

Submission
No 231

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

Name: Mrs Kristy Brennen

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Dear Sir/Madam

I am a support coordinator that works for a not for profit provider that services south western, south eastern and Sydney metropolitan regions. I have been a support coordinator for approximately 18 months and before this worked in the NDIS LAC program in south western Sydney. Prior to the full NDIS roll out I worked for another not for profit in the Hawksbury/ Nepean trail area both during the trial period and before under the old ADHC funding models.

I have assisted many people to navigate the mine field that is the NDIS and I have seen some very limited successes, but more importantly I have seen some terrible outcomes for families, communities and the services also in these areas and since the roll out.

I have seen first hand the issues with service provision across all areas and all age groups covered by the NDIS. I have seen massive issues for the implementation of the NDIS in New South Wales. I have seen some families having to surrender children into the care of Family and Community services who did so with such heavy hearts and with the understanding that this is the best way that they could get the funding they required to try and live a life that had some meaning. I have seen marriages breakdown due to the stress and pressure placed on them by a system under pressure and by services that are understaffed and unable to keep up with the demand for qualified staff. I have seen children placed into group homes with the hope that they will be looked after by responsible services with the best intentions of the client in mind. I have seen truly heartbreaking instances of people being let down by the implementation of the NDIS and promises that were made and never kept.

I would like to explore the following points of reference for this submission in the hope that I can outline more of these issues and the experiences of people with disabilities, carers, service providers in New South Wales with the implementation of the NDIS.

The NDIS Roll out across Sydney was met with excitement about the change and the possibilities that it was promising. It did not take long for this excitement to turn around. With the trial areas we quickly ran into issues around staff costing and promises not being met by the NDIS, for example that clients in the first year would be no worse off from the funding changing from ADHC to the NDIS. I found in many cases this was simply not the case many families ended up in a much worse situation often requiring several long and lengthy appeals to the NDIS for reviews and to even take this higher through the appeals process. I remember a family in the Hawksbury area who have 2 children who are severely disabled and require 24 hour per day care. They are tube fed and often require suctioning. I remember that this family went through 5 plan reviews per child to even get close to the level of service that they require. After the 5th review they were informed that if they attempted to apply for another their funding would be cut. This was told to them by an NDIS planner in their region.

There are also issues with staff and costings around staff with the NDIS providing \$49.63 per hour under the current price guide but to get decent staff and retain them most need around the \$25 per hour - \$30 per hour to be able to support their families. This leaves approximately \$19.63 per hour to cover superannuation, insurances, administration and training and development which is just not possible. In the south west we have lost approximately 20 services since the roll out of the NDIS. This means in some areas there has now been a monopoly of service to just 3 or 4 different services

meaning there is little to no choice and control for participants. This has also meant that in some areas participants are waiting for up to 9 months to get support (especially allied health supports) and then their NDIS plans are being cut as they haven't used the funds, further limiting the choice that participants get.

When I was working as an LAC we were actually informed to try and limit the amount of funding that we were applying for if we thought the family had enough or was maybe over funded we had to cut the plan hours. If they were a person under the age of 18 that most of the care should be done by the parent regardless of circumstance. This meant parents with multiple children, sometimes multiple disabilities that required 24 hour care and support that this had to be majority done by the parents, most of these parents had to work to support these children also. This was the case with some of the children I have had the pleasure of trying to help and the families I have gotten to know. I had families where both parents worked and one had to give up working, they had to sell their house or consider handing their child over to FACS as they couldn't cover the care needed and the family expenses. It's a terrible decision to make to have to choose between family expenses or having to give up your child.

There is also issues with no emergency support for example if a clients primary care giver suddenly ends up in hospital or even dies its taking NDIS up to 6 months to make a decision about what should happen to that client in the mean time they are shifted from pillar to post, with assurances given by the NDIS that bills and support will be paid often this is just a verbal offer as NDIS often do not put this in writing services all over the state have been stung by this meaning that they are now less likely to actually assist the person with the disability in crisis. I have been told by the NDIS that in their eyes there is no such thing as a crisis situation. I had a client whose mother passed away suddenly and he required constant support, he was legally blind and couldn't do anything for himself, he was left in limbo at a respite house for 4 almost 5 months before the NDIS decided that he could move home by himself even though he needs 24 hours a day support. This client has repeatedly been a strain on the health system since due to him not being able to look after himself and ending up in hospital. It took several review attempts and a plan over the phone to now is at the stage where he now has received a transitional plan to now get him the support that he needs. This took from October last year 2017 until June this year 2018.

The education of the other government funded supports has also not been up to where it needs to be to best support a successful roll out of the NDIS across Sydney and the state of New South Wales. For example I have found time and time again that there is little to no knowledge of the NDIS and what is covered by this in the most important areas including health and education. I have had school transition officers not know what the NDIS will fund nor how to ask for the funding in such a way and with what supporting documents that ensure that the participant gets the support that is required. I have had social workers from the hospital believe that support coordinators like myself are able to perform tasks of case management when we are a capacity building support and are unable to provide this sort of assistance. This also reflects back to the NDIS itself in not understanding how things like the Medicare health plans work and that these sessions with allied health are not free but incur a gap fee sometimes into the hundreds of dollars that these families would not have had to access if it wasn't for the Participants disability. The amount of times that something has been explained as the "Responsibility of health" or the "responsibility of education" when neither of these know that this is the responsibility of them or they are not funded for these

things either causing more stress for the families who are just trying to get support for their loved ones.

People with complex care in my experience this is a massive issue and many people who fall into this category but are not under the care of a support coordinator end up never getting the assistance that they require in this area and therefore their plans are never properly in acted. There is an overwhelming lack of understanding of disabilities among the NDIS planner and LAC program causing them to not understand what level of care these participants require. This was no more evident for me when I met with a planner who asked my client who has a diagnosis of Downs syndrome; how they caught it? How long they have had it? And if it could be cured? This was a deflating and demeaning experience for a high functioning member of the community. For those who have severe and complex mental health issues that have NDIS supports they are often never able to fully utilise their plans and never receive the support that they require, this is especially true of those who need assistance to increase supports or who have not been given the correct supports in the first place and then need to review.

The Local Area Coordinator is supposed to provide 13 hours of support on average to each client who they do the planning for. I am yet to meet a single client or LAC who stated that they either received or supported someone for this length of time. There are many NDIS participants that are too scared to even attempt to do a review as they have heard along the grape vine that if they attempt to do this they will loose more funding. The more complex the clients the more likely without a support coordinator will they are able to never effectively use their plan.

Privatising government services, in my experiences all this has done is created a monopoly of services with one service in particular having taken over a large majority of group homes in south western Sydney, now know that they can pressure families into accepting anything they give them including sidelining funds that are not for them/ the family would like to use a different service, demanding information of a personal nature that is normally protected under the NDIS guidelines and then if families refuse they can be threatened with being evicted from these homes. This has happened across most of the privatised previously government disability services. This move to privatise has removed the accountability and has been a great hindrance to transparency. There is another organisation that has now simply gotten too big and has cornered the market on allied health supports since they changed over from being an ADHC department. This means that in some areas of Sydney they are your only choice for a provider as they are the only ones with capacity to take on new NDIS clients.

The NDIS could be a great thing for those with a disability if these issues are being resolved and there is the opportunity for growth and development of new services and better working and pay conditions for staff. There also needs to be better education for families, staff, ndis personnel and people with the disability.

Without a change the system will fail and people with disabilities will continue to suffer, families continue to breakdown, suicides will occur, people will continue to die waiting for supports.

Thankyou
Sincerely

Kristy Brennen
Support coordinator

