

Submission
No 187

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

Name: Name suppressed
Date Received: 9 August 2018

Partially
Confidential

I am a carer for my husband who is an NDIS participant and pleased to provide this submission to the inquiry into the implementation of the National Disability Insurance Scheme and the provision of disability service providers in New South Wales.

1. Rights- Self-determination, choice, privacy and freedom from discrimination

- NDIS has put up many barriers for my husband and I to make choices during the plan review process.
- Initially, NDIS were adamant that they could no longer provide a face-to-face plan review meeting in our home, despite the stressful nature of the task of travelling to a public venue (further than the local office) with very poor parking and wheelchair accessibility, and the stress for a person with acute anxiety to be in a closed room with strangers. I have a problem with hearing on the phone, and my husband has a problem with expressing himself, so phone interviews are unproductive and extremely stressful. I believe NDIA continues to deny people face-to-face assessments in their home.
- It was only after I lodged a complaint and accessed support from our local member of parliament that I was contacted by an NDIS staff member apologising and informing me that we could have a face to face plan review meeting in the home. The whole process was very stressful and took precious time away from addressing both my basic needs and those of my husband. NDIS were full of apologies; I find it really concerning and upsetting that you need to get your local member involved to have your complaint managed.
- I do not feel that the NDIS planners or persons with approved delegations recognise carers or the need for them to have their person supported for 24 hour periods (support in the home) to enable carers to have respite so they can recharge to go back to their caring roles. I have found them to be dismissive of the stresses of sleep deprivation and the demands of caring for someone who is severely disabled 24 hours a day, 365 days of every year.

Recommendations

(i) That all NDIS participants have the **choice** to have a face to face plan review meeting in their home, or at a **local** NDIS office, or a telephone meeting.

(ii) NDIS to work in partnership with Carers NSW to identify how carers can be supported; having access to a minimum of 28 days per year of 24 hour support each NDIS plan i.e. carer eligibility.

(iii) For carers to have access to knowledge of the NDIS processes that will equip carers to support the NDIS participant they are caring for.

2. Participation and Inclusion – Opportunities for meaningful participation and active inclusion in the community.

- NDIS planners did not work together with my husband and I or demonstrate that they valued my role as a carer.
- The planner did not take into consideration the functional capacity of my husband, the complex care routine and what actually would be required in hours of support for him to be able to access activities of his choice in the community and to participate his own personal care routine.
- The NDIS time frames to amend a plan, review or changing circumstances are not responsive to enable a participant's active inclusion- 3 months.
- NDIS planners ask questions which they read from their computer which takes an hour and half and the software does not encourage our involvement about us. They require us to answer multiple choice questions which often are not relevant to our situation and not delivered in a way that would involve my husband.
- Disability is individual – and I remember the publicity about how plans would be tailored to suit individual cases, but now the individuals have to fit into boxes that really **don't** fit, and there is no opportunity for meaningful participation or inclusion, because no-one wants to know.

Recommendations

(i) NDIS to have a person-centred approach ensuring that NDIS participants are in the centre of their plan/service design. Planning needs to focus on the abilities they do have. Recognising more than one support worker will be required for some supports for participants to be able to participate in the care routines. NDIS to develop a process/tool for planners to follow Re: person-centred and

NDIS **participants** to be provided with this process/tool to assist with the preparation for the planning meeting.

(ii) NDIS to identify time-frames for decision making and implement them RE: processes.

(iii) NDIS participants to be provided with planners' direct phone lines to discuss plan review information.

3. Individual Outcomes- For an NDIS participant to make decisions about their life to have the supports to work towards achieving their goal

- Whilst NDIS provide funding for core supports to NDIS participants with a complex care routine, the current pricing structure does not provide disability providers the ability to invest time in the staff for training, debriefing, supervising and support or for the coordination of rostering.
- Our experience for the past three years (we were participants in the trial site) is that Disability Providers are finding it very difficult to recruit a skilled workforce when wages are driven by the pricing structure that is low.

Recommendations

(i) A pricing structure which allows for Disability providers to be able to recruit skilled quality workers, provide office infrastructure to support staff with training, debriefing, supervision.

(ii) The NDIS plan reviews – The planners to provide written reasons (why a support is being reduced/removed from a plan- how they have measured that it is no longer required) not just referring to the NDIS Act and section etc. and how they have determined these necessary supports will be provided by some other means.

4. Feedback/Complaint- NDIS participants to expect an effective complaints management systems

- NDIS do not have time frames allocated for NDIS participants regarding when a complaint will be acknowledged, responded to and a resolution sought.

- Through my husband's three plans we have frequently contacted the 1800 number and have lengthy waits until the call is answered, to always have the NDIS call centre staff tell us there is nothing they can do except take the message and send it to the relevant NDIS office. If you don't hear back you can contact your local member.
- My husband's plan review has been going on for months and after an exhausting time of phone call enquiries and complaints, and no-one being able to provide information or even return calls, we were informed of the decision. The outcome was that they (NDIS) made a mistake and should not have approved the equipment request!
- Why did it take months and months to come to this decision, months and months of tax payer's money to approve the equipment request then months of tax payer's monies to inform us that they made a mistake? The mistake involved NDIS sending an email to the Occupational Therapist informing her that the equipment request application that was lodged was approved and to go ahead and organise the equipment. The initial organisation for the equipment was already underway.
- For months and months of the Occupational therapist's time (that came out of my husband's plan with no outcome for following this up) and months and months of coordination of support time (that came out of the plan for no outcome) all because NDIS does not have any business systems in place. And months and months of client and carer stress, and wasted precious time. When I say precious time it can be wasted opportunities for me to have a shower or cook a meal or actually have a cup of hot tea – or even have time to sit down and read a book to our grandchildren. All things carers go without because their disabled person comes first when it's a severe disablement requiring 24/7 care.

We pay the price for all NDIS mistakes with increased stress and time deprivation in ways able-bodied people can't even imagine, and there isn't even an effective complaints management system.

Recommendations

(i) NDIS develop a process with time-frame attached for decision making Re: equipment request.

(ii)NDIS to acknowledge equipment request in writing to the participant that the request has been received, and enclose a flow chart stepping out the process and time-frames for the determination Re: reasonable & necessary.

(iii)NDIS provide written communication of outcome to the participant.

5. Service Access- To be supported by NDIS when they decide not to provide a support or when there are barriers to us being able to access the support.

- My husband is still having many challenges since being an NDIS participant (over 2 years) to receive support (CORE) services. We have met with many agencies and when they are informed of the support that is required i.e. two person transfers, implementing a behavioural support plan, bowel care routine, I am informed they do not have any suitable support workers and would need to recruit. The recruitment process happens and then we are informed that no suitable applicants applied who matched with the skill set needed.
- NDIS have been informed of this at our planning meeting and their response was to reduce the funding in my husband's core supports because we did not spend it in the previous plan. There was no acknowledgement of the time (and effort) taken to try to find support staff, and the fact that it is a slow process; also that many do not stay when they work out they can get the same money elsewhere for doing less complex tasks. There has been no acknowledgement that support staff who can cope with complex care are not as numerous in regional areas as they are in the city. We have approached many registered providers who have not been able to provide staff. This workforce issue applies to the majority of the disability providers in our LGA.

Recommendations

(i) NDIS to be reporting and capturing NDIS participants' information when they are not able to access a service and report the information to the NDIS quality and safeguards Commission each month for action.

(ii)Disability Service Providers who are registered for Core supports be required to provide evidence to the NDIS when they are unable to accept a referral for an NDIS participant with a complex care routine.

(iii)NDIS to have a pricing structure to support recruitment of skilled workers.

6. Service Management- NDIS participants have support from NDIS that has policies and procedures in place that participants are informed of when receiving support and they are reviewed if not working.

- When I have asked NDIS staff they have informed me they do not have time-frames for getting back to participants when a complaint is made.
- When I have asked for direct phone numbers we are informed that we are not allowed to contact the planners directly.

Recommendations

(i)NDIS to have a process for good communication with participants- that does not have call centre staff as the only access to communicate with staff, that the staff/planners can be contacted directly.

(ii)NDIS to identify how they are going to actively plan to the participants i.e. to provide us with the list of questions they need answered before the plan review. These can be completed and submitted before the planning meeting. This will enable the planner to have our information in the NDIS data base with the algorithm calculation of what funding is the bench mark etc.

Then the actual plan review meeting can be person-centred on what we plan to achieve in the next 12 months and individualised. If support hours required are above the bench mark for that particular planner to handle, participants could then be provided with the option to present our case to the next higher up delegate for consideration of reasonable and necessary. This would then prevent the amount of plans that a need to have a plan review because the planner wasn't qualified to work with a particular benchmark amount.

(iii) Plan review meetings to have a component to provide input into processes to capture continuous system improvement and for this information to be forwarded to the NDIS Quality Safeguards Commission.

Thank you for this opportunity to be heard.