Woden Community Service
Submission to the Productivity Commission:
Enquiry into the NDIS and its costs
March 2017

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About Woden Community Service – background and NDIS experience

Woden Community Service (WCS) is a well-established and regarded not-for-profit community organisation that has provided a wide range of services to the broader Canberra community for over 45 years. WCS’s services are flexible, responsive, innovative and person-focused. The services are funded by the ACT and Australian Governments, the National Disability Insurance Agency (NDIA), the Primary Health Network and fee-for-service.

WCS has been true to its mission and purpose since it was established in 1969. Our values of hope, community, integrity and responsiveness continue to form the cornerstone of every service we provide – from child care to working with seniors. We have a strong, respectful service intent that offers flexibility and choice to people across the ACT and we work with stakeholders to build a vibrant and connected community.

WCS is considered a leader in its field for a range of disciplines. All areas of our organisation have been expanding rapidly over the past five years as we are recognised for the way we work individually and in partnership with government and other community partners. The diverse suite of services WCS delivers reflects the breadth of the community we work with. A vibrant volunteer program supports the work of the organisation and a strong peer workforce is developing in some areas, particularly mental health. WCS is also a provider of National Disability Insurance Scheme (NDIS) services.

WCS services include:
- NDIS Services
- Children, Youth and Family Services, including OneLink – ACT Government’s Human Service access gateway
- Children’s Services, including early childhood education and care
- Social Inclusion Services, including Commonwealth Home Support, Community Transport, Assistance with Care and Housing for the Aged, Social Groups and Volunteers; and
- Mental Health and Housing Programs, including Personal Helpers and Mentors (PHaMs), Partners in Recovery (PIR), Supportive Tenancy Service, and Squalor and Hoarding support.

WCS has worked to integrate our services as we acknowledge the interface of issues within people’s lives that create complexity and vulnerability. WCS believes that it is the responsibility of the provider to manage the complexity of the service system to provide greater ease of access and improved outcomes for people accessing those services. Collaborative service partnerships have underpinned WCS’s service delivery over the past 10 years, acknowledging that when organisations work together better outcomes can be achieved by leveraging the diverse capabilities of each organisation. WCS enjoys service partnerships with a range of not-for-profit agencies in the ACT and with the ACT Health Directorate’s Mental Health Justice and Alcohol and Drug Service for the delivery of mental health services.

WCS and the NDIS experience

WCS has been actively involved in the ACT whole of jurisdiction transition trial to the NDIS having previously delivered both disability and mental health programs that have had their funding transitioned into the Scheme. WCS has been delivering NDIS services since the beginning of the ACT trail in mid-2014 and spent the previous year, 2013/14 preparing for our NDIS transition.

In the disability area, WCS was block-funded from the ACT Government to provide two programs that have now been fully transitioned into the NDIS: Community Supported Respite (CSR) for young
people coming out of school, and the Community Living Skills (CLS) for older people with the aim of providing community participation.

In the mental health area, WCS was funded to provide the Housing Assistance and Recovery Initiative (HARI)/Housing Assistance and Support Initiative (HASI) packages through the ACT Government for participants with psychosocial disability, and two block-funded mental health programs, Partners in Recovery (PIR) from the Department of Health, and Personal Helpers and Mentors (PHaMs) from the Department of Social Services. Many participants from these two programs have now transitioned into the NDIS and both programs have been in the process of phasing out, as their funding has been nominated to be transferred to the NDIS.

WCS now has almost three years of experience in delivering NDIS services and has been making the necessary adjustments in its program delivery models and business processes to suit working with participants with individually funded packages. WCS has also been integral to helping many existing program participants and others who have come to us for support with their NDIS application and planning processes.

WCS has chosen three areas of specialisation in its NDIS service delivery.

- NDIS Support Coordination and Plan Management (currently for 87 participants).
  - This involves liaising with participants and their families, external agencies, allied health practitioners and the NDIA on a daily basis, initiating reviews for plans that do not meet participants’ needs, preparing evidence based documents for reviews, coordinating services to provide the best outcomes for clients, budgeting and processing invoices on behalf of participants and developing and initiating capacity building programs for participants who want to self-manage their plans.

- NDIS Ability Services – (currently for 54 participants).
  - The Ability Services team develop and provide 1:1 support services that help participants to achieve their goals. This also involves liaising with external support coordinators and clients who self-manage their plans.

- NDIS Mental Health Recovery Service (currently for 67 participants).
  - WCS’s NDIS Mental Health Recovery Service offers participants a range of opportunities in “Life Transition Planning” and “Capacity Building”. As well as their plan coordination role, Support Coordinators of this Service help design and implement capacity building activities that are consistent with the goals the participants want to achieve from their NDIS plans. The Support Coordinators link participants with the most suitable workers among the Service’s experienced Support Worker team who, in turn, can provide assistance that includes mentoring, peer support and individual skill development which may include participation through one of the Service’s psychosocial support groups. Other core supports and services are provided through referral to external service providers.

The NDIS teams at WCS have been actively involved in development of the NDIS as part of the ACT trial site. Staff have regularly participated in forums, committees, consultations, training and planning across the ACT jurisdiction to help with a smooth transition across both the disability and mental health sectors.
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Executive Summary

Due to its location and previous service experience, WCS has been deeply involved with the NDIS right from the start and has been assisting participants with application and planning processes and providing NDIS services for three years.

The Submission takes the form of three parts, the first setting out the major concerns that WCS has regarding the NDIS – both with regard to its fundamental structure and with regard to its implementation as it is being managed by the NDIA and the associated cost-inefficiencies.

The second part is composed of case studies which illustrate various difficulties which could be redressed, as well as some which may be a necessarily endemic feature of the NDIS’s structure.

Finally the third part offers some reflections on certain questions posed by the Issues Paper.

Our primary and more immediate concern due to our experience with the Scheme has been focused on the difficulties with the administration of the Scheme, with the complexities of the arrangements and the difficulties of operating in an ever-changing environment. Some of these administrative difficulties are having an immediate impact on the costs of the Scheme. In particular, features such as the current refusal or incapacity of NDIA staff to make simple amendments to a plan rather than undertaking a full-scale review are hampering the efficient running of the Scheme. Other problems come with the nature of a large and rapidly growing bureaucracy with staff who can scarcely be trained because the guidelines are yet to be established. Nevertheless these administrative problems are cost ineffective and need to be redressed.

In our role working with a range of people with a disability in Canberra we are very conscious of the gaps in the coverage of the NDIS. These gaps arise both for people who fall outside of the Scheme’s Individually Funded Plan (IFP) arrangements and also there are gaps for the people who are eligible for an IFP. For instance, the issues of crisis management remain largely unaddressed by the NDIS funding arrangements. Although ‘resolving points of crisis’ is indicated to be a role of a Support Coordinator there is no clear definition of what this involves or how it is to be paid for within limited Support Coordination budgets. All of this means that it is crucial for steady block funded arrangements to co-exist with the NDIS, because there are many functions that cannot be supported by individuals with plan funding. The costs of dismantling the block funding arrangements cannot be overstated.

The NDIS funding arrangements, which prioritise individual, privatised choice over a more systemic approach may have benefits for certain individuals, but it is important that we keep sight of the benefits of a community with in-depth experience and the associated insights and capacities that come with this understanding. This offers priceless benefits to individuals with a disability.
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Part I: Issues of Concern to WCS

Introductory comments

As outlined above in ‘About Woden Community Service’, WCS works with a significant number of people who are accessing the NDIS, or who should be accessing the NDIS, or who need to access the Scheme’s ‘Information Linkages and Capacity Building’ feature. As an agency whose clients have a wide range of (dis)abilities, and in particular those who are living with psychosocial disabilities (PSD), and as an organisation working in a jurisdiction that has had a uniquely early rollout of the scheme, we are in a position to provide valuable details of our experiences working within the NDIS.

We have chosen to focus on these ‘engaged’ experiences in this submission but note that there are significant issues raised for those who are not able to participate in the NDIS for one reason or another. While we have discussed some issues raised by the process of inclusion here, we are hoping that the issues raised for those living with a disability but who are nevertheless excluded from the Scheme will be dealt with in other submissions. More generally WCS gives endorsement of the submissions of the ACT Council of Social Services; the Mental Health Community Coalition, ACT; Community Mental Health Australia; Mental Health Australia and the National Disability Services.

This enquiry by the Productivity Commission focusses on cost issues around the NDIS. Specifically it is described as ‘A study to review the costs of the National Disability Insurance Scheme (NDIS).’ http://www.pc.gov.au/inquiries/current/ndis-costs The focus on ‘costs’ needs to incorporate an understanding of the different forms of ‘costs’ that the Scheme involves – not just the immediate budgetary impact on the Government’s spending and revenue. Lost opportunities, stress created for those involved and the losses (and gains) implicit in restructuring the community sector all need to be understood as part of the NDIS’s ‘costs’.

In particular WCS believes that the costs inherent in the NDIS’s administration include not only any inefficiencies in the administration of the Scheme but also the costs and burdens the Scheme’s administration creates for people with a disability and their carers. The ‘costs’ must include the negative impacts the Scheme may have on organisations working with people with a disability. Consequently this submission considers not only issues around the Scheme’s method of administration, but also how these impact on people with disabilities and their carers. Finally the submission also looks at the costs and impacts of the Scheme on the WCS itself – as one representative organisation that is being impacted on significantly by the NDIS’s funding arrangements.
1. NDIA administration- complexity and the burden on participants and providers

The NDIA is a huge bureaucracy with staff who are having to adapt to frequent changes in policies and who have limited and inadequate training, which results in problems with communication and means the administration of its funding arrangements is often inefficient and stressful for agencies and participants alike.

The problems with the size and complexity of the organisation are not merely ‘teething’ problems, as referred to in the Issues Paper, but go to the heart of the Scheme’s effectiveness.

Communication

- The NDIS arrangements involve layers of complexity that have to be navigated through, making the system a huge administrative burden for providers and participants. Being part of a trial site has meant having to cope with the goal posts regularly changing – with very little communication from the NDIA when this has happened, which often means that we have had to find out about changes or new interpretations of the rules through a process of trial and error. Often there are mixed messages from the NDIA about what to do and it is only when we are trying to claim funds that we find out there has been a change in the system. At the moment there is a particularly sparse number of communications coming through from the Agency.
- At the beginning of the trial staff at the NDIA were more approachable, and as time has progressed it has become harder and harder to have direct contact and help. We had many forums with them earlier in the trial but those have now totally fallen away – closing these useful communication channels.
- There has been huge inconsistency in information provided. The big turnover in staff and/or poor training make it difficult to find ‘the truth’. It’s not unusual to be told “I don’t have the answer to that” without there being any information provided as to where/how to get the answer. It is rare for planners to put anything of substance in writing.
- Planners are no longer able to be contacted directly- every phone call and all correspondence has to go through the Braddon phone number and email – which functions as a bit of a ‘black hole’.
- Portal issues can rarely be resolved with one phone call, questions bounce around different sections of the Agency and in fact NDIA staff often need to ask the Support Coordinator (SC) if they know what is wrong.
- Some participants are becoming so frustrated they have opted to ‘camp out’ at the NDIA until someone sees them in order to get things resolved.

Payment System

- It has been a challenge for us to train staff in the process of billing hours and making sure this covers all our work. The complexity of the system takes staff away from their direct participant support. Previously block funded staff have found this the most challenging.
- The mixed messages coming out from the NDIA and the complexity of the system have often meant that it is only at the crucial stage of claiming funds that the problems or incompatibilities become apparent. This has placed stresses on participants, agencies and service providers alike.
- The portal shut down last year impacted on us significantly. We were unable to have plans approved during the three months it took to sort it out, and during that time we had to carry a number of participants who had not yet entered the scheme but had their ACT Government funding for support cease. We were promised that plans would be back-dated
when they did finally get approved, but this did not happen. We couldn’t bill during this period and it has required countless additional WCS admin hours to catch up with billing.

Delays
- Our staff are always having to wait on hold to the NDIA, a standard wait time is 45 minutes, but often it goes up to 60 or 90 minutes (even 4 hours has been known to happen!). This time then needs to be charged back to the participant’s package and increases costs, while not providing value for money. This has a particularly significant effect for those on plans with a limited number of Support Coordination hours.
- When being transferred to the local (Braddon) office we are usually cut off or they aren’t available to take the call, resulting in the whole process starting over.
- Emails are not returned within a reasonable time. It is not unusual for it to take 4 weeks to get a reply to an email. WCS staff now follow up weekly with emails red flagged in order to try to get replies.
- We have submitted several formal complaints to the NDIA over the past year and it has taken sometimes up to 5 months for them to respond (despite our follow up of these complaints). This totally flies in the face of what the NDIS should aspire to in terms of complaint response. The Agency feels like a monolith that is impossible to penetrate!

Recommendations
- Review the 7% cap on administration, particularly during the phase of ‘full roll-out’. This would enable sufficient staff to be trained and resourced and effectively employed as the Scheme commences its optimal levels of operation.
- Develop a Service Level Agreement so that expectations are clear on all sides, especially around the appropriate time to return calls/respond to emails.
- Improved communication approaches. Particularly in the case of complex plans, Support Coordinators and planners should be enabled to contact each other directly, which would make for more cost efficient processes.

2. Plan Coverage and Equity within the NDIS for differently held packages

Inappropriate exclusions
- We do not have scope in this submission to discuss exclusions made on the basis of the narrow definitions of a relevant disability in the legislation (including the discriminatory age based provisions). However there are exclusions, as the case studies show, that result from a flawed process of evaluation of eligibility for an individually funded package (IFP). The appeal processes that result are likely to impose a significant cost – both for the Agency and for the (dis)abled person and their support community. Good processes will help avoid incorrect decisions and minimise costs.

Inadequate funding
- As the case studies show, a successfully managed plan can contribute significantly to the individual’s wellbeing, which fulfils the clear aim of the Scheme. A necessary element in establishing a successful package is sufficient and appropriately targeted funding. The following is a table which evaluates the likely success of various packages, some of which may have been inadequately funded:
**DIS Plan comparisons of participants in our service with complex and enduring mental illness and co-occurring conditions.**

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"Improved Daily Living" (therapy services) and "Health & Wellbeing" budgets to meet therapeutic needs.

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**Sustainable Plan likely to succeed in goals and building capacity for greater independence from services in future**

**Poorly allocated budget areas, unsustainable and at risk of failing to meet goals or sustain engagement**

**Poorly allocated budgets, unsustainable and at serious risk of failure**
An inappropriate choice between Plan/Self-Managed packages and Agency Managed Plans

- When the funding for supports under a participant’s plan is managed by the NDIA, only registered providers of supports can provide those supports (subsection 33(6) of the NDIS Act). Accordingly, a person or organisation seeking to deliver supports or services to participants whose funding is managed by the NDIA must apply to be a registered provider of supports. Registered providers are required to follow the NDIS Price Guide for charging services.

There is no restriction on who may provide supports under a ‘plan managed’ plan or a self-managed plan. These participants are able to exercise choice about the selection of their providers. It is only when funding for a participant’s supports is managed by the Agency that the supports must be provided by a registered provider of supports.

It is not hard to see that self or plan managed NDIS Plans have advantages over agency managed plans. For example, when participants are self or plan managed psychologists can charge what they are accustomed to in their private practice and invoice directly without further ado. The participants are able to claim the full amount back from the Scheme. Registered psychologists, on the other hand, have to follow the NDIA price guide and, to be paid, they have to navigate the time consuming NDIS portal (with all its many faults, failings and delays). What incentive is there to register then? Why would such providers do that when they can restrict themselves to self or plan managed participants?

The disincentive to register goes for many other providers of services. Gardening is particularly difficult to obtain for agency managed plans – they can’t get anything or there is a prohibitive waiting time. Gardening businesses are not interested in being paid $42.05/hr as dictated by the NDIS Price Guide – their services are generally quote based but an estimated equivalent would be a minimum of $60/hr.

Just Better Care (JBC) which has delivered a quality support services is another case in point. JBC has de-registered itself as of this month. JBC is a good service provider that has now exited all their clients who are agency managed and will only provide services to people with plan or self-managed plans – no longer restricted to what they consider unsustainable pricing restrictions imposed on registered providers they are charging a rate that they do consider sustainable as well as competitive in a less restricted marketplace. Other agencies are also contemplating exiting the registration process.

This of course sets up a kind of two tiered system and an inherent injustice - the have-nots. Those whose plans are agency managed are disadvantaged and excluded from using unregistered providers in an unrestricted and unconstrained marketplace. This will continue to create a distortion in the market and it is a very concerning trend. Even the language reveals this double standard. The category for "financial intermediary" (plan management) is called "Improved Life Choices" (Support Category 14). People whose plans are self or plan managed have all the advantages of "improved life choices". But the "poor relations" who are agency managed have to accept what is available in a still very underdeveloped market. It is a restricted market place for the have-nots.

The process of choice between being agency managed or plan/self-managed would seem a bit arbitrary and include elements of luck or previous experience with a suitably supportive agency. Effectively those who are agency managed have been deemed (or have deemed themselves) as incapable of self-managing. Those that can navigate the system and have the education to do this, or the contacts within the system or the initiative to make these
contacts, can take advantage of the supports offered by an agency and are likely to have much better outcomes in their plan implementation.

**Recommendations**

- Improve processes of evaluation undertaken by NDIA staff so that they ensure the evaluation relies on a comprehensive understanding of the condition in question.
- Ensure levels of funding that will enable the successful implementation of plans.
- Sufficient communication provided by the NDIA to ensure participants appreciate the different implications of being self or plan or agency managed. In particular ensure that agencies are supplied to potential participants which can advocate and act on behalf of those who are being evaluated for a plan.
- Consider amending subsection 33(6) of the NDIS Act, which requires that plans for agency managed participants must specify that all services used must be registered. An amendment could allow for greater flexibility when it is deemed necessary, for instance when geographical and market constraints mean that no viable registered service exists.

3. **Pricing**

- In many cases the pricing for plans is so restrictive that it makes the opportunity to provide a flexible and quality service to participants unsustainable. We have had to employ a lesser skilled workforce to cater for the shift to lower wages, and have very limited capacity for supervision and training of staff. We are concerned this will have an impact on the quality of service we provide.
- We are also finding that some providers are choosing not to register so they do not have to comply with the NDIS pricing structure and can charge what they determine the services are worth. This limits our ability to find good providers for some of the services we need, for instance there are almost no registered psychologists in Canberra, which makes it impossible to use these services when someone needs it when they have an agency managed plan.
- Many of our Support Workers (SW) have their own lived experience of mental illness. The NDIS has created a great opportunity for the employment for people who are on their own recovery journey. But it is, therefore, even more essential that they have the support they need to do this work. WCS needs to be able to regularly check in with these workers, to be able to debrief with them and to give them opportunities to communicate if they are finding challenges in their interactions with participants. We have office-based staff to do this role with our team of SW’s but again we are unsure of the sustainability of the role due to the pricing limitations of the NDIS. We have a number of SW’s who have flourished through this work, but we are acutely mindful of the need to support them and the funding arrangements are difficult to maintain.

**Quality and risk: a safeguards framework is needed**

- WCS is sometimes referred clients by the NDIA, but we get very little information from the NDIA about a new participant if they have not been associated with WCS before. Risks such as substance use or previous violent behavior may only come to light after the person has agreed to use our services. WCS has experience working with people with these issues but we are likely to need additional resources to do this effectively and safely and these resources may not be available in an active plan. This then raises the difficulties of adjusting plans (see further below).

**Workforce changes -- a cost of the NDIS?**

- The pricing structure of the NDIS and the difficulties inherent in the shift from block funding are making it increasingly difficult to retain staff, attract and pay for good skills and provide appropriate supervision.
• In our work with people with a psychosocial disability, regular contact with Support Workers (SW) is critical. We have SW’s report in to us and be able to discuss their interactions with participants. We are currently paying for all SW’s to come to a regular team meeting for reflection and discussion to share ideas and experiences. This sort of supervision is essential in the mental health area, and knowing when and how to interact with participants who are unwell can be challenging and confusing for a staff member who does not have prior experience of working in this area. We are still to determine if this is affordable under the NDIS model but feel it is a critical part of our service.

NDIS funding compared with block funded arrangements
• WCS has traditionally worked with block-funded services for our disability and mental health programs so the transition to an NDIS workforce has been significant. We have had to move to a mostly casual group of workers, or employ workers on limited term contracts. We have also had to ask workers to come to us with their own car with comprehensive insurance, their own mobile phone, a Working With Vulnerable People check and a first aid certificate. We aim to employ people who have or are working towards a relevant qualification such as a Cert IV in Mental Health, Community Services or equivalent.
• Even so, it feels as though we are creating a two tier workforce – as workers in block-funded programs tend to have higher qualifications, have greater security and we can afford to give them additional training and the supervision they need as well as access to work cars and phones.

Recommendations
⇒ Ensure funding arrangements which can ensure the supervisory and training responsibilities of the sector can continue. In particular the continuance of some elements of block funding is crucial.
⇒ Quality and risk - the safeguards and standards regarding referrals of clients with dangerous behaviours are not yet in place and need developing. They are necessary to address the lack of information about a new participant and will ensure fewer risks to participants and risks to WCS staff (and any associated costs).

4. Plan implementation
The difficulty involved in implementing
• It has been a challenge for our teams to understand plans and work out the best way to design a service for a participant. This difficulty has been exacerbated by being part of a trial site where the structure of plans changed a number of times.
• The NDIA has flagged the creation of a new ‘Plan Implementation Team’- however there has been no information regarding how to contact them via a direct email. Contact is through the local office number and email. This ‘Team’ was apparently established some time ago, but information regarding it has been difficult to find and uncertainty remains as to what the Implementation Team will actually be doing.
• A participant has been emailing the Implementation Team regarding getting some funds “released” from their plan but after 6 weeks without any response (apart from a Business Support Officer telling them that “it’s being worked on”) hope is beginning to fade regarding this initiative.

The realities of support coordination and all the complexities it creates
• ‘Responding to periods of crisis’ is articulated as a part of the role of a Support Coordinator (SC), although there is very little explanation from the Agency as to what this means. It has extra complexity in the psychosocial disability (PSD) area due to potential episodes of mental illness and for people with intellectual disabilities. The SC budget is often so tight it does not allow for the time needed to do this sort of response work.
• The Support Coordinator’s role is made all the more difficult when there is inadequate communication between the SC and the NDIA. Particularly regarding Plan Reviews (see below).
• There can be all sorts of complexities in a participant’s life that need to be sorted through before a plan of NDIS supports can be put in place – such as hoarding and/or squalor in their living arrangements, substance use, and physical illnesses. It can take time to address these and find solutions for a way forward and Support Coordinators may not have the knowledge required. We feel there is a role for having a specialized coordinated short term response service that can work with the SC to help to sort through these issues, but it would need to be funded within a plan. If these issues of complexity are addressed properly at the beginning of a plan implementation there would be increased chances of improved outcomes for the participant and therefore less long term financial stress for the agency.

Funding for capacity building
• ‘Capacity building’ is the most significant part of the plan that allows for recovery/rehabilitation work and therefore improved longer term outcomes for participants. If properly utilized emphasis on capacity building should create cost savings in the future. Our experience is that these budgets are being reduced as plans are reviewed and more resources are being added to core elements of the plan, funded at a lower level and therefore involving less skilled services and staff. To minimize costs for the Scheme in the long term it would make most sense to ensure adequate ‘capacity building’ resources are included in plans where there is potential to make a difference to someone’s independence and longer term reliance on the Scheme.

Recommendations
⇒ Increase funding for capacity building
⇒ Investigate methods for responding to more complex cases, particularly since these are likely to be the most cost intensive situations.
⇒ Provide information about the Implementation Team role, contact information, reasonable time frames for returning calls etc.
⇒ NDIA to advise Support Coordinators and service providers in a timely manner that a plan review has taken place to ensure that they can take the appropriate action.

5. Plan Reviews and amendments
The process and the reality
• Reviews – we were led to believe that these would be a time when the participant and SC could talk to the NDIA about progress against goals. This has not been the case. Reviews are brief and often done with no warning to either the participant or the SC on the phone. Sometimes a participant with psychosocial disability (PSD) does not even understand that a review is taking place. It is likely that other forms of (dis)abilities will also have difficulties understanding the processes.
• Some plans are being ‘reviewed’ 3 months before they should be scheduled. This does not allow for preparation for a review or evidence of achievement against goals to be prepared.
• Early reviews have also impeded the services planned by providers. A new plan can be issued without warning to the participant and then existing service bookings in the portal are no longer active, causing major billing issues and confusion all round. One of the main aims of the ‘service booking’ as explained to us when it was introduced in July 2016, was to quarantine part of the budget for a provider to ensure certainty for all parties. Activating the review process early, and failing to communicate about the process and its outcomes, serves to undermine this certainty and the functionality of the Scheme.
There is often no chance to review the plan before it is ‘approved’, thus causing difficulty if the plan is inadequate or unsuitable.

The NDIA are pushing for phone reviews due to the need to bring on big numbers of plans. This is not appropriate for many participants and there has been no consultation about this change in process.

Cuts to capacity building and support coordination

As plans are being reviewed they are often cut back in the areas of Capacity Building supports, as mentioned above, and also in Support Coordination hours. Both of these aspects of the plan are crucial particularly for improved outcomes and for plans with any level of complexity and regular crisis support needs.

Amending plans rather than reviewing plans would be a more efficient approach

Prior to 1 July 2016 it was possible to ask for an amendment of a plan if it needed to be addressed in one area. This is no longer available to us or participants. Instead an entire review is needed, making the whole process more cumbersome, delayed and often unnecessary. It has sometimes resulted in a worse plan being issued and a review process can take months. We have been informed that this change is because the new IT system was built in ‘accordance with the legislation’.

Overt messages have been given out that supports could actually decrease if plan reviews are requested, which has deterred some participants from asking for a plan review for fear of having reduced support, when there is really a need for a part of a plan to be changed.

Plan reviews requested in January are still waiting for review dates to be advised.

Recommendations

- The NDIA should have the ability to amend plans for minor changes and errors.
- Consideration should be given to a process where up to a certain percentage of the funding can be amended without going to a full plan review.
- To ensure successful implementation of plans sufficient/reasonable Support Coordination hours must be given.
- To ensure the possibility of rehabilitation through a plan’s implementation sufficient/reasonable Capacity Building must be provided for.
- There needs to be a renewed emphasis on ‘choice and control’ and fully involving the participant.

6. Block funding needs to be continued

- Continued block funding is needed to help complement the activities of Individually Funded Plans, and also to cater for people with a disability who are not eligible for a Plan. Public support for the NDIS was premised on the idea that the increases in funding would augment pre-existing structures and organisations rather than destroying or removing them. The costs to the community of ending previously block funded programs are significant. Furthermore there are cost efficiencies in block funding programs which are lost when there is a sole reliance on individually funded plans. The two approaches need to complement each other and create positive ‘synergies’ rather than competing for funds destructively.

- In the mental health area we have had three programs that have had their funding shift to the NDIS – two Commonwealth and one ACT Government funded. The slower transition of phased out funding for the Commonwealth programs has helped with many of the delays that have eventuated with the NDIS. The ACT Government funding ceased more abruptly, causing a great deal of angst for participants and us.

- Another significant agency in the ACT which supported children experiencing difficulties, either temporarily or more permanently, Therapy ACT, has shut its doors since the NDIS commenced. Therapy ACT was able to triage and direct families to the appropriate services, either within Therapy ACT or elsewhere. The agency functioned as a ‘guide’ for these
families, with the additional benefit of offering an in-house broad cross section of therapists and services who had the ‘imprimatur’ of being government funded. Many of those therapists have gone in to private practice and the NDIS will accordingly have increased costs to support the select number of plan funded children who can access those services. Families will have the significant difficulty of having to select the appropriate therapists with what will probably be insufficient information to help them in their selection. Furthermore children whose difficulties do not constitute a permanent disability may not be able to access or identify the services at all. Many of these destructive outcomes could have been avoided if sufficient block funding was maintained.

- In the mental health field there are no clear solutions as yet to cater for the people in the Personal Helpers and Mentors scheme (PHaMs) and the Partners in Recovery scheme (PIR), who are not eligible for the NDIS. The loss of referral pathways for people experiencing a period of mental distress is marked and having an effect on other block funded programs such as housing and family programs. Staff at the WCS have been collecting data about the effect this is having on our other block funded programs, as they struggle to cater for people who are not in the NDIS and have lost other program opportunities. This is particularly marked in the mental health area where we are in a period of considerable reform and change, if not total confusion. The introduction of the NDIS, causing programs to be cashed out to contribute to its funding, is a nightmare – several other States have watched what has happened in Victoria and the ACT and have chosen to do this in a different way, keeping their State funding in place. Meanwhile here in the ACT there has been no path forward for filling the gaps that have been created by the closure of programs. We need programs like PHaMs and PIR to continue for the shorter term episodic response, for people who are not eligible, and for those who refuse to go into the NDIS. The uncertainty about these programs and lack of communication from DSS and the DoH has been extremely difficult for everybody in the field.

Tier 2 of the NDIS will be reliant on block funded programs
- The roll out of the NDIS has been back to front. It would have been better to have Tier 2 (Information, Linkages and Capacity Building (ILC)) in place before rolling out Individually Funded Plans (IFPs). In mental health, block funded programs would identify those who were likely to need an IFP and help them enter the scheme, while working with others to get them back on their feet and supported in the community instead of accessing the NDIS. Unfortunately the reality has been that we have been pressured to test the eligibility of most people in these programs as there have been no other alternatives for support. More participants from PHaMs have entered than we originally anticipated. In the absence of block funded programs more people will be forced towards the NDIS, which could contribute to avoidable higher costs.
- The NDIA has said that the ILC will provide ‘information, linkages and referrals to efficiently and effectively connect people with disability, their families and carers, with appropriate disability, community and mainstream supports.’
  https://www.ndis.gov.au/html/sites/default/files/ILC-Policy-Framework.docx However, for those not on Individually Funded Plans, the ILC’s support will only be meaningful if there is available, appropriately funded ‘disability, community and mainstream supports.’ The current approach has been to cease the funding of many such services as the NDIS is rolled out. For the ILC to be able to make meaningful referrals block funded programs will need to continue in parallel with individually funded arrangements.

Recommendations
- Continue block funding of schemes that are necessary for those not able to access IFPs, and also which function to complement and augment the services available under IFPs.
Part II: Case Studies

Note that all names have been changed to protect participant’s privacy. Also note that these descriptions of situations that have arisen under the NDIS have been selected to demonstrate issues of particular concern to WCS. Many more case studies could have been drawn upon.

**Case Study No. 1**

**Male, 48, with severe psychiatric disability and functional impairment, after an inappropriate investigation, was deemed ineligible for NDIS supports as his functional impairment was not considered to be severe enough. Review pending.**

The 48 year old male has had a severe psychosocial disability that is attributable to a psychiatric condition (severe Obsessive Compulsive Disorder (OCD), anxiety and depression) for 24 years. His functional impairment is completely disabling and affects his ability to undertake any social interaction, care for and manage himself, and undertake daily living activities. His mental illness has a particularly debilitating effect on his ability to manage time, his sleep patterns and daily activities.

He cannot undertake any form of employment or purposeful activity due to his lack of functional capacity and inability to care for himself.

Due to his severe mental illness, he is unable to function capably in society or live and manage a household alone. He is currently isolated and disconnected from any social and community supports and requires assistance in all activities of daily living (shopping, attending medical appointments, medication management, washing, cleaning etc.).

His daily rituals and behaviours consume all his time, resulting in chronic sleep deprivation. His ability to manage his mental illness has markedly deteriorated to the point where he is totally reliant on his sole carer, his mother, who has Parkinson’s Disease, a progressive neurological disease.

Despite numerous attempts with a range of health, clinical and community-based interventions, he is prisoner of his own illness, completely cut off from the outside world, and most aspects of his life and state of mental capacity remain substantially and permanently impaired.

He requires long term complex rehabilitation with support from a wide range of health, social and community services if there is any hope of improvement in his life.

An Access Request Form was submitted to the NDIA. This was following written advice from the NDIA that either this form OR other supporting information was required as the first point of entry. No advice was provided that additional supporting material as to the severity of the mental illness or functional capacity was required at this time.

The Access Request Form was completed by his treating psychiatrist and the limited questions on the Access Request Form were completed. Unfortunately the application was assessed without appropriate or fair consideration of any other supporting or historical evidence of the individual’s severe psychiatric disability or his debilitating functional impairment.
Case Study No. 1 (continued)

Following receipt of the Access Request Form, an NDIA Access Assessor rang his residence and proceeded to ask a series of probing and personal questions about his mental illness, his medications and his life goals. No verification of her identity or reference to an NDIS reference number was provided over the phone.

He was unable to provide sufficient and detailed responses to the very personal and difficult questions that were asked of him. The result of this phone conversation was then recorded in the decision letter. At no point did the Access Assessor ask to speak with his full-time carer but conducted the conversation without her being present. This demonstrated a complete lack of understanding of the difficulties that people with a mental illness face, particularly with their often limited insight into the severity of their condition, which is often concomitant with severe mental illness. No regard was given to ascertaining his capacity and capability, or lack thereof, when answering the probing personal questions over the phone.

The second issue is that the questions appeared to ignore the need to seek additional information about his experience with his mental illness. At no point did the Access Assessor provide an opportunity for him or his full-time carer to provide this information over the phone, in writing or via a face-to-face meeting. This information would have been supplied promptly, providing the appropriate and necessary background and historical information.

The decision letter detailing his ineligibility for the NDIS was based on the premise that he needed to ‘explore all other relevant health options’, including programs such as the Partners in Recovery program. However, the Partners in Recovery Program is no longer available for new participants as it is transitioning to the NDIS.

At no point did the Access Assessor ask about what treatment options he had explored over the years. If this had been asked, the Access Assessor would have learnt a great deal about the difficulties he had experienced and what services and supports he had tried, without much improvement in his functional capacity.

A further follow-up phone call was made directly to the Access Assessor the following day to attempt to clarify some of the previous conversation. The Access Assessor was extremely unhelpful and rude and claimed she was not at all interested in the individual’s mental illness diagnosis or level of severity, rather his level of functioning, which, in fact, she had never asked about. This phone call was most unhelpful and extremely upsetting to the individual’s carer.

Throughout this request for access to the NDIS, the NDIA has not had any regard for how deeply distressing it is for the individual to constantly talk through his mental health issues and problems. Furthermore, the NDIA has not taken into account any of the necessary and supporting background information into the individual’s history with his severe mental illness or his functional impairment.

As a result of an eligibility decision being made on limited information, another more complicated and time consuming internal review process will now need to be undertaken to hopefully achieve a better outcome for the individual seeking support from the NDIS.
**Issues raised/commentary**

- The need for a sensitive process when making enquiries of a person with a disability. In particular the need to establish competence or capacity to handle the relevant questions, and also to establish whether the participant needs support and advocacy from another source.

- The NDIA’s inappropriate referral to a program that is no longer accessible illustrates both the need for the NDIA to provide accurate and meaningful alternative referrals, but also the need for block funded programs such as the one they referred the possible participant to, to have continued funding.

- In order to avoid the additional costs of reviewing decisions, both for the Agency and for the participant, the process of decision making needs to be improved.

- Various guidelines, including the need to consider the ability of the possible participant to handle questions; the use of written communications or face-to-face interviews as an alternative to a phone interview should be considered. The fact an initial assessment has been completed by a psychiatrist might flag the need to approach the issues of competence or comfort sensitively.

- The general issue of inappropriate denials of access is raised by this scenario. This also raises questions about what meaningful supports and avenues of redress are available to someone refused access – i.e. how is a decision to be challenged and who is to do it, with what supports.

- Another issue raised is the need for the NDIA to communicate more effectively the processes that need to be gone through. The fact the applicant’s carers were unaware of the need for documentation increases the costs of administrating the Scheme. Assessors also need to ensure the applicants themselves are fully aware of the significance of their interviews, and that they are offered a meaningful chance to involve carers, or other advocates, into the discussion.
Case Study No. 2

Male, mental health issues, applied to participate in NDIS but the delays and processes used were harmful to participant

In 2016, a WCS Personal Helpers and Mentor (PHaMs) staff member worked with a PHaMs participant, John, to assist him in transitioning to the NDIS. We submitted his completed Access Request Form in person to an NDIA office on April 05, 2016. According to the NDIS website “The NDIS Act requires the National Disability Insurance Agency (NDIA) to make a decision or request information within 21 days of receiving a complete access request”. We did not receive confirmation that John had been granted eligibility until October 10, 2016. My participant waited over six months with no clear explanation as to the delay. During this waiting period we made numerous attempts to find out what was happening with his application. John personally made phone contact with the NDIA on several occasions and was told that his application was still being processed. The WCS staff member contacted the NDIA at least five times by phone and twice via email to find out what was happening with John’s application. The phone calls and emails were either not responded to or we were told that the application was still in progress and that we should reassure the participant. On one occasion, WCS staff received a phone call from the NDIA on the 29/07/2016 stating that they were returning my phone call from 04/07/2016. John also enlisted the support of a worker at Gugan Gulwan Youth Aboriginal Corporation and they assured John that they were going to escalate his case within the NDIA. The Mental Illness Fellowship program Your Voice, Your Choice was also involved with John and they too struggled to find out any further information. In August 2016, Your Voice, Your Choice were informed that the NDIA held no record of John’s ARF. The original (date stamped) ARF was then resubmitted. Nevertheless, no response was received until October 10, 2016.

Impact on PHaMs Participant

The participant has a long history of feeling let down by services and alienated from the community due to his disability and Aboriginality. This unsettling limbo situation with his NDIS eligibility determination left John feeling cynical of ‘the system’ and of achieving his recovery goals. WCS staff witnessed his levels of depression, anxiety and disconnection increase during this time.

Planning Process

John and WCS became aware of his planning meeting one day before it was scheduled. John was willing to proceed, however, and the planning meeting went smoothly. John, his carer, and the WCS staff member were able to articulate his goals and complex needs adequately in this meeting. John stated that he required assistance to reduce social isolation and to build his skills and capacity in a wide variety of areas: job searching, using computers, life transition planning and developing independent living skills.

John’s First Plan

John received his first NDIS plan in early December 2016, eight months after applying for eligibility. Unfortunately, after waiting so long, the completed plan was inadequate and does not provide the reasonable and necessary supports to meet his complex needs and to address his recovery goals. There is no budget in the plan for skills and capacity development. There is no budget to support him to find and keep a job, to access therapeutic support, to help him build independent living skills and to mentor him through life transition planning. The budget in John’s plan does not address his stated goals, improve his independence, build his capacity or suitably enhance his economic participation. It leaves him in a disadvantaged position when compared to the support that he received as a PHaMs participant. We have applied for a review of his first plan.

John’s NDIS Experience

John is motivated and has the potential to be an active participant in his psychosocial recovery with the right level of support and intervention. Unfortunately, John’s first plan and budget does not match the discussions that took place in his planning meeting. His transition from the PHaMs program to the NDIS has been long, arduous and disheartening for him.
Issues raised/commentary of Case Study No. 2
- Unexplained delays in processing applications
- Inadequate funding
- Insufficient communication and notice from the NDIA
- A lack of cultural awareness and sensitivity to the special needs of Aboriginal applicants
- A lack of recognition of the level of support that people with severe and complex disabilities need to navigate the complex, convoluted and often arcane access and eligibility requirements of the NDIS.
- Without funded programs such as PHaMs and PIR (all of which are ceasing, or have ceased – for instance Your Voice, Your Choice) how are people without assistance expected to cope with applying for the NDIS?

Case Study No. 3

Female, 61, living with BPD, chronic pain, comorbidity
*Administration.*
When Joan’s plan was implemented the budgets were not available on the Portal. Consequently Service Bookings couldn’t be made and it took over a month for this to be addressed by the NDIA. It took over 12 hours of the Support Coordinator’s time (with no alternative but to be charged to the participant’s Coordination budget) liaising with NDIA and unpaid Service Providers. This was only rectified at the end of February 2017 four months after the Plan started. In the meantime Joan was made extremely anxious and embarrassed as she had a range of unpaid bills and upset Service Providers that her Coordinator had to deal with (and who also remained unpaid over that time).

At the Annual Review the participant asked the Planner to send the Plan to the Support Coordinator (SC) as receiving mail makes her extremely anxious. This was agreed to by the Planner; however the SC did not receive the plan and it went straight to the participant in the mail. SC had to attend the Braddon Office to receive a copy of the Plan.

Also at the Review the participant affirmed that she had realised after a year of NDIS involvement that she actually needs assistance; whereas she had not realised this prior to experiencing support (limited insight of the severity of her mental illness is a symptom of Joan’s condition). The support given through NDIS has made her recognise how socially isolated and fearful she has become. She also talked about wanting to increase her social skills through psychosocial support. However, when the Plan was received it only had half-an-hour of Capacity Building a week included, a budget that is inadequate to address the nature of Joan’s condition.

As the SC was tied up liaising with the NDIA and Service Providers, the cut-off for the Review passed and it will now need to go through a “Change of Circumstances” process.

Issues raised/commentary
- There are serious deficiencies in navigating the NDIA Portal. Delays of the kind described above occur with monotonous regularity and frequency. It causes distress to participants and impacts on the very core and viability of service providers.
- Five Plans that were affected in this way were recently re-activated by an NDIA employee who initiated personal emails and phone calls to one of this organisation’s Support Coordinators (NDIA staff are not allowed to do this). He resolved the issues in five minutes – ensuring all of the five affected Plans, which had not been able to claim for the previous four months, were functioning properly. The employee in question is no longer employed at the NDIA.
- No recognition of the role of the nominated support provider (such as the Support Coordinator if a Plan is in place, or a PHaMs, PIR worker or other advocate if not) to assist
participants with complex needs to navigate the complexity of the NDIS system. There is no mechanism to ensure this special role of assistance for participants is respected by the NDIA.

Case Study No. 4

Sarah, 55, living with paranoid schizophrenia

*Administration*: WCS first contacted the NDIA for review after initial Plan (March 2016) was manifestly inadequate given the complexity of Sarah’s needs and there was only a budget for Support Connection not Support Coordination provided (Support Coordination recognises the need for resolving multiple points of crisis and supporting complex needs and range of services – Support Connection does not). Later the Support Coordinator was given permission by the NDIA to use funds flexibly until a Review could be conducted, including using Coordination.

The Review took place in early February 2017. SC was told Support Coordination would no longer be given or that it would be no more than 10 hours of “Connection” per year unless we could prove we required more. The Planner said he would give 110 hours of Connection due to the complexity of the participant. Upon receiving the Plan there was actually one hour of Support Coordination a week. The Participant actually attended the Review, whereas her initial Plan was “mirror funded” as she was so stressed about the Planning process and could not attend, cancelling the initial planning appointments three times before mirror funding was offered. Capacity Building support and work with the Coordinator enabled the participant to attend the Review Planning Meeting.

Now Plan has been received no Service Bookings can be made as the Portal says the Plan Management budget has zero dollars in it. Currently in communication with NDIS; SC has to take screen shots of the Portal Service Booking Error for the NDIS to understand the issue.

**Issues raised/commentary**

- This case study is one example of many which highlight the lack of recognition by the NDIA of the need for specialist Coordination for people with complex conditions such as paranoid schizophrenia. Since the beginning of the financial year the NDIA has been significantly reducing funding for participants with complex psychosocial disability in the areas of “capacity building” and appropriate levels of Support Coordination with its additional function of resolving points of crisis.
- Recent plan reviews received have significantly reduced capacity building activities while often giving increased Core Supports. This is counterintuitive. In the realm of PSD it should be the reverse. Increased CB in the initial years should enable core supports to be reduced over time because of the *recovery focus* and increased opportunities for skill development and participation. These outcomes cannot be achieved without sufficient budgets in Capacity Building and hours provided for specialist Coordination, the domain of recovery focused work.
- The current ACT/NSW NDIS Price Guide provides a brief definition of the three levels of Coordination. Support Connection is inadequate for the level of PSD for the majority of our NDIS participants – we regularly provide “Specialist Support Coordination” – the higher level of Coordination, but we have never been provided this in the Plans for those of our participants with the most severe and complex mental illness.
Case Study No. 5

**Liz, 52, living with paranoid schizophrenia**

Liz’s first plan was approved in March 2016. Her mental illness is very complex, she is a very vulnerable person requiring high levels of support. Her initial plan was inadequate to meet her needs, albeit utilised to its limit. Towards the end of last year the participant became very unwell, with multiple admissions to hospital beginning in mid-November 2016.

In the midst of this NDIA called the participant and asked her if she was happy for her current plan to continue – much later we discovered this to be a “phone review”. Her Support Coordinator and key support in her life was not notified. The participant doesn’t remember the phone call because of the psychosis she was experiencing at the time. At the end of January the Coordinator contacted NDIA to discuss what was happening with her Plan, not knowing that a supposed Review had already taken place. A range of administrative issues ensued, including what could be called the ‘misplaced plan’ syndrome. The NDIA later advised that the initial Plan had been extended for another year and that the participant had approved this by phone on the 7th November. There was no paperwork supporting this, although a member of the NDIA staff sent a copy of the old Plan with the old dates. The SC received advice from that NDIA worker that we should put in a Change of Circumstances Form as the three-months had passed since the Review. It should be noted that the participant had been in hospital from the week after the phone call from the NDIA and she currently resides in Brian Hennessy Rehabilitation Centre.

**Issues raised/commentary**

- This case highlights once again the issues with complex participants whose conditions can both augment, and also be exacerbated by, a range of administrative problems with NDIA processes. It’s an unfortunate combination and the administrative problems need to be remedied in order to avoid undermining the aims of the NDIS.
Case Study No. 6

Peter, 38, living with paranoid schizophrenia and comorbidities

Peter’s story of a person with complex psychosocial disability is told in the following request for a Review of the case. Peter’s initial Planning Meeting was done without Peter being present, due to his anxiety about the process. Peter was a participant of the Housing Assistance and Recovery Initiative (HARI)/Housing Assistance and Support Initiative (HASI) program, a Commonwealth/Territory funded program for people with complex and persistent mental illness also at risk of homelessness, being transitioned to the NDIS. The Planner and SC discussed support requirements which all seemed satisfactory. The Planner stated she would send the Plan to the SC within a week. The eventual Plan however, only included an hour of “Capacity Building” a week, which significantly impacts on the ability to provide recovery focused services. The letter subsequently sent is included here:

Sept 2016

Dear ….,

Thank you for your time yesterday on the phone regarding P’s recently released NDIS Plan. I would like to take this opportunity to summarise our conversation yesterday as well as raise some other concerns.

As discussed yesterday, you advised me to utilise P’s Core Supports budget to address the serious short fall in his “increased Participation” budget. Unfortunately, even by combining both budgets (Core & Capacity Building) it doesn’t provide “reasonable and necessary” support over the duration of the Plan if you take into proper account P’s high and complex needs and severity of psychosocial disability. Furthermore, it leaves him seriously disadvantaged compared to the services he currently receives from us and thus breaches the “no disadvantage” commitment of the NDIA. As you are undoubtedly aware, this commitment was made through the Intergovernmental Agreement for the NDIS (IGA). The commitment is that people who become participants in the NDIS should be able to achieve at least the same outcomes under the NDIS.

After explaining to P how his NDIS Plan will affect the level of services he has been accustomed to receiving through the HASI/HARI program (all of which are reasonable and necessary services under the NDIA’s definition), he has advised us to immediately request an internal review on his behalf.

Under NDIS guidelines, reasonable and necessary supports are funded to help participants reach their goals, objectives and aspirations in a range of areas as well as:

- increase their independence
- increase social and economic participation and
- develop their capacity to actively take part in the community

Additionally, for supports to be considered reasonable and necessary these supports must:

- be related to the participant’s disability
- not include day-to-day living costs that are not related to a participant’s disability
- represent value for money
- be likely to be effective and beneficial to the participant; and
- take into account informal supports given to participants by families, carers, networks and the community.

All of P’s supplementary, clinical and preplanning documentation for his NDIS application were based on the support he was currently receiving and the above principles of what is reasonable and necessary and likely to be effective and beneficial to him in his recovery and in terms of his life goals and aspirations.

P’s NDIS Plan does not reflect the level of his needs and the severity of his psychosocial disability reported to you through his ARF, supporting evidence, “Getting Plan Ready” document and the Planning Meeting itself. P is diagnosed with paranoid schizophrenia and suffers from regular episodes of psychosis, high levels of paranoia (including hallucinations), isolation, loneliness and depression. On top of this he struggles with motivation in the face of these issues, particularly around making healthier life choices and addressing serious substance use issues. P has a severe trauma background as a result of childhood sexual abuse and is still experiencing grief and loss in relation to the deaths over recent years of his mother, father and brother (the latter two died as a result of their own substance misuse).
Issues raised/commentary

- Similar issues to case study 4, above, i.e. the needs of complex PSD participants are not being understood or accommodated by the NDIA.
## Case Study No. 7

**A female participant who went for an early plan review faced unfortunate consequences for the administration of the plan**

One of my participants went for an early plan review on 6 February 2017. According to her old plan, the review was to be in April 2017. The new plan began on 21 February 2017 and all the service bookings that were active in the old plan were made inactive on the portal by the NDIA. Due to what would seem to be a glitch with the portal, the SC was unable to make a standard service booking to activate the new plan. Although the plan says there is $1369.12 in CB Choice and Control, when the SC made the service booking there was an error message that says there are no funds available. 3 emails have been sent to the NDIS about this with no response. Recently a formal complaint was sent in.

This is particularly problematic for reviewed plans because we have regular services already in place. Our participants continue to receive services but we are unable to pay any invoices, because we cannot claim the funds from the portal. Also in the case of my participant she wants to go to hydrotherapy but we can’t start this until we know that the service can be paid for through the portal.

We waste an inordinate amount of time trying to sort these issues out with the NDIA. WCS has at least four participants that are affected by this ‘glitch’, and, in the absence of responses to emails, have already spent 45 minutes (mostly on hold) to the NDIS trying to sort this out – to no avail.

### Issues raised/commentary
- Communications with the NDIA taking too long and not being responded to.
- The necessity of contacting the NDIA to rectify inefficiencies in their processes and staff resources or plan resources going to fix inefficiencies in the NDIA’s systems.
- Management of plan transitions causing significant difficulties for service providers, participants and service coordinators.
- Reviews being conducted too early.

## Case Study No. 8

**Participant received insufficient notice of a plan review**

Participant received a phone call from NDIA asking if they can call her on a particular day but no clear reason was given. She asked if SC could be there and was told yes. When they called they said it was for a review of her plan (2 months earlier than date on her current plan). SC had discussed in preparation for the likelihood that the phone call would be a review and when participant was asked what she wanted she articulated her wishes but when the plan came out it did not reflect this as it had no capacity building in it and only a small amount of support coordination. My concern was that she wasn’t told why they were calling, or that she could have a face to face meeting for review of the plan. Also that it was 2 months prior to the earlier plan’s conclusion. Finally, if she hadn’t let her SC know there was no process that ensured the SC would be there to provide support to the participant.
Issues raised/commentary
- Insufficient funding in particular plan areas.
- Inadequate communication from the NDIA.
- Failure of communication regarding the review and the SC’s role at the review.

Case Study No. 9

The impact of a provider deregistering
Requesting review of plan: one of my participant’s guardians refused to put in for a review of plan in order to stay with a support service who had deregistered and was no longer accepting NDIS managed plans. Their reason for this was concern they would lose much needed funds to provide their son with capacity building in a number of areas of activities of daily living/social and recreational capacity building as a result of changing to plan management.

Issues raised/commentary
- A culture of fear is being created for participants and carers, and there is grave uncertainty among providers as well when the goal posts are continually shifted by the NDIA and reasons are not being communicated. The questions keeps coming up: Will hard won supports for these vulnerable participants be taken away? (See Richard’s story below).

Case Study No. 10

Portal issues
Having to wait several days before receiving a response in regard to a participant who wanted to access another service for Support Coordination. This resulted in participant being left with no support for several weeks as the inflexibility of service bookings having to have a 2 week time lapse between closing and rebooking. No leniency or leeway from the NDIA to alleviate the situation for the client and this affected support being offered from the new agency who attempted to liaise with the finance section, as well to no avail.

Issues raised/commentary
- ‘Portal’ issues frequently arise, and the problem isn’t simply the unhelpful software or the computer interface – rather it’s because the portal is the gateway to funding, so when it malfunctions, for all the many different reasons that it does, people are left without funding or they are blocked from accessing the planned supports they need. The portal is the site of so much grief because it’s where all the problems with the system coalesce, leaving people and agencies unable to access support or seriously out of pocket and dealing with all the stress that this entails.
Case Study No. 11

A good news NDIS story (so far).

Richard is 30 and was formerly a HASI/HARI participant. Prior to receiving his NDIS Plan he was admitted to Brian Hennessey Rehabilitation Centre (BHRC) for over 12 months. Prior to this, all other services and programs had failed in being able to meet his complex needs. He had been in both the PHaMs and then PIR programs over a period of several years. Housing was one of the major contributing factors in these programs not being able to assist him adequately. Before his admission to BHRC he lived in a public housing complex known for its high levels of violence and drug use. He had been transferred from several complexes like this since he left home in his early 20s, to his continual detriment.

Richard has a diagnosis of paranoid schizophrenia and mild intellectual disability. The combination of these conditions made him extremely vulnerable within the environments he lived. Things went from bad to worse. All the while he had the stoic and articulate advocacy of his parents. But it is unlikely the positive outcomes that are now being achieved would have occurred without the admission to BHRC and through the determination of his parents. There he was able to cease his illicit drug use, and have the medication for his mental illness fully reviewed. He finally received the care that he needed. He was also able to hand back the property to Housing ACT and receive help to apply for a further priority transfer. His parents and BHRC staff were also able to assist Richard to submit the NDIS Access Request Form with clinical and psychosocial evidence and other supporting documentation. Housing ACT came to the party with allocating Richard a property that would at last meet his needs and was mindful of his vulnerability. He now lives in a small Public Housing complex with an older demographic. It is quiet and safe and in the vicinity of his parents’ home, whom he still relies on.

All these things came together with an NDIS Plan that is flexible and responsive and recognises the high level of PSD, complex needs and degree of coordination required to bring together the supports and services that will begin to secure for Richard a better quality of life and greater opportunity. The Plan helped the transition from BHRC to Richard’s new Public Housing property and has assisted him to build on his independent and daily living skills, access to services in the community and mainstream services to address complex health and mental health issues and increased social and community participation. His parents have stated that Richard has never had the quality of support and level of services he now enjoys.

However, this turnaround has been gradual and step by step. Richard will need consistency in his future Plans to build on these achievements and to maintain progress. One thing that would make Richard’s current Plan even more flexible and responsive to his needs would be to have Plan Management (Increased Life Choices – Support Category 14 - which allows for accessing services not necessarily NDIA registered); but the parents are reluctant to ask for this. They have heard the stories of other less fortunate NDIS Plan recipients and fear that the supports so hard won for their son over so many years may be taken away from him by the NDIA’s internal review process. They fear that these supports for their son are not secure into the future and will be taken away by planners without understanding of the nature of psychosocial disability and recovery (see case study 11 above).

Issues raised/commentary

- While Richard’s story is a positive one, once again the uncertainties surrounding funding arrangements can be very destructive and threaten the good that can be done by the Scheme.
Part III: Answers to some questions posed by the Issues Paper

**Thoughts of a community based CEO involved in an NDIS trial site**

Due to its location within the ACT, Woden Community Service has been deeply involved with the NDIS right from the start. The following contains my responses to selected questions posed in the Productivity Commission’s Issues Paper ‘National Disability Insurance Scheme (NDIS) Costs’. It represents my thoughts on our experience over this time. It has been at times, and indeed remains, a very challenging journey and one that has tested our resolve and resources to their outer limits!

Both myself and the staff of WCS stand ready to give further evidence on these issues if the Commission has further questions or has specific issues it wishes to investigate. We would welcome the opportunity to contribute further to this Inquiry.

**Why are utilisation rates for plans so low?**

The introduction of the NDIS changed the nature of supports available to a person with a disability. People living with a disability under a block funded rationed program did not have access to the range of support services available through the NDIS. However adjusting to this radical change in arrangements takes time, and when you are living in stressed circumstances the process of adjustment can take even longer. Early plans included or acknowledged a broad range of services required by individuals, however those individuals were overloaded with services that they couldn’t utilise in the initial stages of their plans. If the resources could have been released over time rather than all being available from the beginning a higher utilisation rate would have followed. As it happened under-utilisation of plan resources has been viewed as a signal that the plans were over generous and included unnecessary provisions. However, in fact under-utilisation was more a reflection of the implementation process than any evidence that the supports were unnecessary.

The process of connecting people to services was very poor and changed frequently over time. The planning sessions originally comprised of a couple of meetings with clients where goals were discussed and aligned to funding. They were then pared back to a 50 minute session with approved plans then being emailed to clients with a list of registered agencies who could provide the approved services. Clients were left to navigate the system themselves if they weren’t already attached to a service, e.g. families with young children. Plans are now done with little to no input from participants which has led to an increasing level of cynicism around the issue of ‘Choice and Control’ so widely touted as a core tenet of the NDIS.

**Why are more participants entering the scheme from the trial sites than expected? Why are lower than expected participants exiting the scheme?**

The immaturity of the NDIS doesn’t allow sufficient information regarding the low numbers of people exiting the scheme. However initial information was provided in public forums in the ACT which indicated that places would only become available when clients died!

To be eligible for an IFP under the NDIS you must be established as having a permanent disability. It is inevitable that there will be few people exiting the Scheme. That is the nature of many disabilities.

An ongoing issue for mental health providers in the ACT, particularly in the recent past has been the seeming increase in funding for core supports (domestic assistance, cleaning, shopping) and fewer hours for capacity building – it is this activity that will build independent living skills, connect people with social and economic participation and eventually lead people off NDIS reliance.
There is a commonly held view that the NDIS creates reliance by over funding core supports, while it might be argued that these supports are necessary at specific times, however not for extended periods when people will acquire the skills and habits to do them for themselves.

**What factors are contributing to increasing package costs?**

It is questioned if there are in fact increasing package costs – these costs will increase as more people enter the scheme. The planning process identifies the range of services and their intensity required by clients. It is often the first time that people have an opportunity to accurately outline their service requirements through setting their own goals for living meaningful lives with choice and control. The planning process elicits these service requirements and the planners generate the plans which reflect people’s service requirements.

Our most recent experience is a reduction of funding in plans not an increase.

**Why is there a mismatch between benchmark package costs and actual package costs?**

The benchmarks should provide planners with assistance in developing plans, which the planner can consult and then apply the individual’s requirements against the benchmarks to determine an appropriate plan. The benchmarks should not determine the plan as individual differences will not be taken into account. One planner commented that the computer generated the plan. The concerns held by WCS are that people with similar conditions are likely to have widely differing needs in terms of activities and goals which are not adequately reflected in plans.

**To what extent have the differences in the eligibility criteria in the NDIS and what was proposed by the Productivity Commission affected participant numbers and/or costs in the NDIS?**

It is apparent that the NDIA has experienced some difficulties in determining eligibility, especially for people living with mental illness – see the case studies above.

Eligibility has a number of applications in NDIS – eligibility for the scheme, eligibility for appropriate scheduled items, eligibility for capacity building activities (once eligibility for the scheme has been established).

WCS’s Ability and Mental Health services work from a strengths based approach with a strong focus on recovery and capacity building. WCS is concerned about the NDIS focus on the notion of ‘permanence’, especially for people with psychosocial disabilities. This is due to the fact that while most of these conditions, particularly schizophrenia and bipolar disorders, are permanent conditions, if well managed clinically and with appropriate personal supports in place many people are able to lead full and meaningful lives.

In testing eligibility for NDIS people must describe their deficits and the debilitating effects that the condition has on their lives. This in itself is a demeaning introduction to the scheme which doesn’t encourage a description of what people have done to overcome their conditions. Moreover, people feel that if they present too positively, they won’t receive the supports that they need. So they must dwell on, and go into great detail about, the limitations that mental illness or the various disabilities imposes on them, rather than focusing on what they can do with support. This access model is totally at odds with best practice recovery approaches.

Not only are the Access Request Forms (ARF’s) deficit focused, the time delays in decision making regarding eligibility causes much anxiety for potential NDIS applicants. This is exacerbated when people who have been living with a mental illness and have been receiving services from community managed and clinical services are rejected for the scheme!

There is a commonly held view that tying what might be seen as ‘compensation’ or a monetary benefit to an illness or disability is likely to have deleterious effects on an ‘applicant’. It may be possible to reframe the process so that, as I have suggested, the focus is on the individual’s improved opportunities and prospects rather than how ‘severe’ a disability is.
Is there any evidence of cost shifting, duplication of services or service gaps between the NDIS and mainstream services? If so how can these be resolved?

It has been the community sector’s experience that the NDIS is a cost shifting exercise – moving the financial burden and risk from government onto the sector. This has been the case in every instance of transition to implementation of the scheme. The preplanning phase has fallen onto the sector for people who aren’t engaged with services, the planning phase entails hours of work in assisting people to develop their plans for discussion with the NDIA planner, the implementation phase where the sector has to fit together underfunded services for individuals. For example, Support Coordination is intended to identify appropriate services and arrange for service delivery. With reduced Support Coordination hours there is little time to undertake this role thoroughly, especially if there are crises to remedy. It is also our experience that it is not uncommon for Support Coordinators to wait on hold with the NDIA for up to 90 minutes.

There is serious underfunding for the provision of service by the NDIA. The delivery of services is based on the Level 2 SCHADS award – a fairly unskilled level of employment for what is a highly responsible and often challenging role. Most for purpose organisations provide induction, orientation, training and shadow shifts in preparing workers for support roles and to ensure that clients are comfortable with the worker. There is no allowance for any of these activities under the NDIS, however organisations still need to ensure that staff are adequately on-boarded and supported. It also raises concerns about the quality of service provision and about the ability to attract and retain staff. (This will also be addressed in the workforce section).

Are there other early intervention programs that could reduce the long-term scheme costs? How will the full roll out of the NDIS affect how mental health services are provided?

The roll out of the NDIS was conducted back to front – the Tier 2 service should have rolled out first providing support services to people, with a strong focus on capacity building and community engagement (especially from a psychosocial perspective) rather than cashing out mental health support programs such as Personal Helpers and Mentor program and Partners In Recovery, to fund the Tier 3 Individually Funded Plans. This would represent a logical early intervention process which would stream only those who were identified as needing longer term supports to the NDIS. As it is now configured people must test their eligibility for Tier 3, if they are unsuccessful they aren’t eligible for any services at all and are now falling into the yawning gap of no service provision.

The eligibility and planning processes for people with psychosocial disability (PSD) is overwhelming – the name itself (disability insurance scheme) does not readily lend itself to people with a mental illness and for this reason people with PSD do not think that it refers to them. The requirement of people to test their eligibility has created much anxiety for them, the process of testing, the wait for the outcome and if accepted the planning process which requires them to list their deficits and identify the supports required. Perhaps the biggest anxiety provoking challenge is dealing with the NDIA bureaucracy, the inexplicable letters, the preplanning, the face to face planning meeting and then the follow up (or not) once the plan has been approved – does it reflect the supports identified? If not, the only options are to live with a poor plan or go through a review/apPEAL process that may need advocacy.

Just understanding the complexity of the system is overwhelming for advocates and clients alike, as is understanding the power imbalance between the arbiters of the scheme (planners) and the (potential) participants. This has been exacerbated in the ACT due to our “trial” status where processes have changed regularly without notification or explanation. Community managed service staff have been vital in assisting people through all the NDIS processes, even though it was not initially part of their work. The role of staff changed frequently throughout
the trial especially in attending planning meetings and in advocating for substandard and inconsistent plans. The workers often bore the brunt of the planner’s displeasure for their determined advocacy in light of inconsistent plans that were not focused on client choice and control. The transition of people into the scheme would have been impossible without the support of workers, however the frustration of staff has risen due to the increasing tightening of processes and decision making by NDIA staff.

There are now fewer options for people and for services to refer to for support. The advent of the NDIS has drawn resources away from alternative service options or limited those options within existing services as organisations prepare for and deliver NDIS services. Group and community gathering options are rapidly closing in the ACT, reducing opportunity for social participation. “Market based” services will become the focus of service delivery as organisations seek to maintain their financial viability.

As a result the market is driving services away from recovery and rehabilitation principles and practices solely to pursue financial stability – the community is under threat of losing key service skills to organisational survival.

While the ILC held hope for people ineligible for NDIS this is no longer proving to be the case. There is a substantial gap in service for people ineligible for NDIS that needs to be addressed as a matter of urgency.

It must also be noted that there are also people, particularly with psychosocial disability, who are not appropriate to transition due to their perceptions/views of the NDIS or the impact of their conditions that prevent them from wanting to engage with the scheme.

**Intersection between the NDIS and mental health services outside the scheme**

From our experience the NDIA does not have the time to engage with services. Their focus is solely on getting eligible people into the NDIS and those who are not eligible don’t appear to be their concern. It appears there is very little interaction between NDIA and the services with everything being channelled through the formal bilateral process. The local Health Directorate staff rely on the taskforce representatives for an understanding of what the NDIA is considering.

**Planning Process**

The planning process is incredibly time consuming for clients and service providers. For clients, they must first agree to test their eligibility and therefore accept that they have a permanent disability and agree to engage with government bureaucracy regarding their conditions and their personal lives and consent to allow the NDIA to collect and hold often deeply personal information about them.

For this to occur, they must first understand the nature of NDIS and what it means for them. This usually requires continuing conversations, continual encouragement and support and ongoing work regarding the preplanning phase, working with clinical services regarding information for their plans and support through the planning process.

Much of this work is unfunded – some of it is covered by people who are in block funded programs, however there are many who are not. Much of this work falls to the support worker as there often aren’t families or support networks around clients, particularly those experiencing mental illness. The preplanning and planning processes take over 10 hours and in some cases more. The planning meeting with the planner only takes 50 minutes and is now increasingly occurring by phone. It is apparent that there is significant cost shifting to the not for profit sector through this process.

Consistent planning requires consistent planners – WCS’s experience of NDIA planners has been less than satisfactory as they have changed regularly and sometimes not completing the plans they have commenced. In the PSD area we requested dedicated PSD experienced planners, particularly with one set of clients with profound mental illnesses. Originally the NDIA did establish a specialised team to work with this client group however this was short lived and reflected the lack of leadership.

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commitment to this group. The Regional Manager who possessed extensive experience in mental illness moved on and with her the commitment to targeted PSD plans. The plans that are now being created, based on computerized bench marks, do not appear to be consistent. At one stage WCS was informed by a planner that the computer would be generating the plan. We have presented the NDIA with comparative plans for different people with very similar psychosocial disabilities which demonstrate the wild variation in funding for clients. The NDIA did offer to forward this information onto their quality team however there has been no response to this inquiry.

The plan review process that has been recently instituted, without any consultation, is an insult to clients and providers alike. The reviewed plans often have reduced Support Coordination and capacity building hours. The Support Coordination hours are essential for maintaining the consistent delivery of service through close engagement with clients reliant on support coordinators, particularly at times of crisis. There has also been a significant reduction in plan capacity building activities which support people to become more independent and over time will lessen their reliance on NDIS funding. However there has been an increase in core funds for services, such as cleaning and shopping that only tend to create reliance on ongoing funding.

**ILC**

Is the range and type of services proposed under the ILC program consistent with the goals of the program?

One area of major inconsistency is clarity of ILC – this is a shape shifting program since it was first announced. The ILC has been reduced in funding to a paltry amount with such rigorous criteria that only organisations with the time to develop service responses and apply for highly contested amounts would consider it.

ILC, as the Tier 2 service, initially held much promise of supporting organisations that provided information and referral services and built capacity for natural supports for people living with a disability. The reality is that many small targeted associations that previously received small operational grants to conduct their work, such as the Brain Injury Association or the Down Syndrome Association, do not have the resources to apply for ILC funding and as a result will be without funding at the end of this financial year. What will happen to those small independent associations – they may need a larger benefactor to support them and carry their financial burden (however small). The role of the LAC has changed significantly. What is most striking is the fact that LAC is now essentially an extension of the NDIA, doing work on its behalf that was previously done by registered providers, namely plan connection and plan activation rather than connecting people living with a disability to unpaid natural supports, educating and developing an awareness of disability in the broader community, breaking down barriers for people living with a disability which have been the traditional functions of Local Area Coordination.

What factors affect the supply and demand for disability care and support workers?

As briefly stated previously the NDIA’s determination to cost most services at the SCHADS Level 2 severely restricts organisations’ ability to attract and retain appropriately trained and skilled people given the nature of the work. The constant NDIA changes that the ACT experienced over the two and a half year transition made it extremely difficult to maintain a workforce. Processes and rules changed regularly which increased the instability of a highly destabilised sector. The ACT community sector competes with the Commonwealth and ACT Public Services for staff as they offer better pay and conditions. This, combined with the low level of pay, makes the jobs unattractive.
What scope is there to expand the disability care and support workforce by transitioning part-time or casual workers to full-time positions?
If anything the opposite is the case – employees are transitioning to part-time or casual positions rather than full-time employment. Services transitioning to the NDIS arrangements have had to review their workforce arrangements significantly. Woden Community Service made our entire disability service workforce redundant as they were employed at the SCHADS 4 Level. Staff who were prepared to were re-employed at the Level 2 rate on fixed contracts for a minimum of 15 hours per week. This led to some employees leaving the organisation as we weren’t able to offer them full-time employment due to the transitioning arrangements that saw people move from the block funded service to the NDIS with different activities than those we were offering.

“Marketisation”
Are the prices set by the NDIA at an efficient level? How ready is the disability sector for market prices?
No, the prices set by the NDIA aren’t at a sustainable level and are driving services out of business. The only NDIA line item that enables agencies to “break even” is plan/support coordination, although the hours dedicated to this area are restricted and often inadequate. It is planned that Support Connection, which is a less intensive support coordination, will now be delivered by the Local Area Coordination service. As a result, agencies who have established these services are now losing these clients to LAC – for Woden Community Service this means 43 clients are transferring to LAC with the commensurate loss of income and the cessation of employment for those staff employed in this role.

How do in-kind services affect the transition to the full scheme and ultimately scheme costs?
This is a question that can be best answered by funding departments such as Social Services and Health. From the community sector perspective there has been much confusion about in kind arrangements from both state and commonwealth departments and the NDIA alike. This process has not been managed well at all.

How will the changed market design affect the degree of collaboration or cooperation between providers?
In the ACT there was some early work done with services looking at alliances or shared approaches to service delivery, however, this activity did not deliver any significant service integration or shared services approach. It is most likely that there will be increased mergers or acquisitions as there have already been a couple of services that have “gone under” in the ACT. The reality is that most service providers are going it on their own, some, though, have either decided to deregister and provide plan managed services only and not agency managed plans or are in the process of doing so. Their experience of dealing with the NDIA has provoked them into reconsidering their service approach.

How well equipped are NDIS eligible individuals to understand and interact with the scheme etc?
In a nutshell not very well, however, it does depend on the nature of the disability. WCS believes that people who have parent advocates are in a much better position than those who are left to their own devices or who are assisted by a support organisation.

Governance
Do existing administrative and governance arrangements affect the provision of services or scheme costs?
Yes! Constantly changing rules, planner churn, expensive administrative arrangements and an IT system that left providers and clients without the means to claim payments have all been very expensive and have had an impact on the effectiveness of the scheme. Engagement with the NDIA
has been episodic depending on personnel, communication from the NDIA has been almost non-existent (with the latest directive being that nothing will be provided to services in written form!). A lot of information goes into the NDIA however very little comes out. Our representations to the NDIA around issues of concern, mostly those involving participants, have not been given satisfactory responses.

**Does the way that the NDIA measures its performance affect the delivery of service?**
WCS believes there is a NDIA narrative that it is out performing expectations/measures. This is an “alternate fact” and has not been the experience of the sector in the ACT. When the NDIA self-reports its own performance in the glowing terms that it does, it may cause a loss of focus on the need to continuously improve delivery of service, which we believe should be front and centre of the NDIA’s collective consciousness!

**To what extent do the existing regulations provide appropriate safeguards and quality controls?**
The sector is still waiting for the safeguard and quality framework to be delivered – it is now two and a half years in and there is no framework!

**Are there appropriate and effective mechanisms for dealing with disputes?**
No! All mechanisms are extremely time consuming and usually result in NDIS activities on the matter in dispute ceasing until an outcome has been determined.

**Is there a better way for funding the NDIS?**
Yes – increase the Medicare levy, don’t touch allocated welfare payments.