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| IMPROVING THE NDIS EXPERIENCE – Establishing a Participant Service Guarantee and removing legislative red tape | **Abstract**  ***This Submission is a call for action to improve the participant’s experience of accessing and seeking support through the NDIS in a manner that is transparent, fair and informed by the human right principles and social justice.***  ***Noela McKinnon***  ***Policy Consultant***  ***roundsquared***  **PO Box 460**  **Moruya NSW 2537**  **roundsquared.net.au**  **ABN. 75 100 256 264** |

IMPROVING THE NDIS EXPERIENCE – *Establishing a Participant Service Guarantee and removing legislative red tape*

**EXECUTIVE SUMMARY**

​**This submission is a call for action to improve the participant’s experience of accessing and seeking support through the NDIS in a manner that is transparent, fair and informed by the human right principles and social justice.**

As an independent peer organisation providing a range of support services as well as support coordination and plan management to people with disabilities and their families/carers across rural and regional locations of NSW, *roundsquared* is well placed to provide comments on the NDIS experience of a cross section of NDIS participants***.*** *roundsquared* acknowledges that the NDIS experience has been positive for many people with disabilities and their families, some of whom are receiving support/services for the first time in their lives. Many participants, however, are reporting quite different experiences with stories punctuated by frustration with the access and planning processes; wrongly or only partially recorded information; thoughtless comments by planners particularly in relation to the family’s caring role; a disconnect between the construction of their goals and the reality of their needs; difficulties accessing services and supports in their local area due to a lack of allied health professionals and other services; and the unwillingness of other government departments to accept responsibility for providing services and supports recommended in their NDIS plans.

Factors associated with a positive plan outcome include the ability of the participant or their family/carer, to articulate clearly their/the participant’s goals and the supports needed to achieve these goals; having a good understanding of government processes, the scope of the scheme and where services can be accessed from mainstream and community sectors; residing in a metropolitan area where there are multiple service providers facilitating choice and control; and the LAC and planner’s attitude, competence and knowledge of different disability and their impact on a person’s functional capacity. Providing on-going support coordination to participants in rural and regional areas would assist help address these issues by supporting the participant through the process and negotiating with limited services. *roundsquared*also supports draft plans being provided to participants prior to finalisation to ensure the correct recording of information.

The process is even more fraught for people with psychosocial disabilities, many not meeting access despite their long term diagnosis of severe and persistent mental health issues and their receipt of services through Partners in Recovery [PIR], the Personal Helpers and Mentors [PHaMs) or Day-to-Day Living [D2D]. For those that meet access, many planners and LACs have a poor understanding of mental health conditions, recovery and providing a trauma informed approach to the plan meeting.

**Priorities for Action**

Feedback from *roundsquared* members and consultants highlights the need for urgent action to be taken by the Morrison Government to address major problems evident in the administration of the National Disability Insurance Scheme (NDIS). From *roundsquared* perspective, seven key areas are priorities for change. These are:

1. the need for the development of an integrated service model to underpin the Scheme. If the Government is committed to improving the NDIS experience, then a more integrated approach needs to be developed to delivering services to participants in a seamless manner. Government Departments at both the Federal and State/Territory levels need to work collaboratively to break down the silos that currently exist and accept responsibility for providing services rather than using the NDIS as a way to reduce their costs.
   * *Part 2 Objects and principles of the NDIS Act 2013 (p.4-5) states the need for ‘providing the foundation for government to work together to develop and implement the national Disability Insurance Scheme’. This is clearly not happening as currently many Federal and State/Territory Departments see the NDIS as being solely responsible for all the services and supports recommended in a participant’s plan.*
2. the need to reconsider the centrality of goals to the Plan and in the planning meeting. Members and consultants alike report that the process poorly articulates with identifying how the person with disability can maintain/improve their functional capacity and physical and emotional well-being and enhance their social and community engagement.
   * *The focus on goals can often mean that critical issues for the participant are not discussed and therefore not included in the plan. What needs to be remembered is that the planning meeting can be quite stressful and overwhelming for participants particularly for those who have had negative experiences with other government instrumentalities such as Centrelink.*
   * *roundsquared members and consultants are reporting that what the participant has stated as their goals at the planning meeting are not what have been included in their plan but their goals rather massaged by the LAC or planner to fit with the NDIA’s requirements, while the sub-sections relating to the goals are often not addressed at all in the meeting and completed later by the planner or LAC.*
3. need for consistent information to be provided by NDIA planners and local area coordinators to participants and their families/carers as well as greater transparency around the decision making processes.
   * *roundsquared members and consultants are reporting that they have been told one thing by one planner and something quite different by another planner. This is increasing the level of frustration being felt by members when they want to know why a particular service or support has not been included. Parroting off the phrase that ‘the service/support did not meet reasonable and necessary criteria’ without specific information about why is didn’t meet such criteria is quite disempowering for the member as it removes any basis for dialogue on the issue. Requesting a written response outlining the specific reasons why ‘R & N’ criteria were not met, is similarly fraught with planners refusing to provide a written response.*
   * *roundsquared members and consultants**support**ongoing support coordination to assist**participants in rural and regional areas engage with limited services; and the provision of draft plans to participants to enable them to provide additional information or correct wrongly recorded information prior to the plan’s finalisation.*
4. The need for greater recognition of the difficulties and additional costs faced by participants in rural and regional areas in accessing services and supports with additional funding needed to address the cost of/lack of transport services in many areas.
   * *The issues of rural and regional areas were not referred to at all in the discussion paper. Australia is not a level playing field with services equally accessible across all geographical locations. The tyranny of distance is a very real for people living outside the major metropolitan areas with access to a range of services limited or, in some instances, non-existent. Additional time and funding is required in the plans of people in rural and regional areas to enable them to access services in larger centres and to cover the travel times of therapists and support workers to their town/home. Services that are very thin on the ground in many rural areas include bulk-billing GPs, clinical psychologists, behavioural therapists, occupational therapists, orthotists and prosthetists. Poor or non-existent public transport is another issue that undermines access to services for people needing to access services in another centre. Creative models need to be developed to enhance access to allied health professionals and to provide a greater range of low cost community transport options for participants in rural and regional areas.*
5. The need for substantial reforms to the participant pathway to ensure people with psychosocial disability are not deemed ineligible as well as the recruitment of planners and LACs with specific experience dealing with people with mental illness and psychosocial disability. A separate pathway for people with psychosocial disability warrants consideration.

* *CMHA (2019), MHA (2018) MHA (2019), VMIAC (2018) and CDRP (Uni of Sydney 2018) have all raised issues about people with psychosocial disabilities’ accessing the NDIS with CDRP stating in their* ***Mind the Gap*** *report that ‘Current participation in the NDIS of people with a primary psychosocial disability is low and indicates multiple difficulties in the implementation of the Scheme. Latest NDIA figures show that only 6.4% of Scheme participants have a primary psychosocial disability which is less than half the expected numbers’. CMHA echoes similar concerns ‘about the lower than expected numbers of people successfully transitioning’ from PIR, PHaMs and D2D] into the NDIS. CMHA points to only 50% of PIR, PHaMs and D2D participants have applied to the NDIS and that of these only 50% have met access. VMIAC pointed to the lack of fit of the NDIS assessment process ‘with recovery-oriented mental health practice, where the focus is on building hope and working with strengths. Instead the NDIS focus is on permanence and deficits.’*

1. The need for a comprehensive workforce planning strategy that not only includes the improved recruitment and training of NDIA planners and local area coordinators but also looks at skills enhancement training and career path options for support workers; the recruitment and retentions of allied health professionals to areas of workforce shortage e.g. rural and regional areas; innovative training options, financial incentives and workforce modelling to address gaps in service delivery:

* *roundsquared**supports Services for Rural and Remote Allied Health (SARRAH) concept of a Allied Health Rural Generalist Pathway to enable the development of specialist roles within the various allied health professions in non-metropolitan areas. [See:* [*https://sarrah.org.au/ahrgp*](https://sarrah.org.au/ahrgp)*]. To retain skilled support workers in regional areas and to support the role of AHPs, roundsquared supports the development of career paths for support workers through, inter alia, the active promotion of the Certificate IV Therapy Assistance Course and the development of incentives such as fee moratoriums for those undertaking the course.*
* *roundsquared**supports the MHA’s call for reforms to the NDIS pathway for participants with psychosocial disability and ‘for improvements in the skills, knowledge and experience of NDIA and partner staff to work with people with psychosocial disability’. (20*18:5)
* *roundsquared also supports situating a mental health peer worker role within the LAC/planner team to improve their understanding of recovery, social inclusion, stigma and how mental illness can impact on the participant’s physical health, economic and employment status and their social and community engagement.*

1. The need to include an amendment to Sub-section 4 (12) and sub-section 31c the NDIS Act 2013 to directly reference the caring role of families so that they align with the ‘recognise and respect’ terminology of the Carers Recognition Act 2010 and that specific and urgent action be taken to ensure that the NDIA embraces Part 3 s8(1)

* *‘to take all practicable measures to ensure that it, and its employees and agents, take action to reflect the principles of the Statement for Australia’s Carers in developing, implementing, providing or evaluating care supports’ for participants.*

Helen Fisher Mark Pattinson

Director Director

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RECOMMENDATIONS

1. **That a core aspect of the community engagement work of the NDIA and its Partners in the Community [PITC] organisations be to engage with local hospital rehabilitation departments, mental health units and discharge staff to ensure that people about to be discharged from the hospital have a seamless transition to NDIS supports to enable them to access appropriate therapies, assistive technology and support services that will support them in their home environment.**
2. **That Mental Health Australia’s call to improve the access process for people with psychosocial disability by building specific competencies in mental health and psychosocial disability for planners and LACs; ensuring there is expert oversight of plans for people with psychosocial disability; and ‘providing a greater level of information and support (including peer support) for people with psychosocial disability at the pre-planning stage’ (MHA 2018:22) be supported.**
3. **That the planning meeting be made more transparent by changing the focus on goals in the planning meeting with a discussion focused on the needs of the participant and what services and supports would contribute to improving their functional capacity and enhancing their social, economic and cultural inclusion and well -being.**
4. **That the NDIA provide participants with a draft of their Plan prior to the determination of supports and funding to reduce the incidence of wrongly recorded information leading to requests for reviews and to provide the opportunity for participants to highlight incorrect information or omissions and confirm or reject the goals and sub-goals outlined in the draft.**
5. **That to streamline the planning process, that the Local Area Coordinator [LAC] making the booking for the plan/plan review meeting not only verify the participant’s personal details but also ask if there are any changes to their informal, community or mainstream supports; and complete the WHODAS, PEDICAT or other disability instrument appropriate to the participant’s situation.**
6. **That the following measures be taken to improve the transparency of the decision making process and the consistency of information provided to participants Improving the recruitment process for LACs and planners so that people with a sound understanding of disability, functional capacity and support needs and options are actively recruited;**
   1. **Improving the training of LACs and planners so that they understand better the legislation and rules that underpin the NDIS and develop plans that are in accordance with this legislation rather than based on assumptions or ill-informed prejudices.**
   2. **Providing planners and LAC with more time to provide a person-centred approach that ensures that all the relevant information about a participant’s situation and needs is included in the development of the plan. This will ultimately be a time saver as it should reduce the number of requests for light touch and full reviews;**
   3. **Providing participants with a draft copy of their plan so that they can see if their information is recorded fully and the goals that are articulated in the plan are theirs and not the edited version of the LAC or Planner so that funding can be more easily related to the goals;**
   4. **Providing participants with written justification for any cuts of more than 10% to any part of their plan budget, how these reductions have been determined, and what evidence they have used to make their decision.**
7. **That support coordination be retained for all participants in ‘thin market’ areas such as rural and regional communities beyond their first plan to assist participants identify therapy and other support options in the region if not in their local community**.
8. **That an integrated service model be developed to underpin the NDIS with inter-Departmental protocols in place to ensure that participant’s need are central thereby enabling them to access the services of other instrumentalities relevant to the achievement of their goals and their improved functional capacity and social inclusion. Such protocols need to provide clearly articulated processes and timeframes for responses from other instrumentalities and clear guidelines as to how to progress service engagement.**
9. **That *subsection 4 (12*) and *subsection 31(c)* be amended to align with the ‘recognise and respect’ terminology of the Carers Recognition Act 2010’ as outlined in the COAG agreed amendments from 2015 NDIS Act Review.**
10. **That the NDIA work collaboratively with other government departments and allied health and care workforce groups to attract and retain allied health professionals and support workers in rural and regional areas and that the Morrison Government support the concept of an Allied Health Rural General Pathway to enable development of specialist roles within the various allied health professions in non-metropolitan areas. [See:** [**https://sarrah.org.au/ahrgp**](https://sarrah.org.au/ahrgp)**]; and the development of career paths for support workers through, inter alia, the active promotion of the Certificate IV Therapy Assistance Course through fee moratoriums and scholarships.**

*INTRODUCTION*

***roundsquared***is an independent peer organisation providing flexible and responsive support, mentoring and consultancy to people living with disability and families of people living with disability. A key focus of ***roundsquared*** is to assist our members (not referred to as clients) lead good lives through improving opportunities for social, economic and cultural inclusion as well as access to supports that will enhance their functional capacity. ***roundsquared***  consultants work with the individual and their family to utilise their NDIS funding in the most effective manner to achieve their goals and to facilitate access to appropriate mainstream and community resources and services. ***roundsquared*** also supports members through crisis resolution and with building self-advocacy skills. ***roundsquared***is a for purpose company: i.e. since our establishment we have distributed our surpluses to members and employees. From March 2019 ***roundsquared*** is donating 50c from each invoice processed to overseas charities.

***roundsquared*** has 256 members ranging in age from 3 to 65years with disabilities across the spectrum including physical, intellectual, cognitive and psycho-social; many having multiple and complex needs. Our main office is located in Moruya with our members located in southern NSW (Eurobodalla, Bega, Illawarra, Shoalhaven and Southern Highlands LGAs). Members, consultants and support workers are also located in greater Sydney and Northern Rivers. All consultants have several years’ experience in the disability sector, many with their own lived experience of disability or as the parent/carer of a person with disability. Three ***roundsquared*** consultants are experienced LACs who have provided an insight into the training and other issues for planners.

***roundsquared*** considers the principles informing the NDIS provide the basis for a more inclusive society for people with disabilities in Australia – a society informed by a human rights framework where individual agency and choice and control are pivotal to effecting Australia’s obligations under the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD). ***roundsquared*** however, believes the NDIS has lost its way with political, economic and bureaucratic expediencies taking precedence over the needs of participants as evidenced by more participants receiving reduced funding in the plans; the increasingly unrealistic perspective of planners in relation to parental responsibility to provide support to their child/children with disabilities; the long lead times for home modifications and larger assistive technology items; and the rising number of requests for reviews of reviewable decisions and AAT applications. Underpinning these concerns is the increasing dominance of an insurance paradigm at the expense of the human rights of the person with disability and their families/carers and the lack of transparency in relation to the decision making processes informing the construction and funds allocation to participants.

***ROUNDSQUARED*’S RESPONSE TO ISSUES RAISED IN THE DISCUSSION** **PAPER**

*This response is made on behalf of the* ***roundsquared*** *members and their families who have reported to us issues of dissatisfaction with their NDIS experience. The process of responding has been quite onerous and demonstrates the complexities and difficulties experienced by participants trying to access the NDIS and secure funding that enables them to build/maintain their capacity and enhance their opportunities for social and economic participation and inclusion.*

**THE GOVERNMENT’S COMMITMENT TO THE NDIS**

***roundsquared*** notes that the Government has acknowledged on page 1 the need for improvement in ‘the quality of planning, communication with participants, their families an carers and the administration of reviews’ and that ‘efforts are underway to address the concerns about timeliness, quality and consistency of decision-making and to provide stakeholders with further information about how access and planning decisions are made’. Mention is then made of the NDIS Pathway Reform that incorporates the new NDIS Participant Pathway designed to provide a single point of contact for participants, easier to read plans and better training of NDIA planners in the diverse needs of people with disability.

To date there is little or no evidence of any improvement as a result of this new pathway. Plans are no easier to read as a result of the changes to the development of goals and their sub-sections on ‘how these will be achieved’ and ‘how the participant will be supported’. This process may appear logical to bureaucrats and others who are used to strategic planning and professional development planning, but for many people with disabilities and their families/carers this process is onerous, confusing and quite disempowering. For example, in developing their goals participants are not to include the word ‘support’ as this is not considered a goal but rather a means to achieve a goal. For some however, accessing support to assist them to access the community, for example, is a goal in itself as locating a ‘support’ person can be difficult, as can developing rapport and confidence with that person to be able to access the community. Section 33 (1) states: ‘A participant’s plan must include a statement (the participant’s statement of goals and aspirations) prepared by the participant’. Section 33 (8) states: ‘A participant’s statement of goals and aspirations need not be prepared by the participant in writing, but if it is prepared other than in writing, the Agency must record it in writing.’ Nowhere in the Act does it state that the goals and aspirations of the participant can be ‘massaged’ by the LAC or Planner to comply with internal directions of the Agency such as not including words such as support in their goals.

The two-tiered approach to planning where LACs do the planning meeting and develop the plan with the NDIA planners determining the funding to be provided for core and capacity building supports is not working well for many participants. The reasons that it is not working can be that the LAC has not provided comprehensive information and justifications in the Participant Conversation Template (PCT) to justify supports. This might be the result of poor training; the inability of the LAC to articulate clearly the situation; time constraints resulting in a rushed planning meeting; a lack of understanding about the importance of particular information to the participant’s disability and level of functional capacity; the ever-changing NDIS processes; or the failure of reports to be uploaded on the system. Alternatively the fault can lie with the planner who has made assumptions about the level of support needed for a particular disability type and who gets some sort of perverse sense of power in being able to be tough with the expenditure of public funds. What is becoming increasing evident is that a good plan is very much dependent on getting a good LAC and planner who are both empathetic to the participant’s situation and realistic and fair when determining what are ‘reasonable and necessary’ supports.

Many participants have reported that the goals that they stated at the time of the planning meeting are not the ones that have appeared on their plan. This increases the sense of disconnection between the participant and the process. For example, a participant said that her goal was to get a new wheelchair. But the goal in her plan was that she wanted to improve her mobility in the home and the community. The participant wanted a new wheelchair not to improve her mobility in the home and community, but to improve her comfort as her body weight and shape had changed and the wheelchair was old and getting worn on the arm and headrests. This indicates the assumptions that the planner made in relation to the goals of participants. It was not person-centred but informed by the planner’s experience and assumptions. There may well be participants who find this process relatively easy and worthwhile particularly if it enables them to argue for additional supports under an umbrella goal. For others the process is overwhelming as they try to reinterpret their needs (e.g. for a wheelchair or personal support for community access) into acceptable goals. Many participants do not come to their planning meeting with the goals and sub-sections completed. This is particularly the case where the participant does not have a support coordinator to help them or where their family member or carer is similarly intimidated by the process. The goals are often formulated at the planning meeting, and as the time frame allowed for the planning conversation is not sufficient to coach the participant through the process, the LAC or planner writes the goals. This process fails the test of being person-centred for many participants.

What also needs to be considered is that the planning process can be quite daunting for many participants leading to increased levels of anxiety. ***roundsquared*** consultants report that many of the members they support through the planning process express high levels of anxiety about the planning meeting. These reports are consistent with the findings of the AIHW (2019) ***People with Disability in Australia***, where 32% of people with disability reported high to very high levels of distress compared with only 8% of the people without disability.

KEY ISSUE: RURAL AND REGIONAL

The discussion paper also acknowledges that when the NDIA processes are not effective they impact on key cohorts such as children, people with psychosocial disability and people requiring specialist disability accommodation (SDA), home modifications and assistive technology. Another cohort that warrants particular attention are participants in outer-regional and rural/remote locations. The Australian Institute of Health and Welfare (AIHW) 2018 found that access to health professionals such physiotherapists, psychologists and OTs in outer regional areas was about 50% less than people in major cities. Access to medical specialists is even worse averaging about 35% of the accessibility in metropolitan areas. (AIHW 2018 p8). These shortages have major implications for participants in rural and regional areas whose disability often requires trips to Sydney or Canberra from the Eurobodalla to access medical specialists and the more specialised allied health professionals such as OTs for car modifications, prosthetists etc.

Also to be considered is the health status of people in rural and regional areas (AIHW 2018) which is poorer than in metropolitan areas due to lower socio-economic status, more dangerous occupations such as farming, long haul transport and mining, and higher levels of smoking and obesity. To cover the needs of rural people the patient-to-provider ratio needs to be higher than in urban areas to address not only the needs of participants on the NDIS but also people with chronic health problems such as asthma, diabetes, cancer, musculoskeletal issues, osteoporosis and cardio-vascular disease.

At a recent ***Thin Markets*** workshop run by Ernst Young in Canberra, attendees pointed to the change in the structure of the allied health workforce in rural and regional areas as a result of the NDIS with an increase in the number of sole traders leading to fewer opportunities for graduates and undergraduates to be mentored in these areas. This increase in sole traders has effectively reduced collaboration between professionals as each seeks to carve out their market share. Such a situation may respect participant confidentiality but can limit opportunities to develop different models of service delivery that are more responsive to individual needs as well as being able to provide mentoring to new graduates. If market forces are left to find their own equilibrium, participants in rural and remote locations will either have to wait longer periods of time for assessments, equipment, home and vehicle modifications and therapies; or travel considerable distances to access services; or simply go without because it is just all too hard.

***roundsquared*** welcomes the changes to assistive technology and is pleased there is no longer a need for quotes for items under $1500. As with access to allied health professionals and medical specialists in rural and regional areas, access to assistive technologists is very limited in many rural and regional areas with very few assistive technology assessors. This increases the wait times for assessments and provision.

An increase in the supply of Specialised Disability Accommodation is needed particularly to address the needs of younger people who are in residential aged care. In rural and regional areas the options are few and far between. The NDIA needs to be more proactive about increasing the stock of accessible housing throughout Australia both in the public and private markets. More affordable and accessible housing would not only benefit people with disability but with our ageing population would result in fewer demands for home modifications that are time consuming and far more expensive than inclusion at the time of construction.

KEY ISSUE: PSYCHOSOCIAL DISABILITY

The need for improvement is nowhere more needed than for people with psychosocial disability. The area of psycho-social disability highlights a lack of understanding on the part of planners and LACs. The ‘episodic nature’ of mental health conditions and the concept of ‘recovery’ are poorly understood by planners. The episodic nature refers to periods when the escalation of symptoms occurs – it does not mean that the underlying mental health condition is not present when such escalation of symptoms is not present. However, this misinterpretation has resulted in many people with lifelong conditions such as bi-polar disorder, schizophrenia, borderline personality disorder and PTDS failing to gain access to the scheme.

The stress of the application process often deters people with mental health conditions from reapplying resulting in a lack of access to services and supports that can lead to crisis situations. Many physical disabilities such as MS can have symptoms that are episodic particularly in the early stage but they are not denied access to the NDIS. As has been the case historically, physical health and disabilities are far better understood and responded to than mental illness and psycho-social disabilities. Such a dichotomous approach to the determination of access to the NDIS and to the supports available to participants does not reflect a person-centred approach to the needs of the individual to enable them to enhance their functional capacity through access to services and supports to reduce their social isolation and enhance opportunities for social, cultural and economic participation. The following case study illustrates some of the difficulties experienced by people with mental health conditions accessing the NDIS.

Case Study Joan (alias)

*Joan has been diagnosed with PTSD, depression and anxiety. She has a partner and a son who are both participants of the NDIS. Joan has been denied access to the NDIS because she will not give the history of why she has developed PTSD. She has provided reports from her GP, psychiatrist and psychologist. Joan is unwilling to reapply as she does not want to be told yet again that she must re-live her trauma in order to access support. Such a determination shows a complete lack of understanding by the planner of the nature of PTSD and is not consistent with either providing a person-centred or a trauma-informed approach to the planning process. It is also falls short of being informed by an understanding of what recovery is.*

The current participant pathway is not just a poor fit but for many people with psychosocial disabilities the process is a ‘negative one, resulting in additional trauma and distress’. (MHA 2018:8). The Mental Health Association (MHA) goes on to explain that ‘People with psychosocial disability often experience the inherent vulnerabilities which result from a personal history of mental health hospital admissions and potentially involuntary treatment, including seclusion and restraint. This can make it difficult to navigate an often fragmented mental health sector … [where] …mental health services are generally poorly resourced, operating in an environment where there are major gaps in service provision across the country and ongoing uncertainly about the provision of support both within and outside the NDIS.’ (MHA 2018:4) ***roundsquared*** supports the MHA’s call for the NDIA to ‘develop an overarching psychosocial disability strategy’ that includes

* reforms to the participant pathway for people with psychosocial disability
* improvement in the skills, knowledge and experience of LACs and Planners to work with people with psychosocial disability
* reforms for reference packages to ensure a substantial improvement in the quality of plans for people with psychosocial disability
* a communications strategy to understand how these changes will be put into practice. (MHA 2018:5).

**THE PARTICIPANT SERVICE GUARANTEE**

***roundsquared*** members welcome a Participant Service Guarantee that will set ‘new standards for shorter, but realistic timeframes for people with disability to get their NDIS plan and have their plan reviewed’. However, realistic timeframes also need to put in place for s48 and s100 reviews to ensure that (i) the participant is informed within 14 days whether their request for a review has been successful or not; and if not, the reasons why; and (ii) the review is conducted within 30 days so that a new plan that is responsive to the needs of the participant is in place to maximise goal achievement. Currently, in relation to (i) the participant is not informed that they have been unsuccessful in their request for a review. They are to assume that if there is no response within 14 days they have been unsuccessful. In relation to (ii) participants are currently waiting up to 9 months to have a review. This effectively means that they are waiting until their next scheduled review. For a participant to have to wait nearly a year for a review of a reviewable decision because particular items have been omitted or their significance misunderstood by the planner, is not a reasonable response from the NDIA.

**Possible principles for NDIA service standards**

***roundsquared*** makes the following comments in relation to the key discussion questions.

1. **Which of the principles [below] do you think are important for the NDIA to adhere to and why?**

***roundsquared*** sees all of the principles as important. However, better wording is required to embrace a real sense of change and commitment. Our suggested changes are in **Purple.**

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| **Principle** | **Description** |
| Timely | ~~The NDIA processes will be easier to understand and use, enabling decisions about access, planning and review to happen promptly.~~  **NDIA processes provide a timely response that enable the participant to understand how and why decisions were made about access , planning and review**. |
| ~~Engaged~~ –  **‘Consulted with and involved’ are preferred as they denote a more active involvement**. | The NDIA ~~engages~~ **consulted** **with and involved** people with disability, their family and carers and other support persons when developing operating procedures and processes. |
| ~~Expert –~~  **Informed**  is a better word as NDIA staff would not be expertsunless they have qualifications in OT or similar. | ~~NDIA staff have a high level of disability training and understand the impact particular disabilities have on people’s lives. They understand what supports are most effective for a person’s disability.~~  NDIA staff have a high level of training so that they understand the nature and limitations on functional capacity of a particular disability. Staff will have a sound understanding of the most effective supports available to enhance the functional capacity of the person with disability and will have subject matter experts in the areas of Assistive technology, specialist disability accommodation, psycho-social disability and children and young people with disability. |
| ~~Connected~~  **Cooperative and collaborative** approach to policy and program development | The NDIA works well with **other Federal, State and local** governments, mainstream services (such as health, education, justice services), disability representative groups and providers to ensure people with disability have coordinated and integrated services. |
| ~~Valued –~~ **Heard and respected** would be better words as currently there is evidence that this is not happening | Participants, their families, carers and other support persons feel ~~valued~~ heard by planners in their interaction with the NDIS and that their situations are respected by planners rather than informed by assumptions/preconceived ideas. Participants are provided with up-to-date information and resources so that they know where to go if they need further assistance. |
| ~~Decisions are made on merit~~  Problematic wording – this is not a job application  **Decision/decision-making process is transparent.** | The NDIA acts in a transparent, informative and collaborative ~~spirit~~ manner so that participants understand why decisions are made.  Decisions also need to be consistent across planners and locations. |
| ~~Accessible~~  Inclusive  What about people with disability in rural and regional areas!!!!! | All people with disability can understand and use the NDIS and the NDIS ensures its services are appropriate and sensitive for Aboriginal and Torres Strait Islander people, people from Culturally and Linguistically Diverse (CALD) backgrounds, LGBTQIA and other individuals.  The NDIA ensures people with disability in rural and regional areas are not disadvantaged further by lack of services and higher costs associated with accessing services in these areas. |

1. **In your experience with the NDIA, do you think they fulfilled the above principles? If not, how are they falling short?**

From ***roundsquared*** s perspective there are many instances where one or more of these principles has not been fulfilled.

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| **Principle** | ***roundsquared***’s **examples of falling short** |
| Timely | No. While first plan and scheduled plan reviews may occur on time, the turnaround times for requests for unscheduled reviews and even light touch reviews for smaller items is far too long. Many of the reviews would not be needed if information had been properly recorded in the first place and person-centred approach been followed. Participants requesting a s48 review will not be advised if they have been unsuccessful in getting a decision to have a review. Instead they are expected to know that ,if there is no response within 14 days, then their request has been unsuccessful. For those who are successful, a s100 review will occur but the waiting time for these is now in excess of 9 months. This can effectively place the review date around or even after the date of the next scheduled review.  If a participant decides to go to the AAT because they have not been granted a review, the wait is again more than 9 months. |
| ~~Engaged~~  Consulted with and involved | No. ***roundsquared*** operates mainly in rural and regional areas. It would appear that very little has been done by the NDIA in these areas to engage with people with disability. The community capacity building role of the Partner in the Community organisation would also appear to have been very hit and miss. No community mapping has been undertaken in the Eurobodalla to provide participants and organisations supporting people with disability up-to-date information about services in the community or nearby. Critical shortages of allied health professionals exist in many rural areas as evidenced in the Ernst & Young project Building the Local Care Workforce (BLCW). |
| ~~Expert~~ –  Informed | No. From ***roundsquared’s*** experience with NDIA planners and the local area coordinators engaged by the Partners in the Community, it would appear that the experience, expertise and qualifications of planners and LACs may well be suited to the bureaucracy but fall short of an understanding about the range of disabilities; the scope of functional capacity related to particular disabilities; the inter-relationship of disabilities eg intellectual and psycho-social disabilities; and the impact of the caring role on families. This is hardly surprising when the position descriptions and personal qualities/attributes sought for planners (APS4 & 5) within the NDIA are considered. There is no requirement for applicants to have qualifications in the areas of disability, mental health, early childhood development, rehabilitation or community/ health education to undertake these positions. The emphasis is on administrative tasks such as gathering information, determining supports, completing and reviewing plans as per Agency guidelines and processes and contributing to the achievement of KPIs.  Some examples of the lack of knowledge displayed by planners include:   * A planner questioning why a woman with advanced MS would need continence aids; * Streaming as ‘general’ 2 sisters in their 20s with the genetic condition, spinal muscular atrophy; * A planner refusing transport assistance but funding travel training in a rural area where public transport is all but non-existent.   The most urgent need for training, however, is in the area of mental health. Planners and LACs need to have a good understanding of the concept of ‘recovery’ and to be able to provide a planning environment in which the person is at ease and able to discuss in a non-judgemental way their situation. |
| Connected  Cooperative and collaborative | No. Several anomalies exist between the NDIS policies and processes and those of other government departments. One such example that impacts significantly on people with psychosocial disabilities is the different amounts funded through Medicare (GP Mental Health Care Plan) and the NDIS for consultations with a psychologist. Through Medicare the amount is approx. $120 and through the NDIS approx. $190. The result is that psychologists are charging a gap payment of between $20 and $70 for consultations under a GP MHCP. NDIS participants must use the 10 Medicare MHCP consultations before they can access additional psych consultations through the NDIS. As many are unable to afford the gap payment they are failing to access these appointments. |
| ~~Valued~~  **Heard and respected** | No. *roundsquared*has reported several instances where the role of the parent or other family member has not been respected or validated. Planners in southern NSW are making value judgements about the level of support that should be provided by parents to children, particularly those over 10 years, without due consideration for the family dynamics or what level of support would be provided by parents/carers to a child of a similar age without a disability.The following comments were made by an NDIA planner to a participant’s mother at the beginning of his review meeting ‘X will not be receiving any core supports in his new Plan …as he is 11 years old’ and, ‘this is the parents’ responsibility, not the government’s’. On receiving her son’s plan, the mother contacted the planner’s supervisor. The supervisor supported planner’s perspective and told the boy’s mother: ‘You have become dependent on this funding. You had the child and he is your responsibility’.  The comments made by the supervisor do not reflect current community attitudes towards supporting the caring role of families of a child with a disability. To be told that ‘you had the child, he is your responsibility’ suggests a victim blaming mentality designed to blame and shame the mother for the child’s disability and needing to access support. |
| ~~Decisions made on merit~~  **Decision making process is transparent** | **No.** Decisions should not be based on merit but on the needs of the participant for support and services to improve their functional capacity and enhance their opportunities for social, cultural and economic engagement with the community.  ***roundsquared*** members and consultants have expressed concern about the lack of transparency in terms of why funds have been reduced significantly from the previous year or why certain supports or items have not been funded based on ‘reasonable and necessary’ criteria. This has resulted in a number of complaints to the NDIA over recent months about the work and comments of planners to our members and the lack of consistent information and transparent processes that are involved in the decision making process. From ***roundsquared*’**s perspective many planners would appear to have limited knowledge about the nature and scope of particular disabilities and conditions including mental health; child and adolescent development milestones; reasonable parental responsibilities and trauma informed care.  **Lack of transparency**  Four issues impact on this transparency:   * The use of ‘reasonable and necessary ‘as a catch all response by planners to queries about why something wasn’t funded or funding was reduced from previous year; * Participants are not made aware of their streaming status which impacts on the level of funding and whether a participant is eligible for ongoing support coordination; * There is increasing evidence of LAC s and planners ‘filling in’ or ‘re-interpreting’ the goals, the process to achieve the goals and the supports required to achieve the goals. ***roundsquared*** members have reported where sections of another person’s plan has been ‘cut and pasted’ into theirs without the name of participant changed. * Participants are not provided with a copy of the Participant Conversation Template where justifications are provided by the planner or LAC for particular supports and funding, as well as identifying options for mainstream supports (e.g. GP Mental Health Care Plans) or community supports.   **Lack of consistency of advice from NDIA**  ***roundsquared*** is finding that more participants particularly children are receiving reduced funding with many having their core funding cut or entirely removed. ***roundsquared*** has sought both light touch and unscheduled reviews for such cases. The rationale for such reductions is not related to any change in the capacity of the child or the family. In fact it could be argued that the child’s needs have increased as they are reaching important developmental milestones such as puberty and starting or finishing high school. Planners, when queried, about these core funding reductions have responded by indicating that the cuts are based on ‘reasonable and necessary’ criteria or *that it is now policy for core funding not to be available to children under 15 years except in exceptional circumstances*. Comments have included that the support previously had been based on the use of the wrong disability instrument (WHODAS used instead of PEDICAT) resulting in a higher core funding allocation than would normally be expected of a parent of a similar age. Two complaints have been lodged by ***roundsquared*** on behalf of these decisions as they would appear to be direct contradiction of the advice provided by Emma Young Senior Complaints Officer to Mark Pattinson, ***roundsquared*** Director, on 27 November 2018 that states: ‘I can confirm the NDIA does not have a policy in place that excludes children under 15 years from receiving ‘Core Support’ funding, rather a planner will make the decision based on all evidence provided at the planning meeting.’ Hence the need to have access to the PCT so that participants can ensure that relevant information has been included. |
| ~~Accessible~~ Inclusive | No . Access to interpreters is very limited in rural and regional areas and for people with sensory or psycho-social disabilities this can mean considerable difficulty understanding the processes involved accessing the NDIS. The planning process of the NDIS is problematic for many people but with for rural and regional participants the tyranny of distance, thin markets, conservative attitudes and lower socio-economic status exacerbates these inadequacies.  The offices of the NDIA and its PITC also need to be wheelchair accessible. The current office of Uniting at Batemans Bay is very difficult for people with a wheelchair to negotiate as the car parking is down a ramp at the back of the building. There is no cover if raining and the incline is far too steep for a wheelchair to negotiate. The one disabled parking space is used by one of the LACs. Parking on the street is often very limited. |

1. **What other key principles are important for the NDIA to follow, that could be included in a Participant Service Guarantee?**

Other principles that ***roundsquared*** sees as important for the NDIA to follow and that should underpin the NDIS Participant Service Guarantee are

* Ensuring a genuine person-centred approach to participants during the planning process;
* Providing greater respect for the role of parents/families support people with disabilities;
* Ensuring planners and LACs skilled in trauma informed care do the plan meetings with participants with psycho-social disability, refugees, Aboriginal and Torres Strait Islanders and victims of abuse.

1. **One way to measure these principles is through a set of Service Standards. Some ideas for what these Service Standards could be are listed in Attachment A. Do you think these Service Standards are fitting? Are there other standards you believe should be included?**

|  |  |  |
| --- | --- | --- |
| Principle | Description | Service Standard |
| Timely | ~~The NDIA processes will be easier to understand and use, enabling decisions about access, planning and review to happen promptly.~~  **NDIA processes provide a timely response that enable the participant to understand how and why decisions were made about access , planning and review**. | The NDIA makes decisions in a timely and responsive manner:   * Once the NDIA has appropriate information. Access requests are made in **21** days. * Participants are offered a planning meeting within **14** days of receiving their access met decision. * First plan approvals take less than **7 days after their First Plan meeting.** * Plans are approved within 7 **days** of their final planning meeting following the provision of all necessary evidence. * Plan amendments are considered within **7days** of the request. * Plans involving SDA or AT requests are made within **28 days** and 14 days respectively of the information being provided. * Participants who request an internal review of decision are contacted within **14 days** of the request **regardless of whether the decision is is supported or rejected.** |
| ~~Engaged~~ –  **‘Consulted with and involved’ is preferred as it denotes a more active involvement**. | The NDIA ~~engages~~ **consulted with and involved** people with disability, their family and carers and other support persons when developing operating procedures and processes. | ~~The NDIA works with people with disability to ensure their processes and operating (procedures) are designed to be understood by people with different abilities and needs~~.  **The NDIA consults with and involves people with disability and their support organisations and peak organisations to ensure processes and procedures are easily understood by people with different abilities and needs**. |
| ~~Expert –~~  **Informed**  is a better word as NDIA staff would not be expertsunless they have qualifications in OT or similar. | ~~NDIA staff have a high level of disability training and understand the impact particular disabilities have on people’s lives. They understand what supports are most effective for a person’s disability.~~  NDIA staff have a high level of training so that they understand the nature and limitations on functional capacity of a particular disability. Staff will have a sound understanding of the most effective supports available to enhance the functional capacity of the person with disability and will have subject matter experts in the areas of Assistive technology, specialist disability accommodation, psycho-social disability and children and young people with disability. | ~~NDIA staff have a high level of disability training and understand the impact particular conditions have on a people’s lives. They understand what supports are most effective for a person’s disability~~.  From the position descriptions for Planners in the NDIA and LACs with the PITC, there is no requirement for applicants to have qualifications in the areas of disability, mental health, early childhood development, rehabilitation or community/ health education to undertake these positions. The emphasis is on administrative tasks such as gathering information, determining supports, completing and reviewing plans as per Agency guidelines and processes and contributing to the achievement of KPIs.  NDIA staff need to have a high level of understanding of disability and understand how different levels of functional capacity can impact on a person’s physical, emotional, cognitive and psychological, well-being as well as on their social and economic participation. Future recruitment process will see as highly desirable qualifications in the allied health professions, nursing, rehabilitation, metal health, health education/promotion and early childhood /education.  To complement this new recruitment approach, the following will be encouraged:   * staff incentives to undertake further study to understand the nature and scope of disabilities e.g. Cert IV or Diploma of Mental Health, Cert IV Mental health peer Work, Cert IV Allied Health Assistant Course as well as short courses or on-line courses on e.g. mental health recovery, assistive technology, autism and early onset dementia * Development of Communities of Practice to promote learning opportunities for LACs and Planners to understand better the nature of different disabilities; the trajectory of degenerative conditions; the social, economic and health impact of caring; options for assistive technology. |
| ~~Connected~~  **Cooperative and collaborative** approach to policy and program development | The NDIA works well with **other Federal, State and local** governments, mainstream services (such as health, education, justice services), disability representative groups and providers to ensure people with disability have coordinated and integrated services | There needs to be consistency with other government programs such as consistent expectations of parents by Centrelink and NDIS; and consistent payment schedules for consultations psychologists under Medicare Mental Health Care Plan and NDIS sessions with psychologist. The impact of the silo approach to policy and program development is also evident with certain supports considered the responsibility of other government agencies resulting in confusion for the participant and inertia in relation to their needs. The NDIA therefore needs to establish constructive and collaborative mechanisms to ensure no gaps exist in the delivery of services to people with disability and that anomalies that exist in government policies are addressed so that a consistent approach is provided to address the needs of people with disability and their families. ~~works constructively and collaboratively with broader service system to ensure that there are no gaps for NDIS users where possible.~~ |
| ~~Valued –~~ **Heard and respected** are better words as currently there is evidence that this is not happening | Participants, their families, carers and other support persons feel ~~valued~~ heard by planners in their interaction with the NDIS and that their situations are respected by planners rather than informed by assumptions/preconceived ideas. Participants are provided with up-to-date information and resources so that they know where to go if they need further assistance. | ~~The NDIA ensures that the broad community understands the purpose of the NDIS and where they can go if they need further assistance.~~ This service standard does not relate to the principle or description. The issue is about the participant being able to access services and supports in the community. Informing the community about the NDIS is a far broader issue and requires an overarching national approach with more specific targeted messages at local and regional levels as well as to specific groups such as CALD communities, LGBTQIA and Aboriginal and Torres Strait Islander communities.  Suggested wording  The NDIA work with State/Territory and local governments as well as peak organisations supporting people with disability and their local Partners in the Community will ensure up-to-date local mapping of services and agencies in the area are developed and maintained. |
| ~~Decisions are made on merit~~  Problematic wording – this is not a job application  **Decisions/ the decision-making process is transparent.** | The NDIA acts in a transparent, informative and collaborative ~~spirit~~ manner so that participants understand why decisions are made.  Decisions also need to be consistent across planners and locations. | ~~The NDIA acts in a transparent informative an collaborative spirit.~~ **The NDIA’s decision making process is transparent with participants provided with full explanations in plain English as to why a decision has been made with details about where additional supports may be accessed in their region.** |
| Accessible  What about people with disability in rural and regional areas!!!!! | All people with disability can understand and use the NDIS and the NDIS ensures its services are appropriate and sensitive for Aboriginal & Torres Strait Islander people, people from CALD backgrounds, LGBTQIA and other individuals.  The NDIA ensures people with disability in rural and regional areas are not disadvantaged further by lack of services and higher costs associated with accessing services in these areas. | The NDIA provides information to meet the needs of specialised groups including CALD, LGBTQIA and Aboriginal and Torres Strait Islander people to enable them to access to the NDIS like any other citizen. |

1. **Do you have any ideas on how we can measure how well NDIA has delivered on each of the principles?**

Outlined at Attachment A is ***roundsquared***’s suggestions on how the NDIA is delivering on these principles.

Getting Started: Eligibility and application

1. **What are some of the significant challenges faced by NDIS participants in the access process?**

***roundsquared*** operates predominantly in rural and regional areas where access to health professionals is limited, and with very few GPs providing bulk-billing services. As it takes a longer consultation to complete the Evidence of Disability (EOD) form this can mean that the person is significantly out of pocket with the co-payment required. This in itself has been a disincentive to applying for the NDIS for some people and particularly those with mental health conditions.

The turnover of GPs in rural and regional areas is higher with many GPs being Overseas Trained Doctors (OTDs) with limited experience of Australia’s health and welfare system. Getting their heads around the Medicare requirements alone can be confusing without having to understand a parallel system with the NDIS. For some of these OTDs they do not readily understand the principles of the NDIS and, unlike a medical certificate or Work Cover claim, they are required to make an assessment of the person’s capacity across five domains: mobility, self-care, learning, participating in social activities and ability to manage day-to-day life. It is not uncommon for GPs to fill in the form with the diagnosis and medical and pharmaceutical treatments but without any information on the impact of the condition on the person’s functional capacity. Some participants have reported that GPs do not want to fill in the forms as they do not see it as part of their role but more the role of an OT. This can make it very difficult where there is a shortage of OTs and other allied health professionals to fill in these forms. Health professionals report in relation to psychosocial disabilities that they ‘need clarity and certainty about the NDIS eligibility criteria …and what the NDIS can offer their patients’; with GPs requesting that Medicare rebates reflect the expertise and time taken in preparing evidence for their NDIS application.’(MHA 2018).

Participants have also raised concerns about the need to determine what their primary disability is. For people with, for example, a physical and a psychosocial disability it can be difficult to determine which is the primary one as both have a significant impact on their lives and functioning. To comply with the NDIS requirements, the physical disability will often be nominated as the primary one due to the stigma that continues to be associated with mental illness. Determining a primary disability is a chicken and egg situation, as an improvement in a person’s psychosocial outlook can lead to an improvement in the person’s physical condition and visa versa. ***roundsquared*** supports a participant who has a range of physical disabilities as well as a psychosocial disability. His initial request for access was denied and he appealed this access not met decision. He was finally considered to have met access, but he was advised that this would only be for his psychological disability. This is a very reductionist view of a person’s health and functional capacity and is not consistent with a person centred approach. This is a disability focussed approach that gives no recognition to the interrelationship of his physical issues to his sense of self-worth and ability to achieve his goals.

The access process is particularly difficult for people with **psychosocial disabilities** where the ‘episodic nature’ of mental health conditions and the concept of ‘recovery’ would appear to be poorly understood by planners. The following case study illustrates some of the difficulties experienced by people with mental health conditions accessing the NDIS. [See Case Study – Joan above].

The MHA (2018) found that: ‘Psychosocial disability can also have a direct impact on a person’s ability to navigate the complicated access and planning processes. Some impacts relate to the mental health condition or disability, such as difficulty processing information or fluctuations in mood. Some impacts are secondary, such as the effect of a person’s previous traumas, including from a history of being treated involuntarily and subjected to restrictive practices. Some traumas may precede the mental health condition (and psychosocial disability), such as childhood or life traumas.’ (ndis\_psychosocial\_pathway\_consutlation\_project\_-\_final\_report\_-\_may\_2018) Re-traumatisation is a very real issue for people with a psychosocial disability. There is a need for the access process to be better informed about trauma and how to develop and implement processes that are trauma informed.

For people who are homeless and likely to be eligible for the NDIS, finding information about the Scheme as well as actually meeting access requirements is fraught with difficulties. The MHA (2018) recommends an ‘assertive outreach’ that includes:

‘mapping places where people with psychosocial disability who would normally be considered ‘hard-to-reach’ are likely to be in their local area and conducting site visits to these places to engage with people with psychosocial disability, carers and service providers in locations where they feel comfortable and discuss what the NDIS has to offer for them.’ (MHA 2018:16)

This ‘assertive outreach’ needs to be followed up, the MHA argues, by personalised NDIS engagement support that includes people with specific skills, knowledge and experience with psychological disability to assist potential NDIS participants understand the NDIS and provide consistent guidance and capacity building support throughout the NDIS access and planning process.” ***roundsquared*** supports such processes being put in place to support people with psychosocial disability.

1. **The NDIS ACT currently requires the NDIA to make a decision on an access request within 21 days from when the required evidence has been provided. How long do you think it should take for the NDIA to make an access decision?**

It would be preferable that a decision was made within **14 days**. The issue is not so much the time it is the need to go back to get additional information as the form is not easily understood and/or the person did not have someone to assist them; or as outlined below the Evidence of Disability (EOD) form was filled in incorrectly by the GP or other health professionals.

1. **What do you think the NDIA could do to make it quicker and easier to access the NDIA?**

The decision to terminate the contracts of the Ability Linkers has not been a positive step to addressing this issue. The Linkers played an important part in southern NSW by providing people who wanted to find out how to apply for access and details of the processes involved. The Linkers could provide people with information about the NDIS and connect them with LACs to advise/assist with the application process. With the termination of the Ability Linkers it is imperative that the front line staff at the NDIA and Partners in the Community (PITC) offices can fill this role and assist potential participants with understanding the access requirements for the NDIS.

Another issue that needs to be considered in answering this question is where are new applicants for the scheme likely to come from? For people aged over 7 years of age, their need to access the NDIS could be as a result of an accident (MVA, fall, diving accident etc) or illness (MS, MND, meningococcal disease, stroke, complications from diabetes, psychosis etc) that has significantly decreased their functional capacity. In many cases, a hospital admission and lengthy hospital stay and rehabilitation will have been involved. There is evidence that some of the sub-acute mental health units have people staying extended periods due to a lack of services including supported accommodation in the community. This is neither an appropriate outcome for the person nor a good use of health resources. It is therefore vital that the NDIA and its PITC organisations work with hospital rehabilitation departments, mental health units and discharge staff to ensure that people exiting the hospital have a seamless transition to supports outside the hospital including accommodation and supports. This includes insuring that all the information and reports from specialists and therapists are included as evidence of disability.

**RECOMMENDATION 1**

**That a core aspect of the community engagement work of the NDIA and its PITC organisations be to engage with local hospital rehabilitation departments, mental health units and discharge staff to ensure that people about to be discharged from the hospital have a seamless transition to NDIS supports to enable them to access appropriate therapies, assistive technology and support services that will support them in their home environment.**

1. **Does the NDIA provide enough information to people when they apply for access to the NDIS? If not what else could they provide that would be helpful?**

There is an expectation that people have access to the internet and will be able to download the information that they need. This does work for the majority of people and/or their carers. However for some who are either not computer literate, or do not have access to the internet this does not apply. ***roundsquared*** consultants have reported that for some participants it took them 2 or 3 attempts to gain access and the best assistance was someone sitting down with them and going through the form and their supporting documents to ensure everything was provided. The Ability Linkers played an important role in this area often accompanying people to GP appointments to explain to the GP what was required in the EOD form. The Ability Linkers also liaised with the LACs and Planners to ensure they had up-to-date information to provide to people. In Batemans Bay the Ability Linkers were located in the same building as the NDIA and Centrelink and therefore provided a ready resource for people. The LACs, by comparison, were located some distance away and up a hill, that was often difficult to access for people with mobility issues.

The NDIA expectation that LACs would be providing community connections and assistance to people who needed assistance with access, or could provide assistance with those who had failed to meet access to connect with mainstream and community services to assist them, was very seldom fulfilled in southern NSW, from the ***roundsquared*** perspective. LACs who now work for ***roundsquared*** report that they were flat out doing planning meetings with participants who had met access to develop or review their plans. With the travel often involved to do these plans and the administrative burden placed on the LACs to fulfil their PKIs and participate in training, there was little time for any assistance to those seeking support with access. In fact in the latter part of 2018, there was a directive from the District Manager of Uniting that no community capacity building activities were to be undertaken, as every LAC was needed to do planning meetings.

Office location is very important to facilitating opportunities for interaction with the people with disability, their family and carers and other community organisations. Easy access to the building and staff able to provide information and explain process are vital. A lack of access to disability parking and a location away from public transport is not conducive to improving community understanding of the scheme.

1. **Is the NDIA being transparent and clear when they make decisions about people’s access to the NDIS? What could the NDIA do to be more open and clear in their decisions?**

Lack of transparency would be one of the main criticism of the NDIS made by participants and ***roundsquared*** consultants alike across the range of NDIA decisions from access to review and implementation.

People have commented that when they are deemed not to have met access there is little by the way of explanation. Many people do not readily understand that a debilitating health condition does not necessarily mean that they will meet access to the NDIS. Despite the theory behind the NDIS, that people who are ineligible for the NDIS will be connected with services and supports of mainstream and community services, the reality is quite different with few provided with follow-up support.

As mentioned above, people with **psychosocial disabilities** face particular challenges with access including issues requiring a more personalised and sensitive approach with individualised assistance and information, as well as targeted outreach initiatives to engage with those who have experienced trauma, are socially isolated or homeless. The impact of a person’s psychosocial disability can make it very difficult to navigate the NDIS processes (MHA 2018:21).

**RECOMMENDATION 2**

**That Mental Health Australia’s call to improve the access process for people with psychosocial disability by building specific competencies in mental health and psychosocial disability for planners and LACs; ensuring there is expert oversight of plans for people with psychosocial disability; and ‘providing a greater level of information and support (including peer support) for people with psychosocial disability at the pre-planning stage’ (MHA 2018:22) be supported.**

**Planning Processes: Creating your Plan**

**10a. What are some of the significant challenges face by NDIS participants in the planning process?**

The challenges facing NDIS participants in the planning process can begin with the call to organise the meeting. Planners and or LACs doing the bookings have failed to tell participant of the new address of a PITC organisation or emphasised the need to bring reports to the meeting. If the meeting is to be done at the participant’s home, there is often no risk assessment done by the booking person. This can place an LAC in an unsafe situation or result in a new meeting being requested due to difficulties with accessing the property (e.g. aggressive dog/ access difficult due to broken paths/rubbish etc).

Attending a planning meeting can be quite daunting with many participants and their carers becoming anxious and confused. LACs and Planners often have planning meetings scheduled back-to-back, and lack the skills to help the participant feel more at ease and able to provide information relevant to their situation. Participants can feel anxious when:

* they don’t know the LAC or planner;
* the LAC/Planner has not provided an overview of what will happen in the meeting;
* the access process has been protracted;
* they have had to travel a considerable distance to the meeting;
* the LAC/Planner is officious/bureaucratic rather than empathetic and sensitive;
* reports from their therapists, doctors etc have not been sent through to Agency;
* they have to repeat their story particularly if there is trauma involved;
* they find it difficult to state goals rather than the supports they need;
* the LAC/Planner uses jargon or is generally not easily understood;
* they have experienced difficulties with government authorities before e.g. Centrelink; and
* they are not supported by a partner/friend/carer or support coordinator at the meeting.

Other issues that present significant challenges include:

* when it is obvious the Planner/LAC has not read their reports prior to the meeting;
* when the LAC does not have access to the PEDICAT instrument to determine level of disability of a child.( If the LAC doing the meeting does not have access to the PEDICAT and there is not an LAC in the office with a licence, then the person/parent must be rung after the meeting to complete the PEDICAT so that the plan can be finalised an sent to the NDIA for developing plan building and funding.); and
* When the IT systems fail and the meeting has to be postponed and completed by phone or is completed with the LAC writing notes.

1. **Are there stages of the planning process that don’t work well? If so, how could they be better?**

In early 2019 the planning process around goals was changed. Prior to this the participant provided 2 short term goals and up to 5 or 6 medium to longer term goals. Now each goal must be include responses to ‘How I will achieve this goal’ and ‘How I will be supported’. This process is very confusing for many participants. From the plans developed for ***roundsquared*** members, it is clear that this process is just as confusing for planners and LACs. Many ***roundsquared*** members have received their plans and looked at the goals and indicated that these were not the goals that they stated during the meeting, an assertion backed up by the support coordinators who have attended with the member.

*Case Study - Maryanne (alias)*

*Maryanne is a woman in her fifties with an ABI who lives with her partner. She has 2 short term and 4 medium to long term goals. Each goal is poorly articulated with the ‘How I will achieve this’ section, often bearing little or no relevance to the goals, as shown in the short term goal below. When the participant received this plan her main goal had been omitted entirely, undermining her progress in the previous plan and ignoring key reports provided by the therapists.*

***Short term goal*** *– I would like to go on a supported holiday*

*How I will achieve this – I will continue to make decisions for my life*

*How I will be supported - My support coordinator will support me to connect with a service provider who can assist me to go on a supported holiday*.

*The planner is also very confused about the difference between a short term and a medium to longer term goal. The goal outlined below is surely a short term goal as it relates to her everyday life. There is no reference in either goal as to any role the informal supports or mainstream or community supports might play. This is an example of either an incompetent or very lazy planner.*

*Medium to long term goal - I would like support to maintain my house and yard, and support to go shopping and access the community.*

*How I will achieve this - I will re-engage with my current service provider to have my services continue throughout this plan.*

*How I will be supported - My provider will continue to support me.*

The issue of cutting and pasting goals and sub-goals seems to be developing as an art form for some NDIA planners and LACs.

*Case Study – Jet (alias)*

*Jet is a young child with autism who is non-verbal and suffers from extreme anxiety. He had 2 short term and 4 medium to longer term goals. In the section ‘How will I be supported’, exactly the same words were used for every goal:‘(Jet) will continue to be provided with opportunities at home and in other natural settings to practice skills and strategies to support the goal. There will be a plan in place that assists Jet and (Mum) to achieve the goal.’ If the same words can be cut and pasted for this sub-section of every goal what is the point of having these sections. This is again evidence of an incompetent or lazy planner.*

Jet’s mother is requesting a review of a reviewable decision as the goals outlined in his plan were not those discussed at the meeting but were merely cut and pasted from the previous year’s plan. This is not a person-centred approach that reflects an understanding of the unique needs of the participant and his family situation.

It is not surprising that participants and their families find it difficult to understand how supports are linked to their goals, when the goals are not even the ones they stated. Even when the goals are basically what they stated, there is still a disconnect in terms of understanding how the goals link to their supports. Some have mentioned that this seems like a back to front logic, where the goals is more a bureaucratic construction than a means for determining the support needs of the participant. The need to articulate goals can be quite distressing for a parent with a child who has limited functional capacity and must then participate in a game of ‘define your goals’. Referring to the case studies above, do the goals outlined and the process to achieve them, really provide any useful purpose for either the participant, their family, their therapists or support services. ***roundsquared*** would suggest they don’t.

If goals are to be the basis by which funding for services and supports are provided, then they need to be SMART goals – **Specific, Measurable, Achievable, Realistic and Timely**. In the case studies provided, none of the goals fitted the SMART criteria.

**RECOMMENDATION 3**

**That the planning meeting be made more transparent by changing the focus on goals in the planning meeting with a discussion focused on the needs of the participant and what services and supports would contribute to improving their functional capacity and enhancing their social, economic and cultural inclusion.**

Trying to ensure that all information is recorded accurately is another major challenge for many participants. The structure of the planning meeting is not conducive to developing a coherent picture of the participant’s functional capacity, historical factors that may impact on them, and/or their social and community connections. The planning meeting with its various lists of questions provides a scattergun approach that provides small snapshots about the person’s life but limits the opportunity to put it into contextual framework from which to develop a plan reflective of both their aspirations and needs. ***roundsquared*** members are often remarking that what is contained in their plan is not what they said in the meeting whether this be in relation to their goals or their profile. If they were to be given access to their Participant Conversation Template (PCT), participants are likely to report an even higher level of poorly recorded information with assumptions made by LACs and planners about the participant’s situation and abilities. The result of these inaccurate recordings is increasing requests for light touch reviews, reviews of reviewable decisions, complaints and AAT appeals.

To reduce the incidence of plans with wrongly recorded information, the NDIA could provide participants with a draft of their Plan prior to the determination of supports and funding. This would provide the opportunity for participants to highlight incorrect information or omissions about them and to confirm or reject the goals and sub-goals outlined in the draft. It would also provide the opportunity to provide additional information that the participant had not mentioned in the planning meeting either because they forget, were anxious or didn’t have time due to the time constraints of the meeting. Should a significant impasse develop between the planner and the participant about the draft, then a delegate would be required to mediate the situation providing very clear and written information about why something had been included or not. Alternatively a new planning meeting could be organised, with a different LAC and planner.

Loss of documentation such as reports from therapists provided by the participant to the NDIA is another issue that has been raised by participants. This has occurred when reports have been provided to the LAC or planner at the meeting as well as when documents have been uploaded to the Agency. IT outages may explain the failure of some to upload. LACs and planners need to provide a receipt for any reports provided to them or photocopy the documents and return the originals to the participant.

**RECOMMENDATION 4**

**That the NDIA provide participants with a draft of their Plan prior to the determination of supports and funding to reduce the incidence of wrongly recorded information leading to requests for reviews and to provide the opportunity for participants to highlight incorrect information or omissions and confirm or reject the goals and sub-goals outlined in the draft.**

1. **How long do you think the planning process should take? What can the NDIA do to make this quicker, remembering that they must have all the information they need to make a good decision?**

This is not an easy question to respond to as each person and their situation is different. For some people with a straight forward situation where their support needs have not changed; appropriate services and supports are in place; large AT items and major home modifications are not requested; their health status is stable; progress is being made towards goals; and their informal supports are constant; then the planning process can be quite straight forward and take less than an hour.

However for many others the situation is far more complex as a result of deteriorating capacity, changes in family situation/informal supports, hospitalisations during the year,

loss of therapists in the area, the need for new/additional AT and/or home modifications; and for children they are in periods of transition from primary to high school or high school to work/other training. Issues with people with mental health, sensory, cognitive and communication difficulties the process will obviously take longer.

One way in which the planning meeting could be reduced is for some of the questions to be asked at the time of booking the meeting. This could include not only a verification of personal details, but also at this time participants/carers could be asked about any changes to their informal, mainstream and community supports as well as completing the **WHODAS**, **PEDICAT** or other disability instrument appropriate to the participant’s situation.

Another way to streamline the planning process and reduce the stress on the participant is to provide additional funding for support coordination to support the person prepare for their meeting and ensuring that all reports are provided and up-to-date. Lack of support coordination is proving to be a major factor impacting on the under-use of funds due to confusion as to how funds can be used, how to go about engaging services and identifying service providers in a thin market.

**RECOMMENDATION 5**

**That to streamline the planning process, that the Local Area Coordinator [LAC] making the booking for the plan/plan review meeting not only verify the participant’s personal details but also ask if there are any changes to their informal, community or mainstream supports; and complete the WHODAS, PEDICAT or other disability instrument appropriate to the participant’s situation.**

1. **Is the NDIA giving people enough, and the right type of information, to help them prepare for the planning meetings? If not, what else could they provide?**

The NDIS Act 2013 states in S17A(i) ‘People with disability are assumed, so far as is reasonable in the circumstances, to have capacity to determine their own best interests and make decisions that affect their own lives’. Anecdotal evidence from ***roundsquared***  consultants and members indicates that planners may well assume capacity but this is more a reflection of the need to keep the meeting to schedule, than it is a genuine commitment to hearing and understanding the participant’s perspective. S17A(i) needs to be read in conjunction with S17A(ii) that emphasises the need for participants with disability to be ‘supported in their dealings and communications with the Agency’ to enable them to maximise their choice and control. This also highlights the deficit in the skills and experience of NDIS planners and LACs in terms of their understanding of the NDIS Act and a lack of expertise and experience in disability and care needs.

For participants who are articulate and can understand the system, the information provided is probably enough as they are able to search out additional information if required and have the confidence to seek assistance if needed. For others the NDIS processes are challenging and they are uncertain as to where to go to obtain assistance. If they have a support coordinator they can go to them but if this is not the case, they can try to talk to a LAC or a planner or even go into the office of either the NDIA or PITC. Some LACs and planners have a poor track record when it comes to returning calls to participants, an issue made more difficult when offices such as the Batemans Bay Uniting office do not even have a landline number to ring. For people with intellectual disabilities and others with limited education, written information is of little use. For people of Aboriginal and Torres Strait Islander background the information is also not provided in a user friendly manner. To address the issues with these groups more targeted information dissemination needs to be investigated including working with Aboriginal Medical Services and organisations, the provision of specialist support coordination services for intellectual, cognitive and psycho-social disabilities.

Currently LACs with PITC organisations are expected to complete the planning meeting in 90 minutes. This one-size-fits-all approach is not person-centred as it fails to recognise the vast differences in participants, their informal supports or lack thereof, their ability to self-advocate and the complexity of their disabilities and location. A common response from PITC management when issues are raised about the need for more time for certain plans is that it balances out with plans that take less time. This is an erroneous assumption as there are far fewer planning meetings that take less than 90 minutes than there are ones that take more time. With many LACs doing 2 plans a day which includes submitting the plan to the NDIA with recommendations and justifications for supports based on the meeting and therapy and other reports, there is pressure to complete the meeting on time. For people who are already anxious and confused this is counterproductive to the development of a good plan that reflects the goals and functional capacity of the participant. Greater flexibility needs to be provided to cater for the needs of those participants whose situation is complex and/or their ability to articulate is limited by their cognitive, sensory, mental health or physical condition.

Lack of consistent information from LACs and planners is another common issue raised by ***roundsquared*** members and consultants. For example some NDIA planners advise that participants must use the 10 Medicare consultations with a psychologist/counsellor through a Mental Health Care Plan before they can access any sessions with a psychologist through their NDIS plan. Others do not make this stipulation. This example shows the lack of consistency of information provided by NDIA planners, but also the inconsistency in NDIA policy and processes, as participants are not expected to use the five Medicare consultations with allied health professionals through a GP Chronic Disease Management Plan.

In another instance a planner has told a participant that she cannot have any bathroom modifications such as grab rails and hand-held shower as she does not own the property. Her partner owns the house and has given approval to do the modifications yet the planner maintains her position. This information is incorrect. A person renting a property is able to have modifications done provided the landlord agrees. The same applies where the partner is the homeowner.

1. **Is the NDIA being responsive and transparent when making decisions in the participants’ plans? If not how could this be improved?**

**ABSOLUTELY NOT!!** Lack of transparency about the decisions made by the NDIA is an issue constantly raised by ***roundsquared*** members.

The NDIA is not responsive or transparent about its decision-making processes. Even prior to their first plan meeting, participants are not advised as to how they have been streamed nor how the decision as to their streaming level has been made and/or how the streaming decision impacts their level and types of support. The four levels of streaming include general, supported, intensive and super-intensive. An example of a type of support that will not be provided to someone streamed ‘general’ is support coordination, with this becoming increasingly more difficult to get for participants streamed ‘supported’.

From ***roundsquared***’s perspective this lack of transparency enables planners and LACs to avoid due diligence in the development of participant plans with many ***roundsquared*** members and consultants reporting that getting a good plan was like a ‘lucky dip’. If you get a planner or LAC committed to a person-centred approach and with a depth of experience and understanding of the NDIA policies and processes then your chances of getting a good plan are increased significantly. If however you drew a short straw and got a planner/LAC who was more interested in fulfilling their KPIs or getting the meeting over as quickly (*as one LAC said – ‘it must be beer o’clock*) as possible you were more likely to end up with a plan that did not reflect the issues raised in the meeting or the content of reports. **A good plan – that is one that is reflective of the person’s needs and aspirations - should not be a lottery.**

Over recent months ***roundsquared*** has lodged a number of complaints with the NDIA about the lack of transparency and the inconsistency of information provided to participants. Of particular concern has been the advice from planners that children under 15 years are not eligible for core support as things like personal care and social support should be provided by the parents.

*Case Study – Henry (alias)*

*Henry (alias) is an 11 year old boy with a complex range of issues including autism, ADHD, dyslexia, anxiety and depression, left sided weakness and global growth delay. He experiences difficulties with learning and monitoring his emotions resulting in angry outbursts and temper tantrums. In his 2018-19 Plan, Henry received funding of $21, 000 of which $9500 was in Core supports. These core funds were mainly used to engage a support worker for 2 hours a week to ‘explore and participate in community based activities of interest and to develop, build and maintain friendships’.*

*In June 2019, a NDIA planner, Batemans Bay told Henry’s mother and a* ***roundsquared*** *support coordinator that he ‘would not be receiving any core supports in his new Plan …and as he is 11 years old’ and, ‘this is the parents’ responsibility, not the government’s.’ She indicated that there would be some increase in his capacity building budget. This meant that his overall funding fell from $21,000 to $12,000. The loss of the core support funding means that there is no opportunity for Henry to put these skills into practice by accessing the community with a support worker.*

*Shortly after receiving a copy of Henry’s Plan his mother contacted the planner’s supervisor. The supervisor supported planner’s perspective and told the boy’s mother: ‘You have become dependent on this funding. You had the child and he is your responsibility’. She also went on to say words to the effect that ‘there had been a meeting of NDIA planners the day before and that the direction from above had been to provide no more core funding for children under 15 ’.*

*Case Study – Kia (alias)*

*Kia is a 14 year old Aboriginal girl with complex PTSD and a range of challenging behaviours including emotional instability, self-harm, property damage, verbal and physical aggression and unintentional self-risk. In 2017-18 Kia received $22,500 in core support and another $24,000 in capacity building supports. On 10 October 2018, Kia’s 2018-19 plan was approved but her core funds were reduced to $5725 with $20000 allocated for capacity building. As a result of the significant drop in core funding the family was put under considerable financial stress as her mother had to reduce her working hours to be available to supervise her in the community and after school.*

*On 5 December 2018,* ***roundsquared*** *lodged a review of a reviewable decision request. On the 15 January 2019 a planner emailed Kia’s mother outlining the reasons for the reduced funding stating that ‘the Agency had excessively funded some participants’ plans as part of the transition to the NDIS scheme’. It was further claimed that ‘the incorrect disability tool was conducted in the last plan which provided some false information and impacted on the funded supports.’ The planner also stated Kia should be accessing mainstream services such as after school and vacation care and that core supports had been adjusted accordingly. The NDIA, however, provided no further information as to the request for a Review of a Reviewable Decision.*

*On 14 February 2019* ***roundsquared*** *again lodged the Review of Reviewable Decision request with the NDIA. When the 14 days elapsed and the NDIS had still not responded to the second request, Mark Pattinson (Director* ***roundsquared****) lodged a Reportable Incident Notification as the lack of funding provided in the participant’s plan had proved insufficient to ensure the participant remained safe within the home and the community.(Reportable Notification application 28/02/2019).*

*The situation continued to escalate with Kia removing herself from her mother’s care in May 2019 to couch surf at friends’ places. She was considered at high risk of being on the streets. In May 2019 a Change of Circumstances request was submitted on behalf of Kia by* ***roundsquared****. An OT report was provided outlining the challenging behaviours and the risks associated with her reduced funds. It was also pointed out that most of her funds had been used trying to avoid such a situation developing. In June 2019 Kia‘s mother was advised that the earlier decision not to review Kia’s plan had been set aside and a Plan review meeting was scheduled ‘as the NDIA is not satisfied that your current plan meets your needs, and so agree that it should be reviewed’.*

*On 17 July 2019 Kia’s new plan was approved providing $18,000 in core supports ‘to assist with daily activities and community participation’ and $19,000 for capacity building. This**Plan will provide her with the core supports she needs to ensure she can access the community in safety and with support as well as reduce the financial and emotional pressures on the family and family relationships.*

The initial decisions in both these cases would appear to be a direct contradiction of the advice provided by Emma Young Senior Complaints Officer to Mark Pattinson, ***roundsquared*** Director, on 27 November 2018 that states: ‘I can confirm the NDIA does not have a policy in place that excludes children under 15 years from receiving ‘Core Support’ funding, rather a planner will make the decision based on all evidence provided at the planning meeting.’

In many other cases participants have requested details as to why they have had their funding cut or specific items rejected. All too often the planner will hide behind the words ‘reasonable and necessary’ without giving an explanation as to why funding has been reduced or why certain supports were not deemed ‘reasonable and necessary’. This inability to provide an explanation leaves the participant in the dark as to the grounds for appealing the decision particularly if information/reports have not been considered that recommend such supports. This type of response is a form of passive aggression as it does not provide the participant with the means to understand why a decision was made and also makes them unsure whether they should seek a review or if they would be wasting their time or even risking a further cut to funds.

**RECOMMENDATION 6**

**That the following measures be taken to improve the transparency of the decision making process and the consistency of information provided to participants:**

1. **Improving the recruitment process for LACs and planners so that people with a sound understanding of disability, functional capacity and support needs and options are actively recruited;**
2. **Improving the training of LACs and planners so that they understand better the legislation and rules that underpin the NDIS and develop plans that are in accordance with this legislation rather than based on assumptions or ill-informed prejudices.**
3. **Providing planners and LAC with more time to provide a person-centred approach that ensures that all the relevant information about a participant’s situation and needs was included in the development of the plan. This will ultimately be a time saver as it should reduce the number of requests for light touch and full reviews;**
4. **Providing participants with a draft copy of their plan so that they can see if their information is recorded fully and the goals that are articulated in the plan are theirs and not the edited version of the LAC or Planner so that funding can be more easily related to the goals;**
5. **Providing participants with written justification for any cuts of more than 10% to any part of their plan budget, how these reductions have been determined, and what evidence they have used to make their decision.**
6. **If you have been in the NDIS for more than one year, is it easier to make a plan now than when you first started? What has the NDIA improved? What still needs to improve?**

Being with the NDIS for more than one year is no guarantee of the planning process becoming easier or more transparent. For many participants and their families they are more confused and mystified by the decisions and processes than they were with their first plan. In ***roundsquared***’s experience this has been the case where the plan is for a young person under 15 years of age; the participant who has not spent the majority of their funds from the previous plan; the participant has a psychosocial disability; or the participant has complex needs. For many, support coordination is only provided in their first plan as the NDIA assumes that a participant’s services and supports are already in place and stable; when the reality in regional and rural areas is loss of services and therapists.

Many participants find the review process onerous. For those with a significant underspend of their plan funds, they have concerns their plans will be reduced accordingly, with the unspent funds seen as evidence of them not needing the supports/services. The situation is often the opposite with many underspends a result of difficulty accessing services. Southern NSW is experiencing shortages of OTs, speech therapists, behavioural therapists and child/psychologists, with particular hot spots being Ulladulla and Batemans Bay. Many therapists have no capacity to take on new clients, with people placed on long wait lists. The situation is quite dire for children with behavioural issues related to autism, ADHD and anxiety.

**Planning Processes 2 : Using and reviewing plans**

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

Underpinning the challenges for many NDIS participants is a lack of understanding about what services and supports they can access through each category. This is especially difficult for people who had support coordination in their first plan but the continuation of support coordination has not been deemed ‘reasonable and necessary’ in the new plan. The NDIA Act emphasises the importance of enabling participants to exercise ‘choice and control’ in the planning and delivery of services. Removing support coordination effectively dis-enables a participant’s choice and control when trying to access services in ‘thin market’ situations such as is being experienced in the southern NSW.

**RECOMMENDATION 7**

**That support coordination be retained for all participants in ‘thin market’ areas such as rural and regional communities beyond their first plan to assist participants identify therapy and other support options in the region if not in their local community**.

Three issues need to be considered here. The first is the assumption that participants can access and coordinate the services in their plans to achieve their goals; the second is the shortage of services particularly therapy services in rural and regional areas; and the third is a lack of any integrated service modelling on the part of the NDIS to ensure that services are available in different areas and that government mainstream services such as housing, education and health are on board to work collaboratively so that the participant can access the services funded in their plan.

*Case study – Ivy and Poppy (aliases)*

*Ivy and Poppy are sisters in their 20s who live with their mother in a Department of Housing property . Both women have a degenerative condition that requires them to mobilise using a motorised wheelchairs. To enter and exit the house their mother needs to be home as they cannot reach the door handle. This means that the sisters are dependent on their mother to be home to exit and enter the house. Being unable to exit the house without their mothers’ assistance means that their mother has little time to pursue her own needs as she must be around to facilitate the women’s access. This is also a safety issue as the women would not be able to exit the building in the event of a fire if their mother was not at home. Requests have been made to Housing to change the door to enable an automatic door opener to be attached to the women’s wheelchairs to facilitate entry and exit. This would give them greater independence and safety. However, housing is reluctant to provide a new door with automatic entry. This impasse undermines the goals of greater independence set by both women in their respective plans.*

**KEY ISSUE: LACK OF ANY INTEGRATED SERVICE MODEL**

**The lack of any integrated service modelling by the NDIA to ensure that services are available on the ground for participants and that mainstream services such as housing, health and education are on board to work collaboratively with participants and not just use the person’s needs for service as means for different departments to abrogate their responsibilities to people with disability, is a fundamental flaw in the current system.**

Participants who have elected to have their plan Agency-managed are reporting major difficulties with accessing therapy services and other supports as many allied health professionals have decided not to continue their registration with the NDIS. The reasons behind this include the cost of NDIS registration; the paperwork and red tape involved; the delay in payment of fees and the lack of recognition of their registration with their respective professional organisations. There are very few psychologists, OTs or speech therapists in southern NSW who have maintained their NDIS registration. These therapists are therefore unavailable to those participants who are Agency managed.

*Case Study – Emanuel (alias)*

*Emanuel is a single man in his 40s with schizophrenia. He had his first plan developed 12 months ago and as he was very socially isolated and had been homeless he elected to have his plan Agency managed. Some months into his plan, the organisation providing him with a support worker withdrew from the area and his psychologist withdrew his NDIS registration. Emanuel explained his situation to the NDIA and asked if he could change to either self-managed or use a plan management agency. He was told to submit a request for a review. After a few weeks when he had received no response he rang and was told that he had been unsuccessful with a review. As a result he has not been able to access psychology services for some months. Recently his GP also left the area and this has left a further void in his supports as he now has to re-tell his life story to a new GP and develop a rapport. This situation has meant that his plan is underspent and that he has also lost access to professionals who can provide reports on his functional capacity re his psychosocial disability. Where is the agency’s duty of care to this participant?*

The above case study demonstrates the difficulties faced by people who are agency managed in a situation where providers are deciding not to be NDIS registered. The NDIA needs to be flexible about this stipulation that services engaged must be NDIS registered to avoid participants slipping through the cracks and being placed at risk.

Lack of transport options including public transport and transport for people needing to remain in their wheelchairs during travel are proving to be major challenges for participants in rural and regional areas. Southern NSW has very limited access to vehicles that can take motorised wheelchairs. Access to these vehicles is often needed for participants to access services in either Wollongong or Canberra such as specialist OTs, prosthetists or short term accommodation. The vehicles usually needs to be booked some weeks ahead and then a driver found who is able to take the person with either a support worker or parent/carer. When a vehicle is off the road for any reason, this causes major problems as another vehicle can be very difficult to locate. Some rental companies have wheelchair vehicles available with a lift but they are usually located in Wollongong or Canberra requiring someone to pick up the vehicle and drive it back to the Eurobodalla or Shoalhaven area to transport the participant. Such issues do not occur in metropolitan regions and the NDIA needs to look at strategies to improve transport options for their participants.

1. **Is the NDIA giving people enough, and the right type of information, to help them use their plan? If not what other information could the NDIA provide?**

Lack of consistent information, lack of transparency, illogical and confusing processes are the issues. As outlined above planners have told the parents that the NDIS no longer provides core supports to children under 15 years. ***roundsquared*** has been advised that this is not NDIS policy. This may well be the case but is it an internal directive? LACs have also mentioned concerns about the tightening up of funding for consumables and low cost AT for participants with some suggesting that the needs of people with disability are secondary to the Government’s commitment to a Budget surplus. If such internal directives are being given, these need to be made public with the reasons for such directives clearly outlined.

For many participants who received services through State disability programs, the relationship between their disability and the services provided was quite clear. With the NDIS there is a disconnect in the logic, with the participant needing to articulate goals for which funding will be provided for services and supports to achieve the goals. The elephant in the room is their disability. The articulation of goals and how they will be achieved, may provide a means to measure the effectiveness of the services and supports to achieving the progress towards the goals, but do the goals actually limit the focus on the broader needs of the participant? (see **Recommendation 7**)

More information needs to be provided to participants and their families about why a support or service has not been considered ‘reasonable and necessary’. Such an explanation needs to provide alternative support options that would meet the ‘R & N’ criteria. (see **Recommendation 6** )

1. **What other advice, resources and support could the NDIA provide to help participants to use their plans and find supports?**

Support coordinators within community organisations play an important role not only in assisting participants access services and supports in their community consistent with the goals outlined in their plan and how the different funding components - core and capacity building – can be utilised to achieve these goals. Support coordinators also provide an important first point of contact when a participant experiences a change of circumstances, such as the need for hospitalisation or the loss of a key informal support, that will impact on their plan. Support coordinators can liaise with the Agency to determine options for the person and support them to exercise their choice and control in making a decision as to what they want to do. When services are withdrawn from an area impacting on the supports for the participant, the support coordinator plays a key role in identifying alternative services or therapists. Participants without support coordination are often not equipped to deal with the implication of changing circumstances, either in their own situation or affecting their access to supports, to their plan.

An option that the NDIA could consider to help participants use their plans and find supports would be to engage experienced participant peer mentors with community organisations to provide hands-on coaching to participants without support coordination to help them identify their options and organise their support/services.

There is, however, little point in coaching participants in how to engage services where the services do not exist or are so thinly spread that long waiting lists exist. To address the issue of ‘thin markets’, the NDIA needs to work with peak organisations such as Services for Australian Rural & Remote Allied Health [SARRAH], rural and regional communities and other Federal and State Government departments to develop innovative strategies to recruit, retain and support a range of AHPs to relocate to rural and regional areas. (see SARRAH 2019 ***Strategies for increasing allied health recruitment and retention in rural Australia***).

**RECOMMENDATION 8**

**That an integrated service model be developed to underpin the Scheme where inter-departmental protocols are in place to ensure that participant’s need are central thereby enabling them to access the services of other instrumentalities relevant to the achievement of their goals and their improved functional capacity and social inclusion. Such protocols need to provide clearly articulated processes and timeframes for responses from other instrumentalities and clear guidelines as to how to progress service engagement.**

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

Please refer to responses to Question 15 above in relation to challenges faced by NDIS participants when having their scheduled review.

In the case of an unscheduled review the level of anxiety increases with participants concerned that they may lose more funds. This anxiety is accompanied by frustration with the time delays in getting a Review often waiting several months. As mentioned the lack of clarity around why particular supports were denied in the Plan based on not meeting ‘R & N’ criteria means that participant is unclear of what additional evidence they need to provide to get across the line. In the case of a review due to a change of circumstances rather than a challenge to the NDIA determination, the review process is clearer as the evidence required is understood e.g. reports of a deterioration in functional capacity; death or incapacity of a primary carer.

1. **What can the NDIA do to make the process easier and more effective?**

To make the process easier and more effective, participants need to be provided with copies of their draft plan prior to the delegate’s approval to ensure all information is recorded correctly as well as provide an opportunity to include information that the participant omitted to include during the planning meeting. If the participant is happy with the information and the goals outlined and knows that all reports from therapist have been provided then there is a better chance of the plan funding reflecting the expectations and needs of the participants.

Light touch reviews are currently available to participants to make minor changes within the first 3 months. These in effect are adjustments, not reviews. This provision needs to be extended to reduce the need for full reviews throughout the duration of the plan. ***roundsquared*** supports the concept of ‘plan amendments’ referred to in the discussion paper, as a means of speeding up the process in situations where the participant’s goals and outcomes have not changed. (See **Recommendation 7**)

1. **How long do you think plan reviews should take?**

For a scheduled review, participants should be advised by the LAC or planner that their plan is coming up for review 3 months out from the end date of the plan. This enables the participant to gather reports and other evidence to inform the plan review that ideally should be conducted 4 to 6 weeks prior to the end date to ensure a seamless transition to the next plan. The actual plan review meeting is dependent on the complexity of the participant’s situation and whether there has been any significant change in their functional capacity, informal supports or living arrangements. The 90 minutes allocated for a review should be indicative not prescriptive.

**Appealing a decision by the NDIA**

1. **What are some of the significant challenges faced by NDIS participants when they seek a review of an NDIA decision?**

From ***roundsquared’s*** perspective, the greatest challenge for participants and their families is trying to understand why a decision was made not to provide funding for a service or to reduce a service or support to the participant. A planner’s response that the service/support was found not to be ‘reasonable or necessary’ does not, by itself, provide a justification for a decision and leaves the participant unclear about what the critical ‘deficit’ is to challenge.

The Australian Lawyers Association (2019) in their recent submission to the Joint Standing Committee on the NDIS argued that ‘the review process provides only a nominal level of accountability’ with ‘decisions that are clearly wrong at law are not corrected’ (ALA 2019) forcing the participant to seek an external referee such as the Commonwealth Ombudsman or a determination through the AAT. ***Roundsquared*’***s* experience would support the ALA perspective that the internal review process lacks transparency.

1. **Are there any other issues or challenges you have identified with the internal and external review processes?**

The process and costs associated with the AAT process, including case conferences prior to a Tribunal hearing, are quite anxiety provoking for participants. It is not unusual for participants to have the plan they are seeking a determination on to expire prior to a hearing resulting in the whole process starting again. For many participants the process is a ‘David and Goliath’ experience with the NDIA able to engage lawyers whereas the participant is often self-represented. Being a ‘no cost’ jurisdiction if the participant does engage legal representation, they have no recourse to recover the legal fees they have paid out to get a fair and reasonable decision at the Tribunal. A not uncommon occurrence is for the NDIA legal team to make an offer to the participant prior to a Tribunal hearing. While such an offer reduces the anxiety for the participant of a Tribunal hearing, the acceptance of such an offer means that there is no decision by the Tribunal thereby avoiding a precedent for others appealing similar decisions by the NDIA. While this may be a common legal strategy, it is not evidence of transparency. What also needs to be considered here are the basic human rights of the person with disability. Waiting 9 months or more for a decision can have a detrimental impact on the person’s health and functional capacity, and raises questions about the how socially just such a process is.

According to a recent article in ***The Australian*** (30/09/2019): ‘NDIS spending data reveals 18 law firms and other legal consultants were engaged at a cost of $30m to support the NDIA in its response to three royal commissions and the introduction of the Administrative Appeals Tribunal Applications and Decisions Division’. It would be interesting to know how much the combined dollar value of applications from participants making appeals through the AAT would have cost the NDIA. Was the amount paid to law firms greater than the amounts sought by participants? (An answer would be appreciated!)

1. **How could the NDIA improve the decision review process?**

Reducing the long waiting time for review decisions to be made is critical to improving the process. Participants seek reviews because they genuinely believe that their situation and level of need has not be understood by the planner and without the additional supports they will be unable to achieve their goals, sustain or improve their level of functional capacity, remain safe and/or maintain the level of their informal supports.

Many participants/parents of participants have expressed that they are made feel quite guilty by planners when they ask why their/child’s funds have been reduced or a particular service or support has been determined to be not ‘reasonable and necessary’. Some have reported that they have felt like second rate citizens or that they have been made to feel that they are ripping off the system or failures as parents when they ask for an explanation from a planner. Some of the comments made to participants outlined in the case studies above give an indication of the attitudes and prejudices of some planners. ***roundsquared*** has lodged complaints with the NDIA about such comments.

When an application for a review of a reviewable decision has been accepted, strict guidelines need to be imposed as to the timeframe by which the NDIA must complete the review. No more than 60 days is recommended by ***roundsquared*** to limit any adverse impact on the participant. Specialised teams with expertise and experience in disability support need to undertake these reviews. If such specialised review teams do not exist then the NDIA should make it a recruitment priority.

1. **How long do you think reviews of decisions should take?**

Where unscheduled reviews are requested and the NDIA agrees to conduct the review (s48), such reviews should be completed **within 60 days**. Participants requesting reviews are doing so because of what they consider to be a fundamental omission in the plan funding that will impact not only on the achievement of their goals but could also affect their safety, the sustainability of informal supports and/or leave them short on funds to pay for critical services. Currently the requirement for the plan funds to be all but spent before a review occurs assumes the reason for a review is just about getting increased funds. This assumption is flawed as many applications for an unscheduled review are about the lack of, or cuts to, core funding items that cannot be funded from inflexible capacity building allocations.

**Removing the red tape from the NDIS**

1. **Do you think that there are parts of the NDIA Act and the Rules that are not working or make things harder for people interacting with the NDIS?**

***roundsquared*** notes that the amendments recommended in the 2015 review of the NDIS Act have yet to be legislated. As shown in our case studies above, the expectation of support by NDIA planners particularly of parents is unrealistic and at times quite disrespectful. ***roundsquared*** therefore strongly supports the amendment to *subsection 4 (12*) and *subsection 31(c)*  to ‘amend principles that directly reference carers so that they align with the ‘recognise and respect’ terminology of the Carers Recognition Act 2010.’ ***roundsquared*** generally supports all of the suggested amendments and welcomes changes to *subsection 14 (a)* to better define the nature and scope of the Information, Linkages and Capacity Building (ILC) in the legislation as there is very little evidence of any capacity building in southern NSW.

**RECOMMENDATION 9**

**That *subsection 4 (12*) and *subsection 31(c)* be amendedto align with the ‘recognise and respect’ terminology of the Carers Recognition Act 2010’ as outlined in the COAG agreed amendments from 2015 NDIS Act Review.**

1. **What changes could be made to the legislation (if any) to:**
2. Improve the way participants and providers interact with the Scheme?
3. Improve the access request process?
4. Improve the participant planning and assessment process?
5. Better define ‘reasonable and necessary’ supports?
6. Improve the plan review process?
7. Improve the internal merit review process?
8. Improve the way other government services interact with the Scheme?

***roundsquared*** has answered questions (a) to (g) above in various parts of this submission. Rather than repeat these points there are two critical issues that need to be factored into the legislation. The first is the need to make reference to how the NDIA is to develop mechanisms to ensure a more integrated response from other mainstream Commonwealth and State Government Departments including Health, Housing and Education, so that participants do into fall through the gaps due other government instrumentalities not accepting their responsibility for supports to NDIS participants. Secondly specific reference needs to be made to the specific requirement for different service models in rural and regional Australia. Such models need to be flexible as well as acknowledge the difficulties of accessing services such as allied health professionals, and other factors that contribute to higher costs for participants accessing services in rural areas e.g. the higher cost of petrol, the lack of public transport options, poorer internet services and the impact of the drought.

**RECOMMENDATION 10**

**That the NDIA work collaboratively with other government departments and allied health and care workforce groups to attract and retain allied health professionals and support workers in rural and regional areas and that the Morrison Government support the concept of an Allied Health Rural general Pathway to enable development of specialist roles within the various allied health professions in non-metropolitan areas. [See:** [**https://sarrah.org.au/ahrgp**](https://sarrah.org.au/ahrgp)**]; and the development of career paths for support workers through, inter alia, the active promotion of the Certificate IV Therapy Assistance Course through fee moratoriums and scholarships.**

**Plan amendments**

1. **What are the significant challenges faced by NDIS participants in changing their plan?**

Time lags from when an application for a change to their plan and an actual review occurring are significant challenges for participants and the parents/carers of participants. This is particularly challenging when the need for a critical support or service for the participant was emphasised in the planning meeting but has not included, or referred to, in the plan. Such omission impacts on the ability of the participant to achieve their goals but more importantly can impact significantly on their quality of life. Such situations increase the psychological, emotional and financial stress on the participant and their family while they wait for a review decision and try to manage in the meantime.

Losing support coordination is also proving to be a significant challenge for participants seeking a change to their plan as they try to understand the processes involved, the information required, and how to navigate the system. LACs and planners often provide conflicting information as to why a service/support was not provided, often hiding behind the words ‘reasonable and necessary’ to justify the decision but with no explanation as to how the service or support did not meet ‘R & N’ criteria. (see **Recommendation 7)**

1. **How do you think the ‘plan amendment’ could improve the experience for participants? Are there ways in which this would make things harder or more complicated for people?**

***roundsquared*** sees the option of a plan amendment as a definite move in the right direction as it would reduce the stress of completing a new review and be an effective mechanism for reducing the increasingly adversarial nature of the plan review process. A plan amendment would allow the participant/parent/carer to concentrate on just those areas of the plan that need changing rather than the whole plan. Introducing plan amendments should reduce the number of full reviews of reviewable decisions and make the process for the Agency and the participant more efficient by reducing administrative and legal costs.

1. **How long should people have to provide evidence that they need the changes they are requesting in a plan amendment?**

Participants should have up to 28 days to provide evidence that they need the changes they are seeking in the plan amendment. In most instances evidence by way of reports from therapist and other service providers will have been provided at the review, and only updates will be required. If something more specific is required the time required may take longer due to professional shortages and wait times for appointments.

1. **Are there other situations during the planning cycle where a quicker and easier way to make changes may be necessary?**

As stated in Question 14 above***, roundsquared*** believes the situation could be improved if the following measures were taken:

* Improving the recruitment process for LACs and planners so that people with a sound understanding of disability, functional capacity and support needs and options are actively recruited;
* Improving the training of LACs and planners so that they understand better the legislation and rules that underpin the NDIS and develop plans that are in accordance with this legislation rather than based on assumptions or ill-informed prejudices.
* Providing planners and LAC with more time to provide a person-centred approach that ensures that all the relevant information about a participant’s situation and needs was included in the development of the plan. This will ultimately be a time saver as it should reduce the number of requests for light touch and full reviews;
* Providing participants with a draft copy of their plan so that they can see if their information is recorded fully and the goals that are articulated in the plan are theirs and not the edited version of the LAC or Planner so that funding can be more easily related to the goals;
* Providing participants with written justification for any cuts of more than 10% to any part of their plan budget, how these reductions have been determined, and what evidence they have used to make their decision.

1. **How else could the NDIA improve the process for making changes to a plan?**

Another option for making changes in the plan would be to enable light touch reviews to be conducted throughout the entire period of the plan provided the funding amount sought is no more than 10% of the gross plan value. This could be particularly useful towards the end of the plan when a participant may have run out of funds for therapy due to the need for more intensive and regular sessions at some point during the year because of an unforeseen situation. Planners with particular delegations would be able to sign off on these adjustments in a similar manner to the light touch process.

**CONCLUSION**

Improving the NDIS experience for participants and potential participants requires greater transparency around the decision making processes as well as consistent information being provided to participants from LACs and planners. Greater transparency and consistent information requires LACs and planners to be well informed about the NDIS Act and the scope of the scheme. It also requires that they have a broad understanding of different disabilities and their impact on a person’s functional capacity as well as experience in the disability sector. Public sector experience is simply not enough. Such understanding is critical to the development of a good plan during the planning meeting. Here the assumption that a person with disability has the capacity to determine what is in their own best interests and to make decisions [Section 17A(i)] about their life must be must be combined with a genuine commitment by the LAC or Planner to hear and understand the participant’s perspective. LACs and planners also need to have a very sound understanding of other Commonwealth and State/Territory Government responsibilities and the scope of their respective programs.

All of this needs to be based on an integrated service model that clearly outlines the responsibilities of other government instrumentalities in supporting and providing services to people with disability.. This is not the case currently with different Departments seeing the NDIS as responsible for supports and services that clearly lie within their responsibility. Protocols, policies and procedures need to be in place to ensure that other instrumentalities do not shirk their responsibility to provide critical elements of a person’s NDIS plan and that clear referral pathways are in place to expedite access to services.

Hand in hand with an integrated service model is the need for a national care workforce strategy to ensure access is available to allied health professionals and support workers across metropolitan, regional, rural and remote. Being unable to access required AHPs can impact adversely on a participant achieving their goals and maintaining/improving their functional capacity. Government incentives need to be provided to recruit and retain AHPs in rural and regional areas, with funding provided to develop flexible models of care to support the AHP in terms of continuing professional development and reducing the incidence of burnout.

Nowhere is the need more urgent for improved transparency, consistency of information, better trained LACs and planners and improved access to services in rural and regional areas than in the area of psychosocial disability. With the termination of the PIR, PHaMs and D2DL programs as of 30 June 2020 people with serious mental illnesses on these programs will be transitioned to the NDIS. To date only 50% of those who have applied have be assessed as eligible. This transitioning process could be the litmus test for the NDIS.

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