

Submission
No 98

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

Name: Name suppressed
Date Received: 10 July 2018

Partially
Confidential

Attached is a letter I sent to Rob De Luca in November 2017. My concerns still stand, so despite the date I still consider it relevant.

8 November 2017

Rob De Luca
Chief Executive Officer NDIA
GPO Box 700, Canberra ACT 2601

Dear Rob,

I am writing this letter to share some experiences of the NDIS so far, and to express my concern for the ways in which I feel the NDIS is not meeting the needs of people with disability.

I have been an occupational therapist for 15 years, working primarily for Health NSW in the field of spinal cord injury rehabilitation. In January this year I formed a partnership and ventured into private practice, as the rollout of the NDIS promised great opportunities to improve the well-being of people with a disability. Since January I have had a number of experiences that I have found troubling, a few of which I have summarised in the case studies below.

Ms G

I worked with Ms G in her first 12 month plan, and witnessed her experience as she participated in a plan review. Ms G is an accountant by trade and very meticulous with record keeping; because of this skill set she felt confident to self-manage her NDIS plan. Despite being an intelligent and capable woman she had significant trouble navigating the NDIS Portal, and finding service providers to meet her needs. It was approximately 6 months after her first plan started before she was in a position where she understood the scheme, could operate the portal, was connected with service providers, and could therefore start receiving NDIS funded services.

As a result of this time lag, at the end of her 12 month period her NDIS funds were underutilised. She attended her planning review meeting with explanations and evidence as to why she was unable to fully utilise the funding in her first plan. She went to great lengths to formulate a clear list of goals that she would like to address in her second plan, along with estimated costings for these, which happened to approximate the funding provided in her first plan. Despite providing a convincing case, when she received the details of her second plan, the funding allocated was exactly the same amount of money that she had managed to utilise from her first plan, i.e. the equivalent of 6 months funding. This indicates that the planning officer paid no regard to Ms G's individual circumstances, nor the goals and costings that she had provided for the second plan, and approved what appears to be a plan that is purely dollar-focused. This outcome also conveys that the NDIS operates on a 'use it or lose it' policy - those participants who successfully use up their funding will have it fully replenished, while those who for whatever reason were unable to fully utilise their funding will have that funding removed. This policy promotes wastefulness and does not cater to the needs of people whose life circumstances are complex and fluctuating.

Mrs S

Mrs S is a lady with multiple sclerosis who I worked with back in February and March this year. From my assessment it was obvious that she was having significant difficulty managing her daily life, and needed various pieces of equipment to make her safe and as independent as possible in her home environment. Examples include a replacement four wheeled walker, as her existing one was broken and unsafe, a riser recliner lounge chair, as she was unable to safely stand up from her own lounge chair, and an adjustable bed, as she was unable to independently get herself in and out of bed and due to shoulder pain was unable to sleep on a flat mattress.

After making my assessment and submitting the equipment requests to NDIS in early March, I received a number of concerned calls from Mrs S and her husband over the following months asking if I had heard any news about the outcome of the application. Mrs S's condition is progressive and over these many months of waiting she had deteriorated, and her daily activities became more and more

difficult. It wasn't until mid-October (7 months) that a determination was finally made and the equipment ordered with the suppliers. Such timeframes are unacceptable for people whose needs are urgent and who are at risk of injury and secondary health complications as a result of non-provision of services and equipment.

Mr H

Mr H is an intelligent man who works as an accountant and is living with a spinal cord injury. I commenced working with Mr H as he was approaching his NDIS plan review at the end of his first 12 months, and found that my role was primarily to provide basic information around the functioning of the NDIS, what his entitlements were, and to dispel misinformation that he had been provided. Mr H relayed what he had been told by his original local area coordinator, which I found very concerning. The things that he was told include:

- he was not permitted to self manage his NDIS plan, with no explanation as to why.
- if he was unhappy with his plan he could lodge an appeal but it would be of no benefit because he wouldn't be provided with one. Mr H did lodge an appeal, and indeed this did not result in any due process.
- that because he was living in a rental property he couldn't explore modifications to another home that he owned, despite the fact that he was only living in the rental property because the home required minor modifications
- that funding provided in the assistive technology funding category could not be used to pay for maintenance of his existing equipment, despite this being explicitly the function of this funding category.

Unfortunately, Mr H is very trusting, and so took the LAC's information at face value. As a result of this misinformation, Mr H became so confused about the functioning of the NDIS that he had used virtually none of his funding in his first plan. This experience highlights the prevalence of misinformation and its impact on participants.

Mr W

Mr W is a gentleman who has been living with a spinal cord injury for approximately 40 years, and due to a change in his physical functioning required the introduction of a new piece of equipment - a mobile shower commode. This piece of equipment is extremely commonly used amongst the spinal cord injury population, and I would estimate that 80% of the time the cost of these comes to between \$2,500 and \$3,000.

I submitted a lengthy application for this piece of equipment and was extremely surprised to have it rejected on the basis that it was 'over benchmark pricing' (which I later discovered is approximately \$1,700), with the recommendation to instead use a piece of equipment that was less expensive. It was through my clinical reasoning and weighing up of the suitability of lower cost options in the first place that led to the recommendation in my application, so rather than follow the request to use a lower cost item, I spent a further two hours writing an additional lengthy report detailing down to the finest detail why the mobile shower commode was an appropriate recommendation.

Thankfully, this lengthy report was accepted and the equipment funded. However the additional two hours required to formulate the report cost the NDIS an additional \$351.14, and the participant lost two hours from his funding allowance that he could have instead used for other services.

What I find troubling is not the need to justify my recommendations, but the lengths and costs that I need to go to justify them. I'm convinced that it was inexperience on the part of the assessor who received my application that led to it being initially declined, simply because it was above an arbitrary benchmark pricing limit. Had it been an experienced assessor who knew what was common for people with spinal cord injuries, the additional two hours justification would not be required. What is additionally troubling is that it is those people with the most complex disabilities who have the most complex needs who are almost always going to require equipment over benchmark pricing, and as such these people will be the most unfairly disadvantaged.

The experience with this participant was not unique, and I've had to do this on a number of other occasions. This experience highlights the impact of having low-skilled, dollar-focused assessors evaluating the applications for funding.

These examples highlight the areas where I feel the NDIS is off-course. I would summarise my experiences and concerns as follows:

- the NDIS is focused on minimising costs rather than on the well-being and unique, fluctuating needs of individual participants
- processing times are excessive and have resulted in participants waiting unreasonable (and at times unsafe) lengths of time for determinations.
- the scheme is confusing, and information provided to participants is inadequate, resulting in participants who are very poorly equipped to set about having their needs met
- the staff in key decision making roles appear low-skilled and inexperienced, with little understanding of the needs of people with a disability, particularly those with complex needs in specialty areas. Experienced clinicians are often met with rejected applications and accompanying reasoning and recommendations that betray this inexperience.
- the 'use it or lose it' policy of having unutilised funding allowances removed undermines the sustainability and participant-focused aims of the scheme.

Unfortunately as a result of these and many other concerns, I am hearing more and more highly skilled providers are ceasing involvement with the NDIS, and focusing their attention elsewhere on better managed schemes such as iCare and CTP. This in my mind is the most catastrophic outcome of all, as it leaves participants with fewer options, less choice and less control. Our business is planning to continue for now, however this is in the expectation and hope that the problems will be resolved.

I have long been, and remain, a believer in the philosophy and underlying principles of the NDIS, that people with a disability should be given choice and control to access services that help them to live a normal life. Unfortunately, thus far my experience is that the NDIS has simply replaced one bureaucratic, autocratic system with another, and left participants with much the same limited access to services as before. I truly believe that with a correction of course, the NDIS can be brought back on track and become what it was first envisioned to be.

If you have any questions, please do not hesitate to contact me using the details below.

Kind regards,