

I would like to tell you about my experience with the NDIS. It has been a frustrating, burdensome and frightening experience. I am hoping that the Committee will intervene with the NDIA to make further improvements to the NDIS, particularly for people with cognitive impairments.

I have a family member who is an NDIS Participant. I am the Nominee for the Participant. The Participant has a complex disability, with cognitive impairment, ill health and behavioural issues, *intertwined*. He lives in a Specialist Disability Accommodation (SDA) facility. He will always need a close level of support, which will be intensive at times. We are in the middle of the First Plan.

The following experiences are provided to illustrate the difficulties of interacting with the NDIS. I will speak about 'we' in this submission because I support my family member in their dealings with the NDIS, and we tackle it together.

Firstly, there was a problem getting a suitable Planner.

This Participant has very complex needs, and was already living in an SDA. Therefore, the expectation was that an experienced NDIA Planner would be allocated. However, initially a Local Area Coordinator (LAC) was appointed. When quizzed about their experience in disability, there was a pause then the LAC replied "My current employer [which was not a disability organisation] has provided good training." So, after many phone calls by myself, and months later, eventually a proper NDIA Planner was appointed and a meeting was held. The delays were unsettling and upsetting for the Participant.

Then a final, and incomplete First Plan arrived.

The Plan does not list all the diagnoses my family member has, and for which disability support is needed. I appreciate that health care is the responsibility of mainstream services, but support to access mainstream services, and psychosocial disability support, is for the NDIS. The problems with the Plan therefore are:

- How do we know whether the Planner accidentally overlooked the other needs, or deliberately left them out, without giving us a reason? Either way, it does not help us to build our understanding of the NDIS, or our ability to use it appropriately.
- Does the Plan have enough funding to cover all needs? As yet this is unknown, and concerning
- Can a service provider assisting the Participant do so effectively, if they are unaware of the scope of the impairments?

We did not appeal the Plan because there were too many unknowns about the process, and it would be too stressful. We have no trust that, at a review, the NDIS will not make the situation worse. So, if the money runs out before the Plan period ends, the deficiencies will then be submitted to the NDIA. Participants should not have to deal with the NDIS in a climate of such uncertainty and budget crisis.

We were not allowed to see a draft of the Plan before finalization. When Plan Review time arrives, I have no confidence that we will be given access to a draft Plan, and the right to update it. We do not want to see the errors perpetuated, and we want the whole planning process to be much more transparent. This is the only way to improve trust and effectiveness in planning.

In summary, only experienced NDIA Planners should be allocated to complex Participants, and Participants should always be given a draft copy of their Plan and a right of reply.

Then there is the administrative burden.

A variety of Service Agreements have to be entered into. Understanding those differing Agreements, and monitoring the performance of the providers is difficult and time consuming. (That effort does not include the research and quote collection that took place beforehand, to enable an informed choice.) How can a person with a cognitive impairment and intellectual disability be expected to understand all that? How can they be expected to administer all that? How can they monitor the performance of all those providers when they don't understand the minutiae of the Agreements or how to record services delivered and compare against invoices received?

The NDIS should improve its Agreement templates – in particular, there should be examples of 'Schedule of Services'. The current templates are at a high level, and do not point the Participants to the areas of service where the Providers are using inconsistent charging practices. For example, whether a provider was charging in time blocks or by actual time spent, and how travel costs would be charged. At times, quotes have a single dollar figure for 'an assessment' with no detail about what the tangible deliverables are that make up 'the assessment'. By the NDIA giving sample Schedules too, Participants and their Nominees would have visibility into what a thorough and fair Agreement looks like. They could then adequately compare quotes. If a provider wanted to deviate from the standard Agreement, they should be obliged to tell the Participant what the changes were and why.

Then there is managing those providers against their Agreements.

For complex Participants with lots of services, provider bookings need careful coordinating. Daily coordination will ensure providers don't trip over each other, or duplicate effort. Also, their performance needs to be monitored. There is a serious lack of clarity about how that monitoring will occur in an SDA setting. This will make it hard to identify underperforming providers, and potentially add unnecessary costs to the NDIS. The many gaps include:

- It has been impossible to get a Supported Independent Living (SIL) provider quote. This is very unhelpful in trying to understand what services my family member can access within his SDA.
- Support Coordinator is off site and only works Monday to Friday 9-5; They do not have visibility into all the Participant's commitments, eg medical appointments, around which to book other providers. So, they are not able to truly co-ordinate. They are more like a brokerage service. They can make sure service providers are appointed, but have little influence or value in the day-to-day operations of those service providers, which have to happen locally.
- The house (SIL) staff are best placed to do **all** the timetabling, but it's not clear how much time they have been given in the SIL Agreement to do day-to-day, background administration for the Participant (as well as face-to-face). Such administration could include making medical appointments, booking taxis, cancelling a community access event at short notice and arranging for rebooking, ironing the job interview outfit, ensuring subscription fees are paid by the Participant for their hobbies, picking up chemist prescriptions, arranging a Foxtel contract, following up when a service provider does not attend, and urgently ensuring there is another staff member available to support the change of plans, filling out insurance claims, taking broken things for repair or replacement, and many more.
- As an offsite Nominee, I have no visibility into day-to-day provider operations. The house (SIL) staff need to monitor the comings and goings of third party service providers, on behalf of the Participant: Did the provider arrive on time? Did they return as scheduled? Was the Participant satisfied with the outing? If the Participant was sick, did the house staff ring the provider in time to avoid the Participant incurring a cost? Did the provider fail to deliver the service, but it appeared on the invoice anyway? – the house staff wouldn't know; As the Nominee, I see many invoices, I can't verify whether the service took place, unless the house staff tell me.

But the ability for house staff to monitor Agreements presupposes knowledge of Agreement conditions. I don't know if house staff have read all the Service Agreements to know, for example the clauses about how much notice is needed for 'inability to attend'. I don't know if house staff know the time slots in which the third party provider is supposed to be delivering a service. And how do house staff record, and report if a Participant is disgruntled with the service they received? What is the role of SIL house staff to report an under-performing service provider?

This lack of clarity about who is responsible for which parts of Agreement management poses a significant risk to the Participant, and the NDIA, of incurring costs that they shouldn't have. The NDIA should acknowledge that, in practice, where there are cognitively impaired residents of an SDA, a number of stakeholders have to collect and *combine their knowledge* of the facts, to ensure billing and payments are done properly.

There are problems with the NDIS Participant Portal.

The information it gives is not enough. This is a barrier to us building our understanding of the NDIS and our ability to navigate it, in a more independent manner. For example:

- The portal lists some, but not necessarily all the documents that were supplied at the Planning meeting. There is no way for the Participant to click through to see the contents of the documents listed. So we have no visibility into what evidence has been used by the NDIA to allocate funds, and whether we actually need to supply more information. The Participant should be able to look at the full content of all the documents listed on the portal.
- The portal shows a drawdown of funds paid by the NDIA direct to the Support Coordinator. We have no way of verifying the charges. We have not been given either an invoice or itemized statement from the Support Coordinator, which would allow an opportunity to confirm particular service delivery. The Support Coordinator charges in blocks of time. It is entirely unclear as to what took place during that time. Was it three phone calls? A reply to a text message? A face to face meeting with a mainstream provider to facilitate access? Travel? The NDIA wouldn't know what actually happened, and neither do we. This is not helping us to build our understanding of how to budget for the Support Coordinator, nor have enough information with which to exercise choice and control. The Support Coordinator providers should have to submit an itemized account to Participants, with enough detail so that the Participant can verify services, even if after their delivery, preferably with new, detailed Item Numbers.

We want the NDIA to do more to fix the interface with mainstream services.

We have recently encountered two problems with mainstream services.

- VCAT made an Order for a Financial Administrator to be in place. That's a good thing. However, they told the Administrator to supply financial Statements to the Participant only *annually*. This is nowhere near often enough. The Participant wants to know their state of affairs throughout the year, to try to learn to budget better. When asked if the Statements could be issued quarterly instead, VCAT said , no, that would be too onerous for the Administrator. So, the approach by VCAT and the Administrator is at odds with the principals of the NDIS. The NDIS says only the least restrictive practice should be used, to still enable the Participant an opportunity to build their capacity, if only a little.
- My family member had a mental health episode. They went by ambulance from the SDA to an emergency psychiatric unit. The nurse assessor said, it's not a mental health problem, just a "containment exercise" by the SDA, and sent the patient home. Many bad things happened that day at the SDA due to the mental health episode. In the evening the ambulance was called again. The Participant arrived at the same psych

emergency unit. The same nurse assessed the patient as not ill. But the SDA rightly refused to take the Participant home, knowing his behaviour was so out of character. So, the patient remained in emergency until the next morning. At that time, a Psychiatrist assessed the Participant. He was then admitted as an in-patient with a psychotic episode. This situation was bad for all concerned: inadequate access to the right care for the Participant; SDA/SIL staff time to manage the episode at home *and* its consequences; adverse impact on other SDA residents; additional callout to ambulance and GP services. It looked very much like a case of discrimination against a disabled person by the mainstream hospital.

The NDIS Plan period is too short and ongoing impairments not acknowledged.

The NDIA should recognise that my family member has an ongoing functional impairment, including a genetic executive brain dysfunction. On that basis, the NDIA should guarantee a recurring baseline budget. Assumptions should not be made that the provision of supports last time, have 'cured' him of his impairments.

The NDIS should not make Participants and their Nominees 'jump through hoops' every year, considering that the prognosis for functional capacity into the future is already known. The NDIA should therefore offer a guaranteed minimum budget, say for 24/7 SDA SIL, and another minimum amount for maintenance of attendance at a program or community activity. This would reduce frightening the Participant and Nominee with a risk of inadequate funds, that would lead to a decline in health, wellbeing and capacity, or even becoming homelessness.

- A Plan of one year is too short. It does not allow time for the Participant and Nominee to become competent in using the Plan. The Plan period should be longer, say two or three years.
- It is hard to get all the services in place quickly in the First Plan. Most of the stakeholders are in learning mode. Therefore, all the needed services may not have been activated for the full year. Some funds may not be spent. This should not mean an automatic reduction of funding in the next Plan.
- The Support Coordinator services are rumoured to be cut by NDIA in subsequent Plans, on the assumption that the Participant has 'built capacity'. This is a false assumption. My family member, with genetic planning and organizing impairments, will not be able to ever reliably coordinate his own affairs.
- If my family member is functioning well (for him), this is because of the 'scaffolding of supports' that *are in place*. Therefore, the NDIA should not seek to remove those supports on the assumption that he has now 'built capacity' which will be maintained by his own volition. It is not possible with the genetic characteristics of his disability.
- Life can run reasonably smoothly when adequate supports are in place. If not, there is an escalation in incidents and an increase in demand on other services like police,

ambulance and hospitals. The NDIA should factor in those other potential costs to the community if they contemplate cutting back disability support funding to this Participant.

People with complex disabilities *must* have a *choice* of providers

- The NDIA should ensure that there is an SDA/SIL provider of last resort available to complex clients. A 'last resort' provider needs to be available at times of acute crisis for a Participant, and when there is a chronic under-supply of appropriate service in the sector. At present, State and Federal authorities seem to be actively avoiding this issue.
- The best 'last resort' model would be an *integrated* service; that is, the landlord is also the provider of the SIL services. This would enable the most responsive and flexible support, as needed by complex clients. The best provider for an integrated service would be State and Territory governments, as they have the most resources. An integrated service would be another offering in the disability service sector, giving Participants more choice. Participants could select the integrated service if they wanted to.

Dealing with the NDIS and all the service providers has required constant vigilance, by me the Nominee. It is exhausting. And I am an educated person, without a disability. It is of great concern that if I was not available to support the Participant, services would be inadequate, with an adverse impact on the wellbeing of my family member.

As it is, the uncertainty, complexity and slow pace of access and implementation has caused anxiety for my family member.

There has to be a better way to:

- have clarity about the funding and support to be delivered
- have the right people involved in practical operational tasks, and
- have the charges by providers managed effectively.

Fragmentation of services has rarely been seen to have a good outcome for vulnerable people. I look forward to the Committee's report on the progress of the NDIS, and recommendations for improvements in the care of complex Participants.

Thank you.

Name withheld