

Inquiry into the implementation, performance and governance of the National Disability Insurance Scheme in the ACT

I thank the ACT legislative assembly for asking about my experiences.

My NDIS journey

I followed the development of the NDIS from the time it was announced, even though initially I was unclear as to whether I would be entitled to participate. I followed the media coverage and Legislation and participated in very many workshops, forums and discussions in the lead up to the trial site starting in the ACT.

I am now 67, with physical disabilities and consequential mental and psychosocial issues.

I applied for access to the NDIS in mid-2014 in the ACT. I was refused access at the end of the possible time line, by phone, despite asking for written communication. The assessment seemed to me not to have been adequate. I sought internal review which was, in my view, mishandled. However, I was granted access at the beginning of 2015, albeit with inadequate information of the bases on which it was granted. When I tried to overturn apparent decisions not to accept certain conditions I was told refusals were not relevant because participants were treated "as a whole person". That has not proven to be the case.

The planning issues were complex and my thinking difficulties extreme so it took till the middle of 2015 to get a plan in place because the planner said it couldn't be done until everything was resolved. I was happy with the plan even though it didn't give me everything I asked for. The planner did an excellent implementation, including resolving new problems which arose for agreed items.

The second plan was also good. The then CEO, David Bowen, helped me to get funding for a new hoist during the plan.

Before my third plan, the then CEO, David Bowen, wrote a letter to all participants saying that, contrary to media reports, there were not practices in place to reduce plans. I believed him after he had helped me. I now question to what extent it was true and why he said it since it seems substantially not to have been true.

I struggled through several other problems to prepare for the planning meeting at the NDIA and had some last-minute advocacy help. However, if I had known there were indeed new practices in place to reduce plans, I should have taken much more detailed steps to prepare for the planning meeting, perhaps preventing the distress and heavy workload since.

The planner did not raise issues she later used in her adverse decisions (including that community participation money was only to try new things rather than to allow participation for which a participant didn't have funds as I'd previously been told). She did raise some unexpected ideas (that transport allowance did not cover car running expenses) and agreed that I could make submissions within days. I did that and there was no comment on my arguments in her adverse decisions. I therefore had no reasons to doubt my understandings.

I struggled the full allowed three months to prepare a detailed application for internal review.

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In my request for internal review, I set out excerpts from relevant documents and arguments as to why my requests were "reasonable and necessary". I attached composite pdf documents providing documents quoted, in chronological order of preparation, without a linking index so individual documents could only be accessed by paging through the documents (or searching with useful words). I eventually found a better way of producing a composite document which provided access to each source document in alphabetical order of filename within the composite document. I submitted these with my change of circumstances form seeking early review due to needing transport to help to move home due to substantial mould infestation to which I am sensitive.

I struggled to get straight answers from the helpline about communication issues, for which I was finally told after many calls that I would need to make a complaint to get action. The early review was granted.

My communications with the review planner often felt like a combination of Alice in Wonderland and Yes, Minister, with her responding "past what I asked".

During the internal review meeting, the planner was courteous, respectful, patient and untroubled by disagreement or emotion. She said words to the effect that changes of practice had been made following a review of the trial sites but that there were no public documents about it to show what practices have changed, their reasons and justifications for them and the legal documents implementing the changes. The internal review upheld all the adverse decisions.

If the changes of practice are legal, I have wasted three-quarters of a year of my life fighting them. However, I have found no evidence on the website that they are legal.

I am now without adequate funds for transport and community participation among many other things, strongly negatively impacting my community participation and well-being, so that I am unable to meet most of my goals.

My perspectives on the Legislation, NDIA and NDIS

I would have a great deal of empathy for organisations and people who strive to be effective and efficient. I would also have a great deal of empathy for organisations and people who struggle with inadequate resources, too much work and not enough training. To some extent, these apply in the NDIA, but in many respects they may be claimed but are not adequate explanations for what I can only consider bad faith.

I consider that current communication and decision-making procedures are often wrong, harmful and working against scheme objectives. Such decisions are presumably being done to please the federal government, with or without direct direction from the government, who should instead be ensuring they are being done right.

I had a Mobility Allowance under the Social Security Act. It folded into Transport Allowance under the NDIS. My needs have increased, not decreased. They claim the rules have changed between the two schemes but they haven't significantly in my situation. In particular, both schemes provided for support in situations where people were unable to use public transport, as applies for me. I provided a recent medical report to that effect for the review. The NDIA also claimed that providing transport

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allowance as well as vehicle modifications would be a duplication of support, when of course they can both be necessary to provide access to transport and both are simultaneously allowed for in the guidelines.

The first announcement of the changed rules with regard to transport allowance, as far as I can work out, was a Q&A in August 2017, months after my plan decision, saying they didn't fund car running expenses. There was no explanation that this was a change in policy or any explanation as to why there had been a change of policy.

It appears that people in the community sector believe the new policy but nobody has provided me with the proof.

Taking away the transport allowance seems to me like appropriation of property without recompense. Losing 10% of my income is a bitter blow from which my well-being may not recover.

The NDIA repeatedly claims that a requested support should be covered by the health system. However, both guidelines and Q and As have indicated that the health system is for treating conditions and the NDIS is for improving functional capacity. My arguments to that latter effect when requesting support have been brushed away.

It was particularly frustrating to be told that the National Disability **Insurance** Scheme couldn't pay for the extra disability related costs of insurance because "maintenance, warranty, and due care" are provided. However, they are not able to protect items against other losses such as through theft or fire. Replacement (not promised) would require a new plan with consequential delays. So insurance is still needed and should be able to be funded as an extra disability related cost.

The review declined some supports on the basis that I could re-allocate from other approved funds as if approved funds are a "magic pudding" to cover everything, way beyond some discretion between approved categories.

It seems to me that the NDIA has struggled throughout with understanding and believing some participants' comments and requests about communication needs. In my case, requests around memory difficulties and thinking problems have sometimes been evaded. These included the opportunity to record discussions and the need to exchange information and do decision-making by email.

Essentially, I have experienced some bad processes, some bad communication and some bad decisions, along with many good experiences.

I suspect that the NDIA are relying on people not appealing to the AAT to determine legality.

I consider that much of what I have discussed above is bad public administration, sometimes delivered with systemic and maybe individual bad faith.

I am grateful that the ACT legislative assembly is reviewing participants' experiences of the NDIS.

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Valued apparent changes

Allowing plans to be put in place while they're still being worked on.

Again having a personal contact.

What should be done differently

Communication

Always advise participants of the reasons for which they have been given access, e.g. which conditions and which functional impairments and enable participants to appeal adverse decisions with which they disagree. This would avoid later arguments about whether a particular requested support is covered by access approvals.

Start by publishing the review/s of the trial schemes and all resulting changes.

All changes to practice should be properly discussed on the website. Not just saying something different in a Q and A.

Ensure NDIA staff are accurate and helpful in their communications.

Allow recording of conversations.

The helpline should find a pathway for participants to access whatever they were seeking. It is not acceptable to say the only solution is to make a complaint, especially when it's only about finding information, rather than pursuing a decision.

Decision-making

Preferably, any internal review should consider and report on the merits of all arguments submitted. If the internal review won't consider and report on the merits of all arguments it should be finalised as soon as possible after receipt of the request so the matter can progress swiftly to the AAT where arguments would be considered and responded to.

Policy-making

The NDIA should consult on and publish the details on interfaces with health, education etc

Reverse all implementations of practice changes until consultation done, existing appeals are resolved and consultation has occurred. Ensure all changes are legal.