

**Submission  
No 74**

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

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**Date Received:** 10 July 2018

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Please bear with me when I ask you to imagine the day your child was born (apologies for being presumptive that you have children) and the elation you felt that they had all their fingers and toes and were healthy.

Now imagine being told when they are 18 months old that not only do they have a degenerative neurological condition but that their health and life span was going to be unpredictable and cherish every moment with them. No one tells you at the time that this journey is going to be not only an uphill struggle emotionally and physically but that you will have to jump through lots of bureaucratic hoops from the health dept, the education dept, the transport dept, the community that you live in but that this journey will financially cripple you as you have to move homes and get a second mortgage to adapt that home for your child's wheelchair.

Now, how happy would you feel when the government tells you they have found a nirvana solution to all your problems and that they are there to help you through this? Ecstatic as I was? Hopeful as I was too? I couldn't wait for the NDIS to roll out on my doorstep and help me through this stressful predicament of everyday life. I put a new (but second-hand) vehicle that could be adapted for my son's wheelchair on my mortgage confidently knowing that the NDIS would fund the \$15 - 20,000 conversion required as I was told.

Fast forward 12 months from the start of my son's plan. I am now told (verbally of course as no one wants their job security threatened) that the application for the vehicle to be adapted will not be looked at for the next 6 - 12 months. I have just been informed that the home modifications application that we put in in October 2017 has been denied after waiting for an answer for the last 9 months. It has been 12 months also since I told the planner that I urgently need a shower commode chair as my son can no longer stand and I'm finding him too tall and heavy to safely manoeuvre him in and out of the shower or on and off the toilet. I am still waiting for that!

I am tired of making phone calls, emailing and writing complaint after complaint to people who are 'terribly sorry' but it is 'out of their hands' and they cannot change 'the system'. Can you tell me if the NDIS was supposed to be another wall for us to get over? Shall I even bother to continue the ascent up that proverbial steep climb? Or you can just tell me it was just a joke on us and actually closing down all those already set up support systems was a way of saving money as you knew we would eventually tire from pursuing the NDIS and just give up!

My son's condition has now deteriorated 100% in the last 9 months to a point where he needs a major life threatening operation before Christmas. I have no idea how we will manage getting him home from hospital without suitable transport or if the shower commode chair (that we still don't have) will be appropriate to his needs. I didn't imagine that we would be political pawns in a never ending game but that is how we are made to feel.