Submission
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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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Submission to the Inquiry into the implementation of the National Disability Insurance Scheme (NDIS) and the provision of disability services in NSW

NSW Parliament

To whom it may concern,

Paragraph 1 – Introduction – brief description of yourself and your situation (or your family/friend if you are writing on behalf of someone else).
I am 31 years old and both my parents have intellectual disabilities. I have mental health problems and a mild learning disability, but I am currently studying at a tertiary level and I work part time. However, my main occupation my whole adult life has been as a carer for parents. This has been a rollercoaster and has always been difficult at times. Sadly, the last four or five years of my life have been particularly nightmarish.

Approximately 18 months ago my mother passed away from Motor Neurone Disease and dementia at 60, after having entered a nursing home two years earlier at 58. I continue to care for my father. In around March 2017, when I was still deeply traumatised by grief and busy with estate matters, we were informed my father was eligible for the NDIS. Since then I have been thrown in the deep end of "support coordination," trying to navigate a maze of incomplete plans and missing information. I have had to deal with 4 LACs in 2 years, and my own mental health and education has suffered.

I did consider seeking help from the NDIS myself, but I was told that I would need to collect as much information and put as much effort into organising it as my Dad. After not having the space to process my grief, and being exhausted by my father's plan, I was simply not mentally and emotionally capable of seeking an NDIS plan myself.

<u>Here are some things that happened:</u>

My Mum

- When we got the diagnosis the hospital staff told me she would need to be fed 6 times a day, and need wheelchair access to the bathroom and bedroom. It also made her more impulsive, and she had to be put on 24 hour watch because she was trying to break out of the hospital. I realised I could not take care of her in our house so I was charged with finding her a nursing home. It was a horrible and difficult thing to have to do. My hands were shaking, and I wasn't eating or sleeping properly.

- I really didn't understand how the system worked. There was no "How to" guide. There was no hand out or factsheet about our rights. I was not given information about the aged care complaints system. I was just being asked for money. Banks and governments wouldn't give me anything unless I had some paperwork with things like power of attorney. It was extremely difficult and stressful.
- When I found one, everyone around me was 80 or more, and my mother was a sprightly young woman under 60. It was frightening and distressing. It was even more so when I found that if she needed to go to the bathroom she had to scream and wail because she couldn't speak. I would find bruises on her that could not be explained. They would not tell me or log any of them if I wasn't there. There was a low staff to patient ratio (3 nurses at night to 30 or 40 patients when patients critically needed help- when my mother would fall). They provided defective wheelchairs with broken brakes.
- The organisation called were paid to assist me to understand the system with regards to both my mum and dad. They helped me to look after my own mental health as well. The worker there gave me goals and helped me to manage my life.

My dad

- When I was still grieving my mother, I received a letter in the mail telling me that my father was eligible for the NDIS. I had no idea what had happened. I felt taken completely by surprise and violated. There was no warning from ADAC that they were going to send all my Dad's information to the NDIS, and that I would be the support coordinator.
- I went to a meeting in Bankstown. I was not feeling well at the time, and nobody explained to me what was going on. Nobody in the Inner West had any information about the NDIS at the time. I did not know that the meeting I went to was a planning meeting. Nobody told me.
  - A planner showed a total lack of understanding of my Dad's disability, and appeared to assess him based on first impressions. This is totally unacceptable for people with neurological and intellectual disabilities.
    - For example, my father is not capable of taking public transport alone or navigating outside of his own neighbourhood. He will become confused and disoriented and anxious. The planner said to me "If he can walk, doesn't that mean he can go places by himself?"
- 6-8 months later, I got a letter saying that my dad had been approved for the NDIS and was going to receive only enough to meet half of his goals.
- Next there was an "unscheduled review." That was enormously stressful.
  - We had asked for a respite carer to accompany him to Dubbo to visit my Aunt on occasion. They explained that "We are not funding transport" and "We

can’t use the word respite”. But this was my father’s goal. This left neither of us with any choice or control. We are trapped.

    - Then they asked me to front up with piles of evidence. My father had no paperwork to substantiate his claims, and the NDIS was reluctant to give him more funding as a result.
        - They said they needed more “information pertaining to the person,” and confined themselves to other generalisations. That was all. They did not explain what “information pertaining to the person” and such things meant.
        - Not even the health professionals I needed to get the information from understood the NDIS. They had not had any formal support from their associations or their groups, and the NDIS hadn’t worked with them. They felt lost and out of the loop. I didn’t know what to say to them either because the NDIS didn’t explain it to me.
- Over the past 2 years I have continued to struggle.
    - I have not ever had the appropriate information to be a support coordinator
    - It was a nightmarish time. I was still administering my mother’s estate and cleaning out her belongings trying to grieve, and continuing to be my father’s only caregiver. To this day I feel that I have not had the time or space to grieve as a result of this
    - I have had 4 LACs in total, over 24 months. At least the last 3 told me who they were. I didn’t get a chance to develop a relationship with them making it hard to work together with them.
    - The NDIS is still convinced my dad understands the finer points of his plan. He does not understand almost any of it, and I have become his go-to explainer and advocate on all matters.
    - Despite the strain on my mental health, I try to avoid seeing my psychologist more than once a month. Even combined, Medicare and Carers NSW do not fund sufficient counselling for me.
- The most important thing that made a difference to me was the help of outside organisations.
    - elped me with the support coordination. They explained to me what words to use, and how it should be written. They counselled me because I was a carer and didn’t know the system. They organised funding for the psychometric testing, which was a serious concern, because I survive on the carer payment.
    - However, now have gone silent and stopped talking to me. They seem to have disappeared. I felt like they had gone when I needed them the most. I think this is because I am not eligible for the NDIS.
    - Family Advocacy also assisted me to understand the particulars of the NDIS and break down the information so it was easier for me to make sense of it. It was a constant struggle and the advocacy group had constant calls from me. They helped me to understand the plan and work out what to specifically provide.

  - A carers group for people with intellectual and neurological disabilities enabled me to get help. They suggested I allocate for transport and respite, but just word it differently. They gave me thoughts and considerations I would not have considered previously.

<u>What this means:</u>

- Currently persons with complex care needs do struggle to deal with the NDIS. NDIS staff assess them on the basis of simplistic and formulaic rules, or first impressions.
- Close coordination and cooperation between various health professional associations and the NDIS should be a priority. The professionals need to be a part of making it work, and they need to know it inside out.
- We need a dedicated ombudsman or agency to assist persons with disabilities in aged care and those responsible for them.
- Carers of persons in going into nursing homes should have access to an advocate as soon as the hospital tells them this is necessary, as well as fact sheets and clear guides.
- All persons under 65 at risk of going into nursing homes should be made priorities for urgent NDIS care plans to avoid situations like my mother's.
- Carers should be included in all decisions to do with disabilities, from the top levels of government down to the finest points of NDIS plans.
- The mental health and long term lifestyle of carers needs to be considered, because there is not enough funding and support.
- There needs to be tighter regulations on pricing. The obscene amounts charged by support people and providers rip off carers and people with disabilities. This exhausts plans quickly. I have heard similar stories from members of my carer group.
- Ask permission to make someone a support coordinator. Don't assume.
- Give proper information to people on how to navigate the NDIS, including examples of what information needs to be collected.
- Persons with intellectual disabilities desperately need a consistent relationship. LACs must be kept consistent.
- Advocacy organisations like Family Advocacy are absolutely crucial to making the NDIS work and keeping carers from falling apart. They must be fully funded or the NDIS cannot operate efficiently. The NDIA should keep a strong relationship with advocacy organisations and make use of their experience and skills. These must be funded by the government no matter what happens to the NDIS. Without advocates so many of us will fall through the cracks.
- Clearly organised and sufficiently funded services need to be provided to those who are not eligible for the NDIS.
- Mental health services need to be better funded. The current system does not allow for sufficient mental health treatment.

Sincerely,