

NDIS Review Submission

Please find below my submission to the NDIS Review.

Please do not make public any personal contact details, including my name or email address.

Thank you for accepting my submission, and thank you for the time to read it. I hope somehow my submission contributes to a fairer, more equitable, reason-based system of support for the participants.



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I am a 66-year old woman who has no disability; as a public servant I am adept at case managing, assessing, report writing, making recommendations, and making decisions, and I am quite capable of multi-tasking. In the short time I have been a managing NDIS affairs for my daughter and grandsons, I have found the NDIS system to be ridiculously labour intensive and complicated. It is a dreadful discredit to the government that a system supposedly set up to support people with disabilities, in fact has created an unworkable, punitive system for those with disabilities. My experience of the NDIS is that the service providers and registered NDIS providers are protected at the expense of the participants.

Following is a list of key points of concern and on-the-ground issues as my family and I have experienced:

1. The NDIS system is labour intensive for participants/nominees, including approval of multiple invoices everyday, navigating conflicting information between that provided by the NDIS contact centre and that provided by support coordinators and plan managers, preparing for a plan review, and dealing with the aftermath of a plan review. This is particularly disgraceful as participants have enough to deal with on a daily basis because of the issues that go with disability. The system should be one of simple and easy navigation for the participant. Daily approval of invoices (often multiple invoices) includes checking invoices for correct and full details, contesting about invoices or incorrectly paid invoices. Because daily approval of service provider invoices is an onerous and time consuming task, my daughter had authorised auto approve for service provider invoices. As my daughter's health declined, I took on the responsibility of communicating with the registered NDIS provider about invoices and service provider issues, and I decided to look into invoice approval (we now no longer auto approve after discovering a complete mess). In no time at all I discovered that invoices with incomplete and/or incorrect details were paid, that service providers were taking advantage of the short notice cancellation policy, that support workers with no training in the industry were claiming the highest capped rate, and through this mess my daughter and grandsons were not receiving value for money. In short, the system has worked in favour of the service providers, not the participants.
2. There is an inherent disconnect between the participant, the registered NDIS provider, and service providers. Because many service providers are sole traders, there is no accountability between the service provider and the employer, and there is no tracking of a service providers movements. Issues that need addressing or resolving involving service providers are left up to the participant to deal with: there is no support for the participant, as the NDIS provider picks and chooses what issues they are prepared to deal with. I have had several invoice/service circumstances which I have questioned, and I have had very conflicting advice from the registered NDIS provider about their responsibility or mine; wherever possible, they will put anything that needs sorting back on my shoulders, which again demonstrates this system is labour intensive for the client.

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3. The registered NDIS provider we deal with has mismanaged my daughter's and grandsons' plans, leaving them without therapy supports for months at a time. When contested, we are invariably told that it's up to the participant/nominee to keep track of their funds; this refusal to accept responsibility begs the questions - what is their role and why are they paid a monthly fee from my family members' plans? Information from the registered NDIS provider is inconsistent according to my query or complaint. This is particularly with regards to invoices that are not completely or correctly detailed and with regards to questions about payment. I feel much of my communication with them is trying to understand their role and their responsibilities, which opposes their supposed role of support and assistance.
4. Service providers claim the highest capped payment rate. There is not one service provider who has provided therapy or support for my family members who charges less than the the capped rate. As an example, my daughter and grandsons' physiotherapist charges over \$100 per hour more than for a client who is not NDIS funded. When I first became involved in their NDIS world, my grandsons had a support worker who did not have a clue about support and who had absolutely no training in the support worker industry - he was useless in helping my grandsons reach their goals. He not only charged the highest hourly rate, by text he would cancel minutes before (and sometimes after) a shift was due with excuses including that his wife was tired after a bad night because of their baby and he wanted to stay home so she could have a rest, and sometimes he would cancel with no explanation, just the message that he couldn't make it that day. Yet if there was a short notice cancellation he would claim every cent that he felt was his due. On one occasion he started driving for a Monday morning shift on a public holiday (even though no shift had been arranged) and when he phoned to check if the shift was expected, he advised my daughter and grandson that he would claim the hour for driving - and this was public holiday rates!! Another support worker would only work Sundays or public holidays; on the last occasion he drove to my daughter's house on a Sunday to discuss a job which had been communicated about through email; on arrival he advised he couldn't do the job but he would be happy to assist, and he charged the full hour even though he was present for twenty minutes. Cleaners have cancelled within one hour of the due shift with excuses such as needing to visit a friend in hospital, needing to take a relative to the airport. But the worst thing is the abuse of the short notice cancellation policy .
5. The NDIS short notice cancellation policy 7-days notice is absurd and appalling, and favours only the service provider. How on earth can a participant know if they are going to be unwell or have an unexpected medical appointment in under one week - this is unreasonable in every sense. The cleaners who used to provide cleaning for my family members used this policy to their advantage at every opportunity. If they texted to advise they were sick (usually a cough and cold symptoms) my daughter, who has vulnerable health, would ask them not to return until they were symptom free; they then would capitalise on the 7-day short notice cancellation policy by not returning for a couple of weeks, and updating to my daughter a day or two before each due shift

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that they were still sick, and my daughter would ask for them to return when symptom free, and they kept claiming under this cycle of text communication. When I approached them about a service agreement and that we did not agree with the 7-day policy and it needed to be negotiated, they became very defensive about their rights and their position, and thereafter they never availed themselves to discuss the matter further. Their service (if it could be called that) came to an end when they sent my daughter a text outrightly complaining about not being able to claim as they had been under the 7-day policy, and that they didn't like to miss out on THEIR money, without any mention by them about concern for my daughter going without the service. The 7-day cancellation policy has set up a culture and mindset of entitlement; in fact so much about the NDIS system as it currently is, is simply a shortcut way for people to make lots of money very quickly without having to do very much. And all at the expense of the participant. It is disgraceful.

6. When I first became a nominee for my daughter and grandsons I felt very overwhelmed by the complexity of the system. I could not understand why the service providers charged top dollar, and even though I asked and enquired, it took some time before the registered NDIS provider support coordinator advised about negotiating price through service agreements. Whilst I am sure the original idea was for the participant to have greater input through service agreements, and for this to be considered choice and control, the reality is that it is more work for the participant. My daughter had no understanding of the need for service agreements because that same support coordinator failed to mention it. Hence all the service providers have charged the capped rate. As I have understood more and more of the system, I have started negotiating for service agreements, including a fair hourly fee, and the service providers have taken affront to being expected to work for a lesser rate than they have become used to. To quote from the NDIS Pricing Arrangements and Price Limits 2022 - 2023 : *Providers should not charge NDIS participants more for a support than they would charge anyone else for the same support.* But in point of actual fact, the NDIS has not only created a culture of entitlement, it has fostered and nurtured it. All at the expense of the participant.
7. I have been involved with one plan review. The review was months overdue (even though we had received official communication from the NDIS advising the review would be no later than a date that was months earlier), and consequently my daughter's funding exhausted and she was unable to proceed with therapy. In my daughter's previous review the wording of her goals had been changed, and did not reflect her actual goals. In this review, we were advised some of the outcomes were to suit the goals, which they absolutely did not. I have no idea of the credentials of the planners and the decision makers, but they have not demonstrated any reason for confidence in their ability to understand about the diagnosis of lifelong conditions, what the challenges of those conditions mean, and what supports are actually required. The decision to no longer support certain therapies and consumables was poorly argued by the planner; in fact she argued that one item that had been purchased could be considered for refund to the NDIS as it was an everyday item -

she failed to see that the item was recommended by two therapists and is directly related to my daughter's needs; the argument that the NDIS won't support everyday items is ridiculous; the NDIS supports physiotherapy because the need is related to my daughter's condition; however, many people who consult physiotherapists are not necessarily NDIS participants, and therefore physiotherapy could be seen as an everyday therapy; the decision makers seem to pick and choose at will what they deem NDIS approved or not, and we have not seen demonstration of much reasonable thinking in that. Over a year ago an Occupational Therapist recommended a ramp and grab rails in the bathroom for my daughter; these recommendations were also recommended by the physiotherapist, yet they are still to be actioned; the planner advised they are everyday items and the NDIS was not required to pay for them; I beg to argue that an able bodied person does not require ramps and grab rails, and that the planner demonstrated corrupted thinking, and one wonders about the skillset of such people. Since that review, my daughter has been denied therapies and consumables that had previously been approved and that she had received because the decision makers claimed one of my daughter's conditions needed to be proven as lifelong - as I pointed out to the planner, my daughter was born with the condition, it is progressive and deteriorative, and she will die with it - if that isn't lifelong, I don't know what is; the planner, needless to say, was lost for words, and suggested we get a letter from the doctor, even though my daughter's doctor had submitted a letter of diagnosis. As my daughter said to the planner when she was telling us about the outcome of the review, it is insulting to the participant to be so misunderstood and to be judged by people who clearly do not understand that which they are making decisions about. It is an affront that participants are made to jump through unreasonably hard hoops to prove their conditions, when on an everyday basis they suffer. Perhaps the decision makers would do well to walk a mile in the participants' shoes - one week would do it I reckon - instead of making decisions from positions removed from the coal face.

8. A concerning point is that through mismanagement of funds there is the possibility a participant is expected to repay for consumables purchased or pay for services provided when funds have exhausted. This is a current circumstance that we are battling. Because my daughter's review was so very overdue, funds exhausted. Invoices for therapies within that time since submitted have not been paid, and I was told by the support coordinator that I would have to pay these invoices privately. Where is the responsibility of the support coordinator who assured my daughter that she would keep track of funds and not let her run out? And what arrogance to presume that the family will 'pick up the tab' of many hundreds of dollars. Similarly, an invoice was recently paid by the registered NDIS provider that I had not approved because it was submitted prior to the service, and it included an hourly fee for a letter that was never discussed or authorised with my family member. Again, the lackadaisical attitude by the registered provider astounded me - email communication simply advised that the invoice was already paid and if I didn't agree I would have to seek to have the payment refunded. What arrogance and what irresponsibility!! I have

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taken to task the registered NDIS service provider and demanded they seek the refund and to not proceed until I authorise an invoice that I am confident of. All of these dealings take time, energy, and effort. And that is on top of all other daily responsibilities. I can see why my family members chose auto-approval of invoices, AND I can see how their funds unreasonably dwindled. This is a system that favours the service providers and the registered NDIS provider, who can apparently do as they like, and if questioned, they place the blame and responsibility on the participant. Shameful and disgraceful that it is allowed.

9. Learning about, understanding, navigating, managing, and keeping on top of the NDIS system has been a minefield for me. One problem point is that I have regularly received conflicting advice from the support coordinator/plan manager and from the NDIS contact centre. It is the most frustrating thing. I ask a question and get totally opposing answers, whether it be about pricing, how the system works, how support workers should claim according to the time they work - never once have I received consistent advice, which of course leaves me with no confidence. The big excuse is always that the guidelines can be interpreted to mean such and such. With huge amounts of tax payers money at stake, I would think the guidelines should be less interpretable and more certain. And again, by defaulting to this excuse, the registered NDIS provider evades responsibility; too often, the registered NDIS provider is defensive of their position if I question them, which is an odd response, unless they know their integrity is questionable. And I am left confused as to what is the answer and how to proceed with an issue.
10. The issue of poor quality support from the varying service providers, time and again letting down my family members (the participants) brings me to the next point. I have worked as a trained support worker some years previously; across two Australian states I have had extensive training and I have significant qualifications in the field. During the NDIS disasters of support workers and cleaners who have let down my family members, we asked could family be employed as service providers and the answer was a definite *No - because they might let family members down or they might take advantage of family members!!* Considering our story with service providers, that is a reply loaded with insult and hypocrisy!! Have the bureaucrats considered that true choice and control would not limit service providers to non-family and non-friends? And most significantly, have the bureaucrats and decision makers not considered that as it currently stands, there is poor workforce quality, with lack of understanding of role, lack of understanding of charter and responsibilities to the participant, lack of understanding about the purpose of the work vs a quick way to make money without accountability. There is a glaring propensity for a serious disconnect between the service provider and the participant, yet all this has been allowed by the NDIS, whereas people with care, concern, values, and the desire for best service are denied employability because they are related or friends. The following is taken directly from the NDIS website regarding Code of Conduct: *The Code is designed to work alongside other elements of the quality and safeguarding arrangements to promote a safe and skilled workforce within the NDIS. Providing quality supports for people with*

disability involves not only the right capabilities but also the right attitudes. If that is the case, many of the service providers should not be employed and should not be paid as many are not in any way professional; we have discovered some support workers we have had (recommended by registered NDIS providers or Local Area Coordinators), have not any background in the care industry and have not sought training or up-skilling. Yet they are legally allowed employment and legally allowed to invoice for capped pricing. The NDIA's presumption that friends and family should provide care that is not acknowledged by remuneration attests to the decision makers' lack of understanding about relationship dynamics and the rights of the participant. Even at base level Centrelink acknowledges carers by way of remuneration in pensions and allowances.

In summary, our experience with the NDIS has been tiring, frustrating, at times insulting, and hard work just to navigate on a daily basis. Surely this system, supposedly designed to support the participant, should be less labour intensive, ensuring quality support, easy to navigate processes, and straightforward information that does not leave one confused.

Regarding key targets:

Achieve goals - Ensure that the participants' goals are not re-defined by the planners and decision makers. Ensure the participants' goals are achieved and are the focus, not the service providers' goal of making money quickly for little work. Planners and decision makers' qualifications and skillsets need to match the job so that participants receive funding outcomes that match their needs, not match the planners ideas of their needs. And the decision makers need to understand the participant's goals through the participant's lens, not put their own interpretation on goals and expected outcomes. Listen to the participant, trust their knowledge of what they want and need through their daily experience, and respect their needs. The power by the decision makers to redefine goals and to claim that outcomes match goals (when they blatantly do not) needs to be removed, replaced by skilled understanding through respect of the participant's actual circumstances. It should not be the decision makers' right to mould the participant's needs to meet the decision makers' opinions.

Receive value for money - Ensure it is the participants who receive value for money, not the service providers and NDIS providers receiving money for little valuable input. Ensure trained, experienced staff or friends and family with expertise and skills are the workforce. Put in place **an interconnected system that supports the participants** vs a system of disconnect between participants, service providers and registered NDIS providers; less sole traders who answer to no employer replaced by employed staff (including family and friends), trained by and accountable to their employers would ensure greater chance of accountability and responsibility, and the organisation that does the hiring and firing would have clarity of records about who worked when and where, so the burden of invoice approval (checking correct and honest information) would be part of their job, not on the shoulders of the participant. Requirement of employers to be suitably accredited with an understanding of the importance of staff training is as important (one service

provider we interviewed who owned and ran his support worker company admitted he didn't think any training in the care sector was required - his criteria for someone to be employed was friendly personality - needless to say, we did not proceed further!).

Reasonable and necessary supports - The decision makers need to consider not limiting supports because of the issue regarding financial sustainability; rather, the NDIA needs to emphatically put a stop to price gouging and poor quality input by service providers - do not punish the participants because the system has been poorly managed and has allowed for sloppy use of tax payers' money. And the decision makers need to understand reasonable and necessary supports through the lens of the participants, not through their bureaucratic lens.

Regarding key problems:

The system as it stands is **not participant friendly/supportive regarding the 7-day cancellation fee policy**. This policy supports the service provider only, and it is not even vaguely reasonable or fair to the participant. Most cancellation policies across the board are 24 - 48 hours - how did the decision makers ever rationalise this as supportive of the participant? Clearly they didn't. Rectify this by introducing a fair and reasonable approach that considers the participant; as it stands, all preference and consideration is about the service provider.

The system as it stands is **not participant friendly regarding the challenges of learning, understanding, and navigating the system**, including daily vigilance of approving invoices. Rectify this by removing the current model that allows information to be interpreted (a sure recipe for potential corruption and irresponsibility) and replace with a streamlined system of clarified information that doesn't need endless reading of document after document of jargon in an effort to have an enquiry answered.

The issue of **participants' funds being fraudulently and irresponsibly used** through price gouging and rorting by service providers who have worked out how to play the system to their advantage - at the expense of the participant - is damning to say the least!!! And insulting when, through the argument of sustainability, funding is questioned and even reduced, when the system has given blessing to abuse by service providers and registered NDIS providers. A tighter system that removes the disconnect between service provider (often sole traders who answer to no-one) and participant, and that insists on accountability and traceability should be the replacement. The registered NDIS provider we go through has a 'approve this invoice policy within 24 hours or it will be automatically paid' which supports them, not the participant - all policies and processes should inherently consider the daily needs and struggles of the participant, over and above the preferred administrative 'needs' of office preference.

Confidence in the decision makers is thin due to **punitive and unreasonable outcomes from policies and processes**. Appointment of decision makers needs to ensure the ability to understand participants' daily struggles and challenges, needs and goals, hoped for outcomes, and funding fairness from the participants' position, not from a bureaucratic position; and it is from that same participant position that all decisions should be made.

Regarding key outcomes:

The NDIS absolutely must be
participant supportive
participant friendly
participant focussed
integral and honest

The NDIS experience for participants and their families should not be punitive. It must be a stress free, easy to navigate, easy to live, and reliable experience; one that includes confidence through a dependable system and through trustworthy people.