

**Submission
No 166**

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

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My son is a young man who entered the NDIS in July 2017 after being on Direct Funding through ADHC. I, (his mother), self-manage the funds and we employ our own support people directly. The NDIS has been a reasonable transition to actually get on to the Scheme. We have completed our first plan and then had the same plan extended for another six months without a review. I think this is to allow the NDIS to catch up with reviews in our area all being due around the same time. What I did find though, when we were coming on to the Scheme, was that the LAC's had no idea how the self-management worked. They didn't even have their office completed in our area so there was no place to visit to ask questions and when I asked any questions they didn't know the answers ("oh we are doing a training session next week on that"). Too late – our plan was already started which meant our old funding was no longer available – we were starting without support. I managed to figure things out for myself and hope I got it right. About five months later I had an LAC ring me and tell me that she was the one for me to contact but that was way too late. When I thought my review was coming due I tried to contact this LAC and other LAC's to make sure we were getting a review in time but I couldn't get onto them. I don't think the system works so well for those of us who rarely contact anyone. When I did eventually get contacted by someone who said I could extend my plan, it was someone else entirely (another LAC I think).

What I am finding with the way the NDIS is structured is that it is difficult to plan too much in advance - we don't know how much funding we will have to manage after our next review which I have been told could happen any day now despite the extended plan being until the beginning of December. This makes it difficult to retain workers as it is all so uncertain how many hours we will be able to offer support people after each review. It takes time to recruit and train good support people so this is a real problem with the Scheme I believe.

The reviews appear to be about reducing funding as people are supposed to have achieved their goals. However, I believe the timeframes are too short for some people to achieve goals that would justify a reduction in the amount of support people will need. Some people will always need more support no matter how many goals they achieve.

My belief is that people should be given an amount for their first plan and this amount would carry over each year. This way the money would be available if needed and any funds that weren't spent in that year would remain in the NDIS pool. This would stop people thinking that they have to "use it or lose it" in regards to their funding and make the overall management of the money

much smoother and easier. The reviews then could be about making sure the money was being used appropriately for people to achieve their goals and ensure that the amount is sufficient to cover a person's needs. The review shouldn't be about reducing funding as it then wouldn't be necessary – if people didn't use the money in any given plan it remained with the NDIS to be used elsewhere. The other thing to consider is that people's lives change all the time, for example, someone might spend an unexpected amount of time in hospital one year so don't need as much support that year – they don't want to be worrying if that means their support will be reduced for when they get out and need more support again. The idea of receiving the same amount each plan would allow for the ups and downs of someone living an authentic life in the community.

If this idea is not possible (and I can't see why not) then at the very least there should be a cap on the amount of money that can be removed from a plan in any given review so that we can better manage transition to less support. In our case my son can take a number of years to reach some of his goals so to take away support when everything is starting to make real progress is a very difficult thing to manage.

The other problem that I can see is that plans seem to finish on the day they are due to run out and this is final. No more money until a new plan kicks in. I find myself getting very stressed when the end of the plan is coming due hoping that the person doing the plan review will contact me in time and the new plan (and therefore the funds) will be available so that we don't have to wait for weeks with no money. The obvious solution to this is that the current plan stays current until such time as a new plan is ready. People's lives don't stop to wait for new plans.

I have noticed that people are getting a lot less funding after their review despite having high and complex needs, particularly if they are self-managing outside of the DSP's. Emphasis seems to be on the support representing value for money in that the cost of support is reasonable as compared to the benefits achieved and the cost of alternative support. I'm not sure how this is determined in cases like ours where we are not using DSP's for support as there is no comparison between the support my son currently enjoys and the support he would receive from a DSP (which I would presume is the alternative support being alluded to by the Senior Planners who are quoting this particular part of the NDIS Act), NDIS Act 2013 section 34(1)(c). We fought so hard for Direct Funding in NSW so we could bypass the DSP's - I am now concerned that the NDIS may be trying to force people to go through DSP's again effectively taking away choice and control. I believe this trend needs to be kept an eye on.

There also seems to be a disconnect between what is discussed at review meetings with an LAC and what a Senior Planner decides a person should get to support achieving their goals. I'm unsure whether this is because the LAC's don't appear to have had the proper training or if the Senior Planners have another agenda entirely (perhaps to reduce funding?) This trend also needs to be kept an eye on I believe.

Perhaps this has something to do with Senior Planners who work in the Lismore office in Northern NSW calling themselves "Senior Planner, Service Delivery, Queensland South, NDIS". If these planners have indeed come from Queensland and Disability Services Qld. then we know that the culture and system that they have come from is far inferior to that of NSW who have been much more progressive where disability is concerned. Why would northern NSW fall into Queensland South for the NDIS I wonder?

Thank you for considering this submission - I would be happy to be contacted if need be or to do a further update to this submission once we have had our first review.