

Supplementary  
Submission  
No 107a

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

**Name:** Name suppressed

**Date Received:** 28 July 2018

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Partially  
Confidential

I would like to make a submission to the NSW parliamentary committee in relation to the Implementation of the National Disability Insurance Scheme and the provision of disability services in New South Wales.

While I and my daughter now have access to the NDIS and I have previously provided a submission to the enquiry about the delays and difficulties applicants have in initially accessing the scheme I would like to make a further submission to the enquiry about the issues that arise due to the "Review" requirements and practices of the NDIS.

Whilst NSW Family Services and my local State and Federal members have all been so helpful, the last two years have been made unnecessarily difficult by my dealings with the NDIA. I passionately believe that the proper implementation of the NDIS would significantly help many people with disabilities and particularly those with Hereditary Connective Tissue Disorders such as Ehlers Danlos Syndrome. I would be happy to meet with the committee and/or any member of parliament to discuss these issues.

Please find attached my submission in relation to the systemic and policy issues I believe NSW government could significantly influence to provide a better outcomes for NSW residents particularly in relation to those around the "Reviews".

Regards

Dear Committee Members,

**Re: NSW Parliament inquiry into systemic and policy issues concerning implementation of NDIS in NSW.**

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 permanent, incurable genetic condition. I would like to provide you a perspective on the ongoing adversarial approach taken by NDIS and the impact on individuals and families with disabilities.

Due to our genetic condition being very complex and rare it is normal for diagnosis to take over a decade. My daughter was diagnosed at age 11 and I was then also diagnosed. At that time NDIS had already been rolled out to our area and I sought to access the scheme to meet our disability related needs. It took over 12 months and an appeal for my daughter to be able to access NDIS and approximately 23 months, an appeal and tribunal application for myself to access the NDIS.

As you can imagine the process to go through reviews and appeals is frustrating and exhausting and as part of the process the applicant must prove that their condition is permanent and severe and will require support for their lifetime. So after all the specialist visits the costs of reports etc etc you can imagine my dismay when I receive the upcoming schedule plan review reminder and instead of telling me that they are reviewing our needs and what level of funding may now be appropriate they are advising that they will be reviewing eligibility.

So after proving we qualified we will now have to fight all over again about eligibility, and face the prospect of losing access, we will also now have to pay for reports from all of our specialists all over again, what a waste of money.

For many families trying to gain access or to provide evidence for such a process, the costs to obtain specialist reports is for many prohibitive, the waiting times to get to specialists is exhausting and then falls outside timeframes required, the specialists are sick of filling out reports and forms instead of helping patients, and some refuse to do so. For families struggling on low incomes with multiple members of the families coping with complex disabilities and health issues the additional cost of such reports is prohibitive.

**Vulnerable families will need extra support so they can deal with the NDIA systems.**

I would request the Committee members consider requesting that NSW Family Services ensure that every family that Family Services is currently working with and every family that has had a notification of "child at risk" on in the past 2 years that has either a child or parent with a disability in the household should be provided with the assistance of an advocate to assist them to access the NDIS and to deal with the ongoing review process, as the bureaucracy and distress caused by the NDIA systems is not something that a vulnerable or disadvantaged person can or should be asked to try to deal with on their own. I am highly passionate about social justice, I am highly educated with post graduate qualifications and I have over 10 years experience in working in the community services sector and yet it took me over 23 months to access NDIS for myself, and required the support of an advocate and legal aid. NSW government is going to have to support applicants to access NDIS and deal with

the review process in order to avoid the NDIA shifting costs back to them by making the application process prohibitively difficult.

Throughout my entire experience of trying to access NDIS I have been treated in a manner which makes me question the “intentions” and “performance indicators” of those staff 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 obstruct access 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 committee to advocate for a formal investigation of 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.

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 advocate for change to the culture and practices of the NDIA that obstruct access to the NDIS.