

Marie Johnson
Canberra

This submission is provided to help inform the review of the operation of the NDIS Act, and in particular to provide insight into the urgently needed re-engineering of the NDIS administration.

This submission has also been provided to the 2019 Review of the NDIS Act and NDIS Participant Service Guarantee led by Mr David Tune AO PSM, via the website engage.dss.gov.au.

This submission describes the catastrophic case of my adult daughter, in her dealings with the NDIA.

My daughter has asked that I support her in writing this submission. My daughter has a complex and debilitating range of psychosocial and physical disabilities, which has significantly and permanently impacted her functioning and ability to engage in day to day life.

In writing this submission, I am drawing on my somewhat unique experience - of lived experience in addition to my deep internal knowledge and experience as former Head of the NDIS Technology Authority. I wrote the business case for the NDIS ICT systems, and for this to be based on co-design and the principles of the UN Convention on the Rights of Persons with Disabilities. I have an exceptionally deep knowledge of the NDIS processes, and the NDIS ICT system which were delivered by DHS. I have a deep understanding of NDIS capability, operating model and culture. I also have considerable operational knowledge of the cross government capability, systems and architecture on which the NDIS is dependent.

Perhaps somewhat unique, I believe there would be very few people with this deep level of direct internal knowledge of and experience in the NDIS operating environment – in addition to the “outside” lived experience of interacting with the NDIS.

I detailed my continuing and very significant concerns with the NDIS ICT systems in a Submission to the Senate Inquiry into the NDIS ICT Systems outlining the issues, as I believed that no other independent commentator and person with both lived experience and internal experience of the reach would be able to. (Link to submission from Senate website: <https://www.aph.gov.au/DocumentStore.ashx?id=f3ea66e3-e39c-42bc-b4d3-ded2f415d0a6&subId=659057>)

My daughter's case is illustrative of the far reaching and systemic deficiencies of the NDIS for people with psychosocial disability. In fact, for all people with disability and their families.

This submission describes my daughter's harrowing and tortuous experience in dealing with the NDIS. My daughter's two young sons, my grandsons, also have disability. My daughter's interaction with the NDIS is not only tortuous for herself but is exacerbated by the extreme anguish in dealing with the NDIS for her sons.

BACKGROUND TO THE LODGEMENT PROCESS

My daughter lodged her application in person with the NDIS on 6 December 2017 at the NDIA Offices in Braddon ACT - in a large lever arch folder providing in excess of 400 indexed pages of medical reports, assessments and other medical evidence. It took my daughter more than twelve months to assemble almost 20 years of medical evidence, including having made additional specialist appointments for reports and assessments to be written at very considerable cost.

I accompanied my daughter to the NDIA offices in Braddon to support her when she was lodging her application on 6 December 2017. In anticipation of the tortuous processes that my daughter went on to actually experience, I took photographs of my daughter at the NDIA offices, the lever arch folder with her application, which was stamped and receipted by the NDIA officer at my insistence.

The officer at the NDIA in Braddon balked at the in-person lodgement, notwithstanding that for the best part of a year my daughter had been told by the NDIA that applications could be made in person. In fact, the UN Declaration on the Rights of Persons with Disabilities states the human right to receive and impart information in any form. The officer at the reception counter initially refused to accept the application, stating that it was too large. The officer - in full view of other staff and others in the open reception area - flicked through the lever arch folder, looking at the medial documentation, calling out sensitive words and stating that because the folder was too large, that she would have to pull it apart.

Throughout this sickening experience, my daughter was standing at the reception counter in the public area in full view of everyone in the office. In front of everyone, my daughter started to break down, cry and shake. I intervened and asked if my daughter could sit down and be given a glass of water. I insisted that the officer stamp and receipt the documents and I took photos of the receipted documents.

It cannot be argued that my daughter's treatment that day, and for the following almost two years, was an unfortunate isolated incident.

The reason why I took the photos, is that I knew the gross deficiencies in the NDIS culture, capability and processes and anticipated the very difficult time my daughter would have. For me, this was a nightmare I could not save my daughter from.

There would be perhaps no other NDIS applicant or family who would have the insight at the beginning of their journey to make such documentary recordings from the outset.

NDIA LOST THE APPLICATION AND ALL THE MEDICAL RECORDS

The NDIA lost my daughter's NDIS application - including the 400+ pages lever arch folder of medical evidence. My daughter's application was refused on 2 March 2018.

We engaged solicitors to assist us with seeking a Review of the NDIS refusal and this Review process started in May 2018.

In addition to the photos we took at lodgement, we have maintained a detailed chronology and analysis of the various interactions with the NDIS. This chronology shows that on TWELVE times, information was provided/re-sent/re-requested. The NDIS admits to not having all the documents, and inconsistencies on the part of the NDIS as to what they had and when they received it.

In total, more than 30 medical reports and assessments have been provided to the NDIA over the past 22 months as part of a seemingly never-ending process of application and review, describing in extensive detail, the diagnoses and impacts of my daughter's long-standing, complex, significant and permanent psychosocial disability.

My daughter's treating psychiatrist has provided three written statements specifically addressing the NDIS; and my daughter's general practitioner has provided two written statements specifically addressing the NDIS. In addition there are five psychologists' reports including a detailed clinical assessment and needs based assessment addressing the NDIS criteria. There are five letters from sleep disorder specialists, and detailed reports from bariatric surgeons, dieticians and eating disorder specialists including an eating disorder psychiatrist. All this is in addition to the almost 20 years of medical history provided.

Yet again, in August (2019) as part of the Review process, which was initiated in May 2018, the NDIA requested the same information which had already been provided in 30 medical reports and assessments. In response to the further information requested by the NDIA in August (2019) as part of the Review process, we provided a further two large lever arch folders of documents, including re-submitting yet again the (lost) 400-page lever arch folder of the original NDIS application (from 6 December 2017).

Of great concern, my daughter's condition and her function has significantly worsened over the almost two years since the original NDIS application was made – across all her health, functioning and social dimensions. My daughter's worsening situation has been documented in statements by her treating psychiatrist, psychologist, eating disorder specialist and sleep disorder specialist. The NDIA was informed on multiple occasions of my daughter's significantly worsening situation, with no response.

My daughter herself, has made two detailed personal statements of her very complex situation and ongoing needs, and the impairment and impact of her disability, against the NDIS Act Section 24 and multiple sub-sections. The first of my daughter's personal statements was made in support of her original NDIS application of 6 December 2017. The second of my daughter's personal statements was made in support of the Request for Review of 3 May 2018.

PSYCHOSOCIAL "PATHWAY"

The NDIS does not have the culture nor the capability to manage the psychosocial caseload. The complex needs and circumstances of people with psychosocial disability are being processed and examined by NDIS staff who have no experience or professional background in this area.

Our family experience and evidence is that over a protracted period of time, the NDIS psychosocial support team and NDIS psychosocial pathway processes - simply do not exist.

Various statements in public documents on the NDIS website, in the media and in public forums - regarding the improved psychosocial “pathway” - is utterly false. If there was any truth to the statement that there was an improved psychosocial pathway, then my daughter would not have suffered this damaging and traumatic experience over a protracted period of time.

NDIS SYSTEMS AND PROCESSES

From my detailed knowledge of the NDIA systems, processes and culture - and our lived experience - my daughter's experience is not isolated, by the evidence, it is protracted and systemic.

There are very serious questions to be asked about why detailed and highly sensitive medical and personal documents and records are repeatedly lost. There are further questions about the control framework and application of standards for the protection of health information.

These documents and records - covering the most sensitive personal and family information - are far more sensitive than the medical records held by My Health Record.

From the dozens of emails and interactions we have had over a protracted period of time, a great many people in the NDIS had their hands on my daughter's documents and are responsible for losing the documents.

The NDIS ICT systems are deficient in the capability to manage, workflow and protect personal and medical documents. The surrounding processes exacerbate this deficiency, and this has been our own direct experience. This would not be the case if there were a robust document management and workflow system in place.

As stated above, there would be perhaps no other NDIS applicant or family who would have the insight at the beginning of their journey to make such documentary recordings from the outset.

With my knowledge, and given the high turnover of senior staff, I believe that there would be no-one in the NDIA with an end-to-end knowledge of the systems and processes.

Furthermore, none of the systems and processes are accessible. To the contrary, it is not possible to navigate the NDIS without substantial professional and expert assistance. This makes the NDIS manifestly unjust.

None of the NDIS systems or processes have been co-designed. There is a lack of design, a lack of accessibility standards and no functionality in the catalogue, one of the most essential and relied upon elements of the NDIS. The catalogue urgently requires complete redesign, re-engineering and to be built as a functioning element of services infrastructure.

The systems have no intelligence. The website and key concepts are not able to be navigated and understood without assistance. Letters are produced without mandatory fields such as dates and names, and envelopes are manually hand addressed.

It is my combined lived experience and professional view, that the NDIS requires complete re-engineering, shaped by comprehensive and on-going co-design. The issues are far-reaching and systemic and not something that can be sorted with ICT “fixes”.

I anticipated the trauma that my daughter would face and that’s why I took photos at the beginning of this nightmare journey - and yet with all my detailed internal knowledge and ability to engage solicitors - I could not prevent the damaging impact of my daughter interaction with the NDIS.

PERSONAL STATEMENT OF MY DAUGHTER

My Daughter has prepared a personal statement and this is provided with this submission. This personal statement outlines the profound impact of the NDIS processes and delay on my daughter and her family life.

SUMMARY

On 24 September, our solicitors submitted the documents requested (again) for the review - two very large lever arch folders including the 400+ pages of the original NDIS application and a second folder with an additional several hundred pages. Approximately 600 pages in total.

Shortly after, on 14 October, my daughter received a letter from the NDIA setting aside the previous decision that she was ineligible and granting her access to the NDIS.

In the literally dozens of interactions with the NDIA over the past two years, my daughter significantly worsening condition has been highlighted many times in letters from many specialist doctors and appeals from myself, requesting that my daughter initial application and then decision review be expedited. This whole process has been catastrophic and sickening. my daughter personal statement describes this impact on her.

Once again, with my internal knowledge I am now readying and supporting my daughter for the chaotic processes ahead.

No one can say to us “sorry” – that this was an unfortunate and rare instance – I know too much and have seen too much internally. I knew this would happen and that is why at the outset, I took photos and documented in substantial detail, my daughter interaction with the NDIS.

We do not want nor expect an apology.

My daughter requests a statement on how and where her sensitive medical and personal information is being stored and protected.

My daughter wants to be heard and to be treated with dignity. In making her statement available, my daughter hopes that her experience will be taken into account in the review and reform of the NDIS, so that others do not suffer and can be supported to live full and dignified lives.

In support of my daughter and her sons for their futures, I will remain an active advocate for the reform of the NDIS.

Yours sincerely

Mrs Marie Johnson on behalf of my daughter and our family

My daughter's PERSONAL STATEMENT

To the Relevant NDIA Officer

Here is an updated statement that I have written, with support, on how the extreme stress of the NDIS process that I have encountered, has significantly worsened my mental health. In particular, the two years that it has been since I lodged my application, the mishandling and maladministration of my file, has left myself and my family, without greatly needed funded supports for two years. This has resulted in severe stress on my husband, who in addition to working full time, is also now my full time carer and carer of the family; and ongoing hardship as we have had to forgo essential services altogether, which has resulted in a substandard way of living. It has also been an extreme source of stress for my mother, who as my advocate has handled the last two years of the process for me and put in hundreds of hours of support in different forms, in addition to the many other commitments that she has in her own life. And now we have had to engage lawyers over many hours to try and force a final decision.

This has been far from a simple and straightforward process that anybody could access, despite their individual circumstances. The amount of complex information on the website is utterly overwhelming. In my case, my disabilities impact my ability to read and comprehend information. I struggled for two years getting together the extensive information and medical evidence required to support my NDIS application – and for this incredibly sensitive information to be lost, disregarded and not considered has caused me extreme mental distress and suffering.

It has been so horrendous that myself, and my psychiatrist, have questioned whether it was worth proceeding due to the severe stress and anxiety, and the implications on my life of the worsening of my mental health. Many of my documents have been lost or not replied to and during the whole process I have felt bullied and like they were doing everything in their power to knock back my very meritable application. This situation is all about me, but for your information, I have also had significant issues with my son's NDIS renewal plan. I wonder whether there are entrenched issues across the system.

Finding out that filling in the form was not enough - as an example, my psychiatrist was asked to fill in this "simple" form three times - and at the start of 2016 I started a year long project of collecting 20 years of supporting documents from all over the country. Not only was this process extremely labour intensive, I often had to go through wormholes to try and find long lost documents and records, submit an FOI and there was also costs involved. But the worst thing about doing this, was that it was extremely distressing. My illnesses have had different symptoms at different points in time, but at different stages I have been very, very unwell. The result of this was about an almost 400 page folder, neatly organised and tabbed.

So, following what was on the NDIA website about submitting applications, and that I could hand my application in over the counter at one of the offices, my mother and I, folder in hand, presented at the Braddon office. I was expecting that it would be a warm and welcoming office with warm, welcoming, understanding and accepting front counter officers. I was expecting that maybe, because of the nature of the information, that I would be taken into an office so I felt comfortable in handing over and explaining my application and answering any questions the officer had. That before this happened there might be a few applicants and a ticket system. This whole system was for people like me, wasn't it? Downtrodden people like me? Who in the health system had continually been put down, over and over and over again, disregarded and swatted away, because there was something wrong with us personally and that we had no problems, that our case was too hard, that as we had a mental illness, our brains did not operate at all and we were assumed to have no capacity to make decisions on our own? The effect of this is that consumers doubt themselves, their self-esteem plummeting.

None of this happened. As we entered the office, it did not seem to be set up to receive applications at all. It was very clinical. We approached the front office and a lady came over. She saw the size of the application and immediately started questioning that it was not in the right format. She immediately began flicking through my folder and talking about its contents, in front of everyone else, breaching my rights to privacy, confidentiality and my human right to pass over information in a way that I could. Then she started questioning the mode of application. It's too big to be given here. It won't get through the scanner. It can't be sent by registered post. That we would have to go to another office. Then she started ripping out pieces of my folder. Need this. Don't need the rest. I became very distraught and started crying, because this folder had taken me two years to compile and there was a reason everything was included beyond the couple of front pages she ripped out.

I tried to include the information that I thought the NDIA needed and it was evidence. The way I was being treated especially stung, because yet again the way that I had been treated consistently through my life was happening yet again. I felt embarrassed and wanted to hide. It felt like she was judging me Mum sat me down with water and a tissue and had a discussion with the lady. She asked the lady to stamp and sign the pages she had taken out and mum took photos of these. This turned out to be critical in our case. I am not sure what happened with my folder after that. Between emails involving myself, my mum and our solicitors, it became very clear that this folder was gone.

As an aside, I am really worried that, in Canberra being a small city with a high percentage of public servants, and my previous public service employment myself, and the clear mishandling

and maladministration of my file, that someone I know may have had access to my extremely personal and sensitive information and I feel embarrassed.

My Current Situation

Now my weekday starts at 7.30. I take my medications (my husband reminds me), have a bowl of cereal and go back to bed, sitting there taking an hour to wake up, no energy to help the kids get ready in the morning, no energy to have a shower, often wearing the same clothes I have during the past one or two nights and day. I occasionally go to a cheap hairdresser here and there so that they can wash my hair, I have no energy to do this on my own.

I usually sleep for maybe another two to five hours during the day, too tired to even read a magazine or watch a show. I eat a lot of food, mostly high carbohydrate, high sugar high fat foods and am very obese. Obviously there are phone calls to make and emails to write, and medical appointments to attend to, and children's shows. I try and spread these over the weeks. I rarely catch up with friends as I am anxious and as a result I am isolated. When the children come home, I try and save my energy to spend time with them in the afternoon, maybe a quiet game and read to them at night. They are always smothered with kisses and cuddles and I chat with them all the time and take interest in what they are doing. They are 7 and 11 and try and do things for themselves and help out at home, but I do not want them to be burdened with looking after mummy through doing chores etc. Despite everything else going on, I am an excellent mother.

When my husband comes home, he puts on an easy oven dinner, helps with the children's homework (one is dyslexic and the other has ongoing hearing and speech issues), makes them lunch and gets their bags and uniforms ready for the next day and does any ironing. If I have enough energy, I try to eat dinner with them and watch a show. On the weekend he and/or my children do basic chores - rubbish, wash clothes, clean dinner plates. We do quiet things - visit family, watch a video at home. I am still extremely fatigued. These are my current symptoms, but the nature of my illnesses is that different ones will wax and wane and new, severe ones take their place.

Transport

I would like to highlight the issue of travel separately as it severely affects my life and that of my family's. There are and have been times when I have been severely unwell and not safe enough to drive - in one instance for 18 months. This seriously compounds other issues that my husband and I face on a daily basis, such as transporting himself to and from work, transporting the children to and from school and ensuring that I attend vital medical appointments. This means that my husband sometimes has to work from home, which is not really possible with the type of work he does, or my elderly family members are asked to help out at short notice. It also means that I am isolated in not being able to leave the house to do shopping and contribute to the running of the household or meet a friend. From where I live, buses come infrequently and I need to catch at least two buses to go anywhere. In terms of the school run, catching buses takes 3.5 hours out of my day, which I am not well enough to do. Another option is taxis, but they are too expensive and before and after school care is prohibitively expensive and there is a waiting list.

I am unlikely to ever work or study again. I have tried two different services, CASP and Flourish, but these services operate on the basis that you share the work with the support worker, and I am not well enough to do this. I need someone to do the different things I need for me. Furthermore, the amount of support that you can access through these services is only a few hours each. I need someone who can take as long as needed to meet my needs.

Date: 13 September 2019

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