

8th August 2017

Joint Standing Committee on the National Disability Insurance Scheme
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Dear Committee Members,

I am writing to you both as a parent of a child with a disability and as an individual who has a disability. Both I and my eldest daughter have a rare, complex, permanent, incurable genetic condition. I would like to provide you a perspective on what the process is like for “new applicants” that are not currently receiving support from state based services

After much stress and great difficulty, over 12 months of trying to access services and having to appeal a decision, we have obtained access to the NDIS for our now 13 year old daughter and she is now benefiting significantly from the NDIS. She is a gifted and talented student with an exceptional IQ and whilst her physical disability imposes significant issues we are confident that the NDIS will mean that she will now be able to best utilise her significant academic and intellectual skills across her lifetime to benefit herself, her family and her community. We believe that this investment by her community in addition to the investments we continue to make as her parents will be very cost effective for our community in the long term.

I am continuing to try to access NDIS funding for myself, after over 12 months of trying to access funding and a “saga” of events I find I am frustrated and disappointed that the program that has been established to help me, due to the processes involved, is adding to my stress in a most difficult period of my life. In addition to my disability which causes significant challenges, I was diagnosed with breast cancer in 2015 and despite surgery, chemotherapy and radiation treatments throughout 2016, I was diagnosed with a locoregional recurrence with cancer in the lymph system earlier this year, and am now recovering from surgery and radiation treatments and am about to again commence chemotherapy. Unlike many people going through the process of trying to access NDIS, I have over 10 years’ experience working in community and disability services, I am passionate about preventing social injustices, I am capable and articulate and I have a very capable and supportive husband, however I could really do without the additional stress of having to “fight” the system.

Throughout my entire experience of trying to access NDIS I have been treated in a manner which makes me question the skills, training, “intentions” and “performance indicators” of those staff that are tasked with the role of assessing applications to access the NDIS. Whilst it is very important that

public funds are not wasted it appears that there has developed a culture and practices that are designed to deliberately and systematically decline and delay applications in order to try to force applicants to give up.

There appears to be no recognition that those that are applying may be genuine, may be stressed, may not have sufficient supports, may be vulnerable and disadvantaged individuals that should be helped. Instead it is set up to be adversarial and to block access at every possible opportunity. I would like the Standing committee to seriously investigate the training provided to staff, the KPI's, and the performance management of staff. I am highly suspicious that staff are "required" by their managers to politely and "helpfully" obstruct and delay applicants rather than actually be helpful.

Some of the things that have happened to me when trying to access the NDIS include:

- When I requested forms to submit applications for both my daughter and myself - Forms were never sent out
- I requested again – I was told they must have been lost in the mail (I suspect this was the first lie)
- I received forms, completed and sent them in.
- I followed up and was told that applications were not received (that they were lost in the mail – this was a lie)
- I requested assistance of NSW Family Services and indicated that I did not believe that the applications could have been lost in the mail twice
- The applications were found - apparently NDIA had them all along
- Then both applications were declined supposedly because our condition was not permanent (complete bullshit – how does a permanent, incurable genetic condition get to be temporary????)
- With the assistance of the NSW disability advocacy service we Submitted request for review of decision for both my daughter and myself
- Unable to get answer on this whenever we called we get fobbed off and told to wait longer
- Told that letter was sent out asking for Evidence required and it was our fault things were delayed – this was not true – we were never sent such a letter
- Told that due to IT problems that the letters were not sent out
- I sent a number of complaints via the feedback email and I have never had a response to advise if these were investigated or what the outcome has been
- It is our understanding that the review process requires that the person "doing an internal review will make a decision to confirm, vary or set aside and substitute the earlier decision". We could not get advice on what the decision was, but were told that the status of our application was changed and that they will put our application in again to the team to be considered.
- We were told to wait a further 3-4 weeks before we could expect our application to be reassessed.
- Eventually my daughters review was completed and she was granted access to the NDIS but told it may be a further 18 months before her plan could be done. After many follow up calls and assistance of NSW family services her plan was completed and is now finally being implemented.
- However there was some issues with the wording of the support documents I had provided and the reviewer wanted to clarify some issues with specialists – however as the specialists were overseas and not available they advised they were unable to grant me access but if I

could provide further written information to clarify the “label” (name) of my condition then it would be able to be further considered. I was told I could take it to the tribunal or put it as a new application but a new application would be quicker and I would only have to supply the additional information and all previous information would be included.

- I obtained an appointment with an internationally recognised specialist who clarified that I have a rare permanent genetic condition that is significantly impacting me even though there is some issues about what it should be called. (He also mentioned that I have significant medical needs at the moment – not surprising given that I have recently been diagnosed with a recurrence of cancer and the complications that cancer and my treatment has with the interaction with my disability).
- My application was then again declined, now because of my high medical needs.

I am absolutely furious that the fact that I have a recurrence of cancer and therefore have medical issues on top of my disability is now being used as an excuse to decline my access to NDIS.

I have a permanent, incurable genetic condition that is impacting on my daily functioning and need support because of my disability. Yes I have cancer now as well but this does not suddenly mean my disability is “cured” or “curable” or no longer impacting me.

I do not expect NDIA to fund what health should be doing – I just expect the NDIA to do their job and give me access to the NDIS for my disability related supports.

So for me the “saga” continues as I try to obtain access to the NDIS.

Unfortunately in my discussions with other people with disabilities, parents/carers of people with disabilities, health workers, social workers etc there is never any surprise at what I have been through. There is reluctant resignation that this is just how the system is and that many people who are eligible are vulnerable disadvantaged people who do not have the energy to deal with this, and consequently continue to go without supports that they would clearly benefit from and are clearly eligible for.

I would urge the members of the committee to not accept that “this is just how the system is”, I request that you use your health, energy and very best endeavours to investigate thoroughly and to implement change to the culture and practices of the NDIA that obstruct access to the NDIS, particularly for “new applicants” that are not currently receiving support from state based services.