Submission
No 297

INQUIRY INTO IMPLEMENTATION OF THE NATIONAL DISABILITY INSURANCE SCHEME AND THE PROVISION OF DISABILITY SERVICES IN NEW SOUTH WALES

Organisation: Australian Lawyers Alliance

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Inquiry into the implementation of the National Disability Insurance Scheme and the provision of disability services in New South Wales

Submission to NSW Legislative Council Portfolio Committee No. 2 Health and Community Services

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Who we are

The Australian Lawyers Alliance (ALA) is a national association of lawyers, academics and other professionals dedicated to protecting and promoting justice, freedom and the rights of the individual.

We estimate that our 1,500 members represent up to 200,000 people each year in Australia. We promote access to justice and equality before the law for all individuals regardless of their wealth, position, gender, age, race or religious belief.

The ALA is represented in every state and territory in Australia. More information about us is available on our website.[1]

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[1] www.lawyersalliance.com.au.

Introduction

1. The ALA welcomes the opportunity to have input into the Portfolio Committee No. 2 (Health and Community Services) inquiry into the implementation of the National Disability Insurance Scheme (NDIS) and the provision of disability services in New South Wales.

2. The ALA's main concerns regarding the implementation of the NDIS in New South Wales are: the lack of training and knowledge amongst National Disability Insurance Agency (NDIA) staff responsible for developing care plans; the lack of support for NDIS clients to assess the adequacy or appropriateness of their care plans and difficulty in seeking a review of a plan; the delays in the calculation of Compensation Reduction Amounts (CRAs) by the NDIA; and the unwieldy bureaucracy surrounding the NDIS.

3. Above all, the ALA sees the inadequacies in the NDIA's implementation of the NDIS in New South Wales as an access to justice issue. As the following pages will demonstrate, we believe that, from the experience of many of our members, NDIA systems and processes are restricting access to justice for their clients.

Poor training and skills of NDIA staff

3. The ALA is concerned that the qualifications and skill set of NDIA staff is resulting in considerable problems for NDIS clients, including inappropriate communication with clients; delays in assessing care plans; development of inappropriate care plans; and failure to advise of rights to review.

4. While understanding the challenges associated with the rapid roll out of the scheme, in our experience the planners engaged by NDIA frequently appear to be underprepared for the role. This may be a reflection of poor recruitment processes, inadequate or inappropriate training, or both.

5. The ALA has received reports to the effect that NDIA planners often do not appear to listen adequately during planning meetings, and that the contents of the final plan often do not reflect the discussions that occurred during the planning meetings.

6. We are also concerned about the prevalence of planning meetings being conducted via telephone – especially for clients in regional and remote areas. We believe that this is a

practice which should be avoided where possible. The issues and sums of money at stake are serious enough to warrant a face-to-face meeting.

7. Poor performance at the planning level inevitably leads to requests for internal review. It is the experience of many clients that the appeals process is frequently slow and unresponsive.

8. Often, when a review of a plan is requested by a participant, they are told some months later that the original plan has been affirmed by the NDIA without any further contact with the client. Clients report feeling like there has been no discussion or genuine consideration of the points made by families caring for people with severe disabilities during the review process.

9. These experiences of NDIA staff and processes – both in terms of the planning and internal review processes – can be demonstrated through two case studies which appear below.

Case study 1

KG is 32 years old and lives in Western Sydney. She has three children with autism who have been on NDIS plans for some time. She has also applied for the NDIS for psychosocial disability as she has PTSD, bipolar, depression and anxiety.

KG experienced problems with the annual review of her plan. After the review, under the new plan there was considerably reduced funding available. $3,500 had been taken off therapy funding in the second year, there was a reduction of more than $2,000 for nappies for the second year, and more than half of the community support had been cut from the plan. In addition, the plan no longer included crucial therapy funding and the key worker support that she needed to help her implement strategies at home.

When KG contacted the planner to express her concerns the planner asked her if there were any child protection issues currently in place. The planner then said that if KG was not able to cope on her own without the supports then maybe there was a concern for her ability to parent her children and whether the planner should request a child protection investigation. KG decided to request a formal review of the plan despite being told that it could make the situation worse.

KG was angry with how the planner had made her feel so she made an official complaint about the planner. Three weeks later the NDIA contacted her to advise that the NDIA had made a mistake, and the proper therapy funding and key worker support were restored, as was the nappy funding. Funding was also provided for the weekend and vacation care programs.

KG described the way that the NDIS planner and the complaints officer had made her feel was one of her worst experiences as a parent. She feels aggrieved that a program for people with disabilities does not put those people first.

- Case study from submission to the Parliamentary Joint Standing Committee on the National Disability Insurance Scheme, 2017

Case study 2

In 2001, aged 18, KH suffered a cardiac arrest and secondary hypoxic brain injury. Since his injury KH has required 24 hour care, managed by his parents. KH lodged a medical negligence claim, including hearings in the NSW Supreme Court and Court of Appeal on liability. The damages were agreed at $8.1M plus costs. The receipt of these damages was taken into account in formulating his NDIS entitlements a decade and half later.

In **October 2016**, KH became an NDIS participant. As part of the planning process KH had submitted a care plan report prepared by an occupational therapist, which outlined KH's requirement for 24 hour care and that his core supports budget should be $352k.

His first plan included a budget of $215,906.08. Core supports was the largest support area, at $196k.

KH sought a review of his plan. In **December 2016** he wrote to the NDIA CEO requesting an internal review pursuant to s100 of the *NDIS Act*.

In **May 2017** (after considerable follow ups), KH received a decision from the NDIA affirming their original plan. Importantly, the internal reviewer rejected the OT's recommendation for overnight care including 1.5 hourly turning. The decision stated that the OT did not have the relevant expertise to comment on KH's care needs.

In **May 2017,** on receiving the internal review decision, KH immediately applied for AAT review. In **June 2017**, he received the Tribunal Documents (T Docs). There were many points of interest in the internal notes and correspondence, including an indication of clear siloing between the compensation team (who calculate the CRA) and the planners. Most importantly was a clear inconsistency between the planner's recognition that KH required 24 hour care and her team leader's insistence that overnight care was not required.

In **August 2017** the solicitor for the Agency sent a draft revised plan for KH. She said that '*while investigating [KH]'s plan in the course of these proceedings the Agency has formed the view that the amount of core supports originally included in [KH]'s plan was insufficient given his level of disability*.' The draft revised plan was prepared by a new planner not involved in the original or internal review decisions. The draft revised plan allowed for 24 hour care, with a core supports budget of $465k and total budget of $488k.

KH has had ongoing discussions with the NDIA and has submitted multiple documents, receipts and spreadsheets at the NDIA's request in relation to a CRA and still has not been advised of the CRA.

10. In our experience, when ALA members contact the NDIA in relation to deficiencies in a client's plan, the NDIA's first response, by default, is to assert the original plan. ALA members report very few cases in which their suggestions for making the draft plan fair or aligned to expert opinion are given serious consideration by the NDIA.

11. The NDIA's default mechanism and approach for reviewing plans, according to the experience and perceptions of our members, is to engage in stonewalling.

12. The ALA submits that poor skills and processes at the planning stage inevitably leads to a request for internal review. An inattentive and adversarial approach to the reviews process

inevitably leads to the engagement of legal representation, both for the client and the NDIA. This means that the whole process frequently becomes more expensive and time consuming than it needs to be.

13. The ALA submits that under-skilled planners and plan reviewers are not giving appropriate regard to the considered professional opinions of experts in disability care.

14. The ALA notes that many planners are appropriately experienced and competent in their role. However, many of our members have described it as ‘a total lottery’ as to whether a client receives services from such a planner.

Lack of support for NDIS clients

15. The ALA is concerned that NDIS clients do not have adequate access to advocacy or support for negotiating an appropriate care plan that is suitable to their needs. The situation will become worse in 2020 when NSW Government funding for disability advocacy services will cease.

16. Without access to legal or advocacy support, NDIS clients face significant barriers in assessing whether their care plan is adequate, or whether they should seek a review of the plan.

17. Often, clients are not well placed to know if what’s in their plan is adequate or realistic. This is especially true for clients requiring supports for psychosocial illnesses.

18. ALA members have related cases of people with brain injuries who, in planning meetings, say that there is nothing wrong with them – and the NDIA reflects this in their plan. Notwithstanding the need for choice and control, such clients need expert supports to help them understand that to which they are entitled.

19. We believe that current processes are creating classes of recipients – a divide between those who have the wherewithal and financial resources to access expertise that will enable them to judge whether or not their plan is fair, and those who don’t.

20. It is the experience of the ALA’s members that clients with sufficient resources gain access to trustee or legal support, and supporting reports from Occupational Therapists (OTs), and are better able to seek a review of their plan and secure the funding that their needs warrant.

21. Clients that have enough money to engage a professional OT or similar are well-placed to get a good plan from the outset. Those without the benefit of such resources are very much on their own. Our members have relayed anecdotes of industry professionals being able to provide advice in pre-planning, using the NDIS terminology and jargon that leads to a better result than the result achieved of those who don't have such support.

22. This 'have and have nots' distinction is also becoming more apparent in the reviews process. Those better equipped to engage support are more likely to have a successful review process than those who are forced to navigate it alone. Once again, we perceive this as an access to justice issue.

23. Client dissatisfaction with their plans seems to be on the rise, and reporting of these cases in the media is intensifying. ALA members report a growing assumption amongst their clients that their plan will be inadequate from the outset.

24. The most common feedback we receive in relation to supports for NDIS clients is that they have to fight for everything. Clients report that the process feels adversarial – and the ALA maintains that this should not be the case. Parents and informal support networks report feeling exhausted by their interactions with the NDIA.

25. Some of these concerns relating to the lack of supports for NDIS clients are illustrated in the following case studies.

Case study 3

A grandmother had to relinquish the care of her severely autistic and disabled grandchild due to the lack of funding, support and respite offered by Family and Community Services (FACS) and the NDIA. The child's package had been reduced from $96,000 to $32,000 under the NDIS and the grandmother was unable to appeal the decision. The package lasted for only two months before there was nothing left.

Her situation had been complicated by her own ill health, and because she had been unable to work for four months while recovering from a motor vehicle accident.

The respite funding had been used up during her subsequent hospital stays and neither FACS nor the NDIA had been willing to offer further support.

- *Newcastle Herald*, 9 December 2017

Case study 4

A single mother has two young, twin sons who are severely disabled and have epilepsy, a daughter, 11, with autism and another son, 10, who has autism. The family is in need of a modified vehicle to help transport the twin boys. The mother has been unable to work and says she cannot afford to upgrade to a new modified car.

The NDIS does not cover the cost of a modified vehicle and the mother is now relying on charitable support. ‘Even if my vehicle was able to be modified, it has to be maximum five years old for the NDIS to cover modification costs’.

- *St George and Sutherland Shire Leader*, 31 May 2018

26. Also in relation to access to supports, ALA members continue to report that their clients have ongoing problems finding good care workers. This was a problem before the NDIS and remains a problem. We appreciate the current focus on ensuring adequate market readiness, and encourage the NDIA to continue to find ways to address this constant and growing issue.

27. Further, where participants have found it difficult to find qualified care workers for people with catastrophic injuries, they have been questioned for not using all of the money set aside in core supports in an original plan. This ‘use it or lose it’ mentality is damaging, particularly in light of the difficulty participants find in getting care workers and particularly in remote areas. If a care worker leaves it can often take some time to replace him/her and participants should not be penalised for this through a reduction in the amount of core supports granted in a plan.

28. We are hearing increasing reports that the delay in any application for a plan to be appealed by a participant (sometimes up to 12 months) means that often, by the time the NDIA has made a decision about whether to affirm or amend a plan, a new plan has already been issued (plans are issued every 12 months).

Delays in calculation of Compensation Reduction Amounts (CRAs)

29. Feedback from ALA members points to a general perception that the NDIS processes have basically ground to a halt in relation to the calculation of CRAs. The response from interaction with NDIA personnel is that the process is too hard and that it’s just not a priority.

30. There is now an expectation that there will be a lengthy delay from when the NDIA is notified of a compensation amount to when a CRA is determined. It is not, in our experience, unusual for a request for a calculation of a CRA to take up to a year or more.

31. The impact of these delays in the calculation of CRAs is that it creates stress on family members caring for people with catastrophic injuries and disabled people who are trying to access services and equipment but don’t know if they will have funding after a CRA is applied. Uncertainty is creating stress.

32. This expectation of delay, along with an absence of any obvious attempt on behalf of the NDIA to address it, has led to a growing ambivalence from support agencies about wanting to proceed in the best interests of the scheme. The advice given to clients is often to keep spending the full plan allocation and to deal with the CRA if and when it gets calculated – because it’s ‘use it or lose it’. This leaves families with great uncertainty for extended periods of time.

33. In our experience, most NDIA clients are at pains to ensure that they are not ‘double dipping’. They understand the need to ensure that they are receiving what they are entitled to – supports that are reasonable and necessary in order to live an ordinary life. This is true in relation to supports received through other compensation schemes, common law processes etc.

Bureaucracy of NDIA

34. The ALA is concerned that the process of navigating the NDIA bureaucracy is exceptionally difficult for people with disabilities and/or catastrophic injuries.

35. The ALA is sympathetic with the pace of the roll out, and balancing the need to ensure scheme viability.

36. The increasingly bureaucratic nature of NDIA systems and processes mainly manifests in three ways, as reported to ALA members by clients:

    i. Impersonal responses:

    There is a feeling that the processes are becoming mechanised – a machine-generated response to highly personalised issues. Clients report inflexibility in the NDIA approach. While we understand the need for predictability in decision-making, we submit that this needs to be balanced with the need for personal understanding and negotiation. We believe that those responsible for the development of the scheme would have had a personalised service provision regime in mind, rather than a production line approach. This is especially prevalent in requests for plan re-assessment.

ii. Delays in decision-making:

Our members and their clients report difficulties in navigating the decision-making structures of the NDIA. This bureaucratic approach to decision-making is most manifest in the delays experienced when questioning decisions. It can take months to get a response to a request for review of a plan and then, more often than not, the result of the review is merely a letter saying the plan is affirmed. It does not make people feel that their issues with a plan or lack of agreement to certain services or equipment is being listened to or responded to appropriately.

iii. Unavailability of NDIA staff:

There is a general perception that the NDIA is understaffed for the work it needs to do – especially in this roll-out phase. This is manifest in stories from ALA members and clients that there is no-one to take calls, no one to return calls and having to re-explain circumstances to a number of staff. Our members and their clients are sympathetic of the pressures NDIA staff are experiencing.

37. Our members are aware of clients withdrawing from the NDIS due to the stresses caused by dealing with the bureaucracy.

38. The impacts of a bureaucratic approach, or the perception of a bureaucratic approach, can be seen in the following case study.

Case study 5

PT uses a wheelchair for mobility due to spinal injuries. She is also a carer for her husband who requires a high level of support due to his disability. Prior to the NDIS, they were both receiving government funded support, which included home modifications to support them maintaining their independence. An Occupational Therapist (OT) completed a report making recommendations, including the need for an accessible bathroom and a fixed ramp alongside the side of their property. After several months, they had received official approval for the home modifications.

In the meantime PT and her husband received a letter from NDIS stating that both had been approved to become NDIS Participants. The OT submitted reports to the NDIA advising of the high risk identified without home modifications. The original OT reports and building quotes were submitted to NDIS.

After six months of awaiting approval from the NDIS for funding of the home modifications PT contacted the NDIA. She was told that no one had read the reports and that her OT would need to resubmit the report using the correct templates. Due to the urgency of the need for the home modifications PT self-funded the modifications.

A further six months later she received a notification that the NDIS had received her request for home modifications and was advised that only some of the recommendations from the OT could be approved.

Four months later PT received a phone call from a Service Delivery Manager advising that the NDIS would not fund the requested ramp. This was over two years after the original OT report identified a need for the ramp.

- Case study from submission to the Parliamentary Joint Standing Committee on the National Disability Insurance Scheme, 2017

39. ALA adds its voice to those of consumer advocates who are calling for a slowing of the roll out process, until the administration and market can catch up.

Conclusion

40. The ALA welcomes the opportunity to have input into the inquiry by the Portfolio Committee No. 2 (Health and Community Services) inquiry into the implementation of the National Disability Insurance Scheme (NDIS) and the provision of disability services in New South Wales. The ALA would also welcome the opportunity to appear before the Committee at the scheduled hearing for this inquiry.

Andrew Stone SC

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