



31 August 2023

NDIA Review Panel

Submission for NDIS review

Introduction

We are writing as the family of John, an Australian Citizen who has severe autism and intellectual disability with a high level of support needs. Until now he has lived all of his life in New Zealand, but will be moving, with his Mum Carole, to Australia to be closer to the rest of the family. John 42 and Carole 74 are the only two members of the family remaining in New Zealand. As John's brothers Robert and Thomas, and Carole's cousins all live in Australia, it is in John's best interests to move with Carole to Australia to be near family.

We will outline our struggles with *Applying and getting a plan* for John and make some comments on the *Support services and marketplace*, as well as *Supported living and housing*.

Applying and getting a plan

We have faced great indignity, distress, and delay from our attempts to work with NDIS to arrange the support John needs for his move to go ahead. There was extremely poor handling of a situation that was only slightly unusual: An application for an Australian Citizen, moving to Australia, who cannot move without disability supports being arranged ahead of time. Due to John's high support needs (requires 24 hour support), it would not be responsible or safe to move John without knowing he will be adequately supported in a timely manner. As an Australian citizen, and in line with the principles of the NDIS (equity and certainty) John should have the same rights as any other citizen to relocate to Australia, even though he has a disability. However NDIS' reluctance to support him has greatly infringed on these rights. It is only after several months of the NDIS failing to recognise the situation and John's needs, that they are now starting work with us constructively to facilitate the move.

We submitted to the National Access Team (NAT) a large volume of evidence supporting John's application, along with an explanation of John's situation and that he would need planning of support in advance of moving. The application was eventually declined on the basis of John not being a current resident. However it took more than 2 months and multiple requests for proof of a current Australian address despite clear explanations (that seemed to fall on deaf ears) from the beginning that John had not yet arrived in Australia.

With this decision and that of the internal review upholding the "declined" decision, there remained no acknowledgement of the challenges of the situation or suggestion how access might be expedited on John's arrival. It certainly came across that John was treated as a "tick box" exercise rather than seen as a real person. There was no recognition of the situation or acknowledgement of John's needs or rights by NAT until more than 3 months after the initial application.

Even before initial application, and through the process, we sought advice from the Local Area Coordinator (LAC) Team at [REDACTED] who were extremely understanding and supportive through the process, but seemed powerless to help, with no influence on the application process, and apparently no ability to facilitate NAT's understanding of the situation.

After 3 months of repeated attempts to communicate with NAT, calls directly with NDIS contact number, meetings/emails with the local [REDACTED] office and multiple contacts with Bill Shorten's office, we eventually found humans from NAT who provided some recognition of the situation and were willing to work with us, even though the path forward would remain unclear until NAT referred us onto the planning team.

In contrast to NAT, the planning team have been extremely understanding and are admirably working with us as best they can within the limits of policy/legislation. However, it is highly disappointing that it took more than 5 months, and required encouragement from a coordinator of support, for NAT to ask the planning team to be involved in this case. This is especially disappointing given that the need to PLAN John's care was clearly stated in the initial covering letter.

Below is a detailed timeline highlighting the challenges we have faced.

- 2 December 2022: - John's mother Carole sent a letter to the NDIS National Assessment Team (NAT), highlighting John's situation and the need for John to receive NDIS support for his move. This was not attached to an application, and presumably this was why no reply was received.
- 09 January 2023: Application sent to NAT, including a covering letter by Carole that clearly highlighted the situation, identity documents for John, as well as evidence of his disabilities. In the covering letter, it was recognised that it was a slightly unusual situation that needed to be navigated, and clearly stated that

John was not yet in Australia, but that steps needed to be taken ahead of time to arrange support for him on arrival.

- “I understand that Australian Residence is a requirement for NDIS eligibility. John is currently not living in Australia yet. However, he will be moving to Australia permanently, so we hope that, as much as possible, adequate support can be approved and planned ahead of time, so they can be in place for when he arrives.”
- 19 January 2023: Email from NAT requesting information to verify John’s address, with an explanation of the evidence required to demonstrate Australian residency. (we had already told them that John was not yet in Australia)
- 20 January 2023: Email from Carole to NAT explaining the situation and highlighting “We understand that NDIS funding cannot be approved for non residents - but given that he will very shortly be a resident, we were advised by the local NDIS office that the rest of the application can be processed, and the location part approved upon arrival.”
- 01 February 2023: Email from NAT to Carole, stating “thank you for your email and providing an explanation to John’s current living arrangements”, yet continued to ask for evidence of John’s current residence (Including a Statutory Declaration as John doesn't have utility Bills in his name).
- 06 February 2023: Email from Carole to NAT with suggested Statutory-Declaration wording and asking if it was satisfactory. Another Email from Carole to NAT attaching a letter from John’s current accommodation provider in New Zealand confirming his current residence there.
- 15 February 2023 Complaint about process made to Bill Shorten’s office by John’s brother Robert
- 21 February 2023: Email from NAT to Carole, stating they would not accept a letter from an Non-Australian Accommodation provider, and continued to request evidence of an Australian address.
- 23 February 2023: Complaint made to Bill Shorten’s office by one of Carole’s Cousins regarding the poor treatment and communication from NDIA.
- 28 Feb 2023: Email from Carole to NAT including a Statutory Declaration indicating John current address in New Zealand and an intended initial address in Australia (This was a nominal interim address, as John had no suitable address to move to due to his high support needs that would have to be met by NDIS).
- Early March 2023: contact from LAC to arrange a meeting, apparently tasked by Bill Shorten’s office to look into the matter further and report back. 6 March Meeting held With Carole, Robert and senior [REDACTED] staff. [REDACTED] (with whom we had already had some contact) acknowledged the problem, and have continued to be supportive of the family but have had no influence on the processes of NDIA.
- 1 March: Carole called NDIS and spoke to someone for some time explaining the situation. They indicated that they had recorded the information given.
- 8 March 2023: Email from NAT indicating that they had the required information to make a decision.

- 21 March 2023: Email sent with a letter formally declining the application. No acknowledgement of the situation. No advice about how access may be gained when John arrives in Australia
- 30 March 2023: Request made by John's family for internal review of the declined access.
- 11 April: Robert was contacted by someone from NAT regarding the situation, this we understand was in response to contact from Bill Shorten's office following up the complaint. This person for the first time in 3 months of communication with the NAT appeared to understand the situation and escalated to her team leader.
- 12 April 2023: We received correspondence from a NAT team leader, who acknowledged the situation, clarified that John meets the disability criteria and the residence was the only reason his access was denied. They indicated that an access request could be fast-tracked on John's arrival. Subsequent to this a planning meeting could be prioritised, but no guarantee could be given as to how long it may take for funding to come through.
- 24 April 2023: Email to NAT Team Leader requesting further clarification around the process and how support might be best prepared prior to John's arrival.
- 27 April 2023: Acknowledgement of request of internal review.
- 28 April 2023: NAT team leader indicated that the NDIA could not provide an estimate of John's potential funding eligibility as this depended on provider's quotes. Suggested finding a provider. Stated that the issue could not be escalated further, as this had already happened. Did not suggest contacting the planning team.
- 5 May 2023: John's family confirmed that they were willing to go ahead with the internal review.
- 9 May 2023: Outcome of internal review confirmed, Access again denied. Again little acknowledgement of the specific situation. Generic suggestion about talking to LAC about interim support.
- May 2023: as per recommendation from NAT, multiple providers were contacted. While some providers were helpful but couldn't provide support to suit John's needs (often due to location), some providers indicated that they could not assist at all because John did not have funding yet. One provider was potentially able to provide support that John needs, and was willing to work with us. However the uncertainty of not knowing what funding might be approved was a complicating factor, and they referred us to a support coordinator to help us navigate the complex situation.
- 2 June 2022 We made contact with the recommended support coordinator who has since been assisting us (currently unpaid as John is not yet a participant).
- June July 2023 The Coordinator made contact with the NAT team leader, and on 19 June requested that the planning team be involved. The NAT team leader contacted the planning team who have been extremely helpful. They requested further information (an OT assessment was undertaken in New Zealand to provide this). The planning team have undertaken an urgent pre-planning

meeting and will ensure that all the needed information is passed on to the home and living team. They are endeavouring to ensure that as much as possible everything is in place for plans to be fast-tracked when John arrives. This is a challenge due to the nature of the legislation that clearly states that someone must be a resident in order to obtain access. However the planning team are doing their best to work with us to overcome the challenges. It is extremely disappointing that it took more than 5 months for the planning team to be involved.

As you can see this has been a particularly distressing, stressful and time consuming process for John's family, particularly for John's mum Carole who has felt abandoned by her country of birth. This distress and indignity arose not so much from the time delays (we understand that processes can take time), but for such a long time the lack of acknowledgement of the situation, or John's rights, or any intent to work with us to support John in his move.

John is fortunate to have family members who are supportive, assertive and literate, in order to advocate for him. Nevertheless we still struggled to be heard, and have benefited from the extra advocacy of a (currently unpaid) coordinator of support. One wonders how persons and families with less capacity to advocate manage communicating in such a dysfunctional system.

To address this problem in the future, the legislation or procedures could be modified so that where access requirements are not yet met, but likely to be met (i.e. the person is going to become a resident), applications could be provisionally approved. The full planning and assessments of funding levels could go ahead as usual, but access not confirmed, and the plan not enacted (ie no funding actually provided) until the person has arrived in the country. The planning team is working along these lines of John as much as they can under current legislation, however formal policy/legislation guiding this process and allowing all aspects of planning, including confirmation of funding levels, and supported accommodation eligibility, to go ahead prior to arrival would be extremely useful, and would have saved our family significant time and distress.

The support and service marketplace

The "choice" aspect of NDIS services has been the opposite of empowering for us. John is moving from New Zealand, where although there are issues, government largely funds and non profit NGOs generally run the kind of housing and support services John needs.

Providing participants choice around the type, timing, and location of supports is Important. However, this privatised system where one is forced to choose from a vast number of providers, the quality of which is almost impossible to reliably assess ahead of time, is not empowering, but potentially disempowering, due to the associated lack of certainty, and risks of receiving poor service.

Supported living and housing

Location is absolutely key here. It's extremely important for John's wellbeing to have family nearby. That means supported living needs to be available wherever family happens to live, or at least close by via sustainable public/active transport.

Even aside from the specific challenges facing us with John's situation, there generally seems to be some lack of clarity around the processes for SDA and SIL. Providers tend to be unwilling to commit (or in cases even discuss) any options without having funding already in place, whereas NDIS seems to indicate that funding is dependent on providers.

Conclusion

We hope that our experiences not only highlight the need for clear human communication rather than a rule/tick box oriented communication. While rules/policies may need to be adhered to, recognising the human situation and working towards alternative solutions is essential. More specifically we hope that a streamlined policy could be brought in to manage applications for Australian citizens with disability, currently overseas, moving to Australia. Such a policy could ensure that support can be arranged ahead of time, but that no funding is provided until the participant is in Australia.

Kind Regards

