

Submission to the Inquiry into the Implementation, Performance and Governance of the National Disability Insurance Scheme (NDIS)

Statement from Louise Bannister - impact on my physical and mental health needs over the 18 months connected with ongoing delays with NDIS requests.

I wish to give you some insight into the impact on my physical and mental health of continual delays, and what seems to be moving goal posts from the NDIA in regards to my NDIS Planning. The delays and lack of information add to the stress of me and my husband and family genuinely trying to find ways to sustain an ordinary life in the community at minimal cost.

Over the lifetime of my three Plans, I have endeavoured to provide all information required, this has included OT reports, multiple up-to-date quotes and details on why the said requests are required.

I strongly feel that this is not an attempt to extract support that is not reasonable. I am conservative with my spending. I have difficulty morally and ethically spending allocated funding on services where costs seem disproportionate to the benefit I receive. For example, in my 2016 Plan I was given funds to facilitate my attendance at the CPA Gym, which had the equipment I could use. I had actually requested a small weekly increase in my transport budget (funding the use of a wheelchair accessible taxi) to cover this, but I was told this was not possible as the transport budget is a set amount. However, I was told that they could give me funding for support workers to take me to the Gym each week. This funding was approved. The support involved being driven by a support worker in their car, each way. It turned out it was costing the NDIS scheme \$480 per week for me to attend a half hour gym session. When I realised this, I could not morally justify this inflated expenditure, and stopped attending the Gym. Most people I know who are participating in the NDIS scheme are trying to be spend their funds conservatively.

My circumstances have changed over the course of the three years. We have a split-level home. I had a very limited ability to walk small distances but my ability to continue to do so is uncertain and fluctuates in accordance with my health in any event. In my first plan in October 2015 we anticipated that a small extension at the side of my home to incorporate a ramp from the lounge room to the bedroom would be all that would be required to provide for me to use my wheelchair as needed. We got in an architect, builder, and OT, and the OT submitted their reports and recommendations early in March 2016. We heard nothing back the entire year even though we queried its progress. As the year progressed I had to spend an extended period in my wheelchair after injuring my foot and it became clear that the ramp was not going to be a suitable solution as there was not enough circulation space for my wheelchair even though I had thought prior to that, that I would be able to manage by doing a little walking as well. So we decided to hold on until my next planning meeting.

By the time of my second planning meeting in October 2016 we had explored putting a granny flat in the backyard for my daughter, who is my carer. Somewhat ironically, our planning application had been turned down, as the small unit was not wheelchair accessible, which is a requirement for all secondary dwellings in the ACT. So we then changed tack to look at putting in a larger granny flat for me, and my husband, that was fully wheelchair accessible, with the plan to rent our existing house to my daughter. Our NDIS planner at the time suggested that we look at a wider range of options. As well the

granny flat idea, we should also consider making major modifications to our home, i.e. to investigate raising the floor to a single level, and also look at the possibility of relocating into a more accessible home and selling our existing home. As far as we know this was included in her plan recommendations. Making my home accessible and being able to age in place, has always been my main goal.

All these options were explored. We met with a local Real Estate agent who then spent 3 or 4 months looking at alternatives for us (and she still contacts me occasionally if something comes up that she thinks may be a possibility), but all the homes we looked at would still have needed major bathroom and other modifications. The cost would have been more than we could afford. For example, a home that the agent recently contacted us about was on the market for \$799,000 – and still was not accessible in the bathroom or kitchen whereas we have already modified our existing home for this. We had had to borrow to do that and are still paying the mortgage. The plan to build a granny flat was halted when my daughter and her fiancé bought their own home in mid January 2017. So we proceeded with providing all the information needed to get funding to raise the floor of our existing home.

My second plan included an extra \$147,000 in core funding. This was a massive increase to the core amount in my previous plan but no indication was given about what this was for. This plan also included an allowance of \$7000 in equipment for a smart drive for my wheelchair to provide for improved use. After trying unsuccessfully to contact the NDIA to confirm that the extra core amount was for my home modifications, I had several disability service providers suggest that the money should have been quarantined into my plan's Capital Budget, until I had submitted my OT reports and building quotes, but it had accidentally been placed in my Core Budget. Their advice was just go ahead and get all of the supporting information and once submitted, the NDIS would realise and it would be adjusted into the right budget. I did this (in good faith) and we submitted all of the necessary documents in early May 2017. I had also followed up on the equipment with a trial, assessment and submitted the necessary quote, which exceeded the amount set aside. I then heard nothing until 7 July, when I received two brief emails within 2 minutes of each other. One said I'd been unsuccessful for my request for home mods and the other rejected the equipment quote. The reason given for turning down my home mods was that building in 2017 wasn't in my plan! The reason for turning down my equipment request was that the quote provided was more than the initial estimate (that had been made by my Planner). (When I did my OT Assessment trial, it transpired that I required an additional front free wheel to allow me to safely travel up curbs and across the parkland to my local community. This wheel hadn't been included in our original estimate).

I was so devastated by this unexpected response that I couldn't deal with what needed to be done, as far as going through a change of circumstances review. I became very depressed over the coming weeks, and decided I would just wait until my next Plan Review later in the year. I had heard on the grapevine that Plan Reviews were taking more than 6 months, so it seemed a better option to just wait for my annual review in November to resolve the issues. No one has been able to give me an explanation of what the \$147,000 was for. And I refused to spend any of these funds as I could only assume it was for mods.

I had my third Plan Review on 24 November 2017. I had a LAC Planner from *Feros Care* and an Advocate from *Advocacy for Inclusion* attend the meeting at my home. I insisted on a home meeting as I wanted the Planner to see the physical access issues in my home.

The meeting went very well. I felt I was really listened to and the Planner captured what was needed. So I was very hopeful that 2018 would be a much better year, both physically and psychologically as we had all of the necessary reports and updated quotes. I received my newest plan notification on 11 January this year and was perplexed and confused. My LAC Planner contacted me, and met with me to explain the situation. This time it would seem my supporting documentation had not even been considered, or read properly. For example, the NDIA have requested further quotes for a platform lift for my lounge room instead of raising the floor, even though the OT report clearly specifies that this is not an option in my small home. My request for minor mods (grab rail in the bathroom and small ramp out the back) doesn't even seem to have been considered at all.

I have been given a substantial amount in my Core Budget again this year. On doing some rough calculations it appears to correspond to my request for alternative accommodation for my husband and I while the Home Mods were undertaken (as I will have to vacate our home for 4-6 weeks). However, this is pointless since no modifications have been approved at this stage – or at least that is the best interpretation I can make of things.

My physical strength has deteriorated over the past two years. I have struggled to find a way of exercising that doesn't exacerbate my other physical health problems. I am aware that I am losing leg and arm muscle and now this after years of seemingly fruitless effort and engagement!

I have battled with anxiety and depression for many years and have had to do so without medication due to very serious physical side affects. I am very proud that I have been able to stay reasonably well with the support of my family and my GP. But the continuing stress of having to constantly jump through ever more hoops, has taken its toll on me, and my supportive family. I am an intelligent person, who is able to self-advocate and self manage, or at least I thought I was. I shudder to think how people with less experience and skills are managing to navigate this dreadful and confusing process, which is far from person centred. Good communication is needed between the NDIS and its clients; it is sorely lacking at this stage. I suspect many people are too tired and overwhelmed to even attempt to seek the resolutions they need in their planning processes.

I would also like to note that due to the drawn out nature of the Planning Process and Reviews it is constantly necessary to get quotes provided updated. Most quotes are only valid for 30 days. I imagine it must be equally vexing for the businesses providing the quotes as it is for me, that they are constantly being asked to quote and requote. The NDIA needs better processes. Perhaps an initial quote with an expectation of 10 per cent on costs over a certain period of time?

When will it end? What do I have to do to actually progress and achieve the inclusion that the NDIS extols and seems to give with one hand and take with the other?

The Plan documents I received provide very little detail that is useful to be able to self manage, or ascertain what the funds allocated can be used for.

So, I am in the dark when a budget amount I don't understand appears in my plan in one place but not in the place where I expect it to be. And I am utterly exhausted by a process that requires some god-like percipience of exactly what equipment I need and exactly how much it will cost so that it does not exceed a pre-estimate in a plan. I simply don't know if the decision-maker rejected the equipment quote because it was over the pre-estimate or if they considered it unreasonable or both. And since I must now seek a review, will the

current quote still be accurate when that happens at some time in the future – it will certainly not be current. Will the new decision-maker require a new assessment in case things have changed if more than a couple of months go by?

As to my proposal for home modifications I don't understand why and if my goal is expected somehow by the decision-maker to be achieved in some other way or if they think the home modification is unreasonable, or if they even properly examined it. How can I address what is 'reasonable and necessary' if there is no guidance from the NDIA on that! Surely, the point of using a registered allied health professional is so that they exercise that judgement – and if that is so, why doesn't my plan have the money in it for the modifications. And if the decision-maker was confused about the quotes why am I punished by being required to seek a review instead of them ensuring that they are clear about what the quote says and what it is for?

These are just a few of the unanswered questions that I have.

Last year in mid December, I began drafting a letter to try and capture my feeling and suggestions for how to improve the process I had been subjected to. I attach this draft below.

Sincerely

Louise Bannister

A black rectangular redaction box covering the signature area.

Attachment: Letter Drafted 14 December 2017 to provide feedback to the NDIA (not sent)

To whom it may concern

I would like to provide feedback related to my NDIS plan experience in 2017. I am a well-respected advocate in the ACT for people with disabilities and feel it is important to share my experience and concerns in the hope that processes can be improved to avoid similar situations for others in the future. Over the last few years, I have been asked to provide feedback, and have observed NDIA responding to feedback and therefore believe you will find my experience and suggestions helpful.

I am now working on my new plan with Feros Care, which is going well, and I'm hopeful that my situation will be resolved early in 2018. I have had two NDIS plans for 2016 and 2017 where home modifications plus assisted therapy and technology were important goals based on discussions with your planning colleagues at NDIA. I was feeling confident after being involved in the NDIS trial period that my self-management was working well. Unfortunately I feel like in 2017 both my physical and mental health has suffered for three main reasons, which included:

1. No ability to review

I was not able to review or discuss my 2017 plan and therefore feel I have now lost a year through not being able to get clarifications on what was approved and what my plan did or did not cover in 2017.

Suggested change to process:

- My case demonstrated how important it is to have the opportunity to review my plan prior to final approval. It is an extra step that means extra time for everyone however it worked well during the pilot phase in ACT.
- I could have asked questions early in 2017 before final approval and this would have saved time and confusion for all stakeholders involved in my NDIS plan process. It would have also limited confusion and there would have been less impact on my physical and mental health.

2. Goals not taken into account when seeking authorisation.

I believed my requests around home modifications and equipment fitted well with the goals in both my plans. My goals for 2017 were:

- **First Goal** - To minimise the effects of my disability by maintaining my physical strength
- **Second Goal** - To find a solution to my inaccessible house
- **My longer term goals and aspirations. Goal** – To maintain my independence through appropriate assistive technology.

However in July 2017, I received two similar "generic" email responses not authorising either of my requests related to home modifications and assistive technology which didn't appear to refer to my plan and goals which I found confusing. I had done a great deal of work, related to both these goals in the first half of 2017 so as you can imagine this was disappointing and disheartening.

- **Home modifications** – comprehensive reporting and quoting was provided and I was hopeful this would progress this significant goal for me so I could start planning for the work to start late 2017/early 2018. This work was based on the 3 initial options I discussed with my planner and that I agreed to investigate.

1. Larger granny flat at the back of our house.
2. Alternate properties.
3. Lift floor of living areas in existing house to make whole house level.

At the time of the planning I agreed with my planner that this investigation would take some time in determining the best option and therefore budgeting for a cost was difficult.

1. Granny flat - challenges with access and meeting development requirements.
2. Alternate properties – conducted extensive investigation but could find any properties that offered the accessibility needed for my growing needs.
3. Appears that while not ideal modifying existing home by lifting floor of living areas in existing house to make whole house level would still be the best option.

The extensive investigation concluded that getting assistance to lift the floor in my existing home would be the best option and therefore next step was to see what funding I could get from NDIS to make this happen. I therefore proceeded to get all the reporting and quotes needed for option 3.

- **Assistive Technology** – Alongside home modifications I investigated and gained quotes for assistive technology, specifically a Smart Drive for my wheelchair. From the time of my conversation with my planner, I trialed the equipment with my OT, who recommended that I also purchase a free wheel for the front of the wheelchair to allow for safe negotiation of curbs and cutaways, when I obtained the quote there was a new model out and therefore the price had increased from estimated \$7000 to over 9,000 and adding the free wheel the total quote came to over \$10000, and instead of discussions about the possibility of taking funds from another area to cover the increased costs I received a blunt “not authorised” email.

I was provided with a “change of circumstances” form for each request or option of internal review however as my requests fitted with my plan and my goals these next step options did not seem appropriate. I did not have a change of circumstances. I also heard that reviews could take anywhere up to 10 months and the prospect of this was daunting and as mentioned my physical and mental health were deteriorating and I did not have the capacity for a potential half year battle so I just withdrew and continued with existing equipment and home set up.

Suggested changes to process:

- It would have been helpful to be able to talk to someone about these non-authorisations to find out if a solution could have been found.
- It would have been helpful for the emails to acknowledge plan and goals and provide more information on why I wasn't successful.

Unexpected amount allocated in Core Budget:

My 2017 plan had a large amount assigned to my Core Budget however details on what this amount was included to cover was not in my plan. Budgets were as follows:

- Assistive Technology \$7,000
- Improved Daily Living \$6,400
- Transport \$2,625
- Core Supports \$146,521

I tried several times to find out what the \$146,521 covered and whether some of this amount was mistakenly included in Core Budget instead of Capital Budget. I tried hard to get answers with no success. I talked to a range of people in my disability networks and they had heard it had happened to other people. People I respect suggested I push ahead with my modification plans and get all the paperwork NDIS required because there might be capacity to split the funding a little differently since my core budget was a great deal more than the previous year. Due to not understanding what the funding was for and how I could spend it appropriately I did not spend much of the core funding because I didn't want to spend it on the wrong thing.

Suggested changes to process:

- For NDIS participants that self-manage to be provided with a comprehensive list (1 or 2 pages) including examples on what Core Budget funds can be spent on.
- Have a contact at NDIS that can investigate unusual amounts in budgets to limit confusion, ensure people are confident with the plan spending and limit people spending/claiming money incorrectly so they have to pay money back.

In summary, I would like to suggest the following 5 improvements to the process based on my experience and the experience of other participants I have spoken to through my work and advocate networks. I believe these will be beneficial for all NDIS stakeholders including NDIA staff.

1. Reintroduce ability to review draft plan before final approval happens and details are locked in for the 1 or 2 years.
2. Provide more details as to why things haven't been authorised. Such emails especially need to acknowledge plan and goals and provide more information on why requests are not successful.
3. Provide opportunities for NDIS participants to talk to someone about non-authorisations to look for solutions without having to go through a whole review and possible appeals process.
4. Provide a comprehensive list (1 or 2 pages) including examples on what Core (and other) Budget funds can be spent on especially for participants who self-manage and do not want to do the wrong thing.
5. Provide a contact at NDIS that can investigate unusual amounts in budgets to limit confusion.

Attached you will find examples of my plans and emails I refer to in the letter. If you have any questions, require further details or would like to discuss further please call me.

Kind Regards

Louise Bannister
14 December 2017