

Submission
No 107

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

Name: Name suppressed

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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 the delays and difficulties I have had in accessing the NDIS have contributed to my stress in a very difficult period of my life. In addition to my daughters disability affecting her extremely during this period causing significant periods of extremely high care needs, I was also dealing with my own chronic pain and various issues caused by my disability and undergoing treatment for breast cancer and also dealing with the complications my disability caused with my cancer treatments. My cancer has continued to recur and has now progressed and is now not expected to be able to be cured. I found the suggestion that my having cancer meant that my disability did not matter offensive and infuriating. My disability related needs did not go away because of my cancer diagnosis. Not having adequate services for my disability needs has exacerbated my pain and distress significantly, at times I have felt that the NDIA were hoping I would give up or die before they had to provide any services.

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.

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 what the process was like for “new applicants” that were not currently receiving support from state based services when they applied for NDIS and the many insights that I gained about the systemic and policy issues which I believe need to be addressed.

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.

Our daughter 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 not only benefit her quality of life but will also be very cost effective for our community in the long term. I have only recently accessed NDIS for myself but it is already significantly improving my quality of life.

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 over 12 months 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 was told that while I would need many services the NDIA considered that they should all be provided by NSW Health.
- With the assistance of NSW Disability advocacy and Legal Aid I submitted application to Administrative Appeals Tribunal and after various case conferences the NDIA agreed that I met the eligibility requirements and tribunal orders were made.
- The NDIA delayed implementation of the tribunal orders and I had to again lodge a complaint. I was told that the matter had been referred to NSW North but that it may be a further 3-4 months before a planning meeting could be scheduled. After raising this with my local Federal member and the Minister the NDIA then arranged for a planning meeting and the implementation of services was able to occur.

So from both my lived experience as a person with a disability, as a parent of a child with a disability and an active member of various support groups for individuals with Ehlers-Danlos Syndrome I would like to provide the following insights on various issues.

Access to NDIS is adversarial.

Instead of recognising the trauma and difficulty particularly for parents of children with genetic conditions that affect both the parent and child and providing assistance to help them gain access to the NDIS the NDIA seeks to block people from accessing services. They make it hard to get the forms to apply, they lose the forms, they delay and delay, they decline people for nonsense reasons and require them to appeal. Many families just give up as it is all too hard.

The reports and evidence that NDIA request is just too difficult for many families

For many families trying to gain access or to provide evidence for an appeal, 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 for appeals, 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.

Hereditary Connective tissue Disorders and Ehlers Danlos Syndrome need to be on the List B.

People with permanent genetic conditions are being declined and told that their disability is not permanent. This often causes families to just give up or require them to go through the process of an appeal and sometimes will then mean that they need to use up the time of an advocate which is a huge waste of resources for all involved.

Whilst in theory the diagnosis being on the List A or List B shouldn't matter as the NDIA staff should be basing the decision on the day to day impact, the reality is that for conditions not being on those lists seems to mean that many staff just automatically decline on the basis of not being permanent.

Those with Connective Tissue Disorders such as Ehler-Danlos seem to be significantly impacted by Hereditary Connective tissue disorders and Ehlers-Danlos Syndrome not being included in List B in the operating Guidelines. i.e. Access to the NDIS 15. List B – Permanent conditions for which functional capacity are variable and further assessment of functional capacity generally is required. This is complete stupidity. How does an incurable genetic condition get to be temporary?? The stress caused by this failure to have up-to-date and accurate guidelines to so many already distressed families is heartbreaking. The time of advocates being used to address this stupid failing of the system is so unnecessary.

NDIA is trying to cost shift to NSW Health

I and others have had NDIA staff phone to “explain” the decline decision – they claim that conditions are medical and health related and the responsibility of Health – it is interesting to note that the information in these phone calls are not the “reasons” that come out in the written letters from NDIA. If this is a deliberate strategy or just the tactics used by certain staff to try to minimise the number of appeals would be something worth investigating. The staff member who “explained” to me was very adamant that whilst I had every right to appeal that it would not be successful. I feel that this is a disgusting tactic for the NDIA to be using to try to dupe many highly stressed and vulnerable individuals out of services which they are eligible for.

Lack of access to services is likely to exacerbate health issues

Many disabilities have co-morbid conditions. Not getting access to appropriate disability services and the stress caused by excessive delays in accessing services, is likely to lead individuals and families into more precarious financial, emotional and physical states. I know for myself personally that without services I am more likely to have significant falls and injuries which will pose increasing costs not just on myself but on the health system. By declining eligible participants NDIA will contribute to the additional costs of individuals and NSW health.

Delays in processing of applications, delays in processing appeals and delays in providing appropriate planning meetings and delays in investigating complaints, all contribute to increased stress for applicants.

Not getting access to appropriate disability services and the stress caused by excessive delays in accessing services, is likely to lead individuals and families into more precarious financial, emotional and physical states. Whilst the NDIA is a new system the delays are unacceptably long.

There is no triage system for assessing urgency of applications

Where families are in crisis and lack of services is causing extreme situations and increasing suicide risk of vulnerable children there is no way of escalating applications. I was able to use the assistance of NSW family services and my local member to assist me but many individuals and families are not aware of these options. Some very vulnerable families and particularly Aboriginal families fear involvement of Family Services due to the history of the Stolen Generation and are not willing to seek assistance from these Departments and many at risk children are not getting the services they need because of the delays by the NDIA in providing services to children and/or their parents, and the fear of their parents in seeking assistance to access services.

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, 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 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 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 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, particularly for "new applicants" that are not currently receiving support from state based services.