under section 25(3), even if a person would otherwise satisfy the early intervention requirement, they would not be able to access the NDIS if:

the CEO is satisfied that early intervention support for the person is not most appropriately funded or provided through the National Disability Insurance Scheme, and is more appropriately funded or provided through other general systems of service delivery or support services offered by a person, agency or body, or through systems of service delivery or support services offered:

(a) as part of a universal service obligation; or
(b) in accordance with reasonable adjustments required under a law dealing with discrimination on the basis of disability. [Emphasis added.]

The second interface is in relation to reasonable and necessary supports. Under section 34(1)(f), the NDIA must be satisfied that the support is most appropriately funded or provided through the National Disability Insurance Scheme, and, as with section 25(3):

is not more appropriately funded or provided through other general systems of service delivery or support services offered by a person, agency or body, or systems of service delivery or support services offered:

(i) as part of a universal service obligation; or
(ii) in accordance with reasonable adjustments required under a law dealing with discrimination on the basis of disability.

In the recent AAT decision of Burchell and National Disability Insurance Agency [2019] AATA 1256, Deputy President Rayment considered that there are two ‘limbs’ of which the CEO of the NDIA must be satisfied. First, that the support is most appropriately funded or provided by the NDIS. Second, that it is not more appropriately funded by some other system of service delivery, such as a health department.

Stakeholders have advised that there are gaps between services, where the NDIA refuses to fund a support on the basis that it considers that that support is more appropriately funded through other services, but where that other support service does not provide funding. Stakeholders suggested that these gaps commonly existed between the NDIS and:

- education services;
- health services;
- corrective services;
- justice services;
- housing services; and
- child protection and family support services.

In Burchell, Deputy President Rayment held that, for the NDIA to deny funding on the basis of the second limb – that is, that the support is more appropriately funded by some other system of service delivery – that support must in fact be provided by another health authority. It is not for the NDIA to evaluate what supports should be provided by other service providers. In other words, the NDIA cannot determine that another service provider should provide a support even if hey do not.

After the Burchell decision was handed down, the COAG Disability Reform Council further clarified the interface between the NDIS and the health system following its meeting on 28 June 2019, through the publication of a fact sheet. 20 The 'Health related supports' fact sheet clarifies the NDIS will fund disability-related health supports 'where the supports are a regular part of the participant's daily life, and result from the participant's disability,' and provides a non-exhaustive list of such supports.

However, despite these principles and further agreements, stakeholders have commented that several interfacing issues remain in the actual mechanics of the NDIS, particularly with State and Territory services. In particular, gaps in relation to housing services and corrective services were frequently raised by stakeholders.

The NSW Government has acknowledged gaps in these interfaces, and has set up the Integrated Service Response initiative. This initiative coordinates support for an individual with support needs that require multiple mainstream and disability support services to work together, and provides coordination between different NSW Government agencies to ensure that the support is provided. There are, however, limitations to this initiative. It only has capacity for 15 referrals per month, and there are high eligibility thresholds for access to the initiative.

Most mainstream organisations observed that the interface between the NDIS and mainstream sectors was not a priority for the NDIA, particularly during the earlier phases of the roll-out. They noted that high level interagency and intergovernmental communications between departmental heads had been successful in providing information about the NDIS and developing escalation pathways for unresolved operational issues or systemic challenges. However it was observed that these meetings were tailing off and the NDIA was becoming less collaborative and more insular.

A number of challenges were identified in relation to the interface between mainstream organisations and the NDIS. Communication with the NDIA, particularly with head office, was a primary challenge identified by mainstream organisations. Difficulties in communication included contacting the NDIA, a lack of NDIA staff knowledge of the NDIS, delays in obtaining responses from the NDIA in relation to the outcome of client referrals, a lack of consultation with mainstream organisations, and frequent changes to NDIA policies.

Other challenges for the interface between mainstream organisations and the NDIS included the perceived inflexibility of the NDIA, the overall complexity of NDIA processes, the increasing amount of bureaucracy within the system, and a disconnect between NDIA policies and how they are applied at the operational level by local NDIA staff.

Mainstream organisations reported that overall there were clear boundaries between the responsibilities of their sectors and the NDIS. However some unresolved issues remained, in particular around which sector is responsible for funding shortfalls.

For the health sector uncertainty was expressed about what should happen ‘in complex cases and chronic health conditions where there are grey areas around responsibility, and who is responsible for rehabilitation services. For example, there was limited clarity about the funding responsibilities for the various services associated with ongoing support of clients who presented initially with health problems (e.g. the supply of medical equipment, personal care and learning supports in schools and other services such as medication management and nutrition).

Issues with boundaries were also identified in the mental health space where confusion persisted around whether rehabilitation for psychosocial disability should be seen as a process of recovery or long term support.

A number of challenges in managing in-kind arrangements were noted by mainstream organisations. These included changes to the portal that impeded the ability to monitor in-kind arrangements. A lack of communication from the NDIA about the transition from in-kind to cashed- out arrangements was reported and organisations were therefore unaware that they were no longer operating under the in-kind arrangements. In-kind arrangements were also evidenced to result in a duplication of services when NDIS participants were not aware of the services they were receiving as a part of their plan.

Although no evidence was collected about how the NDIS had impacted upon demand for crisis services, several barriers were identified in relation to accessing these services. First, delays in NDIA processes had resulted in a bottleneck of participants in the acute hospital system, placing pressure on already constrained resources. Second, concerns were raised about access to funding for accommodation as a result of boundary issues between the NDIA and mainstream services.

A number of service gaps were identified in relation to the living conditions and circumstances for people with disability. Concerns were raised about children with disability being able to remain in foster care beyond the age of eighteen years without their foster parents needing to register as service providers. Similarly, concerns were raised about the lack of funding for accommodation for children living in voluntary out of home care resulting in families having to cover this cost. Mainstream organisations identified service gaps around access to respite, Home and Community Care (HACC) services and equipment, and raised concerns about who would fund home modifications in the future. It was also noted that some providers were now charging for services that were previously free (such as builder who provided quote for home modifications).

Other service gaps identified by mainstream organisations related to people with specific types of disability and the circumstances of individuals with disability. In particular it was identified that service gaps existed around mental health services, prosthetic services, and rehabilitation for people with brain injury.

In addition, service gaps were observed for those not eligible for the NDIS, including refugees and New Zealand citizens residing in Australia, and long service delays were experienced by participants being assessed for eligibility and awaiting plan implementation. Health organisations also observed that due to the increased demand for therapeutic services as a result of the NDIS, clients who were not eligible for the NDIS experienced additional challenges in relation to accessing services.

Duplication of services was identified by mainstream organisations in two areas. First, it was noted that confidentiality processes prohibited mainstream organisations from receiving information about which of their clients were receiving NDIS funding. As a result, issues around the duplication of services for participants were experienced. Second, a higher education organisation identified that NDIS-funded plan management in relation to education goals was duplicating supports provided by their own staff.

Mainstream organisations were concerned about those participants who were less able to advocate for themselves. The consumer driven model implemented by the NDIS required that the person with disability and their family have a clear understanding of both the NDIS and their own support needs and the ability to articulate those needs to NDIA staff.

Moreover participants and their carers needed particular resources including the time, energy and the means (e.g. access to the internet and the ability to afford clinical assessments for providing proof of eligibility) to actively engage with the NDIS. It was identified that the NDIS worked less well for CALD and Aboriginal and Torres Strait Islander participants, those with high support needs or limited capacity, and those who were newly diagnosed or had recently acquired a disability.

Mainstream health and mental health organisations raised a number of concerns about the quality of service provision as a result of the NDIS. The first of these concerns related to the observation that as a result of delays in obtaining NDIS plans, mainstream organisations were filling service gaps and providing services to cohorts of people with disability that they had previously little experience of working with. It was acknowledged that mainstream staff often lacked the disability specific skills required to deliver quality services to these people.

Furthermore, the marketisation of disability service provision had resulted in some providers either not having the appropriate skills to work with, or choosing not to service, more complex clients. It was observed that these more complex clients then inappropriately ended up in mainstream health services.

Better education for people with disabilities and their families about NDIS processes was also recommended to help alleviate some of the difficulties created by unrealistic expectations about the planning process and supports which could be funded.

A further suggestion made by mainstream organisations was to increase the involvement of mainstream professionals in the planning process to allow them to advocate and provide expertise. This was thought to be important given the vulnerability of some people with disability who may unaware of what supports they need.

Clearly, interfacing between the NDIS and mainstream support services continues to be an issue, and will require both policy and legal changes to stop people with disability falling between the gaps of Commonwealth and State and Territory service provision.

The interface between Mainstream systems and the NDIS affect the way in which support coordination services operate to the extent of Support Coordinators experiencing difficulties in trying to connect Participants to mainstream services. This is due to the lack of collaboration and correlation between mainstream services and the NDIS-they simply do not communicate with each other. Stronger connections need to be forged between the two systems.

Support Coordinators have reported that sometimes connecting Participants to mainstream supports and services is extremely difficult, due to the fact that these supports and services tend to put people with disabilities in the “too hard basket”. It all comes back to the fact that we not only need to build the capacity of Participants, but we also need to build the capacity of mainstream supports and services.

There are two advantages of building the capacity of mainstream supports and services for the NDIA. Firstly, if more mainstream supports and services become more confident in their interactions with people with disabilities, there is a change that some Participants will become less reliant on the NDIS and secondly, it will be easier for Support Coordinators to connect Participants to mainstream Supports and Services, saving time paid for by the NDIS.

Inconsistency in Decision-Making

Feedback from the Tune Review suggests the NDIA is not making consistent decisions during planning. Some participants with similar disability support needs reported they received very different types and values of supports in their plans, where the differences did not appear to be linked to their goals and aspirations or their informal supports. This was particularly evident in cases of young siblings with the same disability and similar levels of functional capacity.

It is, however, important to note that a participant’s goals and aspirations are not intended to have a significant bearing on the level of funding provided in their NDIS plan. Rather, when comparing two participants with the same or very similar, functional capacity, of the same age and living in the same region, the NDIS is not designed to provide more funding for one participant over the other on the basis that their goals and aspirations are more expensive.

Nevertheless, consultation feedback demonstrates there is a clear tension between consistency of decision-making and the individualised planning approach, and that more work needs to be done by the NDIA to find appropriate operational responses.

Pilot evidence indicated that sourcing standardised functional capacity assessments resulted in higher quality and more consistent decisions and more equitable plan outcomes for participants with similar characteristics. NDIA staff and Partners reported the information contained in the assessments informed their conversations with participants, which in turn increased their levels of confidence in developing plans. They also found the assessments gave helpful insights and more detailed information about the participant's disability and functioning in different areas of life.

The benefits that have arisen from this pilot indicate it is worth implementing nationally for every person with disability who would like to test their access for the NDIS or who require further evidence to support decision-making about the supports in their plan. If scaled up, this could significantly mitigate the current financial barriers that exist for people with disability seeking to navigate the NDIS. It would also decrease the likelihood that a participant would need to undergo further assessments and produce additional information at the plan development and review stage, unless their circumstances had changed.

The lack of transparency around settlement outcomes at the AAT impairs consistent decision-making and makes it difficult for participants to understand the types of supports they could seek. Based on the most recent Quarterly Report published by the NDIA, approximately 96% of all finalised cases before the AAT were reached through settlement. The nature of settlements are private, confidential and non-binding on non-parties to the settlements.

Increasing the transparency in settlement outcomes will assist with addressing inconsistencies in decision-making, as it will allow some level of public accountability to ensure the NDIA makes decisions consistently with previous settlements. It will also improve the ability of participants to understand the types of supports that are funded, and assist participants to decide what types of supports they could seek.

Inconsistent Decision making can affect the way in which a Support Coordinator does their job. If the NDIA is inconsistent with their decision making and keep on moving the "goal posts", it is virtually impossible for Support Coordinators to do their job properly. Particularly if the NDIA decide to keep changing the decisions they make on how to support a particular Participant, or group of Participants eg: children with Autism. Inconsistent decisi'on making only leads to confusion and uncertainty for all parties involved in the process.

Decreases In Funding

Several participants reported that requests for funding in new plans had been declined because funds previously allocated for similar items hadn't been spent. In most cases where participants were not purchasing all the support in their plans, it was because the market for those supports was not yet developed. Underutilisation of agreed services, equipment and support was particularly evident among participants living in regional areas or those needing highly specialised services and supports – thin markets of limited appeal to providers of goods and services seeking economies of scale.

However, the supply side of the equation is not the only issue. Research also indicates that some participants are ill- equipped to push for new services or to utilise different services, either because they could not access information about their entitlements in a form that suits their needs and circumstances or because they were concerned about being labelled ‘difficult’.

Furthermore, if their health and wellbeing fluctuates over the life of their plan, as is common among people with both physical and psychosocial disabilities, they may only need some services, equipment and support on an ad hoc basis. These situations elicited anxiety as participants grappled with the present and future consequences of not having access to required services, and fears that their needs would be deemed redundant.

Planning and approval processes were guided by considerations of whether requests for funding were ‘reasonable and necessary’. This is open to being assessed in different ways and from different perspectives, and participants’ views could be in tension with the views of those charged with approving funding requests. Many participants felt that their capacities to exercise ‘choice and control’ were undermined by assessments that their requests were not reasonable or necessary without clear notions of what this actually meant.

The Complexity Of The NDIS System

Participants have raised a host of concerns about the complexity of NDIS processes, including planning processes, coordinating care packages and using the online ‘Myplace’ portal (used to view plans, keep track of budgets, request payments and manage services). Many participants claimed that the NDIS has not made things clearer for people with disabilities and had created another complex system with different moving parts and numerous chances for miscommunication and/or breakdown in continuity of care.

Annual planning reviews, which involve forecasting a person’s needs over the next 12 months, required considerable preparation, especially for those opting to self-manage their funds. Many participants made negative comments about the planning processes because of the time and effort that was involved.

A mother of a four-year-old child with a physical and cognitive disabilities explained the effort they go through in preparing their annual plans:

When we go into a plan, we do a lot of preparation with our therapists, hours and hours of talking about what do we need for the next 12 months, what are we going to foresee, what shall we ask for in terms of therapy hours and time. They do a lot of research at their end [the therapists], go to a lot of effort (...) my husband and I sit down together and we talk about it as a family (...) we go in and have this meeting with our planner (...) what I find really frustrating is that you sit there and you have a chat (...) [the planner] sits there jotting notes. Then they give you a plan. They email you a plan and that is it (...) I was horrified at some of the goals she came up with (...) I did not feel comfortable with these goals. One of the goals was for [the child] to continue living with his family at home! (...) I was horrified that it was even in there as a goal, as if he might be taken away from us. It just did not feel right at all. (IV02)

Despite careful preparation, some participant-carers felt that their views and experiences were overlooked:

You feel like you have been talking to a brick wall. (IV03)

While it is to be expected that the NDIS is a complex system, participants believed that the views of people with disabilities, their family members and carers were readily overlooked in planning processes, and that some people with disabilities were disadvantaged because they could not fully understand the system.

Participants raised a range of communication- related issues, including difficulties in obtaining reliable and accurate information from the NDIS, understanding information that has been provided, communicating with the NDIS when queries or issues arose and using the portal system.

Information about the NDIS is available in a range of ways, and there is a strong onus on service users and carers to engage with this information so they can effectively advocate and manage their support needs. The complexity of the system and the need to synthesise complex information about administrative procedures and service providers meant that many participants - particularly if they did not have access to informal sources of support from families and carers - had no capacity to self-manage and needed to engage a disability service to manage funds on their behalf.

In terms of navigating the system, our data suggests that parent-carers of young children were highly motivated to obtain optimal resources and support for them to ensure that they had the same opportunities as other children to live a meaningful and fulfilling life. Participants and parents who could draw on professional experience which gave them an under- standing of the logics of meetings, preparing funding requests and liais- ing with professionals, appeared to be more confident and assertive in their interactions in planning processes, compared to participants who had previously had limited exposure to these kinds of processes.

For most participants, positive gains were undermined, and negligible inconveniences were compounded, by complicated and burdensome administrative processes. The scheme’s funding structure and processes for identifying individuals’ needs are complex and, to some extent, this is inevitable. However, there is potential to simplify administrative systems, clarify aims and objectives of the scheme to promote consistency in decision-making when allocating resources and increase flexibility in response to the varying capacities and resources available to service users.

The NDIS has a complex organisational structure and processes, and it interacts and intersects with other service systems, creating complex environments for service users to navigate. Many service users interact with case managers, planners, service providers and business managers in a range of contexts and across organisational tiers and entities.

Several participants expressed high levels of dissatisfaction with NDIS planning processes, which they attributed to a range of factors, including lack of experience among planners, high turnover of staff, receiving inconsistent advice, unwieldy approval processes, difficulties with technology (both with the system’s portal and in gaining access to computers), and issues related to individual budgets.

Increased investment in training and equipping NDIS staff for their roles may go some way towards addressing the concerns of service users, as well as reducing stress among NDIS employees who are likely to be a target of people’s frustration and anger with the system.

Using The NDIS Online Portal

Many participants reported problems in accessing the Myplace portal which they are required to use to manage their packages, and which has had significant teething issues These issues led to difficulties in accessing care and resources, as well as frustration, stress and an increased administrative burden for service users and carers. One participant offers insights into how some of these challenges unfolded in her situation:

I am not self-managed but I do get on [the portal] to show my supports left over and who has claimed when. They shut the [portal] down in the middle of June and it is still not back up and running. I cannot see what my son's plan is. He has had two more things approved. Cannot approve it until that MyPlace is up to date. The plan that is on there at the moment is only last year's balance and they have just made up completely different line items. It is just a mess. It is really frustrating. I did not want to self-manage because I thought I would struggle with the paperwork but at the moment I am self-managing because I need to keep a track of what we are missing out on, how we can make it up so that at the end of the plan you have not gone over or have got money left over. No one will return your emails, phone calls. Some people are on hold for four hours on the NDIS. It is a debacle. It is really frustrating. Also, in terms of the therapies provided, we have had two services cancelled so far because of the portal issues. Say for example our psych, who is based in Melbourne. Has not been rolled out there yet. Before they change the portal, could claim, no dramas whatsoever. Works in Geelong with another lady. That lady can claim. She cannot. So, she stopped all services inGeelong. (IV05)

Issues with the portal were particularly prevalent in low-income households and we spoke to many participants, particularly those with cognitive disabilities and older parent-carers, who had limited or no access to mobile phones, other devices or the internet. An elderly parent-carer had recently purchased an iPad (at her own expense) and was overwhelmed with the amount of information she had to process:

For people self-managing it's an awful lot of work and yet if we just let NDIS manage everything we don't know anything about it. Have you seen their portal system? (...) My IT skills aren't very good but I went to a meeting to try and learn a bit about it and this is what we were given [shows us a lengthy photocopied document] (...) It's 37 pages with a step by step guide so it gives you some sense of [interviewer: How complex it is!] I'm not even sure if it's working 100 per cent. There's been a lot of trouble over it. (IV39)

A young woman with a cognitive disability reported:

Complaints about the portal were largely made by carers who had opted to self-manage because they felt sufficiently motivated and competent to take on the administrative tasks to assemble a suitable portfolio of services for a family member. Other participants had been cautioned against self-management; in some cases, advice against self-management came from service providers, posing a risk of conflict of interest. There were different levels of choice in 'outsourcing' the management of individual packages to an agency or a Plan Manager. For some service users, this model of service delivery simply replicated the previous system but with more administrative costs associated with providing 'individualised' packages rather than standardised packages.

Many participants with cognitive disabilities that we spoke with appeared to have packages that involved little change from previous arrangements. This was evident in the accounts of participants who were unable to describe their care plans, or recall discussing these plans with anyone, or whop reported that their situations had not changed in the transition to the NDIS.

Generally, participants described complex service systems, challenges accessing and understanding a volume of information and difficulties navigating administrative requirements. Potential for choice and control in accessing services was closely tied with being able to access and assess varied information and this clearly disadvantaged some participants. The potential for increased choice and control in designing care packages and accessing services was also linked to capacities for self-managing funds.

Many participants were unable to this because of the nature of their disability, while others were deterred by the administrative challenges and responsibilities. Most participants who were self-managing their packages were parent-carers of young children. They valued the opportunity to tailor a package of services and support that best meet their needs, although they reported that administrative requirements were onerous and time-consuming.

Some Support Coordinators have reported that the “Myplace Portal” is very difficult to understand and is complex in nature. They have also reported that at times there are major clinches in the system, leading to claims not being paid and as a result of invoices being way overdue, some organisations have withdrawn their services from some Participants.

Reasonable and Necessary Supports

Reasonable and necessary’ is one of the first terms people hear about when they start to engage with the NDIS. However, despite being the most important term, as it defines the supports that are funded under the NDIS, there is no clear definition of what it actually means. The legislative concept of ‘reasonable and necessary’ is not unique to the NDIS, with similar constructs being legislated in other compensation schemes in Australia, such as state and territory motor accident lifetime care and support schemes.

However, in its application under the NDIS Act, it is clear from the NDIS rollout that there is yet to be a consistent understanding between people with disability and the NDIA as to what constitutes a reasonable and necessary support. Fundamentally, the confusion results from ‘reasonable and necessary’ being defined in the legislation through high-level criteria around what constitutes a support in-scope for NDIS funding and those other supports more appropriately funded by another service system or through a participant’s ordinary income (including income support).

This is complicated by reasonable and necessary being, in large, a discretionary determination made on a case-by-case basis having regard to each participants individual circumstances. Combined with limited (or at least not easily accessible) information on the NDIS website on how an NDIA delegate makes a reasonable and necessary decision, there is considerable challenge for delegates in applying the ‘reasonable and necessary’ criteria consistently. However, what is clear is that legislative responsibility for determining what is reasonable and necessary, within the established principles, is vested solely with NDIA delegates.

When combined with an immature NDIA workforce and the NDIA not providing explanations of its decisions, confusion around when a support is reasonable and necessary is driving people with disability to seek formal reviews of their plans and, in some cases, escalating issues to the Administrative Appeals Tribunal (AAT) for resolution.

In considering the facts of the matter before it, the AAT is also making determinations as to what is, or is not, reasonable and necessary. While the AAT is not a Court, and its decisions are not binding, it does provide persuasive guidance for the types of support that could be funded by the NDIS. This review also notes that the AAT's decisions, while having regard to the objects and principles of the NDIS Act, may, or may not be making the decisions intended when the legislation was drafted.

Firstly, the NDIA should provide clearer advice on how it decides whether a support is reasonable and necessary, including practical examples, such as case studies or cameos. These should be readily available on the NDIS website and other platforms in accessible formats. Currently, 'reasonable and necessary' is described in vague terms, often simply replicating the legislative criteria. Case studies should address key areas of confusion for participants, for instance, ordinary living costs, health interfaces and transport.

Secondly, the National Disability Insurance Scheme (Supports for Participants) Rules 2013 should be updated to provide greater legislative guidance for NDIA decision-makers in determining when a support is reasonable and necessary. This update should have regard to the recent and anticipated decisions made by the DRC on the interface between the NDIS and mainstream service systems. This is particularly important because while the NDIA must have regard for the decisions of the DRC, the DRC's decisions are not law and do not have formal standing in the context of NDIA delegate decisions.

Thirdly, the DRC should clarify the interface between the NDIS and a participant's ordinary living costs, in order to provide further direction to NDIA delegates in circumstances where it is not clear whether a support is directly attributable to a participant's disability. This can occur where a support provides outcomes that are not solely related to a participant's disability, or where a support would be considered an ordinary living cost for the wider Australian population, but it is not clear if a participant would have purchased that support if not for their disability.

Fourthly, the NDIS Act should be amended to provide clarity to NDIA delegates that, while they must decide that supports in a participant's plan are reasonable and necessary, it is also the function of the reasonable and necessary test to consider how supports are considered as a package in the participant's plan. While this is already inferred through the concept of a 'plan' in the NDIS Act, it is worth clarifying this interaction more explicitly.

Finally, the NDIS Act should be amended to clarify that the absence of a support being provided by another service system, where that service system is considered to be the appropriate service delivery mechanism for that support, does not infer a responsibility on the NDIS to fund that support. On face value, this could appear to be a negative for people with disability as it could potentially enforce, or exacerbate, service gaps for participants.

However, this clarification would provide further certainty to participants and all governments over the role of the NDIS, driving the debate more appropriately towards the reason why the support is not being provided by the other service system.

Importantly, these actions are not intended to narrow the intended scope of the NDIS. Rather, they are intended to ensure participants and governments have a strong understanding of the boundaries of the NDIS. If implemented appropriately, this elevates the debate on the role of the NDIS and what is reasonable and necessary from individual participant experiences to a focus on the structural and systemic issues.

The Value Of Co-Design Within The NDIA

Within Co-Design, NDIS participants and nominees are validated as the experts of our own lives and we act as representatives speaking on behalf of NDIS participants. We are a valuable resource of firsthand information and response to how systems, procedures and service delivery impact our lives for good or for bad. Co-Design rightfully places people with disabilities at the forefront of decision-making that substantially affects our lives.

Lived experience of disability provides an advantage that policy makers without lived experience do not possess, allowing for empathic consideration of the experiences of people with different disabilities and backgrounds. By including a diverse group of people, we offer insight into a range of lived experiences with disability and capture a broader view into the range of interface issues that participants experience. We identify underlying and contributing factors, and their impact on participants and participants' support networks across a variety of situations and circumstance.

Co-design must be purposeful, that is, it must be working towards achievement of clear objectives. Measurement of the achievement of those objectives is as important for co-design initiatives as for any other approach to design. The outcome measures for many health services and for broader scale reform of health systems focus on the impact on the service or system. They are defined by health service providers and funding bodies to reflect their own areas of concern (Batalden et al., 2015).
While there are many examples of co-design in practice, this approach is still new for many people. Tracking the progress of implementation of co-design as a core approach to service and system development is an important area for investigation.

Useful areas for evaluation of progress in the uptake and implementation of co-design include:

- Co-design is embedded in policy as a requirement for all system reviews, planning, service and system design, implementation and evaluation.
- Co-design is a part of the process from the beginning.
- Outcome measures and KPI reflect the importance of co-design
- There is a sufficient budget and timeframe to conduct the work of co-design

Some evaluation methods are more consistent with co-design and collaboration than others. Narrative enquiry and action evaluation cycles are both methods that lend themselves to co-design evaluation.

The benefits of co-design are many:

- Giving a community ownership over the programs that they will be involved in, which helps increase the participation rates;

- The client is viewed as a partner, not just a receiver of the program/service;

- Places community members as decision makers, allowing them to shape outcomes of what they need, and how solutions can be achieved;

- If designed well, co-design can help to build a closer more unified working relationship with communities that may be helpful for continuous collaboration and engagement on other projects.

It is often clear that disability policies have been based on some human consideration, but it is less clear whether people with disabilities have participated, or whether decisions are made by committees that somehow speak for disability (Rieger & Strickfaden, 2016). Either way, there is a fixing that occurs when these policies are completed (Jones, 2014; Rieger & Strickfaden, 2016). De Carlo (2005, p.13) argues that the politics of participation become too settled and unquestioned, which suggests that ‘when we plan “for” people ... we tend, once consensus is reached, to freeze it into permanent fact’.

When policies are taken for granted, they are left unchallenged and kept at a distance, much like disability itself is often marginalised and kept at a distance (Rieger & Strickfaden, 2016). This is not just an issue of access and representation, but a rights and justice issue, as people with disabilities have the right to co-design the policies and programs that will affect their daily lives.

The meaning of co-design lacks a shared understanding, especially in policymaking, where it has become taken for granted and given an influential role as little more than a toolkit (Blomkamp, 2018; Durose et al., 2017). Conversely, understanding co-design as a process and not a product recognises that ‘the process is continuous and ever changing’, which has implications for policy designer whose job is ‘no longer to produce finished and unalterable solutions’ but to continuously co-design and negotiate solutions with people affected by policy issues (Blomkamp, 2018; Sanoff, 1990).

Some of the challenges when creating inclusive co-design processes for policy and program development are trying to understand the lived experience and abilities of all the participants and actively engage everyone in co-design activities. These challenges are often managed through workshops. The challenge of creating inclusive workshop activities that do not rely on able-bodiedness becomes a social justice issue and a design challenge. Studies that document co-designing with people with disabilities have often focused on the person’s disability, their impairments and their inability to contribute to the co-designing process (Cober, Au & Son, 2012; Metatla et al., 2015; Wilson et al., 2015; Salgado & Botero, 2008).

However, Rieger, Herssens and Strickfaden instead concentrate on the abilities of the participants and recognise their expertise when describing their co-design process using multisensorial making (Rieger, Herssens & Strickfaden, 2018; Rieger, 2020a). Rieger and colleagues showed that multisensorial activities must be designed with choice so that people can have agency and be empowered to share their expertise through their preferred activity choice, regardless of their abilities (Rieger, Herssens & Strickfaden, 2018; Rieger, 2020a).

Co-design is usually described as an approach to design attempting to actively involve all stakeholders (e.g. employees, partners, customers, citizens, end users) in the design process to help make sure that the result meets their needs and is usable.

This approach is based on research that suggests that designers create more innovative concepts and ideas when working within a co-design environment with others than they do when creating ideas on their own.

Sometimes an outcome co-designed by the NDIA with people with disability organisations gets over-ridden by the arrangements made by the federal government or between the federal and state governments. When this happens people with disability are left feeling like co-designed decisions have been ignored.

For people with disability and their families, co-designing the National Disability Insurance Scheme means a lot more than consultation. To us it means shared decision-making at all levels. It means doing away with the outdated and inequitable view of people with disability and their families as clients and recipients first, and instead treating us as experts with true capacity to help build the NDIS.

Therefore our preference is for the Commonwealth government, all the state and territory governments and the NDIA to all make further efforts to ensure the voice of people with disability is central to decisions made about the NDIS at every level. However, we understand that some of the discussions and negotiations happen in very complicated circumstances and short time frames and so encourage all parties to always be clear about which decisions have been co-designed and which decisions have not.

Co-design involves hard work but the concept itself is not difficult. Co-design is a place to start an honest conversation between all the people involved in the NDIS, meeting as equals with a common interest.

Co-design practice has existed amongst design communities, particularly industrial or software design, for some time. It has gradually developed to become a more rigorous and widely used approach across a range of contexts. Within the disability sector it is a relatively new discipline that is yet to be widely adopted.

The release of the 2015 NDIA Co-Design Framework is a useful step in clarifying how co-design can be used to shape practice in the disability sector. The Australian Centre for Social Innovation (TACSI) has also had some success within the disability sector using a co-design approach. However what co-design is—and how to use it—is not widely known or intentionally practiced by many service providers.

The current use of co-design is fragmented. It is little practiced amongst organisations, and even less with service users and families. There is an opportunity for service providers and the sector as a whole, to build knowledge and practise of co-design in a more consistent and coordinated way. For co-design to be embedded more broadly across service providers, capability needs to continually be built and shared between them. As mastery develops, the practitioners will be able to lead by example, to help them and their colleagues' decision making in complex contexts.

Infrastructure and bureaucracy can often get in the way of delivering great services for service users. Service providers have voiced frustrations about systemic failures caused by government policy and compliance. In the context of limited resources, providers feel frustrated at the amount of funds required to support paperwork and bureaucracy rather than the service users.

Currently the NDIS represents an 'unknown' for people across organisations. The lack of clarity and certainty as to what the NDIS will do and how it will work means people feel a sense of excitement as well as a sense of apprehension. Specifically there is hopefulness and uncertainty as to how the NDIS will resolve some key industry challenges.

Service providers have stated that service users and their families can be limited in their goals and aspirations for the future. Many service users are disempowered and rely onstructure, routine and people around them, often fearing change. As a result, they can find it challenging to create a vision of a 'good life' or imagining new or better possibilities for themselves.

Changing practice and approaches is challenging in innovating and preparing new models of service and individual purchasing expectations of service users from a model of 'set menus'. This requires a shift in mindset, operational style, staff management and organisational agility. This was felt amongst service providers at the organisational and industry level, where creating real transformation in the industry was felt to be a significant challenge. The result was a sense of overall confusion and fear of the future.

Service providers and families often have to translate service user wants or needs due to their communication ability and the accuracy of this can be difficult to gauge. Due to the complexities and challenges in communication, people don't often take the time to directly communicate or understand the service user and instead defer to family or others who know the service user or can interpret.

Although many service providers are changing from a model of options to one of complete choice for service users, limitations still exist. Access to services that are suitable, particularly in regional/rural areas often leaves little real choice for service users. Transport and actually getting around to engage in activities adds to this challenge for service users and providers.

The Positive Effects of Co-Design are:

•Taps into full range of relevant human and organisational experience• Benefits from the 'wisdom of the crowd' –the sum being greater than the parts

- Breaks down silos – between sectors; between funders, providers and service users; between policy, procurement and service delivery within organisations

- Combines the wisdom of lived experience with the expertise of professionals to maximise benefits.

- Minimises waste by testing assumptions with the end users of potential services

- Shifts focus to more person-led,community-involved preventative services that relieve pressure on costly acute services

The primary stakeholders in the design of programs and services are: first of all, the people who will access and use those services (and in some cases their carers and families); then the people who provide the services; and finally the agencies who fund the provision of services (usually in this context, the Government).

Any Co-Design initiative at the level of systems or strategic policy shifts requires high level endorsement and mandate before it can have a realistic chance of success. Significant resources, including funding and staff time will need to be allocated to support the engagement of participants.

All co-design involves some transfer or sharing of power from funders and service providers to citizens. Those who currently exercise power and control can have difficulty in letting go (Clarkson, 2015) and service users need to be supported and empowered to engage effectively (Phillips A, 2014);

Establishing the right engagement process and mechanisms is important. Basic issues such as establishing scope, expectations, resourcing the process and attending to detail to enable service users to participate is required (William-Powlett, 2013).

A common theme is that service providers and particularly service users say they need information and training to be able to properly engage with the co-design process. (Rosenberg, 2013);

Representation is important because many people with disability, particularly people with intellectual disability, often do not have a chance to have a say about Government reforms and policy. The consultation that happens usually focuses on the views of their parents, carers or service providers.

Peak bodies represent a diverse background of people with a disability who may otherwise not be heard. As a result, they offer valuable insights and knowledge of the issues facing people who have a disability and consult in methods and formats that are preferred by those they consult. This makes their reach profound and significant.

The NDIA did not go through the Co-Design process when it came to the establishment of the role of Support Coordinator and as a result the role of Support Coordinator is quite ambigous and confusing. Support Coordinators themselves quite often do not know what their role entails, let alone service providers, Participants and their familes.

What makes this situation worse is the fact that there is a lack of professional development and no formalised training for Support Coordinators, lead to a lack of consistency in how support coordination services are delivered. Anyone can walk off the street and become a support coordinator, no qualifications. It is doubtful this would of happen, had the role been co-designed with Participants.

The Harmful Impacts Of Appeals

For applicants, the AAT appeal process is hard work. It is often emotionally exhausting for persons with disabilities and their family/caregivers, and people report feeling disempowered by it. People are often intimidated by the number of people on “the other side”, including NDIA staff/ lawyers, and external lawyers.

It is a lengthy process involving many stages and people. In fact, by the time a matter gets to the AAT the participant/family will have explained their circumstances numerous times to:

-Therapists (who wrote reports)
-NDIA planners/ Local Area Coordinators (who ignored reports)
-Internal Review Officer (who may or may not have contacted the participant/family)
-The AAT
-An advocate (or multiple, as they search for someone to help)

Then, as the first step at a case conference, the applicant is required to retell their story again to another group of people. Often applicants do not understand why they must go over things repeatedly, especially when they receive the same outcome. The consistent retelling of their stories can create and contribute to mental distress and in some instances, trauma.

Additionally, ongoing delays are harmful where funding for vital supports is unavailable, and the applicant has no control over how long the process will take. They cannot often gauge the likely length of the overall process. If existing NDIS funding does run out during this process, the participant will either have their supports cease, or need to self-fund supports in the interim. For those who can self-fund (in our experience, the minority), it is unlikely that they will be reimbursed for those amounts if the NDIA does agree they were reasonable and necessary and should have been funded. For those seeking NDIS access, they receive no funding and rely on the often inadequate mainstream system for support.

Therefore, many people will also choose to not continue to challenge the decision through the AAT, due to concerns about the adverse effects that it can have on their mental health. This means that despite many NDIA decisions being changed, there are people who will not pursue a fairer outcome. While the AAT is intended to be a relatively informal process, there are still many elements if the process that closely resemble a trial.

Going through this process can be onerous for people who are already overwhelmed by their life circumstances. Many of the signatories' report clients experiencing additional mental health challenges as a direct result of the stress and interrogating process. Clients have expressed suicidal ideations and have needed to seek additional psychological support as a result of being traumatised by the experience. The reliance placed on informal supports during the process also creates the potential for carer burnout which can result in a higher cost to NDIA.

The Harmful impacts of AAT appeals can have a serious impact on support coordinators, particularly if they have multiple participants appealing the AAT. By having numerous participants appealing the AAT, a Support Coordinator could have multiple participants who are traumatised of the process and who are demanding of their time, leading to the possibility of the Support Coordinator working many unpaid hours.

Another concern is the due to the fact that the ATT process is so traumatic for participants, it is feared that some participants will give up mid way through the process and as a result, will have an inadequate funding package that does not meet their individual needs.

The Legalistic Nature Of The AAT

Some concerns were also raised about the environment of the AAT in dealing with NDIS appeals. Advocates, including Support Coordinators, in particular noted the intimidating environment for people with disability, especially if they were not legally represented, but were facing the NDIA's barristers in conferences. There was often a significant power imbalance, exacerbated by some procedures adopted by the NDIA, and permitted by the AAT.

For instance, several stakeholders noted that they had attended hearings with the applicant in person, where the NDIA's lawyers appeared over the phone. This created two issues. First, some people with hearing impairments struggled to hear and participate in the hearing. Second, some people found the process disrespectful in that the NDIA did not appear in person to address their concerns.

Inconsistency With The AAT

It is well established that inconsistencies are a significant problem in NDIA decision-making. There are many instances where a participant goes through an internal review and the issue is resolved at the AAT, but then that same support is refused at the next plan review. The participant then needs to go back to internal review and appeal all over again, repeating what is often a stressful and time-consuming process.

This can also be inconsistent with the NDIS Act s.33(5)(f) which requires the NDIA CEO to 'have regard to the operation and effectiveness of any previous plans of the participant' when deciding whether to approve participant supports.

Aside from the unfairness to participants who are required to go through the same lengthy and often expensive process, this also leads to an ineffective oversight mechanism and poor government administration. Where a matter has already been resolved at the AAT level, outside of any significant changes in circumstances, resources should not be wasted on needless appeals.

It can be incredibly unfair to expect Participants to go through internal appeals and/or AAT appeals, to repeatedly solve the same issue year after year. It is also a waste of support coordination funding, having Support Coordinators having to prepare paperwork for participants going through Internal Reviews/AAT Appeals each year, based on the same issues each time-that never seemed to be resolved.

Systemic Changes With AAT

The NDIA has often failed to implement, in a timely way, systemic changes to its policies following AAT and Federal Court decisions.

Concerning AAT decisions, the NDIA has taken contradictory positions. If the decision is in favour of an applicant, the NDIA’s position is usually that AAT decisions provide non-binding interpretations of law and policy and need not be implemented by the NDIA. However, if the decision is in favour of the NDIA’s position, the NDIA will adopt this position as if it is law.

While AAT decisions are technically not binding, the NDIA’s refusal to consider and implement relevant changes to policies following AAT decisions renders it an ineffective oversight mechanism, especially where the AAT has consistently decided on a particular policy issue. An example of this is gym memberships discussed below at Part 3(d). The NDIA should have a consistent and transparent approach to AAT decisions.

This failure to make appropriate systemic changes to NDIA Operational Guidelines has also extended to Federal Court decisions. Court decisions that directly contradict NDIA policies and practices are binding and must be implemented systemically at the first opportunity.

The failure to implement decisions swiftly undermines the oversight mechanism of the appeals process, and wastes resources by resulting in confusion and reviews and/or appeals on issues that should be considered settled. This failure forces participants to initiate appeals on similar grounds as previous cases, simply to achieve a similarly successful outcome in the individual case.

Quality and Safeguards Commission

The NDIS Quality and Safeguards Commission is a new independent agency established to improve the quality and safety of NDIS supports and services. The NDIS Quality and Safeguards Commission will work with NDIS participants, service providers, workers and the community to introduce a new nationally consistent approach so participants can access services and supports that promote choice, control and dignity.

The NDIS Quality and Safeguarding Framework provides a nationally consistent approach to help empower and support NDIS participants to exercise choice and control, while ensuring appropriate safeguards are in place, and establishes expectations for providers and their staff to deliver high quality supports.

The framework replaced the existing state-based quality and safeguarding measures which were considered no longer applicable in the new market-based system of the NDIS. Based on the UN Convention on the Rights of Persons with Disabilities, the National Disability Strategy 2010–2020, and the NDIS Act, the framework consists of developmental, preventative, and corrective measures which are targeted at individuals, the workforce, and providers.

The overall objectives of the NDIS Quality and Safeguarding Framework are to ensure NDIS funded supports:

- Uphold the rights of people with disability, including their rights as consumers;
- Facilitate informed decision making by people with disability;
- Are effective in achieving person-centred outcomes for people with disability in ways that support and reflect their preferences and expectations;
- Are safe and fit for purpose;
- Allow participants to live free from abuse, violence, neglect and exploitation; and
- Enable effective monitoring and responses to emerging issues as the NDIS develops.

The Commission has a range of compliance and enforcement powers under the NDIS Act and the Regulatory Powers (Standard Provisions Act) 2014. Inspectors and investigators appointed by the Commissioner have, respectively, monitoring powers and investigation powers that can be used to determine whether the requirements of the NDIS Act are being met.

The Commissioner may enforce civil penalties under the NDIS Act, including for: providing support under a participant's plan without being registered (where registration was required to provide that support); failing to comply with a condition of registration; contravening the NDIS Code of Conduct; or failing to comply with a compliance notice or banning order.

The Commissioner also has sanction powers, including:

- applying conditions to registration, suspending registration, or revoking registration
- issuing compliance notices, infringement notices, or banning orders, and
- applying for injunctions or accepting enforceable undertakings.

Three main concerns were raised in regards to the administration of the NDIA. The first was the difficulty faced by service providers in ensuring they maintain quality standards when the NDIS is under a continual state of change. The second was the limited safeguards in place to mitigate selective processes by service providers, with regards to NDIS participants with high and complex needs. The third concern raised highlights the lack of transparency within the NDIA and with NDIS participants and services providers.

Impacts on the services provided to individuals as a result of the quality and safeguarding issues were identified in the submission of Mr and Mrs O'Dea, parents of a NDIS participant, to the Inquiry Into The Implementation, Performance and the Governance into the NDIS In The ACT.

Mr and Mrs O'Dea noted that the NDIA lacks set standards for providers of both housing and day programs that cater to NDIS participants with high and complex needs. Additionally, they highlighted that this lack of standards results in a number of service providers refusing to facilitate NDIS participants with high and complex needs.

Ms Mary-Anne Brownlie, a participant of the Scheme, informed the Committee that the reduced availability of carers to assist her has resulted in the available carers picking and choosing who they do and don't assist. Additionally, Ms Brownlie noted that the NDIS certification process to be a carer has contributed to a number of carers not providing services in the Scheme, due to the complexities of the process.

In addition to limiting service provisions for participants with high and complex needs, the Public Trustee and Guardian raised concerns with an agency or service provider market that is obstructing a client’s choice and control. The Public Trustee and Guardian further noted that often a service is offered to a client as long as they also accept another service from the same or sister company. The Public Trustee and Guardian is concerned about these practices and hopes that the quality and safeguarding frameworks will seek to improve processes.

National Disability Services, a peak industry body for non-government disability services, highlighted a number of concerns with the new quality and safeguarding arrangements focusing strongly on bureaucratic safeguarding, distrust of the sector and potential unwillingness to show flexibility. National Disability Services also suggested that the limited application of the quality and safeguarding requirements risks quality and safety for participants and places the fully regulated services at a price disadvantage.

The NDIS Quality and Safeguarding Framework (Framework) emphasises building capacity in NDIS participants to participate in the NDIS market and supporting people with disability to make their own connections, noting that 'the actions people take themselves—or that their family, friends and others around them take—are likely to be the most i’mportant component of the quality and safeguarding system'.

A central foundation of the NDIS is that it is intended to be rights respecting, promoting choice and control for people with disabilities to pursue their goals and in the planning and delivery of their supports. The market-based system established by the NDIS is intended to promote this choice and control, by offering people with disability a wide range of providers from which to seek support. Having choice and control includes having the right to make decisions about your own life and circumstances, even if those decisions carry risk. This concept is referred to in the Framework as the 'dignity of risk'.

The 'dignity of risk', as described in the Framework, includes:

- supporting people to take informed risks to improve the quality of their lives;
- working with participants to define acceptable levels of risk in delivering supports to achieve goals; and
- supporting participants in positive risk-taking, including recognising when the risk is something the participant can decide on.

The Framework emphasises that an approach to safeguarding that respects the dignity of risk must weigh strategies for reducing harm against the likelihood of harm occurring and its severity, and the impact this will have on choice and control. However, participants also come into the scheme at 'varying stages of readiness to take control of their supports', and some participants will be unable or unwilling to exercise choice.

The NDIS Act provides the Commissioner with a broad range of compliance and enforcement powers, including:

- Monitoring and investigation
- Compliance notices
- Enforceable undertakings
- Infringement notices
- Injunctions
- Civil penalties
- Suspension and revocations
- Banning orders

However, the Commission’s Compliance and Enforcement Policy states that the Commission’s primary approach to achieving compliance and building the capacity of the sector is educating, advising and encouraging providers and staff to identify and understand their obligations and improve their practices.

The commission regulates all NDIS providers and registers some, and these are subject to all of the registration requirements set out in the act and the rules; for instance, the need to be routinely audited against the purpose built practice standards, the need to have mechanisms in place to manage complaints from people with disability, the need to report certain matters to the commission and the need to comply with worker screening arrangements.

Concerns raised by witnesses and submitters included that:

- the Commission may lack legislative ‘teeth’ to have a positive impact on the quality of services and supports;
- the Commission should have a power to prevent service providers from
- withdrawing services until other satisfactory arrangements are in place; legislative restrictions on the ability to delegate compliance and enforcement functions may increase administrative burdens;
- the evidence requirements associated with banning orders, suspensions and
- cancellations (of registration) may be too high for the Commission to meet within its existing resources; and
- limitations on periods for investigating complaints and incidents and issue infringements may lead to rates of enforcement action.

Ms Kirsten Deane, then Campaign Director, Every Australian Counts (EAC), stated that it is ‘very clear’ from the stories and experiences of EAC members that many people with disability do not consider that the Commission is using the powers at its disposal in an effective manner. Further, the Commission may need a more diverse range of options to ensure the quality and safety of services.

The Intellectual Disability Rights Service (IRDS) noted that one of its clients had made a complaint to the Commission, only to be told that the Commission ‘educate[s] rather than regulate[s]’. The client also asserted that the Commission ‘too readily refers problems away’.

The First Peoples Disability Network (FPDN) similarly stated that if complaints are made to the Commission, they are dealt with from a ‘service quality and regulatory perspective’, rather than the Commission using the extent of its powers to take affirmative action to initiative investigations or ban providers where abuse, neglect and violence are identified.

Some submitters and witnesses also indicated that the Commission’s use of the tools at its disposal has been inconsistent. For example, Autism Spectrum Australia (Aspect) noted that at times the Commission has been ‘heavy handed’ in terms of compliance, while at other times the Commission has been slow to respond or has stated that relevant provider should resolve the identified issue.

The committee also heard from individual participants and their families in relation their frustration about the time taken for the Commission to investigate complaints, with one individual stating that ‘[the] conclusion is that the whole system is premised on most people giving up in disgust’.

A key aspect of the Commission's compliance function is the NDIS Code of Conduct (Code), which sets minimum expectations and conduct expected of all NDIS providers and workers. The Code is intended to promote the delivery of safe and ethical services to NDIS participants by both preventing and correcting poor conduct by providers and workers. Its preventive effect operates by providing a mechanism for taking action against providers who engage in unacceptable conduct in the NDIS market.

Some submitters argued that the Code should be strengthened to assist in preventing violence, abuse and neglect of people with disabilities. For example, the Code may offer too much discretion in its interpretation by providers, and that language used in the code should be strengthened and clarified.

Physical Disability Australia (PDA) noted that the extent to which the Commission takes action in relation to complaints is unclear from the Commission’s activity reports. PDA was able to locate a ‘woefully short’ list of people and organisations that had been subject to sanctions via the Commission’s website and reported that even this list lacked detail regarding why particular actions were taken and required an ‘extensive search’ to locate. Mr Simon Burchill, PDA Manager, stated that information should be made available on the extent to which complaints and allegations of misconduct have resulted in compliance action.

A core concern for Participants and their families is that the Commission takes a reactive rather than proactive approach to compliance and enforcement. The Commission was perceived as relying heavily on complaints and reportable incidents to initiate investigations and compliance processes, rather than proactively monitoring the quality and safety of services and support. This approach is not effective in terms of ensuring the quality and safety of services and supports or building the capacity of the sector. Moreover, this reactive approach places a heavy burden participants, families and supporters.

A number of submitters emphasised the importance of proactive monitoring to ensure the safety of people with disability receiving accommodation supports through the NDIS. For example, the Community and Public Sector Union (CPSU) concluded that the Commission’s monitoring and investigation powers are not being fully utilised because the

Commission does not proactively visit disability accommodation services, and instead relies on complaints and reportable incidents and concerns arising from auditing and compliance activities. The CPSU asserted that a combination of reactive and proactive approaches is needed.

Prader-Willi Syndrome Australia (PWSA) recommended more monitoring and investigation of supported independent living (SIL) services in supported disability accommodation settings, noting the specific vulnerabilities of people with Prader-Willi Syndrome and challenges for this cohort in holding providers accountable for unsafe and poor quality services. PWSA indicated that—as part of this process—the Commission should investigate the appropriateness of SIL quotes and rosters of care, and should ensure that SIL service provision is underpinned by a balanced service agreement.

Particular concerns were raised in relation to Practice Standards relevant to providing Specialist Disability Accommodation (SDA). The Victorian Office of the Public Advocate expressed concern that although the Practice Standards provide that each participant accessing SDA must be able to exercise choice and control and must be supported by effective tenancy management, the Practice Standards do not appear to contain further specification as to what ‘effective tenancy management’ should entail. By contrast, guidelines prepared by Department of Health and Human Services in Victoria provide for matters such as mandatory advertising times and considerations in relation to resident compatibility.

The Summer Foundation observed that the SDA Practice Standards ‘do not provide adequate guidance about the standard of policies and procedures that an SDA provider must achieve to realise performance outcomes’, leaving providers to determine for themselves how to comply with the Standards, which in turn leads to inconsistency across the sector and to poor performance outcomes.

The committee heard concerns in relation to how providers make use of their internal complaints systems to address complaints and support complainants. For example, Mr Tim Chate, a solicitor with the Intellectual Disability Rights Service, emphasised that internal dispute resolution mechanisms are only effective if the provider is ‘professional...morally good [and] motivated’, stating that: ‘if you’ve got a service provider that’s being difficult and just doesn’t want to provide...services then [the system] doesn’t work’.

The committee heard that the complaints process is complex and that it is unclear how the process operates in practice. This may be creating difficulty for potential complainants in accessing the Commission's complaints mechanisms.

The Queenslanders with Disability Network (QDN) reported ‘general confusion’ around the complaints process, including whether they can make a complaint to the Commission; when and how to make a complaint; who may make a complaint; how a complaint is investigated; outcomes from a complaint; and what communication to expect during and after an investigation.

There is also lack of clarity in terms of:

- the agency to which complaints should be directed (for example, whether a complaint should be made to the provider, the NDIA or the Commission)
- the agency that will be addressing the complaint, and the pathway through which the complaint will travel
- the person who will contact a complainant as part of the resolution process;
- the point of contact with respect to the progress of a complaint
- how to escalate a complaint if there is a change of circumstances or a greater perception of risk
- avenues of appeal; and
- the availability of free disability advocacy.

ADA Australia suggested that providing relevant information in the form of a diagram or flow-chart, or using audio-visual materials, might help to facilitate greater understanding and access.

The committee heard that it is sometimes unclear who may make a complaint to the Commission regarding the quality and safety of supports and services—despite the Commission’s stated policy that anyone may make a complaint. Further, participants and providers had received inconsistent advice from the Commission in relation to this matter.

NDIS participants face numerous difficulties in making complaints. In addition to the complexity of the complaints process, the committee heard that participants experience power asymmetries in their interactions with providers and the Commission and may also fear reprisals from service providers.

The Australian Lawyers Alliance (ALA) asserted that the Commission has an important role to play in ensuring complainants are well-supported during the complaints process and called for consideration of whether the current requirements of the Commission relating to complaints enable or hinder fair process. Factors which may make the complaints process less accessible for participants include:

- the 'well-documented' power asymmetry in the complaints process, which may lead to participants struggling to be heard, understood and believed;
- fear that making a complaint will lead to worsened service provision, due to retribution;
- making a complaint may be a source of re-traumatisation;
- complainants are often unaware of their rights.

People with intellectual disability do not feel safe to complain, as they are justifiably concerned about disapproval or retaliation from those they rely on for support. Moreover, a person with intellectual disability may have previously made a complaint and found the process to be daunting or pointless.

Ms Georgi Hadden, a participant, also spoke to the committee about the difficulties that she had faced in making a complaint, with a focus on fear of reprisal from service providers. Ms Hadden stated:

In my situation, because I was vocal in speaking out, not just on me but on other people, the consequences of that were having my assistance cancelled for three days, where I could not access the food or I couldn't access my medication, despite what you read, because I don't have memory... For three days I was refused medication. One worker in Service A told me that management had told them to tell Georgi that they had lost the key.

Speech Pathology Australia (SPA) observed that people with communication disabilities often face significant barriers to being able to report abuse, neglect or mistreatment, because they are not provided with the opportunity, time or means to do so in a way that ‘fits’ their communication abilities. People with cognitive disabilities also face additional challenges making complaints, as they often have a limited understanding of their rights, which increases their vulnerability.

The First Peoples Disability Network (FPDN) stated that making a complaint to the Commission is particularly difficult for Aboriginal and Torres Strait Islander peoples with disability, owing to a lack of trust in government institutions and concerns over disruptions to services and supports. This issue was of particular concern given the lack of culturally safe and appropriate services:

[E]ven for those First People with disability located in metropolitan areas, there is a lack of culturally appropriate disability support. Where services may be limited, making a complaint may risk ongoing service for an individual or create service issues within the wider community. For many First People with disability, the NDIS may be the first time they have had access to any form of formal disability support, leading to a reluctance to raise issues or concern for fear of losing what they may have only recently gained.

Immediate measures to support participants should be taken in the form of increasing access to independent advocates who can support them through the complaints process. In order to achieve this there would need to be a funding commitment from the government, and a clear and consistent process for taking complaints from third parties such as advocates.

In its submission, the Commission noted that it reviews data about reportable incidents to identify 'systemic issues to be addressed, and report publicly on the trends and patterns in reportable incidents, and best practice strategies to improve the quality of supports and services and prevent harm to people with disabilities.

The committee heard that the Commission's approach to reportable incidents demonstrated shortcomings similar to the issues with its approach to complaints. These included shortcomings in the Commission's approach to communicating with participants and providers about incidents.

The committee also heard varying reports in relation to the approach of Commission staff who work with reportable incidents. For example, CPSU reported that Commission staff who manage reportable incidents were expected to work on matters that required training and experience that had not been provided. Cara noted that it has received highly variable responses from the Commission in relation to reportable incidents, which suggest only limited understanding among the Commission's staff of matters such as industrial requirements and procedural fairness principles.

The Junction Works Limited (TJW) noted an instance where a junior officer from the Commission called and spoke to one of their staff in a threatening tone, asserting that TJW should have lodged a report in relation to a reportable incident relating to the neglect of a participant. However, according to TJW there was no neglect to report, and the staff member from the Commission had made assumptions based on potentially faulty third party information. The officer from the Commission also required TJW to lodge an incident via the Commission's portal without first seeking information from TJW about the actual event.

To address incidents such as this, TJW recommended that:

- the Commission seek clarifying information from providers prior to presenting third party information
- Commission staff take a collaborative position with providers to ensure that communication channels remain constructive
- the Commission establish a set of definitions around what it considers to be 'serious injury', 'abuse' and 'neglect'; and
- the Commission establish a triage process to enable providers to know whether an incident reaches the 'reportable' threshold.

The committee heard that providers continue to face difficulty understanding the reportable incidents framework, including understanding which incidents must be reported, and that reporting requirements impose a significant administrative burden.

The committee heard that there is a lack of clarity and consistency as to what is deemed an 'incident' within the Reportable Incidents framework, and as to when an incident reaches the threshold of being a 'Reportable Incident'. This can cause confusion for providers, and limits the Commission's ability to effectively address issues associated with the quality and safety of supports and services.

Submitters pointed to the effects of under resourcing, with VALID, for example, describing the Commission as under-resourced, and unable to operate to its full potential without more staff and training. VALID also commented on the potential consequences of under-resourcing, stating:

Under-resourcing leads to a focus on process instead of rights and relationships. People with intellectual disabilities cannot rely on the NDIS Commission's safeguards if staff are not able to answer every call...if there isn't time to go out to meet the person face-to-face, or if investigations are put off for lack of investigators.

This under-resourcing is most evident where there is a lack of specialist expertise and appreciation of the time needed to work with people who have complex communication or behaviour support needs as they work through the complaints or investigation process.

Similarly, the Australian Association of Social Workers (AASW) emphasised that for providers to be held accountable for meeting standards in the Code of Conduct and Practice Standards, the Commission must be adequately resourced. The AASW asserted that fraud is a major area of concern, stating:

In addition to major fraud cases that attract public attention, there are unethical financial practices, whether intentional or not, that require focus and a commitment from the Commission to address. This may include holding the NDIA to account in their activities in educating providers adequately.

It was a suggested that the Commission does not appear to be sufficiently resourced to allow for an investigation at the request of a provider or participant, and it requires providers to undertake an investigation internally, or appoint an external investigator at the provider’s discretion. Both of these approaches, it argued, lack the independence of a Commission-led investigation, and increase the administrative burden on providers operating in a price-capped environment. Such delays also indicate that available human resources are inadequate for the Commission to execute its functions in a timely manner.

The committee heard that the Commission does not have sufficient staff to effectively perform its functions. In particular, evidence indicated that the Commission may lack adequate numbers of ‘frontline’ staff—such as complaints officers and investigators—to respond to and investigate complaints and reportable incidents.

Due to low staffing levels, the committee heard, officers within the Commission are obliged to deal with high caseloads. A reportable incidents officer may hold up to 120 matters, while a complaints officer may hold up to 60 matters. Members of the CPSU commented on the impact of understaffing as follows:

Frontline operation teams do not have adequate employee numbers to manage the volume of reportable incidents, complaints, or compliance activities currently within the Commission’s oversight. Participants are at risk due to the inability of the Commission Branch functions to perform thorough assessments to ensure the ongoing safeguarding of participants has occurred and NDIS providers are meeting legislative obligations.

Other evidence pointed to constraints on the Commission's ability to launch investigations of its own accord, largely because of limited funding. People with Disability Australia (PWDA) argued that the Commission had a 'reactive rather than proactive approach'. It submitted that this had particularly become evident during the COVID-19 pandemic, when the Commission encouraged individuals to make their own complaints to address the issue of service providers not providing continuity of support. PWDA contended that:

This is problematic as many people with disability live in closed settings where it is difficult and often frightening to make a complaint... Relying on complaints is particularly problematic during the pandemic as people with disability have reduced access to visitors, including advocates who can help them make a complaint. Further, people with disability may not be in a safe situation to risk making a complaint when they may be reliant on this same person for supports.

The problematic nature of relying on complaints to trigger investigations was also recently highlighted by the tragic death of Ann Marie Smith... [I]f Ms Smith wanted to make a complaint to the NDIS Quality and Safeguarding Commission, in the absence of other visitors, it would need to be done through the very person who would be subject of the complaint.

The Commission's communication with the disability sector was highlighted as particularly poor over this period, with submitters stating that there was significant confusion reported by providers about a range of aspects of the transition, including the responsibilities of the Commission compared to states and territories and the NDIA, and responsibilities of NDIS providers and service providers in other sectors.

The committee also heard that the transition to Commission oversight had left some people with disability, advocates, and providers confused as to the correct point of contact for complaints and oversight, with submitters also expressing concern that the transition has left gaps in oversight.

Brain Injury SA asserted that for people living with complex needs in the community, the transition to the NDIS has resulted in a loss of a single point of contact for safety, oversight and coordination when crises occur. Further, service providers do not know where to go when they are not coping with the complex needs of an individual, which may fluctuate in intensity resulting in periodic crisis.

As evidenced through the difficulties experienced during the transition period, there is a complex interface between the Commission's role and responsibilities with respect to ensuring the quality and safety of NDIS services and the roles and responsibilities of bodies providing services in other systems such as the health, mental health and justice systems. The committee heard that, even in jurisdictions where the Commission's role was more established, these complexities are still poorly understood, and may lead to gaps that expose NDIS participants and other people with disability to mistreatment, abuse and neglect.

The Summer Foundation noted that the provision of support to NDIS participants in residential aged care (RAC) occurs under multiple oversight arrangements. Not only is this difficult and confusing for individuals, the Summer Foundation also submitted that providers commonly believe that, as they are not required to register as NDIS providers, they are therefore not bound by the NDIS Code of Conduct. This misunderstanding negatively impacts on the safeguarding protections available to NDIS participants in RAC.

The Commission does not have jurisdiction over forensic services, as these are administered by state and territory governments. Mr McGee indicated that this is of significant concern as people in forensic detention may have complex or multiple disabilities, and are particularly vulnerable to abuse, exploitation and neglect. Moreover, a substantial proportion of individuals in forensic detention are Aboriginal and Torres Strait Islander peoples with disability.

Mr McGee also submitted that state agencies—for example Directors of Public Prosecution—consider forensic orders to exist for the safety of the community and may not give sufficient consideration to the rights of people with disability to whom forensic orders are applied.

The committee heard that people are being held in forensic detention in the 'context of a fractured monitoring and oversight system whilst the state and territory disability programs had been absorbed into the National Disability Insurance Scheme.' Mr McGee explained further:

The reality is that there is a failure of understanding across all levels of government when it comes to forensic orders. The reality of the provision of disability forensic support is it occurs in the disability and health systems, not in the justice system. The orders start in the justice system and are managed by the justice system; the provision of the support that arises out of the orders comes in disability and health systems.

A number of submitters emphasised the role of support networks and community inclusion to assist in ensuring people with disability are not subject to abuse or neglect. Some submitters also called for the Commission to take a role in leading work to increase the natural safeguards for people with disability, such as ensuring opportunities to develop social connections, inclusion in the community, and changing community attitudes toward disability.

Some submitters and witnesses called for increased protections for people with disability who are not participants, and to whom the Commission's reach does not currently extend. Certain stakeholders called for the Commission's reach to be extended, while others called for a new oversight and safeguarding mechanism to be established to cover all people with disability in Australia.

For example, Physical Disability Australia (PDA) expressed its disappointment that Commission's jurisdiction is restricted to providers of NDIS supports, noting that NDIS participants represent only a small percentage of Australians with disability. PDA emphasised that people with disability who are over 65, as well as other people with disability who may not meet NDIS eligibility requirements, still require services and safe, quality supports.

Ms Romola Hollywood, then Director, Policy and Advocacy, People with Disability Australia, called for a wider oversight and safeguarding mechanism covering people with disability in all contexts and settings, stating:

The NDIS Quality and *Safeguards Commission has very important work to do. However, it only provides protection to NDIS participants, who constitute around 10 per cent of people with disability in Australia. The remaining 90 per cent of people with disability receive protection through other regulatory and policy frameworks, which, as we are beginning to see through the disability royal commission, are often not sufficient.*

Approaches to safeguarding need to consider the whole of life experiences of a person with disability, including all the services with which they interact. The committee notes the complexity of the interfaces between the NDIS and mainstream services accessed by people with disability. It is clear that, at this early stage of the Commission's operation and implementation of the NDIS Quality and Safeguarding Framework, these interfaces remain poorly understood, and responsibilities of state, territory and federal bodies are inadequately defined.

The urgency of this work is clear, with the death of Ms Ann-Marie Smith being just one devastating example of the consequences for people with disability when the safeguarding system fails them. As described by the Hon Alan Robertson SC in his report on the circumstances surrounding the death of Ms Smith, the safety and well-being of individual participants in the NDIS is the object of the entire system. It is crucial to continue to build on the NDIS safeguarding system to ensure that participants are supported to be safe and live with dignity.

Some Support Coordinators hold ableist and paternalistic attitudes towards people with disabilities. Ableism refers to " refers to attitudes in society that devalue and limit the potential of persons with disabilities. While paternalism relates to the action that limits a person's or group's liberty or autonomy and is intended to promote their own good. According to the dominant view, paternalism is wrong when it interferes with a person's autonomy. For example, suppose that I throw away your cream cakes because I believe that eating them is bad for your health. This paternalistic action is wrong when it interferes with your autonomous decision to eat cream cakes.

Sometimes Support Coordinators have a notion that they “know what’s best” for the participant, regardless of what the participant wants or needs and that the participant has unrealistic expectations or they don’t know what they really need. Due to the combination of absence of proper training, ableism, paternalism and sometimes even arrogance, Support Coordinators have engaged in unethical practices.

Examples of these unethical practices include sham contracting support workers, blatantly ignoring the needs of participants, trying to make out participants and families are being unreasonable-when in fact it just the fact that they can’t handle the demands of job, paying commissions to allied health professionals, sharing the plans of NDIS participants-without their consent, Support Coordinators thinking that they “own” the funding of participants and Support Coordinators asking for reports from Support Workers, when they know this is unethical.

Sometimes a participant may think they are overreacting, when it comes to unethical practices of Support Coordinators. It would be advantageous for the National Disability Insurance Agency to invest in educating NDIS Participants of their rights and what is ethical and unethical when it comes to support coordination. NDIS Participants are well aware of ethical/unethical practices when it comes to support workers, however support coordination is such a new role that has not been well defined, that everything is very ambiguous.

Planning For Particular Groups

Consultation feedback to the 2019 Review of the National Disability Insurance Scheme Act 2013 (NDIS Act) led by David Tune AO PSM (Tune Review) to suggest that people with disability who have support to navigate the NDIS tended ‘to achieve better outcomes than those who do not have the help they need to navigate the system by themselves’. The Tune Review argued that supported decision-making ‘is particularly important for people with limited capacity to make decisions or self-advocate’. The Tune Review recommended that the Commonwealth Government provide ‘additional funding for people with disability to navigate the NDIS’ of around $45 million over three years to 2022–23.

Planning for particular groups of participants who, because of vulnerability factors, may experience problems during the planning process that many other participants do not. These groups include the following:

- Participants with psychosocial disabilities.
- Participants with other disability types.
- Participants experiencing family violence.
- Aboriginal and Torres Strait Islander participants.
- Participants requiring early intervention.
- Children and young people.
- Participants from low socio-economic backgrounds.
- Participants in custodial settings.
- Participants in out-of-home care.
- Participants from CALD backgrounds.
- Participants with complex needs.

The following issues arising during the planning process that may be particularly relevant for participants with psychosocial disability:

- Planner questions not taking into account the impact of psychosocial disability
- Limited planner understanding of psychosocial disability.
- The planning process overly relying on functional assessments.
- Planners not considering the episodic nature of some psychosocial disabilities.
- Planners not including supports for psychosocial disability.
- The need for support coordination

Mental Illness Fellowship of Australia (MIFA) suggests that planners may not be asking the right questions to determine the functional impact of psychosocial disability on a participant. As an example, MIFA outlined that a planner might ask a participant in a planning meeting whether they can cook, to which a participant might answer yes. Without further questioning, which could reveal that the participant eats instant noodles every meal, the planner might assume that the psychosocial disability has a limited functional impact on the participant.

It has been suggested that planners continue to show a lack of understanding of psychosocial disability and its impacts, such as the impact of anxiety on participants during planning meetings. For example, Amaze argued that there is a lack of understanding among planners ‘of the high occurrence of mental health concerns and autism’. Some parents had reported to Amaze that planners assumed that depression and anxiety are ‘just part of autism’ and not adequately funded mental health issues in plan.

The Australian Psychological Society has suggested that planners were ‘inappropriately’ determining the type of psychological interventions participants needed, rather than relying on experts to do this. There has also been a call for planners and plans to take into account the episodic nature of some psychosocial disabilities and to allow for greater flexibility in funding and service use.

Kelmax Disability Services suggested that because many therapists working with people with psychosocial disability take a recovery oriented approach, their reports when articulating a person’s needs and goals may not align with the language of the NDIS, leading to the participant not securing appropriate funding.

A further concern is that the impact of reduced funding for supports for participants with psychosocial disabilities, which may increase the risk of relapse, increase costs to the health system through admission to mental health units, and cause deep distress to participants and their families.

Since July 2020, the NDIA has made available psychosocial recovery coaches to support participants with psychosocial disabilities ‘to take more control of their lives and to better manage the complex challenges of day-to-day living’. Participants, according to the NDIA’s website, are able to choose a recovery coach with lived experience, or a recovery coach with learned knowledge of psychosocial disability and mental health.

The NDIA also in a publicly available document on the psychosocial recovery coach program, stated that, in consultation with jurisdictions and Mental Health Australia, it has identified the following priority areas for improvement in how it addresses psychosocial disability:

- Improving the NDIS access process.
- Better responses to the episodic nature of psychosocial disability.
- The introduction of evidence-based psychosocial disability supports into the NDIS to improve social and economic participation for persons with psychosocial disability.

There was also concern about planning for participants with multiple disabilities. For example, ADACAS Advocacy emphasised the importance of planners recognising ‘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 proposed that planners work with participants to look at the compounding impacts of multiple disabilities and health issues.

It has been argued that children with multiple disabilities are often granted insufficient funding, ‘well below the sum of the cost of the services needed for each of their disabilities’. It recommended that ‘early intervention supports for children with multiple disabilities be determined for each disability separately.

There was also concern about planning for participants experiencing family violence, particularly women.

Women with Disabilities Victoria (WDV) expressed concern that planners do not have sufficient training in recognising and responding to family violence, even though ‘the rate, length and severity of violence against women with disabilities is extremely high’. WDV noted that the ‘Convention on the Rights of Persons with Disabilities requires that state parties recognise that women and girls with disabilities are at a particularly greater risk of violence, abuse and exploitation’.

Ms Leah van Poppel, the Chief Executive Officer (CEO) of WDV, pointed to research indicating that women with disability experience more violence in proportion than men with disability, or persons without disability. She argued that planners should have training equipping them to deal with instances of family violence:

[W]omen who have experienced domestic violence previously say that planners are not necessarily alive to some of the issues that might come about from having a family member in a planning meeting. Particularly in the instance where a woman with disability is experiencing family violence, one of the ways that that violence can express itself is by denying access to services or trying to limit those and increase the woman's dependency on informal support…

As an example, we heard a story of a woman whose partner took one of the small wheels off the front of her wheelchair while she was still in bed. There are some family violence services and disability services who would go: 'He's just removed a part. Maybe the wheelchair was faulty.' But that is actually restricting that woman's movement completely, and that is a form of violence.

WDV recommended that the NDIA should 'institute clear processes and training around using a risk assessment tool to assess family violence for women with disabilities', with these processes also applied for participants who need Supported Independent Living (SIL) supports in their plans.

Concerns regarding planning for Aboriginal and Torres Strait Islander Participants, included the following:

- The number of Aboriginal and Torres Strait Islander participants with a plan.
- The need for Indigenous planners.
- Culturally appropriate planning and cultural safety.
- Language and communication.
- The appropriateness of planning meetings held via phone
- Need for support coordination.
- The impact of thin markets on remote Aboriginal communities.

The Aboriginal Health Council of South Australia (AHCSA) called for the NDIA to develop strategies to build a strong Aboriginal workforce, particularly planners, arguing that it 'is well-documented that there is a higher success rate for government initiatives when Aboriginal people are involved and employed in meaningful roles'. It highlighted one case study in South Australia where a local Aboriginal person was employed as a local area coordinator (LAC), leading to increased trust in the NDIS and increased community participation. It suggested that the NDIA have designated Aboriginal Planners to work specifically with Aboriginal participants.

The National Aboriginal Community Controlled Health Organisation (NACCHO) proposed that the NDIA establish Indigenous cultural safety accreditation standards for providers to meet and gain certification, and that all NDIA staff, contractors, LACs and planners be required to have completed a minimum level of cultural awareness training. It also recommended that the NDIA develop a strategy to develop a workforce of Aboriginal and Torres Strait Islander planners.

Many NDIS Participants of Aboriginal or Torres Strait Islander descent in the Northern Territory, speak English as a second, third or even fourth language. As such, the provision of interpreters could be considered as a "Reasonable and Necessary" support for these Participants, that may be needed during pre-planning as well as when accessing allied health assessments and developing therapy plans. The 'immediate consideration of the incorporation of funding for interpreters into participant plans' where the participant does not speak English as a first language has been recommended.

It has been noted by Services for Australian Rural and Remote Allied Health that although telephone meetings may be carried out in rural and remote areas, these may not be culturally appropriate. It has been suggested that planning meetings 'be held face to face and preferably with locals who have established relationships within the community' particularly for 'rural and remote Aboriginal and Torres Strait Islander communities'.

In respect to Children and Young People with Disability, it has been argued that the focus, design and expertise of the NDIA does not reflect the population it is serving', with almost half of NDIS participants being under the age of 19. As such, it proposed that the 'NDIA develop its expertise in working with children and young people through developing expert advisory committees', as well as develop 'branches specifically focussed on children aged seven to 12 years and 15–18 years'.

On the issue of developmental stages, Children and Young People with Disability Australia (CYDA) argued that the children and young people with disability have 'distinctly different' service needs to adults with disability, meaning that targeted strategies are required. Furthermore, CYDA reported that that some child participants may experience long wait times to access assistive technology and equipment, sometimes the waiting period is over 12 months.

CYDA contended that plans were focusing on individual therapy, rather than other, community-based supports such as swimming and Riding for the Disabled. CYDA argued that 'what drives development is children's meaningful participation in everyday activities and environments', and that individual therapies should not be exclusively prioritised over other forms of support.

Another disadvantage group when it comes to the NDIS are Participants from low social economic backgrounds. These Participants have limited education and support and may not be able to advocate for their needs relative to participants who are well-supported and/ or are ableto navigate the complexities of the NDIS, particularly requested reviews.

Autism Spectrum Australia suggested that 'the participants who receive inappropriate levels of funding often [have] the least capacity to ask for reviews, or...the means to go through the appeals process'. Families from low socio-economic backgrounds, it submitted, 'are struggling to access diagnostic services...if they cannot pay for private assessments...Waitlists for assessment services, both public and private, are lengthy.

Maurice Blackburn Lawyers expressed concern that the NDIS 'is creating different classes of beneficiaries, and this in turn is creating an access to justice issue'. It suggested that there is a divide between participants 'who have the wherewithal and financial resources to access expertise that will enable them to judge whether or not their plan is fair, and those who lack those resources'.

Another severely disadvantaged group within the NDIS are Participants in Custodial settings. National Legal Aid suggested that without 'proactive discharge and pre-release planning', NDIS participants in custodial settings may have their discharge or release delayed, or they may be more vulnerable to re-offending or readmission if they are discharged or released with inadequate supports in place.

National Legal Aid recommended that the NDIA increase the number of specialised, trained planners working in institutional environments, such as prisons and mental health inpatient settings. It stated that it 'welcomed initiatives to introduce specialised planners and skilled support coordinators to assist clients with complex needs, particularly in institutional settings' . However, it called for an increase in the number of these planners and their training, and emphasised the importance of planning processes taking into account 'the participant's long term plans upon release and informal support networks'.

The Housing Connection reported that the 'NDIA has advised us not to provide services to people who have no funds in their plans'. The Housing Connection argued that this advice leaves cohorts of participants 'at risk to themselves and others', including participants at risk of contact with the criminal justice system who have exhausted their funds. The Housing Connection argued that not delivering 'a service that places someone at risk of harm is not acceptable'.

A small body of evidence concerned child guardianship and participants in out-of-home care. For example, The South Australian Child and Adolescent Health Community of Practice in its submission drew the committee's attention to children under the guardianship of state ministers:

The NDIS does not specifically prioritise services to this group of children and young people, and does not recognise issues such as Post Traumatic Stress Disorder, disruptive behaviour, language impairment and other issues specifically related to the early neglect and trauma these children have experienced when considering eligibility for the NDIS.

Cobaw Community Health suggested that some planners may not have training or experience in working with other government systems, leading to negative impacts on participants who may have a 'long history' with the out-of-home care, child protection and disability services systems.

Another vulnerable group is participants from culturally and linguistically diverse backgrounds. These Participants may struggle to access or understand information about the NDIS and about planning, meaning that they may not be well-prepared for a planning meeting or may struggle to understand goals written in the language of the NDIS. For example, People with Disabilities WA submitted that some participants from CALD backgrounds 'have said that they do not understand the process and what is expected, and are often ill prepared for the meeting with the planner'.

The Housing Connection outlined an example of a Korean-speaking participant who spoke no English, whose request for his new plan to also include a Korean-speaking support coordinator was declined, with the reason that he was only eligible to be funded for a support coordinator once. Despite the participant's lack of English, he was forced to communicate with all his service providers and approve invoices without a support coordinator. The Housing Connection reported that when he contacted the NDIA with the support of a staff member from The Housing Connection, he 'was unable to answer or comprehend any NDIS related terms, ended up crying, and became verbally abusive due to the frustrating circumstances'.

AMPARO Advocacy suggested that planners were not leaving phone messages for participants if they did not answer the phone unless the participant included their surname on their voicemail message. It submitted that many participants and families from CALD backgrounds may not have adequate English proficiency to do this, or may not understand how to do it. Further, planners will only attempt to contact a participant three times, it argued, meaning that ‘people with CALD backgrounds with disability are falling through the cracks and without additional support, not accessing the NDIS.

AMPARO Advocacy also suggested that pre-planning may be especially helpful for participants from CALD backgrounds, as many people from this group may not have been connected to specialist disability services in the past and so may attend planning meetings with little understanding of what they are able to access. Further, it suggested that the NDIA currently provides few resources translated into languages of new and emerging and refugee communities to help participants from these groups prepare for their planning meeting.

There was also some concern surrounding how people with complex needs accessed the NDIS. There are a number of issues concerning the planning for Participants with complex needs. These issues include:

- Limited or no knowledge that a Complex Needs Pathway exists.
- Uncertainty about which participants the NDIA defines as having complex needs and how to access this pathway.
- Concern that experienced planners had been moved to the Pathway, impacting the quality planning for other participants.
- Training needed for planners working with participants with complex needs.

There is some confusion about about what the term ‘complex needs’ means, who is eligible and how participants can access this pathway. For example, Multiple Sclerosis Australia noted that some participants who the NDIA deems complex, ‘intensive’ or ‘super intensive’ have their planning completed by an NDIA planner. Others may have a LAC involved in planning discussions, ‘only then to have the planning work repeated when it became obvious that the participant’s needs were “intensive”‘. Multiple Sclerosis Australia questioned how the NDIA determines whether a participant is ‘intensive/super intensive...and can this process be improved?

ConnectAbility Australia argued that each planner has a different interpretation of what complex needs is. It raised an example of a participant at risk of sexual abuse from family members, who had other government departments and professionals involved. However, according to ConnectAbility Australia, this ‘case was still not deemed complex by [the NDIA]. If this case does not qualify[,] what does?’

People with Disabilities WA suggested that the understanding of NDIS planners of complex needs ‘appears often to be limited and finite’. It argued that complexity ‘can be more than the pointy end situations that may involve mental health, homelessness or justice interface’, and may include:

- Multiple service providers.
- Parent or carer capacity.
- Families who have other members in the same home with disabilities or mental illness.

- Refugee families who have experienced trauma.
- Families from cultural and linguistically diverse (CALD) backgrounds.
- Individuals who have complex needs with communication or behaviour
- Multiple areas of support within a plan.

The Royal Australasian College of Physicians called for health professionals to be able to refer participants directly to the Complex Support Needs Pathway, as well as ‘the introduction of expert resource teams to support services where the needs of participants are highly complex’ and for the NDIA to develop ‘a transparent set of standards, competencies and frameworks in order to reduce any unwarranted variation and to allow for accurate evaluation of outcomes’.

There is also some concern that Planners do not understand certain types of disability. Autism Spectrum Australia noted ‘a steady improvement in the quality of plans, and this is particularly the case with early childhood plans where there is greater consistency and quality’. However, it also argued that ‘participants and families are often desperate to get a certain planner because the planner has expertise and understanding’ so that a participant is not negatively impacted by planner who does not have the appropriate skills. When planners are inexperienced, or have little understanding of disability and limited support, it suggested, there are ‘gross inequities for participants, including funding levels in plans that range from grossly inadequate to excessive.

It has been suggested that the allocation of planners, based on their specific knowledge, whether it’s lived experience or qualifications, to participants will enhance the planning experience for everybody’. Similarly, Ms Kirsten Deane from Every Australian Counts told the committee that:

People certainly tell us that they understand planners and LACs can’t know all things about all disabilities all of the time, but they have to know where to go to get help. They would like teams of specialised planners who deal in particular areas and have a more comprehensive understanding of the issues.

One of the biggest problems for people with complex needs is the absence of adequate, affordable and secure accommodation. In the past, clients who have been provided public housing are vulnerable due to neighbours’ complaints or demands on emergency services, for example, clients with multiple fire service callouts.

They are unable to live sustainably with others because of their behavioural presentation and low thresholds for frustration and distress. As a result, many of these participants have been bounced back and forth between the mental health system and disability system over many years with neither system wanting to accept responsibility for their support.

Only a very small number of specialist disability accommodation (SDA) recipients will receive sufficient funding for a single resident dwelling that may be able to cater to these specific needs.

Many participants with Complex Care needs are caught in the justice or forensic mental health system or may be homeless; leading to negative impact on peoples’ lives, potential breaches of their civil and human rights and high costs to Government.

The lack of suitable housing for Complex Care needs clients leads to:

- suboptimal therapeutic outcomes for individuals, despite the best endeavours of all stakeholders
- poor quality of life (or at worst suffering inadvertent human rights abuses) as people get caught in a cycle they cannot break
- community concern and pushback around housing these individuals – the ‘nimby’ effect
- additional costs being incurred across services systems that may be avoidable, including property damage, incarceration, lengthy hospital stays and other forced detention costs
- Additional strain on emergency services, police, ambulance and emergency departments
- Potential political implications in the event of incidents that may attract negative press
- Increased costs of SIL

In many instances, delayed or inappropriate provision of support leads to avoidable detention under the Mental Health Act 2014 as well as other infringements on an individual’s human rights and significantly compromises their ability to achieve life goals.

The Mental Health Council of Australia stated the over-representation of people with mental illness in the criminal justice system is due to a failure of the health system to provide adequate support for those at risk of incarceration.

The denial of treatment of mental health patients in prison often leads to further offending, longer incarceration (at greater cost) and aggravation of mental health conditions. It is vital for the successful community reintegration of people with a mental illness on being released from prison that they have access to stable accommodation.

Prisons and mental health services are increasingly being treated as accommodation options for people with challenging presentations and often include harmful and restrictive practices. Complex Care needs clients may also be admitted to seclusion (‘SECU’ - the confinement of a patient in a room from which free exit is prevented) merely due to a lack of appropriate supports. While seclusion can be used to provide safety to protect the patient, staff and others, it can also be a source of distress for the patient, fellow patients, staff, family and visitors.

Delays in accessing appropriate accommodation may result in people entering or remaining in detention or the forensic mental health system due to the risks arising from unmet support needs leaving them cycling through unstable and inappropriate forms of accommodation at tremendous human cost.

In the long term, NDIS policies for Home and Living should consider principles and frameworks that are more fit-for-purpose for Complex Care needs clients who can “fall through the cracks”, in particular in circumstances where it is difficult to distinguish between their disability or criminal needs.

Participants in Rural and Remote Areas

An issue for participants in rural and remote areas is a lack of service providers to provide the supports that participants are funded for in their plans, leading to low plan utilisation rates and the possibility of a decrease in funding in participants' subsequent plans. As a result, service providers that do exist in rural and remote areas may feature long wait times and long waiting lists for services.

Services for Australian Rural and Remote Allied Health (SARRAH) noted that some of its members suggested that almost all participants in rural and remote areas were 'complex' because of the additional challenges arising through reduced access to specialist service and fewer resources available to help them manage their conditions.

SARRAH highlighted 'anecdotal reports' of planners deliberately creating plans to include only services that are available in rural and remote areas, rather than what a participant needs, 'thereby undermining broader planning and demand management/supply considerations'. Likewise, Allied Health Professions Australia also suggested that 'planning processes for rural and regional participants are sometimes based on available services rather than participants' needs and goals'.

Somerville Community Services, which operates in the Northern Territory, observed that planning 'for participants in rural and regional areas is compromised by the lack of services available'. It argued that 'this becomes more problematic in remoter regions with many participants being unable to fully utilise the supports in their plans'. It proposed that the NDIA consider alternative funding models for areas where services are limited or non-existent', such as temporary 'hybrid models' that would fund 'non-government organisations or Aboriginal Community Controlled Organisations to underpin individual packages for NDIS participants'

SARRAH made the following proposals to improve allied health services availability, in particular, in rural and remote areas:

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- Supplementary funding.
- Infrastructure grants.
- Loading of fee schedules based on rurality.
- Practice incentive payments to ensure that rural and remote participants can access allied health interventions to an equivalent level as participants in metropolitan areas.
- Enable participants to use local service providers who may not be registered with the NDIS.

Noah's Ark Inc suggested that 'there is currently a severe shortage of planners in rural and regional areas', with long wait times, families being more likely to be offered a telephone meeting, difficulties contacting planners, and difficulties recruiting professionals for planning and Key Worker roles. It proposed the following solutions, among others:

- Incentives for experienced workers to move to rural and remote areas, and for those already in those areas, to remain.
- Incentives for universities to promote careers in early childhood intervention.

- Incentives for allied health professionals to focus on careers in early child intervention.
- Initiatives to enable student placements without creating financial disadvantage to providers.
- Subsidies to enable adequate training of the workforce.

The parent of a participant reported that he had been ‘happy with the expertise and knowledge of the two planners’ who he had worked with, after the NDIA assigned planners from outside the participant’s rural region because of the need for the planners to have more expertise than was locally available.

Vision Australia suggested that phone reviews had been occurring where participants were not aware that phone conversations were actually planning meetings, an issue especially in regional and remote areas that may lead to ‘participants being severely underfunded as a result’.

Some planning meetings were taking place via phone because an area has no local planners, despite many participants being unwilling to have planning meetings via telephone, in some instances because it may be culturally inappropriate.

SARRAH suggested that some planners had limited understanding of issues surrounding travel for allied health providers, such as cost and availability. It further argued that current funding models are not sufficient to incorporate the significant ‘travel time and expenses associated with regional, rural and remote services’. It noted that populations living in rural and remote areas may have lower incomes and higher burdens of chronic disease and disability, especially among Aboriginal and Torres Strait Islander peoples.

Vision Australia argued that recent increases to travel caps in the NDIS Price Guide still were not sufficient to recoup costs for travel to regional and remote areas in some instances, with the ‘costs of providing services considerably [outweighing] the expenses we incur in delivering them.

Occupational Therapy Australia recommended that the NDIA improve its transparency, consistency and fairness in its decisions on the number of hours of support funded in a plan, particularly where a participant’s geographical location may affect how much they can utilise these hours. It suggested that a participant who has access to a local therapist may be able to utilise more hours of therapy than someone who lives further away and may lose therapist time in travel expenses.

Autism Spectrum Australia outlined an example of participants in remote settings ‘receiving exactly the same funding amount for service implementation, despite having very different needs and goals’. It also noted that in some areas, there may be difficulties engaging providers, and suggested that planners or coordinators ‘work with identified providers to create cohorts...[to] ensure sustainability for providers, and ensure access to quality supports for participants in these regions.

Other issues related to planning in rural and remote areas, including the following:

- Plans not indicating that the participant is in a rural location.

- Community service providers, health professionals and organisations providing advice to potential and current NDIS participants in the absence of a local NDIA presence, with these groups rarely compensated for their work.

- Limited notice given to support people and organisations that a planning meeting is occurring, despite some of these individuals needing to make travel arrangements.

- Planners being unaware that deaf participants living in rural and remote areas may only be able to access interpreters through Video Remote Interpreting, and not including communication devices with 4G/5G capacity or data in plans.

- Limited or unreliable internet access, meaning the LAC is unable to access the NDIS planning program during planning meetings.

- Greater wear and tear on equipment, meaning rural and remote participants may need better quality assistive technology to withstand harsher environment and other forms of back-up for some equipment.

Participants who live in remote and rural areas face additional challenges when it comes to the provision of support coordination services. These challenges include limited choices in service providers they can use (in some towns, there is only one service provider), additional travel costs, social isolation, limited access to allied health services, and difficulties with service coordination. In addition to this, there may be a limited pool of applicants in which Participants can recruit Support Workers from.

While there has been some investment in telehealth services from the NDIA, this is not an appropriate option for some Participants. Accessing Telehealth would be extremely difficult for those with a hearing or speech impairment, as well as some people with intellectual disabilities or cognitive difficulties. In additional to this, because of the nature of support coordination services, the use of telehealth could be considered as quite inappropriate at times.

Individualised Planning

The Tune Review heard that participants do not feel the NDIA is taking an individualised approach to planning. Some participants reported their impression was that the NDIA was using a ‘formula’ based on pre- existing criteria or their diagnosis to determine their supports. Others indicated what was put in their plan did not reflect what was discussed in their planning meeting or that the planner disregarded the information they had provided.

Others stated that the plan they received did not link to their goals and aspirations, looked like a stock plan for a person with a certain type of disability or contained obvious errors, such as misspelt names or old addresses.

“I felt that I was not listened to at all, it was not an individual experience and I was given a horrible plan. It had nothing about my disability in it and ignored all my requests. It included information about my family when I didn't mention them as they do not support me and are not in my life.”

NDIS participant, regional Victoria

“In my current plan they couldn’t even spell my surname right!”

NDIS participant, regional Victoria

“Every plan meeting is very different. You never know what is going to happen in each planning meeting, which is stressful as it makes you unsure of whether you’re ready. The last few planning meetings we have had I feel the planners don't listen to us and in some cases have not read reports or evidence we or therapist have given. Sometimes what we have spoken about does not reflect the plan that's been approved and there is absolutely no feedback as to why this happens.”

Carer of NDIS participant, metropolitan Western Australia

The way the planning process is undertaken was one of the main complaints heard throughout this review. It is evident that the lack (or the perception of a lack) of individualisation in planning is leading a small number of participants to feel let down and misled by a scheme intended to give them choice and control.

Some participants with similar disability support needs reported they received very different types and values of supports in their plans, where the differences did not appear to be linked to their goals and aspirations or their informal supports. This was particularly evident in cases of young siblings with the same disability and similar levels of functional capacity.

Consultation feedback demonstrates there is a clear tension between consistency of decision-making and the individualised planning approach, and that more work needs to be done by the NDIA to find appropriate operational responses.

This work is appropriate to the extent it provides more powerful tools for the consistent construction of plans and baseline comparisons and gives participants greater certainty about what they could ordinarily expect in their plan. However, these tools should remain sufficiently flexible to accommodate and recognise the participant’s specific needs, goals and aspirations. Further, the use of tools such as these will never replace the need for trained planners who recognise that aparticipant’s support needs will vary over time, depending on their individual circumstances.

Choice and Control

Choice and control is a fundamental design principle of the NDIS. However, the effective use of NDIS funding can be dependent on information/marketing and the particular service chosen. Notwithstanding the role of support coordination, participants may not know how to determine the quality of a service or be aware of what are evidence-based practice approaches. This can lead participants to feel uncertain when navigating the marketplace and exercising choice and control.
In some cases, this review has heard that, upon approving a plan, participants are simply given a list of available providers in particular categories of support.

All NDIS participants are able to choose their providers of supports. Some participants may ask someone else to do it for them (a plan nominee), decide to manage the supports in their plan themselves (self-manage), or use a registered plan manager.

In other cases, the NDIA and the participant may agree that the NDIA will be responsible for purchasing and managing the supports in their plan.

The review has heard feedback that there are potential risks for participants engaging unregistered providers through plan management without the same risk assessment that is currently required for self-managing participants. These concerns were raised on the basis that having access to an unregistered provider market, while providing greater choice over service offerings, arguably exposes participants to greater risk of abuse, neglect or exploitation – particularly as the additional protections put in place for registered providers are not required of unregistered providers.

Plan management offers the same level of choice and access to unregistered providers as self-management and it is the role of support coordinators and not plan managers to assist participants in choosing and connecting with providers. For these reasons, it is unclear why plan management is an option in its own right rather than a variation of self-management.

Participants talked about issues of choice and control in different ways. Many focused on whether the NDIS was actually meeting their needs, while others discussed the extent to which they had increased choice and control in the kinds of services and support they could access. Many participants reported positive experiences of the NDIS, including receiving increased funding to access services and resources, reduced waiting lists for services and potential positive impacts for local economic development.

Some participants felt that requests for funding involved identifying personal goals and objectives that were not appropriate given the situations of some service-users. Many participants commented that they had not noticed any changes in terms of having increased access to, or choice of, services since transitioning into the NDIS.

Participants’ expectations and experiences of the NDIS appeared to be strongly influenced by their circumstances. Parents of young children tended to have high expectations and be strongly motivated to obtain comprehensive packages of services and support. Because of their children’s age, few of these parents had previous experience of accessing disability services prior to the introduction of the NDIS. Parents of adult children tended to note little difference in levels of support for their children since transitioning to the NDIS, but significant increases in administrative requirements and hurdles.

People living with cognitive disabilities also tended to report few changes in their everyday situations, while people living with physical disabilities had a range of views, from positive changes associated with increased independence to deep frustration with ongoing struggles to gain access to crucial resources.

Many participants reported that, since transitioning to the NDIS, they had not experienced increased opportunities for exercising choice in accessing services. Many people living with a cognitive disability tended to report that their circumstances had not changed and that the transition to the NDIS was largely an administrative matter. This was particularly evident among people living independently with some support, and among those being cared for at home and in institutions. Interviews with people living with cognitive disabilities suggested that they had not received information about things they could ask for, or that this information had been presented in an accessible format.

Because NDIS plans are required to be reviewed annually, many participants could reflect on their experiences over time. Some felt that as the scheme settled in and ‘teething problems’ were resolved they were gaining improved understanding of processes. There was increased flexibility to respond to emerging contingencies by adjusting funding allocations within their budgets. Many participants, however, expressed frustration at apparently high staff turnover in NDIA offices and having to constantly engage with new planners who had varying levels of familiarity with disability services.

Participants’ accounts raised diverse issues around the value of choice, the ways in which the NDIS can support people to exercise choice, and limits on choice that were being encountered. many participants said they were overwhelmed by the amount of information they had to process and the number of decisions they had to make to develop their plans. Some participants were keen to have increased control in managing funding, particularly spending on specific ‘line’ items, because they felt that annual planning processes reduced potential to respond to contingencies such as nominated services not being available.

Several participants reported that requests for funding in new plans had been declined because funds previously allocated for similar items hadn’t been spent. In most cases where participants were not purchasing all the support in their plans, it was because the market for those supports was not yet developed. Underutilisation of agreed services, equipment and support was particularly evident among participants living in regional areas or those needing highly specialised services and supports – thin markets of limited appeal to providers of goods and services seeking economies of scale. However, the supply side of the equation is not the only issue.

Planning and approval processes relied heavily on professional advice provided by physio-, occupational and speech therapists, over the opinions of carers and families, although these professional assessments also appeared to be frequently disregarded in decision-making processes within the NDIA.

This may be partly because the NDIA recognised potential for conflicts of interest of professional therapists who were assessing the needs of service users and providing these services. Nonetheless, a reliance on professional opinions, and inconsistent measures of what was ‘reasonable and necessary’ was fuelling concerns among some participants.

Plan Review Gaps

Once a participant has an approved plan, they can create service bookings in the NDIS portal. Service bookings are used to set aside funding for an NDIS registered provider for a support or service they will deliver in accordance with the participant’s plan. Generally, a service booking will show the type of support to be provided, when it will be provided and the length of time for which it is needed.

Many participants create their service bookings in advance and both participants and providers expressed frustration that when a new plan is approved, all the participant’s current service bookings end and new service bookings must be put in place.

Consultation feedback also suggests that a participant's access to their NDIS supports stops if the review of their plan was not completed and a new plan created by the date specified in their plan.

Both of these issues arise from the way the ICT system is built. There is no legislative reason for why participants should have their access to NDIS supports stalled because of plan review delays, or for providers to need to recreate service bookings once they have been given a new plan.

Reviewable Decisions

Internal review processes are not working as intended. The lack of clear guidance around when an internal review decision will be made prevents prospective participants and participants from exercising their right of appeal.

Clearer and more streamlined pathways are needed to enable prospective participants and participants to resolve concerns about NDIA decision-making and reduce administrative red tape.

Clarity needs to be provided as to the matter before the AAT in circumstances where a prospective participant or participant has lodged an appeal, including the nature of the decision in question and all of the surrounding circumstances.

Participants can seek two types of review under the NDIS Act: a review of their plan (in accordance with section 48) and an internal review of a reviewable decision (in accordance with section 100). A third type of review is created when the participant appeals an internal review decision to the AAT.

Concerns over the multiple meanings of the word 'review' has been raised by participants, the AAT, NDIA and disability peak organisations on numerous occasions, dating back as far as 2015 when the first review of the NDIS Act was conducted. To date, no amendment has been made to address this source of confusion.

Participants maintained that the twin, if not triple use of the word 'review' is confusing participants, and, in turn, potentially hindering their rights to exercise their right of appeal of an NDIA decision. The NDIS Act should be amended so the word 'review' has only one meaning.

Section 100(2) of the NDIS Act states that a person may request the NDIA to review a reviewable decision. If the participant chooses to do this, they must make the request within three months after receiving the notice of the reviewable decision.

Section 99 of the NDIS Act specifies the reviewable decisions related to access and planning are:

a. a decision a person does not meet the access criteria (sections 20(a), 21(3) and 26(2)(c))
b. a decision to revoke a participant's status as a participant (section 30)
c. a decision to approve the statement of participant supports in a participants plan (section 33(2))

d. a decision not to undertake an unscheduled plan review (section 48(2)).

Under s.100(6) of the NDIS Act, should a person request an internal review of a NDIA decision, the reviewer must ‘as soon as practicable’, make a decision to:

a. confirm the decision
b. vary the decision or
c. set it aside and replace it with a new one.

Participant feedback highlighted in the Tune Review suggests some participants who have asked for this kind of review experienced stress and anxiety during the process, the process was unclear, their concerns were not listened to and they were unhappy with the outcome.

Feedback also indicated that people with disability and their carers are concerned about how long internal review processes take and that they did not have visibility of the process.

The Tune Review also sought feedback from participants about what would be a reasonable period for the NDIA to finalise an internal review decision. Of those who answered this question in the long-form survey, over 40 per cent of respondents who had areview (n=515) stated between two to four weeks would be a reasonable period. Anecdotal feedback suggested would be appropriate on the basis the NDIA was not considering the substance of the plan or their request, but merely affirming that a previous decision it made was correct based on the facts of the circumstances.

However, the internal review process, as provided by the legislation, is manually intensive and is broader than a simple desktop audit of a decision. Affirming, varying or setting aside the decision requires due consideration of the facts and evidence of the matter. This includes researching information and fresh consideration of the facts, legislation and policy aspects of the original decision.

Under section 103 of the NDIS Act, a participant may make an application for the AAT to review an internal review decision made under section 100(6). The AAT does not have jurisdiction to review a decision that has not been internally reviewed by the NDIA, nor can it review every decision the NDIA makes.

Evidence suggests that a number of issues are being taken to the AAT, in part, because there is some confusion by the participant, and at times the NDIA, as to whether the applicant is seeking a review of the decision to approve their statement of participant supports under section 33(2) or the decision (deemed or otherwise) to not review a participant’s plan under section 48(2). As both processes are called ‘reviews’ and the considerations are largely the same, there can be confusion by all parties as to what is actually being sought.

The Tune Review Acknowledged that participants simply want a decision about their support needs, not a decision about another decision. The internal review process could be improved through training, clearer forms and a change in terminology – for example, the same form is used to request a section 33(2) review, an unscheduled review under section 48(2) and an internal review of a reviewable decision under section 100 of the NDIS Act. These could be split into separate forms.

To distinguish it from a request for an unscheduled review under section 48(2) of the NDIS Act, consideration could also be given to operational guidelines confirming, in most cases, a request lodged within three months of a plan being approved is a request for a review of a reviewable decision under section 33(2) of the NDIS Act.

The AAT only has jurisdiction to consider the reviewable decision made at the time of lodgement of the application for appeal. The AAT does not have jurisdiction to consider any subsequent decision that the NDIA may have made in relation to the person with disability, including changes to their plan or requests that may have been made by the person with disability. As a consequence, the AAT’s decision can quickly become obsolete if the hearing takes longer than expected.

For example, while the participant is waiting for the AAT decision, they may have a scheduled plan review, which creates a new plan. Alternatively, an internal review decision may be made after the lodgement of the application for appeal. Under these circumstances, the AAT’s decision will only take into account the plan at the time the appeal was lodged with the AAT and not any subsequent plan or decision. Understandably, this is creating administrative red tape and frustrations for both participants and the NDIA.

The timely implementation of an AAT decision is critical for participants as the decision in question may specifically relate to the reasonable and necessary supports in their plan. However, there is no ordinary or legislated timeframe for AAT decisions to be handed down. The time it takes for the AAT to deliver a decision is generally dependent on the complexity of the matter before it. In addition, there is no legislated timeframe for the NDIA to implement the AAT’s decision.

The Implementation of The Participant Service Guarantee

On the 31st March 2022, the Australian Government passed the (Participant Service Guarantee and Other Measures) Bill 2021 that aims to reduce red tape and increase flexibility for participants, their families and carers.

The legislation is centred on improving the experiences of participants, their families and carers and builds upon the recommendations of the 2019 Tune Review. As well as legislating the Participant Service Guarantee, the Bill introduces changes to provide more flexibility to participants and the National Disability Insurance Agency (NDIA), and to make it easier for participants to vary their plans, without the need for a lengthy review.

The bill would revoke the existing prohibition on the variance of a participant’s plan and would instead enable the CEO to vary a participant’s plan (except the participant’s statements of goals and aspirations), without requiring a plan reassessment to be undertaken, or a new plan to be created. Under proposed section 47A, the CEO would have the power to vary a participant’s plan either on the CEO’s own initiative or at the participant’s request, but in either case the participant must be involved in the variation. The explanatory memorandum states that ‘the intention is that any variation will be for the benefit of the participant.

Schedule 2 of the Act requires that members of the Board of the NDIA be a person with disability, have lived experience with disability or have specified skills, experience or knowledge relevant to the Board's operations (Items 46 to 48). Schedule 2 would also clarify the conditions of appointment of the Principal Member of the Independent Advisory Council (Items 49-50).

The Parliamentary Joint Committee on Human Rights (human rights committee) [[acknowledged that aspects of the bill would promote or facilitate the realisation of some of Australia's obligations under the Convention on the Rights of Persons with Disabilities. However, it raised concerns that the power to vary or reassess a participant's plan on the CEO's own initiative and without the participant's consent engages and may limit a number of rights.

A criticism of the bill shared by a number of inquiry participants was that the bill would vest discretionary powers in delegated legislation that these submitters posit should be incorporated into primary legislation. The effect, described, would be that 'the B'ill in its current form implements a significant passage of power from the Federal Parliament to the executive'.

Maurice Blackburn Lawyers (Maurice Blackburn) expressed concern about what the impact of these changes might mean at a practical level in the decision making process:

"On a more practical level, when we look at the decisions that we see coming through from planners or the people inside the agency who are assessing the eligibility criteria or the substantially reduced functional capacity requirement: unfortunately...they get it wrong. If you have a very prescriptive set of formula, you arguably reduce the ability of people to then challenge those decisions. The ability of the AAT to overturn a decision could be reduced. You're really narrowing the ability of people to potentially enter the scheme but you're also narrowing the ability of people to challenge poor decision-making, because the underlying rules become so prescriptive. There's less nuance and there's less interpretation. There might be more certainty, ultimately, but it might be a significantly reduced cohort of people who meet the criteria. "

Participants' confidence in the NDIS is critical to its success, and the committee recognises the crucial importance of ensuring that participants feel heard and consulted in any developments or amendments to it. The committee encourages the government to continue its engagement and consultation processes with participants and other stakeholders so that the scheme may continue to serve the principles upon which it was founded. However, the committee recognises that the timely implementation of these reforms will enable participants to enjoy their beneficial impacts sooner.

The legislation includes a number of timeframes. Most notably, a CEO-initiated reassessment must generally be finalised within 28 days or 50 days for addressing complex needs.The NDIA has created a webpage with their new timeframes, but many of the timelines remain unclear or difficult to understand as they apply to wide-ranging matters and are often open to interpretation.

Further work must be done to ensure these timeframes are representative of the process as experienced by the participant, inclusive of the point of submission of request/evidence, up until they receive an outcome and can access funding. Timeframes must enable participants, close others, and their decision-supporters to experience meaningful transparency through easy-to-access and understandable information regarding specific timeframes for each part of their planning journey.

The Commonwealth Ombudsman will write a report every year to the Minister of the NDIS to demonstrate how the NDIS is living up to the PSG standards. Ideally, the report should be made widely available and participants, close others and organisations should have an opportunity for regular consultation with the Ombudsman.

The legislation focuses on disqualifying criteria and the participant needing to demonstrate their ability to self-manage, rather than on building the capacity of participants and their decision-supporters to self-manage. For the most part, this is designed to reduce unreasonable risk and protect vulnerable participants from undue influence and harm.

Dignity of risk must be considered as furthering the capacity of participants or their chosen plan managers to manage their funds. Considerations around unreasonable risk or harm must be based on clear evidence.

People with psychosocial disabilities have faced challenges in accessing the NDIS due to lack of clarity around whether psychosocial disabilities were to be considered as permanent and life-long disabilities. Terminology has changed from ‘psychiatric condition’ to ‘psychosocial disability’.

In the new legislation, the legal definitions of permanency and significantly reduced functional capacity are separated for people with or without psychosocial disability. If a person has a psychosocial disability, it may be considered permanent despite the episodic or fluctuating nature if:

1. Both
a) The person is undergoing, or has undergone, appropriate treatment for the purpose of managing the person’s mental, behavioural, or emotional condition

and

b) The treatment has not led to a substantial improvement in the person’s functional capacity, after a period of time that is reasonable considering the nature of the impairment (and in particular considering whether the impairment is episodic or fluctuates)

or

2. No appropriate treatment for the purpose of managing the person’s mental, behavioural, or emotional condition is reasonably available to the person
While it is great to see further clarification around psychosocial disability, more support needs to be provided around accessibility of ‘appropriate treatments’ to meet these disability requirements. There are various economic, social, and geographical reasons why people may not yet have access to these.

Unpaid work hours

A total of 2,341 disability workers took part in the online survey during March 2020. Unlike information derived from employers' reports or administrative data, survey findings reflect the perspectives and experiences of disability workers themselves. Participants were from each Australian state and territory and worked in a range of roles and across disability service settings. The vast majority (96%) were in roles involving direct work with people with disability, and two thirds (65%) said they worked with people with high support needs. Over half of survey respondents (54%) had worked in disability services for ten years or more. Most (63%) said their main job was in the not-for-profit sector.

Many workers report they are not paid for travel costs or travel time between clients or to attend team meetings. In addition, workers incur costs in the course of doing disability work, including paying for things for clients with their own money, or paying for things they wouldn't otherwise buy. Only 29% agreed that they are reimbursed fairly for expenses incurred on the job.

Working time arrangements set foundations for provision of attentive, high quality services that meet the needs of people with disability. Poorly organised and fragmented work time leads to rationing of staff time, rushed tasks, under-servicing and unmet needs. As Macdonald et al (2018) point out, employee time is a highly contested resource in disability support provision, and employers' tight control of time underlies wage theft, underpayment and low pay. By contrast, employee control over work time can alleviate stress and enable workers to adjust work around the needs of the people they support (Powell and Cortis, 2017; Cortis and Eastman, 2015).

Workers in supported accommodation settings had, on average, more paid and fewer unpaid hours of work than others, while those working in home-based care and support settings reported fewer paid hours and more unpaid hours of work. This may reflect higher levels of 'wage theft' and other unjust underpayment of work in different disability settings (Macdonald et al, 2018).

Two in five (41%) respondents worked at least one hour unpaid in the last week. Among this group, mean unpaid hours were 6.0 hours (median=4.0). Unpaid work hours were most common among those working in coordination, case management, employment and advocacy settings, where full time roles were most prevalent. For workers in these settings, 59% reported at least one unpaid hour in the previous week. The amount of unpaid work time was also highest among this group of respondents (mean=7.2 hours), who also had relatively long paid hours (mean =34.6 hours). Unpaid work was also common in home-based settings: where 50% of workers reported at least one hour of unpaid work. Average unpaid hours were also high among these workers (mean=6.8 unpaid hours), despite the high prevalence of part time hours in these settings.

In leaving comments about their working time arrangements and how these affected them, many respondents focused on unpaid work. They explained that fragmentation of their paid time, coupled with high workloads, meant tasks needed to be done between shifts, and without pay.

Those who reported at least an hour of unpaid work in the last week were asked to select nnwhich tasks they had performed during unpaid time, from a list of 17. On average, respondents who had performed unpaid work in the last week reported having done more than 6 different tasks during this unpaid time. However, there was a slightly wider range of tasks reported by those working directly for a client in their main role (over 7 different tasks) or in a private for-profit business (just under 7 different tasks) and a narrower range of unpaid tasks among those in government jobs (under 6).

- The most common task, reported by two thirds (67%) of the 960 workers who reported unpaid work time, was completing case notes, paper or online forms or other reporting.

- The next most common tasks related to co-ordination and communication functions: communicating with colleagues or other service providers (reported by 58%), handover tasks (53%), and communicating with a supervisor (48%).

Many also provided social, emotional or practical support to service users and/or their family members during unpaid time. Of those working unpaid time, 42% said they communicated with clients’ family members or carers in their unpaid time, and 39% provided social or emotional support to a client. A third said they used unpaid time to organise or negotiate rosters (33%), or to read client histories or plans (32%). One in five (21%) assisted clients, families or carers with NDIS administration during unpaid time.

As mentioned previously in this report, many dedicated Support Coordinators work many unpaid hours to keep up with the demands of their job. These hours can be spent fixing up the errors of NDIA Planners, assisting participants in crises, or assisting a participant with inadequate support coordination. Support Coordinators maybe also trying to meet the unrealistic expectations of service providers, who set unreasonable KPI’S for their Support Coordinators.

Some Support Coordinators are expected to managed incredible caseloads that can sometimes can be as high as 100 participants, while average caseloads should only consist of 25-30 people of 10-15 participants-if they have very complex support needs. The number of Participants assigned to each Support Coordinator, should be depended upon the support coordination levels of each of the participants which whom the Support Coordinator provides support services.

PART 2: SPECIFIC ASPECTS RELATING TO THE PROVISION OF SUPPORT COORDINATION SERVICES WITHIN THE NDIS

Lack Of Clarity And Consistency

A number of Support Coordinators are frustrated with the lack of clarity and consistency within the NDIA, as not even the role of Support Coordinator is clearly defined. Support Coordinators do not what is expected of them or even what their job enscapulates, making it difficult to set clear boundaries with Participants.

Sometimes Participants have unrealistic expectations of Support Coordinators, expecting them to be on call 24/7 and wanting things that are outside the scope of the support coordination role. While most Support Coordinators wholly support the Participants that have been entrusted to them-sometimes to their own detriment, there are others who consider their support coordination role to be just a 9 to 5 job, Monday to Friday.

While there is a small minority of Support Coordinatiors who treat their role as just “a job”, most Support Coordinators genuinely care what happens in the lives of Participants. As a result they work many unpaid hours, due to the fact that a Participant has received inadequate funding, they’ve had to chase up other service providers, fixing up mistakes made by NDIA Planners or Plan Managers and attending to emergency/crisis situation of Participants. As a result, the role of a Support Coordinator is very stressful and it is very easy to get burnt out

Keeping up with legislative changes and the operational guidelines of the NDIS, can also be very stressful, as changes are made on a regular basis. What guidelines apply this week, may not apply in a month’s time, making it very frustrating for both Support Coordinators and Participants.

Another problem is when the role of Support Coordinators was being developed, there was very little or no consultation with NDIS Participants in the process, so essentially the NDIA developed the role without consulting the people it would affect the most-Participants. Thus, the role is not actually based on the wants and needs of Participants, but rather what the Government *perceives* as the wants and needs of Participants within the system.

When the NDIA established the role of Support Coordinator, they made the role to be deliberately ambiguous, to allow Support Coordinators to be innovative and flexible and to develop their own interpretation of their role as Support Coordinator. Although well intended, the theory behind this notion has backfired on them and has led to a inconsistency of the provision of support coordination service across Australia.

What has made this situation worse is the fact that there is no formalised training provided by the NDIA on the role of a Support Coordinator. Applicants do not need any tertiary qualifications to apply to become a Support Coordinator (apart from being a Specialist Support Coordinator) and there are very little professional development opportunities for those who perform the role.

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But it is not only the role of Support Coordinator that lacks clarity and consistency. It seems as though the decisions that are made by the NDIA are depended on which staff member within the NDIA, is handling that particular situation at the time and how they have interpreted the NDIA operational guidelines. For instance, two Participants may be facing the same situation with the NDIA, but may get two completely different outcomes to their situation, due to the fact that they have dealt with two different staff members. There is no consistency in how staff interpret the operational guidelines of the NDIA and decision making is ad hoc.

Not even the way in which plans are formulated is consistent. It has been reported that NDIA Planners sometimes totally disregard what has been discussed in planning meetings, formulating plans that are full of errors. Errors that are as simple as spelling a Participant name wrongly, the wrong address and even the wrong type of disability. Sometimes Planners formulate plans based on information that is the complete opposite to what was discuss at the planning meeting. Most times, the Participant’s Support Coordinator spends time fixing these errors, not the NDIA Planner.

Even when two Participants have identical disabilities and similar support needs, their levels of funding are completely different. While admittedly, there could be some disparity between their goals, which means that one participant gets slightly more funding than the other, there should not be a significant variance of funding between the two plans, even if the two participant lived in the same geographical location.

There needs to be clarity and consistency throughout the NDIA’S operational guidelines with all NDIA’S staff being on the same page.

Training Of Support Coordinators

A number of Support Coordinators have indicated that they would like training to clarify what the role of Support Coordinators actually entails. They would also like training on topics such as how the NDIS can assist Participants to get paid employment, Specialist Disability Accommodation, other housing options available to NDIS Participants, ILO and other creative line items.

There also should be some training on ethics. While the majority of Support Coordinators genuinely care for their Participants and want them to have a good life, a small minority of Support Coordinators don’t care about their Participants and couldn’t care less about what happens to them, they are only in it for the money.

Values based training could be benefical in ensuring that Support Coordinators are doing their job for the right reasons and are valuing the people they support. Some Support Coordinators have attitudes that subscribe to the theories of ableism and paternalism, integrity is an important part of this job.

Due to the fact that some Support Coordinators have not worked previously with people with disability or may just have poor communication skills, training on how to effectively communicate with Participants, may be advantageous. Unfortunately in some cases, some Support Coordinators would benefit from training in transparency as they don’t seem to rate openness and honesty with Participants and/or their families very high on their priority list.

Although support coordination is not “case management” as such, some Support Coordinators have reported that training in some of the aspects of case management would be helpful in their role and would help them to better understand the support needs of Participants.

Burnout Of Support Coordinators

As mentioned in the previous section, the role of Support Coordinators can be very stressful. Participants can sometimes have unrealistic expectations of Support Coordinators and expect them to do things that are outside the scope of their work, however this is only one of the reasons why the job is so stressful.

Support Coordinators also have to spend time constantly chasing up service providers, who may be taking their time submiting reports for plan reviews or who haven’t signed service agreements. Support Coordinators may have to deal with service providers, who may be doing the wrong thing by Participants.

Support Coordinators may also work a 8 hour day, but may only get paid for 4 hours, due to the rules pertaining to “billable hours”. In addition to this, Support Coordinators may spend a lot of time trying to comply with the red tape of the NDIA, or trying to fix errors made in the support plans of Participants. In addition to this, Support Coordinators have to deal with not being able to contact the NDIA, denials in SDA applications, long waits for approvals for home modifications, dealing with misinformation from LACS or the call centre and the buck passing between government agencies.

Some Support Coordinators are involved in the employment of support workers for Participants. They may only assist with the recruitment of workers, while at other time they are involved with the ongoing management of Support Workers. This means at times, Support Coordinators may have to deal with the unruly behaviour of support workers.

Some Support Coordinators who have previously been support workers, have either stated that they wish they had remained being a support worker, or have gone back to support work, due to fact that being a Support Coordinator is just too stressful. Considering all these factors, as well as the fact that the pay is variable for Support Coordinators each fortnight, depending on the amount of billable hours they have worked, isn’t it any wonder there is a low retention rate, in the support coordination industry!!

Should Support Coordinators Have Previous Experience As Support Workers Or Key Workers

Due to the fact that just anyone can walk off the street and become a Support Coordinator without any formalised training as well as the fact that the person might not be offered any training once they get the position, makes it advantageous if the has had previous experience as a Support Worker, before they take up the position of Support Coordinator.

Some Participants have reported that in instances where Support Coordinators do not have any previous experience with working with people with disabilities, they have very poor attitudes toward people with disabilities, that reek of ableism and paternalism.

By having worked previously as a Support Worker, the person might have some knowledge on the issues facing people with disabilities. While they may not have a complete knowledge of what the job entails, they are more likely to have a basic understanding what the job entail, than a ransom person who has just walked off the street.

Also, some people who have no formal qualifications or who have not work previously with people with disabilities, may have a patronising tone about them. They may adopt the view that it is their job to tell Participants and/or their families , how to live their life or to act as a “guide” if they think the Participant and/or their family, is making the wrong decision about their lives. This is not to say that Support Coordinators with previous experience will not also subscribe to this theory, but it is less likely.

People who have previously worked with people with disabilities are more likely to have empathy towards Participants and their families, due to fact that they have some knowledge on what is it is like to live with a disability. While such persons may not have “lived experience” of disability, their experience as a Support Worker would have exposed them to some problem solving skills needed to deal with some of the issues facing people with disabilities.

Support Coordinators Valuing Participants

Most Support Coordinators feel privileged to be allowed into the lives of Participants and their families however a small minority do not value Participants or their families at all, as they either completely ignore Participants or are constantly argumentative with them.

In some instances Support Coordinators have arranged supports and services for a particular Participant, that are completely unsuitable for the Participant and without any consultation from the participant or their family. They have hired their “mates” as Support Workers, not allowing Participants to choose who they want to work with them, they have also mismanaged the budgets of Participants, with some Participants unknowingly going into debt as a result.

In one instance, a Support Coordinator discussed with a landscaper-the work to be done in a Participant’s yard, again without consulting the Participant. This problem could be rectified using a two pronged approach-training of Support Coordinators and including this aspect in the NDIS Code of Conduct.

Clearer Boundaries On What Are Billable Hours For Support Coordinators

There are two main reasons why there should be clearer boundaries set around what hours should be billable in regards to support coordination. Firstly, it is quite common for a Support Coordinator to work a eight hour day and only get paid for four hours, due to the fact that not all tasks are billable and there are no clear boundaries on what are billable and unbillable tasks.

This may mean that some Support Coordinators may not have fixed wages each fortnight and their pay varies, according to the billable hours they may have worked a particular fortnight. Due to the fact that there is no clear understanding of what are and aren’t billiable hours, it is difficult for Support Coordinators to plan to work a certain number of billable hours each fortnight, to ensure they receive a decent income. This is why the retention in the support coordination field is so low, Support Coordinators are stressed out and receive poor pay.

Because there is no clear understanding of what supports and services are and are not billable, it makes it hard to monitor the budgets of Participants, as Support Coordinators do not know when to invoice them. Do you invoice a Participant for a five minute phone call, an email that takes two minutes to write?

Secondly, while there have been instances where Support Coordinators have simply not known when to invoice Participants, there have also been times when Support Coordinators have billed Participants when they shouldn’t have. Instances where Participants have been overcharged for initial consultation fees, time Support Coordinators have spent researching very common disabilities such as Cerebral Palsy or Down Syndrome, time taken to arrange support and services for the Participant-without their consent and do not meet their individual needs and] time taken to fix the Support Coordinator’s mistakes.

Issues And Barriers In Providing Support Coordination Services To Participants

Some Support Coordinators have reported that it is extremely difficult to provide support coordination services to Participants who have mental health issues/Psychosocial disabilities. Although this cohorts are one of the groups most likely to need ongoing support coordination, due to the episodic nature of their illness or disability, they are less likely to receive support coordination funding after their first plan.

People with mental health issues or psychosocial disabilities tend to have periods when they are well and periods where they are unwell. While they may be able to use their funding when they are well, they may not be able to their funding when they are unwell and actually shut down from their Support Coordinator as well as others around them. The use of their funding seems unstable with a lot of peaks and troughs, mental health issues/psychosocial disabilities are not well understood by NDIA Planners and Participants who should receive an increase in funding, receive an decrease in funding, with the Participant spiralling into crisis mode as a result.

Another group that faces barriers when it comes to the provision of support coordination services, are Participants who live in rural/remote areas of Australia. Finding service providers in these areas is virtually impossible, there are very limited options in terms of support coordination services and travel costs are astronmical. In recent years Telehealth and other types of online consultation services have been trialled, with limited success due to the difficulties experienced for people with hearing and speech impairments.

Another issue is the inconsistency in the lack of information shared between plan managers and NDIA Planners, who often do not communicate with each other and sometimes give conflicting information to Support Coordinators and/or Participants and their families.

Support Coordinators Being Independent Of Service Providers

When Support Coordinators are employed by a particular service provider, there is automatically a perceived conflict of interest, due to the fact that the Support Coordinator may feel obliged to recommend the supports and services of their employer, before recommending other service providers.

Sometimes Support Coordinators may be ordered to only recommend the supports and services of the service provider that employs them by the Service Manager or other Senior Management. In this instance, Support Coordinators need to report this to the Quality and Safeguards Commission.

It is not recommended that Participants receive 100% of their support from one service provider, as it increases the vulnerability of Participants. It could be said that these Participants are "captured" Participants, who may accept poor quality services or even abuse and neglect, due to the fear of reprisals if they complain. Participants may even feel as though this service has control over their life.

There are advantages and disadvantages to Support Coordinators being independent from Service Providers. One advantage is that the Support Coordinator has no obligations to any particular service provider and is free to recommend supports and services that best suit the individual needs of a Participant. Another advantage of independent Support Coordinators is that they do not have to fulfil Key Performance Indicators (KPI'S) of an organisation and are free to fully act in the best interests of Participants and their families.

Disadvantages to engaging Independent Support Coordinators could be if a Support Coordinator has established their own support coordination business, they may charged a bit extra due to business overheads. Another disadvantage could be that they may have less resources at their disposal. In saying this though, smaller independent suppport coordination businesses may have less red tape, than the bigger disability service organisations and they may also provide better quality services.

The Distinction Between Local Areas Coordinators And Support Coordinators

The main difference between Local Area Coordinators and Support Coordinators is that Local Area Coordinators are employed by the NDIA, while Support Coordinators are either employed by Service Providers or have an Independent Business and are not necessarily interested in the needs and requirements of Participants. Support Coordinators are also involved in monitoring the budgets of Participants, whereas Local Area Coordinators do not perform this function.

It is perceived that Local Area Co-ordinators basically do the same job as Support Coordinators, except they work with Participants who have no support coordination funding and they do not monitor the budget of Participants.

Some Support Coordinators are dismayed at the fact that they can not directly advocate for Participants and yet they are supposed to ensure that Service Providers are doing the right thing by Participants, so the role that Support Coordinators play in advocacy is quite confusing.'

A majority of Support Coordinators would like to be engaged more in advocacy for their Participants, or at least know how to assist Participants to engage in independent advocacy. There could be some scope around how Support Coordinators and independent advocacy services could work together to advocate for Participants.

Unfortunately, Local Area Coordinators are also involved in how individual support packages are developed for Participants. This means that they have the power to reduce a Participant's funding, whereas Support Coordinators do not have this power. It is also unfortunate that reducing the funding packages of Participants has been linked with Local Area Coordinators meeting the KPI'S that have been set for them.

Clearer Expectations Of Support Coordinators

Some Support Coordinators have reported that some Participants expect them to do things that are clearly outside the scope of the role of Support Coordinator, and sometimes place unrealistic expectations upon them. Some Participants expect Support Coordinators to be available to them 24/7. This is not possible as we know that Support Coordinators have their own lives to live and are most likely to be supporting numerous other Participants.

It does not help that the NDIS have made the expectations of Support Coordinators so vague. Some Support Coordinators do not know what is expected of them and Participants do not know what to expect from Support Coordinators, hence why Participants have unrealistic expectations at times. While it is understood that the NDIA deliberately left the definition of the Support Coordinator role ambigous, so that Support Coordinators would innovatively and flexibly create their own definition of the role, this has backfired on them to some extent.

The definition of Support Coordinator needs an uniformed approach, not each Support Coordinator across Australia going off on their own tangent-trying to define their role as Support Coordinator as this has led to an inconsistent approach to support coordination services across the board . The NDIA needs to come up with a clear, precise definition of the role of Support Coordinator, as well as clear expectations of what is the scope of Support Coordinators.

Some Participants need clear boundaries, they need to hear what a Support Coordinator can and can't do for them and Support Coordinators need to methodically stick to these boundaries. By clarifying the scope of the role of Support Coordinators, the NDIA is putting into black and white what Participants can expect from Support Coordinators, making it easier for Support Coordinators to refute the unrealistic expectations of Participants.

Valuing The Role Of Support Coordinators

Although Support Coordinators have more responsibilities than Support Workers, they get paid significantly less than Support Workers. Support Workers can get paid up to $45.00 a hour, while Support Coordinators are paid only $32.00 a hour. This is yet another reason why there is a low retention rate within the field of support coordination. Support Coordinators are expected to do a highly stressful job, where is it highly likely that they will burn out very quickly, for less money than Support Workers-this is not a very realistic expectation on the part of the NDIA. More responsibility-for less pay, this equation just does not add up!!

Pay points under the SCHADS Award is another point of contention within the sphere of Support Coordinators. While the level of responsibilities of Support Coordinators indicate that they should be paid at level 5 under the SCHADS Award, some service providers are paying Support Coordinators at a lower level of 3.1, 3.2 or 4, these pay points do not reflect the level of responsibility bestowed upon Support Coordinators or the stresses of the job they perform and seriously devalues the work they do. This could be considered as an unethical work practice on the part of service providers.

How Could The Role Of Support Coordinators Be Improved?

The first thing that would go a long way to improving the role of Support Coordinators is developing an actual definition of the role, to prevent confusion amongst both Support Coordiinators and Participants and to prevent unrealistic expectations of Support Coordinators by Participants.

Another thing that would go a long way to improving the role of Support Coordinators would be to clarifly the legislation pertaining to support coordination and for the NDIA to stop continously changing such legislation. Sometimes the NDIA has deliberately misinterpreted this legislation, so that they can stop a Participant accessing a particular mode of support.

Some of the more experienced Support Coordinators feel that new Support Coordinators should have experience with working with people with disabilities, as well as some kind of formal qualification, before being recruited as a Support Coordinator. It is felt that some Support Coordinators who have had no experience working with people with disabilities as well as no formal qualitifications or training to do the job, are doing “more harm than good” to Participants.

Caps On Caseloads For Support Coordinators

Although the question-”What should be caps on caseloads for Support Coordinators(?)” is a very difficult question to answer and there could ‘be some debate about who can make the final decision on the number of Participants to assigned to an individual Support Coordinator-Service Providers or the NDIA. One suggestion that could make this decision easier is to develop a formula, with factors to be considered when deciding the Support Coordinator-Participant ratio. This formula could include the following elements:

- Whether a Support Coordinator works full time or part time
- The level of experience of the Support Coordinator—have they been in the industry for a while, or are new to the support coordination field?
- The level of complexity of each Participant’s needs
- The type of work involved in supporting each Participant
- The support coordination level of each Participant
- The number of support coordination hours given to each Participant
- NDIA requirements
- The costs incurred by the Service Provider in providing the service-wages, travel, admin and other business expenditure.

- Availability of resources

It is important to remember that each service provider or support coordination business is different in nature and as such they will all get different results from using such a formula. Therefore it is impossible for this formula to be rigid in its' application, as it relies on too many variants such as the size of the individual service provider, their location, number of Participants, funding levels of Participants, complexity of the supports needed by each Participant, and the type of resources at their disposal.

Although capping caseloads for Support Coordinators can be ambigous and an uniformed approach is difficult to apply, the NDIA could design a basic tool that could help service providers decide on appropriate caps on caseloads for their Support Coordinators. The NDIA could use a formula like the one suggested above, develop a completely different formula, or come up with a different way of assisting service providers in making decisions about caps on the caseloads of Support Coordinators, altogether.

It is crucial to bear in mind the fact that if the Support Coordinator/Participant ratios are too high, Support Coordinators will burn out real easily, and will ultimately leave the sector altogether. As it has been stated previously in this report, Support Coordinator burnout is one of the main reason for low retention in this industry.

Better Regulation Of Support Coordination Services

Most Support Coordinators have reported that they would like better guidelines on what they can and can't do-this has been a constant theme throughout part 2 of this report. Support Coordinators have made it very clear that they want more clarification on tasks can and can not be billed to Participants. In one instance, a Support Coordinator billed a Participant from the initial phone call to inquire whether the Support Coordinator had the capacity to take on the Participant, the Participant was also billed for 12 hours work that day, including signing the contract with the Participant.

REPORT RECOMMENDATIONS

1.It is recommended that National Disability Insurance Agency develop more resource materials for Support Coordinators on how to connect participants to mainstream services within the community.

2.It is recommended that the National Disability insurance Agency investigate opportunities to improve working relationships and collaboration between the Agency and mainstream services and systems .

3.It is recommended that the National Disability Insurance provide more precise instructions and information for Support Coordinators on the difference between supported engagement and formal advocacy, as this is an important consideration for support coordinators in determining the scope of their service.

4.It is recommended that the National Disability Insurance Agency provide more clearer divisions between the roles of Local Area Coordinator and Support Coordinator.

5.It is recommended that the National Disability Insurance Agency investigate the feasibilities, as well as the practicalities and the advantages and disadvantages of all Support Coordinators operating independently from service providers.

6.It is recommended that the National Disability Insurance Agency engage in the support coordination market more directly to ensure participants with complex support needs can access a skilled quality support coordinator who meets their needs and who may take on some additional responsibilities, for example around safeguarding.

7.It is recommended that the National Disability Insurance Agency introduce more stringent guidelines and infringements when it comes to Support Coordinators charging participants for services they do not receive or the excessive billing of Participants.

8.It is recommended that the National Disability Insurance Agency devise clearer boundaries on what service items are and are not billiable and ensure that Support Coordinators report on deliverable outcomes, when it comes to providing support coordination servicees to participants.

9.It is recommended that the National Disability Insurance Agency explore the possibility of streamlining the recruitment of Support Coordinators, to ensure that such persons are employed based on merit and not by the use of fraudulent practices.

10.It is recommended that the Quality and Safeguards Commission introduce harsher penalties for Support Coordinators and service providers engaging in unethical practices, that have a detrimental affect on NDIS Participants.

11.It is recommended that the National Disability Insurance Agency review training provided to Local Area Coordinators and NDIA Planners on specific types of disabilities, as well as the use of the concept of Person Centred planning, when it comes to planning for the specific individual needs of people with disabilities.

12.It is recommended that the National Disability Insurance Agency review policies and procedures regarding Local Area Coordinators passing on participant information to NDIA Decision-Makers.
13.It is recommended that the National Disability Insurance Agency review NDIA Planners' information management system to ensure the correct information regarding participants is being passed on to NDIA Decision-Makers.

14.It is recommended that the National Disability Insurance Agency review al policies and procedures relating th NDIA Planners, in an effort to reduce the number of errors in Participant plans. Furthermore, it is suggested that the NDIA pay Support Coordinators directly for fixing up NDIA Planners, instead of delving into the support coordination funding of Participants.

15. It is recommended that the National Disability Insurance Agency reviews professional development opportunities provided to NDIA Planners, in an effort to enhance their knowledge, understanding and expertise within the field of disability.

16.It is recommended that the National Disability Insurance Agency review the recruitment processes of NDIA Planners, with the view of requiring applicants to having qualifications in the fields of disability, early childhood development, mental health, rehabilitation or community/health education.

17.It is recommended that the National Disability Insurance Agency require NDIA Planners to have or gain some knowledge in specific disabilities that are progressive and unpredictable in nature, eg: Multiple Sclerosis, Motor Nerone Disease.

18.It is recommended that the National Disability Insurance Agency mandate that NDIS Planners can not exclude either Participants, Families, Friends, or Advocates that have been chosen by the Participants and/or their family, from Plan Review Meetings.

19.It is recommended that the National Disability Insurance Agency make it mandatory for all participants to be granted support coordination funding within their first NDIS funding plan to build their capacity to understand how the system of the NDIS works.

20.It is recommended that the National Disability Insurance Agency review processes to ensure more transparency in communications between NDIA, LAC/ECEI staff and participants and families.

21.It is recommended that the National Disability Insurance Agency review the decision making criteria of NDIA Planners with a view of giving a certain amount of leeway to the individual circumstances of participants .

22.It is recommended that the National Disability Insurance Agency trial Participants getting a draft copy of their plan, in an effort to reduce incidences of issues such as plan gaps and unscheduled reviews. Participants being in receipt of draft plans need to be complemented with more opportunity for communication and collaboration between participants and their families, the LAC/ECEI staff member working with them, and the NDIA delegate approving their plan.

23. It is recommended that the National Disability Insurance Agency review the guidelines in relation to Supported Independent Living (SIL) Arrangements to prevent the exploitation of Partiicipants living under such arrangements.

24.It is recommended that the National Disability Insurance Agency consider participants being able to change their accommodation arrangements, without having to go through a full plan review.

25.It is recommended that the NDIS Quality and Safeguards Commission review the policies and procedures relating to the oversight, monitoring and investigation of service providers who provide ‘wrap around services’, such as accommodation, support workers, and support coordinators.

26. It is recommended that the National Disability Insurance Agency review processes where participants who are in crisis or experiencing multiple layers of disadvantage can have their request for access or change in circumstances escalated, to reflect the urgency of their situation.

27. It is recommended that the National Disability Insurance Agency make NDIS forms and information more accessible in both online and offline formats to provide greater opportunities for staff to intersect services to support people through the NDIS access process.

28. It is recommended that the National Disability Insurance Agency not automatically assumed that a Participant’s support coordination funding can be decreased over time and that a participant’s individual circumstances be taken into account, when making decisions in regard to support coordination funding.

29. It is recommended that the National Disability Insurance Agency adopt greater transparency in regards to their decision making processes.

30. It is recommended that the National Disability Insurance Agency explore opportunities in which to enhance the “choice and control” of participants.

31. It is recommended that the National Disability Insurance Agency review the policies and procedures that are currently in place for the allocation of support coordination funding.

32. It is recommended that the National Disability Insurance Agency conduct further extensive research into capacity building as it relates to support coordination. Furthermore the NDIA should review its’ expectations in relation to capacity building to ensure outcomes in this area can be more realistically achieved .

33. It is recommended that the National Disability Insurance Agency outlines the elements of capacity building and reflects them in expectations and outcomes.

34. It is recommended that the National Disability Insurance Agency review policies and procedures relating to communication and collaboration between the NDIA and mainstream services.

35. It is recommended that the National Disability Insurance Agency should establish clearer boundaries around mental health, where there is some confusion surrounding whether rehabilitation for psychosocial disability should be seen as a process of recovery or long term support.

36. It is recommended that the National Disability Insurance Agency review it's capacity to monitor in-kind arrangements.

37. It is recommended that the National Disability Insurance Agency review it's participant information processes, in an effort to avoid the duplication of services to participants, both from the NDIS and mainstream services.

38. It is recommended that the National Disability Insurance Agency to develop strategies to prevent participants experiencing delays in obtaining NDIS plans, to avoid mainstream services from having to fill the gaps and provide services to cohorts of people with disability that they had previously little experience of working with. It was acknowledged that mainstream staff often lacked the disability specific skills required to deliver quality services to these people.

39. It is recommended that the National Disability Insurance Agency find more appropriate operational responses to address the tensions between consistency in decision making and the individualised planning approach.

40. It is recommended that the National Disability Insurance Agency develop an appreciation for the lived experience of people with disabilities and their families,.

41. It is recommended that the National Disability Insurance Agency increase investment in training of NDIA staff, in an effort to better equip them in handling the complexities of the system of the NDIS and thus, increasing their ability to handle the concerns of NDIS Participants, thus making them less likely to be the target of people's frustrations with the system..

42. It is recommended that the National Disability Insurance Agency explore avenues to make the "Myplace Portal" more accessible to Participants and their families.

43. It is recommended that the National Disability Insurance Agency provide more transparency around the concept of "reasonable and necessary", as well as what kind of supports they consider to be "reasonable and necessary".

44. It is recommended that the National Disability Insurance Agency should update the National Disability Insurance Scheme (Supports for Participants) Rules 2013 to provide greater legislative guidance for NDIA decision-makers in determining when a support is reasonable and necessary.

45. It is recommended that the National Disability Insurance Agency establish more accessible information and training within regards to the co-design of services, both for participants and service providers.

46.It is recommended that the National Disability Insurance Agency give some consideration to the co-design process, when it comes to designing and estabilishing new programs and services, under the umbrella of the NDIS.

47.It is recommended that the National Disability Insurance Agency review opportunities for professional development and the possibility of formalised training for Support Coordinators. This could be in the form of a registered course, where Support Coordinators gain some type formal qualification at the end of the course.

48.It is recommended that the National Disability Insurance Agency investigate ways in the the process of going to the Administrative Appeals Tribunal could be less intimidating for participants and to ensure such participants receive appropriate legal representation.

49.It is recommended that the National Disability Insurance Agency investigate avenues in which participants can continue to be funded for the supports and services they critically need, whilst undergoing the Adminstrative Appeals process, thus also reducing the chance of carer burnout during this process.

50.It is recommended that the Administrative Appeals Tribunal investigate ways in which their rulings on issues concerning the NDIS can become legal binding, not only for a participant's existing plan, but for any future plans developed for the participant.

51.It is recommended that the National Disability Insurance Agency estabilish strategies to assist service providers to maintain high quality standards, during periods when the NDIS is under a continual state of change, including changes that greatly affect the provision of services to participants.

52.It is recommended that the National Disability Insurance Agency review the guidelines surrounding the participant selection processes by service providers with regards to participants with high and complex needs.

53.It is recommended that the National Disability Insurance Agency investigate avenues in which the NDIS certification process could be simpified.

54.It is recommended that the Quality and Safeguards Commission explore avenues in which to investigate how some service providers may be obstructing the choice and control of participant- "you can only use this service, if you use a service of our sister company".

55.It is recommended that the Quality and Safeguards Commission reviews the powers that are fully at their disposal, to ensure these powers are being use in the most effective manner.

56. It is recommended that the Quality and Safeguards Commission take a consistent approach, when it comes to using the tools at its' disposal.

57. It is recommended that the Quality and Safeguards Commission review the length of time taken in the progress of investigating complaints by participants.

58.It is recommended that the Quality and Safeguards Commission examine the role that the NDIS Code of Conduct plays in the prevent of violence, abuse and neglect of people with disabilities, with a view of strengthening the Code, to prevent too much discretion in its' interpretion being given to service providers, as well as strengthening and clarifying the language that is currently used in the Code.

59.It is recommended that the Quality and Safeguards Commission review the way in which information relating to complaints are reported in the Commission's activity reports.

60.It is recommended that the Quality and Safeguards Commission review what information they can publicly release within relation to investigations of complaints into particular individuals and organisations, stating the sanctions that were imposed in such cases and the reasons why these sanctions were imposed.

61.It is recommended that the Quality and Safeguards Commission take a proactive, instead of a reactive approach to the compliance and enforcement of its' legislatory obligations, ensuring that the most effective methods of monitoring the quality and safety of services and supports provided to participants are being employed.

62.It is recommended that the Quality and Safeguards Commission ensure that its' investigatory powers are being fully utilised in relation to visiting all disability accommodation services and facilities.

63.It is recommended that the Quality and Safeguards Commission review its' monitioring and investigation of Supported Independent Living Services in supported disability accommodation settings. Noting that the Commission should investigate the appropriateness of SIL quotes and rosters of care, and should ensure that SIL service provision is underpinned by a balanced service agreement, that meets the particular needs of the participants in each individual supported disability accommodation setting.

64.It is recommended that the Quality and Safeguards Commission ensure that Practice Standards are being adhered to within relation to Participants who access SDA services, exercising their right to Choice and Control.

65.It is recommended that the Quality and Safeguards Commission ensure that SDA Practice Standards provide adequate guidance to service providers regarding the standard of policies and procedures that should be achieved for services to realise performance outcomes.

66.It is recommended that the Quality and Safeguards Commission ensure that service providers implement effective complaint systems that are user friendly, have accessible information on how to use the system and ensure that participants are fully supported throughout the process.

67.It is recommended that the Quality and Safeguards Commission review the complexity of the Commission's complaint system and explore ways in which to better communicate to participants how the complaint process operates in practice-sending clearer messages to this cohort. It is suggested that providing relevant information in the form of a diagram or flow-chart, or using audio-visual materials, might help to facilitate greater understanding and access.

68.It is recommended that the Quality and Safeguards Commission make clear who can make a complaint to the Commission, regarding the quality and safety of supports and services provided to participants, and ensure that this advice remains consistent throughout the Disability Sector.

69.It is recommended that the Quality and Safeguards Commission make it extremely clear to participants and/or their families that they should not fear any reprisals either from service providers or the Commission, in regards to initiating the complaints process.

70.It is recommended that the Quality and Safeguards Commission strengthen penalties given to service providers who retaliate against Participants for making complaints to the Commission, within regards to their services.
71.It is recommended that the Quality and Safeguards Commission explore avenues in which to increase funding for Independent Advocates to assist Participants throughout the complaints process of the Commission.

72.It is recommended that the Quality and Safeguards Commission ensure that both service providers and participants are aware of the process, when it comes to reporting “Reportable Incidents” to the Commission.

73.It is recommended that the Quality and Safeguards Commission ensure that consistent training is provided for all staff who manage “Reportable Incidents”/

74.It is recommended that the Quality and Safeguards Commission provide more clarity within regards what is deemed to be a “Reportable Incident”, within the Reportable Incident Framework and as to when an incident, reaches the threshold of being a “Reportable Incident”.

75.It is recommended that the National Disability Insurance Agency review the resourcing levels of the Quality and Safeguards Commission, to ensure that the Commission is adequately resourced to fulful all the functions within it’s scope.

76.It is recommended that the Quality and Safeguards Commission provide more clarity in relation to the interface between mainstream services and the Commission, as there is very limited scope for the Commission to take complaints from participants within relation to mainstream services.

77.It is recommended that the Quality and Safeguards Commission take a role in increasing the natural safeguards of people with disabilities, as well as ensuring opportunities to develop social connections, inclusion in the community, and changing community attitudes toward disability.

78.It is recommended that the Quality and Safeguards Commission increase protections for people with disability who are not participants, and to whom the Commission’s reach does not currently extend.

79. It is recommended that the National Disability Insurance Agency come into line with the language use within the areas psychosocial disability and mental health, when it comes to interpreting reports from such allied health professionals, to ensure that participants with psychosocial disabilities and mental health issues are not at a disadvantage, when trying to secure appropriate funding.

80. It is recommended that the National Disability Insurance Agency provide training to NDIA Planners on the compounding impacts of multiple disabilities and health issues.

81. It is recommended that the National Disability Insurance Agency explore the possability of ‘early intervention supports for children with multiple disabilities be determined for each disability separately.

82. It is recommended that the National Disability Insurance Agency provide training to NDIA Planners in recognising and responding to family violence, particularly in relation to Women with Disabilities.

83. It is recommended that the National Disability Insurance Agency ‘institute clear processes and training around using a risk assessment tool to assess family violence for Women with Disabilities.

84. It is recommended that the National Disability Insurance Agency develop strategies to build a strong Aboriginal workforce, particularly planners, arguing that it ‘is well-documented that there is a higher success rate for government initiatives when Aboriginal people are involved and employed in meaningful roles’.

85. It is recommended that the National Disability Insurance Agency establish Indigenous cultural safety accreditation standards for providers to meet and gain certification, and that all NDIA staff, contractors, LACs and planners be required to have completed a minimum level of cultural awareness training.

86.It is recommended that the National Disability Insurance Agency develop a strategy to develop a workforce of Aboriginal and Torres Strait Islander planners.

87.It is recommended that the National Disability Insurance Agency consider the incorporation of funding for interpreters into participant plans’ where the participant does not speak English as a first language.

88.It is recommended that the National Disability Insurance Agency review waiting lists for child participants to access assistive technology as currently, some child participants are waiting over 12 months to access such technology.

89.It is recommended that the National Disability Insurance Agency should review the best ways in which to support child participants, instead of always automatically reverting to individual therapies. In some instances, community-based supports such as swimming and Riding for the Disabled, may be more beneficial to a participant, than individual therapy support.

90. It is recommended that the National Disability Insurance Agency review the access of diagnostic services for participants who come from low socio-economic backgrounds.

91. It is recommended that the National Disability Insurance Agency increase the number of specialised, trained planners working in institutional environments, such as prisons and mental health inpatient settings.

92.It is recommended that the National Disability Insurance Agency review policies and procedures within relation to support for participants who are currently homeless or who are risk of being homeless and coming into contact with the Criminal Justice System.

93.It is recommended that the National Disability Insurance Agency develop mechanisms to assist Participants from Non English Speaking Backgrounds to have better access to information that they can understand on the NDIS and associated Planning Processes.

94.It is recommended that the National Disability Insurance Agency provide training on the special needs of Participants from Non English Speaking Backgrounds, to NDIA Planners.

95.It is recommended that the National Disability Insurance Agency provide a few resources that are translated into languages of new and emerging and refugee communities to help participants from these groups prepare for their planning meeting.
96. It is recommended that the National Disability Insurance Agency provide a clearer definition of the term “complex needs”.

97. It is recommended that the National Disability Insurance Agency review its’ policies in relation to Home and Living and consider principles and frameworks that are more fit-for-purpose for Complex Care needs clients who can “fall through the cracks”, in particular in circumstances where it is difficult to distinguish between their disability or criminal needs.

98. It is recommended that the National Disability Insurance Agency review it policies in relation to the specific issues regarding Participants who live in rural and remote parts of Australia.

99. It is recommended that the National Disability Insurance Agency investigate alternatives to telehealth for participants who live in rural and remotes areas of Australia, particularly for participants who have hearing or speech impairments.

100. It is recommended that the National Disability Insurance Agency review the approach being taken within regards to individualised planning, to ensure that plan are individualised to suit the needs of the individual.

101. It is recommended that the National Disability Insurance Agency ensure the planning process emphasises the importance of individualised planning in meeting the ethos of the NDIS, whicn to give participants “choice and control” over their lives.

102 It is recommended that the National Disability Insurance Agency review operational responses between the consistency of the decisions being made and the individualised planning approach.

103. It is recommended that the National Disability Insurance Agency develop some assessment tools that can flexibly accommodate and give recoginition to the specific needs, goals and aspirations of individual participants.

104. It is recommended that the National Disability Insurance Agency develop some resource materials for participants on how to choose the service provider that best suits their individual needs.

105. It is recommended that the National Disability Insurance Agency ensure that those who offer Plan Management Services are aware of the fact that it is the role of Support Coordinators to assist Participants to choose and connect with Service Providers, not Plan Managers.

106. It is recommended that the National Disability Insurance Agency devise strategies in which to address the high turnover of staff in NDIA offices, as this is one the causes of Participants having to repeatedly tell their story .

107.It is recommended that the National Disability Insurance Agency review the policy of automatically reducing a Participant's funding, if they haven't purchased all of the support stated in their support plan, as sometimes the market for these supports have not been developed or simply are not available in a particular geograpical area. This is particularly prevalent for participants, who live in rural and remote areas.

108. It is recommended that the National Disability Insurance Agency ensure that Participants have continual access to support and services , even if the review of their plan was not completed and a new plan created by the date specified in their plan.

109. It is recommended that the National Disability Insurance Agency review the design and implementation of the NDIA'S ICT system, in an effect to reduce limiting the access Participants have to their support plans, plan review delays, or for providers to need to recreate service bookings once they have been given a new plan.

110. It is recommended that the National Disability Insurance Agency ensure that both prospective participants and participants can exercise their right to appeal, when it comes to internal review decisions and are provided with clear guidance relating to the internal review process.

111. It is recommended that the National Disability Insurance Agency provide clearer and more streamlined pathways that enable prospective participants and participants to resolve concerns about NDIA decision-making and reduce administrative red tape.

112. It is recommended that the National Disability Insurance Agency provide more clarity as to the matter before the AAT in circumstances where a prospective participant or participant has lodged an appeal, including the nature of the decision in question and all of the surrounding circumstances.

113. It is recommended that the National Disability Insurance Agency eliminate the multiple uses of the word "review" as this is confusing and is potentially hindering the rights of participants to exercise their right to appeal a NDIA decision. The NDIS Act should be amended so the word 'review' has only one meaning.

114. It is recommended that the National Disability Insurance Agency review the policies and procedures within relation to internal reviews, with a view of making this process less stressful for all stakeholders (particularly participants) involved.

115. It is recommended that the National Disability Insurance Agency review the length of time taken to finalise an internal review decision.

116. It is recommended that the National Disability Insurance Agency provide more clarity to Participants, the different types of reviews that can be sought under the NDIS Act.

117. It is recommended that the National Disability Insurance Agency consider improving training, clearer forms and a change in terminology – for example, the same form is used to request a section 33(2) review, an unscheduled review under section 48(2) and an internal review of a reviewable decision under section 100 of the NDIS Act. These could be split into separate forms.

118. It is recommended that the National Disability Insurance Agency make the Commonwealth Ombudsman's report on how the NDIS is living up to the PSG standards widely available to participants, as well as other interested stakeholders involved in the process.

119. It is recommended that the National Disability Insurance Agency review policies and procedures that relate to the travel costs of Support Workers, travelling between participants, team meeting and paying for activities of participants-with reimbursement.

120. It is recommended that the National Disability Insurance Agency provide a clearer definition of the role of a Support Coordinator, as well as what kind of expectations Participants should have when it comes to working with Support Coordinators.

121. It is recommended that the National Disability Insurance Agency investigate ways in which the role of Support Coordinator could be more "stress free". Some of the strategies used could be job sharing, hiring someone to do all the research related to the job, etc, investing more in the strengths of individuals within th support coordination team eg: one Support Coordinator's particular strengths SDA, etc.

122. It is recommended that the National Disability Insurance Agency investigate in avenue to improving the efficiently of NDIA Planners, to avoid Support Coordinators spending any unnecessary time fixing up errors in Participant Plans. Any time spent fixing up the errors of a NDIA Planner to a Participant's Plan, should not come out of the Participant's support coordination funding.

123. It is recommended that the National Disability Insurance Agency advise Support Coordinators of any changes to legislation or operational guidelines as they happen.

124. It is recommended that the National Disability Insurance Agency develop a consistent approach in how NDIA Staff interpret the NDIA operational guidelines.

125,.It is recommended that the National Disability Insurance Agency establish a consistent approach in the formulation of the Support Plans of Participants, in an effort to fix some of the errors currently made by NDIA Planners.

126. It is recommended that the National Disability Insurance Agency legislate service providers to make signifcant investments in values-based training for all Support Coordinators employed by their service, and alternative arrangements be made for value-based training to be conducted within Independent Support Coordination Businesses.

127. It is recommended that the National Disability Insurance Agency investigate ways in which Support Coordinators can receive training on their ethical obligation, prior to the commencement of their role as a Support Coordinator.

128. It is recommended that the National Disability Insurance Agency undertake a review into ‘billable hours” for Support Coordinators, with the objective of providing clarification of what are and are not “billable hours”.

129. It is recommended that the National Disability Insurance Agency provide incentives for interested persons to become Support Coordinators and develop strategies and incentives for current Support Coordinators to remain within the support coordination field.

130. It is recommended that the National Disability Insurance Agency make it mandatory for Support Coordinators to have some previous experience in working with people with disabilties or have some qualifications before commencing their role as a Support Coordinator, or give an undertaking to undertake such training before commencing the job.

131. It is recommended that the National Disability Insurance Agency investigate and explore ways in which Support Coordinators could be more independent of service providers, in an effort to avoid conflicts of interest.

132. It is recommended that the National Disability Insurance Agency develops and adopts an uniformed approach to the role of Support Coordinator, to ensure there is a consistent approach to support coordination services across Australia.

133.It is recommended that a review of the SCHADS Award be conduced to ensure that Support Coordinators are getting the correct monetary renumeration for the level of responsibility their position entails.

134. It is recommended that the National Disability Insurance Agency develop guidelines to ensure service providers/independent Support Coordination Business are paying Support Coordinators at the correct paypoints, under the SCHADS Award.

135. It is recommended that the National Disability Insurance Agency develop guidelines, as well as basic tools that service providers can utlilised when making decisions on how to appropriately cap the caseloads of Support Coordinators.

136. It is recommended that the National Disability Insurance Agency provide further clarification between the the role of Local Area Coordinator and Support Coordinator.

137. It is recommended that the National Disability Insurance Agency explore avenues in which Support Coordinators and independent advocates could work together to advocate for NDIS Participants.

138. It is recommended that the National Disability Insurance Agency produce a guide on the role of Support Coordinators , for Support Coordinators. This guide would include what Support Coordinators can and can’t do, as well a clear definition of what are and aren’t billable hours.

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