



## **Roundsquared**

Submission in response to the Productivity Commission Issues Paper:

National Disability Insurance Scheme (NDIS) Costs

March 2017

## About Roundsquared

Round squared is an independent organisation that provides flexible and responsive mentoring support and consultancy services to people living with a disability and their families. Its founders and its employees all have lived experience of disability either directly or through a family member. The organisation therefore, offers a unique and holistic understanding of what it takes to support a person with a disability to have a good and independent life in the community.

The individuals and families with whom we work are respected as members of our organisation. Each member is encouraged to either wholly or in part, direct the supports provided to them. Roundsquared works proactively alongside its members to ensure participants are able to utilise their NDIS plan funding to maximise outcomes and to build their capacity to take control of their lives and direct their own supports into the future.

We are committed to help individuals and families to think differently about what may be possible. We achieve this through informed mentoring, creative support coordination and responsible plan management. Roundsquared only works with individuals who want to self or plan manage. We do not provide direct daily living support services. This important distinction maintains our independence in the disability marketplace.

Our priority is to assist people with disability and their families to lead good, socially inclusive lives. We believe that people with disability and their families must have real choice and control over the decisions that affect them now and into the future.

This submission represents the views and experiences of our membership all of whom are current participants within the NDIS.

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## Introduction

Roundsquared are pleased to provide a response to the Productivity Commission Issues Paper: National Disability Insurance Scheme (NDIS) Costs (March 2017). While not specifically within the terms of reference for this inquiry, we would like to make the following general comments about the scheme before responding to individual questions within the paper. We would further note that our response has been limited to those questions that most directly relate to the work that we do in supporting NDIS participants.

Through our work, Roundsquared is witness to the possibilities for a 'good life', when a participant's plan allows for the right supports to be delivered. 'Getting it right', has significant life-long implications not only for the person living with disability but for their family and personal support networks. Good plans mean parents can go back to being parents and participants can work towards independence through improved social connection and inclusive economic activity. Good plans support the insurance approach upon which the NDIS is predicated.

Roundsquared also works with NDIS participants who have been provided with inadequate and or inappropriate plans. 'Getting it wrong' means these participants are prevented from engaging within their community and from being supported towards employment or achieving their plan goals. Such participants are at serious risk to being worse, not better off, under the NDIS. Poor plans reinforce the notion that 'nothing much has changed' in the way people with disability are valued and supported in Australia.

It is our experience that 'bad plans' or plans that only part way support participants, result from some of the inconsistencies that are inherent in the current implementation of the NDIS. In fact one client participant commented to us that attending the NDIS planning meeting with the Local Area Coordinator (LAC) "feels somewhat akin to spinning a chocolate wheel. You spin, stand back and hope that you are one of the lucky players".

While not exhaustive, we believe that the following points help to explain why some participants are being delivered poor plans and why costs are not being appropriately controlled.

1. There is a 'disconnect' between NDIS planners and participants which is resulting in plans bearing no resemblance to need or discussions with local area coordinators (LAC's). This not only adds to the burden of individuals trying to navigate a new system but is also adding significant cost to the scheme through the number of plans requiring review. We believe this also goes part way to explaining why some participants appear to be underutilising their plans or appear slow to commence accessing supports.

2. The interface between participants and providers and the NDIA is deeply problematic. Our collective experience is that calling the NDIS 1800 number is a frustrating and is peppered with inconsistent responses, countless redirections, long wait times in phone queues and considerable time drag in resolving problems. Call centre operators inform us that they cannot provide information only refer queries in an email to an unidentified person or department. There can be as much as a 3 to 4 month wait time for a response to such queries and when contact is made, no phone number is provided so that return contact can be made. This means that to resolve issues you must re-enter the call centre queue to start the process over. One client participant, who had as a stated plan goal to achieve employment and who had previously completed one year of a transition to work program but had no job support funding within their plan, was caught in this loop for 3 months before they were even able to have their plan put forward for review and only then as a result of a complaint made at the beginning of the process.
3. The significant conflict of interest that exists when service providers are engaged to deliver LAC, plan management, support coordination and direct services to participants. This is particularly problematic where participants are socially isolated with no informal supports or social networks and are living within supported accommodation. If there is a failure of service, then there is no independent support available to such participants. Leaving the service is not an option and we are seeing a number of such participants in real crisis. We see this as a dual failure of the current scheme. Firstly, as stated as a conflict of interest and secondly, as a failure to ensure all participants are properly supported through independent support and capacity building services.
4. Preplanning support for future participants is largely non-existent. Many client participants tell us that they were given as little as 2 days to prepare for meetings and that when they did attend their meeting, they either felt bewildered by the process or were prevented from submitting documentation and reports to substantiate requested supports. As alarmingly, service providers appear to be grooming participants to request services that they provide under the guise of 'helping to prepare' for the initial planning meeting, some even offer to sit in on planning meeting to ensure that these supports are provided.

We acknowledge that while there have been many public forums to provide information about the NDIS we note that they are general in nature and do not provide the intensive independent support some participants require in order to achieve the right plan. We therefore, urge your consideration and influence for a change to the framework such that it would allow for every pre NDIS participant the ability to access pre planning support from an independent plan manager or support coordinator. Such a measure we believe

will go some way towards reducing the number of inappropriate plans being developed that are subsequently referred to the NDIA for review.

It is against this background that we respond to the questions raised in the issues paper.

## Issues Paper Response

### *Experience so far*

- The NDIS is a significant change in the way that people with disability access and arrange support services. For some it is the very first time that they have had any real choice or control over the support services they receive. The disability landscape to date has encouraged passive acceptance of a limited suite of generic services. The NDIS, in contrast, now requires participants to be active negotiators responsible for their own care and services. This represents not only a quantum shift in thinking but is requiring participants to draw on an entirely new set of skills to enable them to develop and implement their plans as well as negotiate the services they require in an open market environment.
- There are participants who have ended up with little support funding not because they need little but because they were unable to identify all the supports they needed or were unable to advocate strongly for themselves in their discussions with their LAC. As an example, we are aware of a participant with a significant vision impairment and history of poor mental health, has a plan which delivers next to no real supports. As a result he will likely remain on the disability support pension rather than be enabled to work towards self-sufficiency and will no doubt, continue to draw on the public hospital system for psychological assistance. We question how is it possible that anyone could consider his plan as delivering him the reasonable and necessary supports to live a good and inclusive life. It alarms us that at no point in discussions with their LAC, did the LAC query what was being requested or explore with that participant what else may be required. Family members of this participant are now locked in on-going and challenging discussions with both the NDIA and the LAC to try to redress the short comings in the plan. This highlights a significant failing in the way in which new participants are being prepared for and assisted into the scheme.
- There are unrealistic expectations of the LAC role. Many individuals in these roles are new to the disability sector as well as to the role of LAC and as such lack skills to help determine a participants real needs or have the community connections to be able to refer them appropriately, let alone pass key information to the NDIS planner in an appropriately nuanced way. Additionally, if a participant's plan does not include support

coordination or plan management they are left to fill the gap on top of their already busy roles. Many participants tell us that LAC's actively discourage them from providing supporting documentation even though they are entitled to do so. Further, we are aware that NDIS planners are not obliged to read such documents even if they are provided. We are concerned therefore that the right information is not getting to the decision makers and that the benchmarking approach that has crept into NDIS planning processes is reducing participants to a diagnosis and not a person who has individual needs and aspirations. The experiences of participants on the Autism spectrum certainly reflects this damaging approach. We do not believe this was the original intent of the NDIS.

- Plan approval and notification processes are ad hoc and confusing. Many participants only become aware that a plan has been generated when they receive advice from Centrelink that mobility payments are ceasing. It is then left to participants to follow up with an LAC or the NDIA call centre to find out what this means and what if anything has been approved. Full plans arrive by mail several days after the plan has been created. Not all participants have their plans explained to them by their LAC. Once the initial planning session has concluded, the LAC can be hard to contact and one client participant's only continuing contact with the LAC after the plan was approved was via SMS messaging. We do not believe this to be an appropriate way to deliver important information or to explain the detail of a plan, particularly if the plan in question bears little resemblance to what was required.
- Plans are written in such a way as to make administration of and compliance with the Price Guide simple. They use terms that are unfamiliar to describe support categories and are supported by explanatory statements that are confusing or in many cases, wrong. They are not offered in an 'easy to read' format and therefore are not immediately accessible by all participants. Therefore, there is inevitably a delay between when a participant plan is approved and when a participant understands their plan and feels sufficiently confident to commence actioning it.
- There is misinformation being provided to participants about how to implement their plan. By way of example, one participant that we are aware of, on receiving their plan, were instructed by their LAC to now wait for someone to contact them before proceeding. They took no action for weeks waiting for someone to contact them. Coincidentally, the support coordinator who ultimately contacted them worked for the same organisation as the LAC. If the participant had been encouraged to seek their own support coordinator in the open market, we question whether or not there would have been a delay in implementing their plan. Therefore what may prima facie, look like participant reticence to implement plans may in fact be a systemic failure to adequately

communicate with participants as to where and how to commence implementation and how to seek independent support to do so.

- Increasing demand for disability services is causing large waiting lists to form delaying plan support activity. There are as yet insufficient providers in some areas to meet demand and this is particularly evident in rural and regional areas, chiefly in relation to allied health professionals. We are also told by allied health professionals such as psychologists and behavioural specialists that the referrals they are receiving from the NDIA do not provide accurate or sufficient information about a participant. This is so problematic that some are considering deregistering as providers. This again speaks to the quality of the information that is populating participant plans.
- There is difficulty in finding providers who are ready to deliver the individualised services that participants are requesting. Many still remain tied to old programs, although these may have been re-badged to fit with NDIS terminology. As an example, a client participant made a request of a large not for profit provider for access to life skills support. The participant was told that it could only be accessed as part of a larger program much of which was not required, nor funded under their plan. We do not see this approach as market responsive nor is it supporting choice and control. Instead we are seeing service providers who are resistive to offering real choice and who remain wedded to a block funding mentality. This is a difficult landscape for people with disability to traverse when lack of alternative service and a fear of retribution is still very much front of mind and front of experience.
- Participant plans are not constructed in such a way as to support flexible and creative approaches in achieving participant goals. This is because the price guide which determines what participants are able to access under their plan is a categorical and narrow listing of what people can have, reading more like a chart of accounts than a framework around which to build meaningful support. If a participant uses their funding for support to attend a social or community activity and over time becomes more independent in doing so, then on-going support to maintain that independence is not currently able to be funded from their plan. We suggest that it would be more cost efficient to fully support participants to use their support funding flexibly rather than to introduce limits on how they can exercise either choice or control.
- Misguided approaches are seeing some participants allocated funding amounts for single use transport journeys in favour of funding for support to develop skills to independently access and use transport. While we acknowledge that this may mean an increased cost to the NDIS in early years of a participants plan, over a life time it must surely reduce cost.

- The insurance approach that underpins the NDIS has the clear aim of reducing the cost of support over the lifetime of a participant by delivering good foundational supports as early as is possible. We do not see evidence that the scheme as it currently stands is working to achieve this. In fact what we are witnessing are continuing disincentives to independence and an on-going medicalisation of disability.

### ***Intersection with Mainstream Services***

- *Education Services*

People with disability are known to have poor educational experience and outcomes. The NDIS has an opportunity to help prevent disadvantage while participants are within mainstream educational settings, and yet, this much needed support is absent from both participant plans and the price guide. There is an incorrect assumption that inclusion in education is synonymous with being able to access the curriculum. Currently, NDIS participants are not able to use plan funding to purchase one to one educational support or support programs. By limiting participants in this regard the scheme is failing to recognise that better educational outcomes are inevitably linked to better employment and self-efficacy outcomes.

As an example, one young participant who had left school and was attempting a TAFE course to build her capacity as a future employee was struggling with some of the course content. They wanted to access some funding to help go over concepts at the end of each day and so that they could practice new skills. They were refused such this raises issues around introducing non-students to an educational environment in terms of health and safety, insurances and privacy.

- *Health Services*

In regional and rural areas in particular, participants who were previously accessing supports via health services are cut off immediately once their NDIS plan activates. There is no transition plan for such participants and subsequently they do not have continuity of service and for some services this represents a very real crisis for the participant and their families.

### ***Planning Processes***

- If the planning process took note of some of the comments made in this submission we believe that it could become a cost effective and more reliable and certainly more



accessible process. We do not believe this is the case at the moment and we cite the large number of plans being put forward for review as evidence of this and even this we believe to be an underestimation of the real number of plans that need to be reconstructed.

- From an external perspective both planning processes and plan development appears to be chaotic and inconsistent with little to indicate they are cost effective or reliable. We therefore recommend that participant plans be randomly selected for review by an independent body to determine if the planning process and the plans that result are meeting participant needs. Such review should extend to consideration of what the participant has been able to achieve within that plan and an assessment of whether or not the plan has been designed to allow the participant to meet plan goals.
- Our experience with participant plans in the trial sites suggests that NDIS plans were better articulated, resourced and understood by participants. We believe that this is because the information and pre planning was conducted by the NDIS planners themselves. While the role of LAC has added to the NDIS cost base it has not as yet added to is cost efficiencies and appears to have hindered rather than supported good plan development and practice.
- Participant plans are structured in such a way as to be difficult to understand exactly how each component can be spent. Many participants and providers require additional support from technical teams to help process claims on the portal because exact funding codes are not always clear and transparent.

### ***Reasonable and Necessary Supports***

- Participants are being actively dissuaded from pursuing reviews with some receiving thinly veiled threats that in asking for a review they risk losing the monies that they have already been allocated. Additionally, the time for processing reviews is excessive with some plans in for review without determination for over 4 months. Participants with plans in review have on the one hand been told to implement their current plan as best they can while others have been told that they cannot access services until the plan has gone through the review process in its entirety. One client participant was told that there was no need for a review because they could just use their core support funding to access job support services. For them to have done so would have required providers to falsely claim hours of service to make up the difference in hourly rates between what is funded under job support in the price guide and what is funded under core supports. When this was raised with both the LAC and the NDIS planner the participant was told to just do it. That plan was eventually reviewed at the participant's insistence and job support was

added as a reasonable and necessary support but not without lengthy delays and the participant forfeiting support for several weeks.

- There are inequities within participant plans because of the subjective and inconsistent application of the concept of reasonable and necessary supports. It is reasonable and necessary for some participants to attend community and social events that are not mainstream disability services, yet in the current regime these are unable to be supported through an NDIS plan. We would argue that it is just as important to build opportunity for incidental and organic social experiences to develop resilience and capacity as it is to attend a group disability program, and more so if the participant goal is to gain independence and open employment. We would further urge that participants be given greater capacity to self-determine reasonable and necessary supports within the confines of their overall budgets. We would also want recognition that some families of people with disability, by virtue of that disability, are socially and economically disadvantaged and that to suggest that these families pay for some items just as everyone else does, completely minimises the significant personal and financial crises these families have lived under for a very long time. For families to continue to function and to adequately support the participant, the participant plan needs to recognise the broader need otherwise there is risk for further participant support cost further down the line when family structures break down.

### ***Market and Provider Readiness***

- We do not believe that the market is or was completely ready for the changeover to the NDIS. This is evidenced by the difficulties participants are experiencing with finding providers capable of delivering services and in navigating the burdensome administrative processes of those providers with whom they do engage. We have multiple client participants who are using services but are unable to get invoices for those services from providers. Time delay for one client participant on service charges is in excess of 12 months. Again, we note that this gives the appearance that funds are not being used, when in fact, they are used but mainstream providers for whatever reason, cannot seem to work out how to invoice for the services they provide. This is far less likely to occur when participants deal with non-registered providers or access in community supports.
- Providers have been slow to fully comprehend and develop services in a truly person centred way. They have customised to meet the requirements of the Price Guide but have shown little in the way of developing or offering innovative supports. Participants are still required to choose from what a provider is prepared to offer and even when they promote individuation the product offered is usually participation in a group activity with an hour of 1 to 1 service with no clear plan for how this 1 to 1 serves the goals of the

participant. What it does however serve is the financial interest of the provider who can now charge almost double for that one hour. One client participant sought to purchase only a module of an existing larger program. As they were about to agree to a plan, they found that the terms of trade of the provider meant that they would need to commit a large portion of their funding to that provider for a 12 month period, even though they would not use the service for the full 12 months. Acceptance would mean locking themselves into an agreement with penalties for cancellation, when what they really wanted was a short one off program.

- The market also appears not to understand that participant plans are confidential documents. Providers repeatedly require participants to hand over their plan before they can offer a quote for services or indicate if they have capacity to assist them. Outside of providing start dates and NDIS client number, there is no real reason for providers continuing to ask for this document. One provider explained that having the whole plan was a requirement for their current administration system because they could not complete an agreement or book in service without filling out all the fields. Another, said it was a service being offered to ensure that the participant was aware of everything that they could access under their plan. With respect, it is the responsibility of the LAC, plan manager and or support coordinator to ensure the participant understands their plan and what can be achieved and not providers.
- There continue to be issues for providers in uploading payment claims through the NDIS portal. When claims reject there are no indicators for the reason for rejection. This means providers are spending inordinate amounts of time and money chasing payment. We understand that the problem is widespread and has some providers looking to de-register and revert to direct charging participants and leaving portal issues to participants themselves or their plan managers to resolve.

### ***Will participants be ready?***

- Change takes time. Some participants are well supported and informed and have been able to manage the transition to the NDIS. There remains however, many current and future participants who will not be able to fully access the NDIS without substantial support. Further, once in receipt of a plan will need assistance to understand and implement that plan. We are concerned that plans are still not recognising this need and are not provisioning for plan management or support coordination. Those plans that do have such supports have insufficient hours allocated within them to adequately fund the amount of time it takes to support participants with complex needs or those implementing a first plan. We are also concerned that there appears to be a shift away from funding plan management services in favour of a financial intermediary service. We

believe this seriously undervalues the role plan managers play in ensuring plan funds are responsibly managed and in negotiating best value for supports provided under the plan. Investment in these items is crucial in developing the long term capacity of participants to not only manage their NDIS plans but financial matters more broadly. We therefore urge attention to embedding both plan management and support coordination within each and every first plan for NDIS participants.

- If participants are not properly supported to prepare for and implement plans then the risk to the NDIS is twofold. Firstly, plans will continue to be developed that do not accurately meet the needs of participants and will result in increasing support needs over the life of the participant and not less. Secondly, NDIS plans will continue to be either underutilised or be used on supports that do not represent best value to either the participant or the NDIS.

### ***Governance and administration of the NDIS***

- There is emerging concern that the NDIS is moving from its original intent to support people with disability to work towards independence, economic security and social inclusion using an insurance approach, towards a model predicated on short term cost minimisation as is being evidenced through the growing number of poorly structured, inflexible and underfunded plans. We see this as a very self-defeating strategy and one that will inevitably cost more for each and every participant over their life time of supports.
- We are further alarmed by the continual demands placed on participants to substantiate their disability diagnosis, when such a diagnosis is already a matter of record and further when doing so does not necessarily further understanding of individual need. It is for this very reason that the Diagnostic and Statistical Manual 5 has moved away from categorical diagnosis towards a more dimensional model which encompasses a need and functioning. Pure diagnosis approaches relegate participants once again to the ranks of the deserving poor rather than equal Australians who are entitled to participate genuinely in the community.
- Crisis case management still remains unresolved under the administration of this scheme with participants left with no avenue for support when provider services fail. There is a real and on-going crisis currently for people within supported accommodation who have no personal support network. These are the most vulnerable of participants and many of them have all of their supports being provided and coordinated by their disability accommodation provider. We are aware of such participants being given notice to vacate with no alternatives in place. Pre NDIS these participants would have been picked up and

supported by aged and disability services but as most of these no longer exist, there is no body who is able to assist. This is placing huge demands on plan managers and support coordinators as these participants are turning to them in a place of both significant crisis and vulnerability. They require and must have a safeguard provider built into and funded within the NDIS who are able to provide flexible resolutions that facilitate support to transition homes, recoup unspent funds and plan a meaningful way forward.

### ***Towards a sustainable future – Concluding comments***

We strongly support the NDIS and value the opportunity for choice and control that it promises to deliver for people living with disability.

We want this scheme to fully realise its vision and in doing so help build a strong and inclusive community for all Australians.

We believe that this vision can only be achieved if the scheme remains committed to taking an insurance approach in supporting people with disabilities.

We urge that best value, cost efficient support is only possible if sufficient resources are provided within initial and early plans to enable participants to truly work towards social and economic independence across their life time.

We support the right of every person living with disability to be able to flexibly direct the supports that are provided to them and exercise real choice and real control.