Submission
No 184

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

Name: Name suppressed

Date Received: 8 August 2018

Dear Sir/Madam,

I write to you in my capacity as a mother, wife, and carer. My husband and two of my three children have disabilities. I am the sole carer for them all.

I would like to detail for you my family's experience of accessing disability services in NSW.

My husband has a number of autoimmune conditions and degenerative conditions which impact his mobility, my 6 year old son is Autistic with severe anxiety and behavioural challenges, and my youngest son has very complex needs.

Our experience in accessing disability supports through the NDIS over the last year has been varied. I will detail them for you in five sections:

1. My 6 year old son's access as a person with existing state services

2. My husband's attempt to access supports as a person with no previous disability supports

3. My experience navigating access to disability supports for my 14 month old son with very complex needs and no existing supports as he was not born before ADHC services were ceased and responsibility transferred to NDIS. The overall impact the shortcomings in provision of disability services have had on our family including timely access to early intervention supports, carer fatigue and exponential increase in administrative work required of carers, as well as the lack of flexibility in the system to adequately address the needs of families where there are multiple people with disabilities relying on the same carer. The lack of coordinated support for people navigating services through the disability, health and childcare sectors.

1. My 6 year old son (H) has been accessing state funded supports since his diagnosis with Autism (level 3) at the age of 22 months. He has had access to HCWA funding, block funding through organisations such as Mission Australia, Lifestart and Interchange Illawarra. On top of this we have self-funded significant amounts of intensive early intervention therapy to meet his needs in the critical early intervention window of neuroplasticity. Pleasingly he has shown amazing gains in capacity over this time.
The rollout of NDIS in the Illawarra region was due to begin in July 2017. In the lead up to this we prepared ourselves as best we could to apply for NDIS supports to meet his needs and build his capacity to live an independent life. After confirming our access eligibility early

in 2017, we were told that we would have a planning meeting within a few weeks. As there was no ECEI partner appointed for our region before the start of the rollout, we did not have a planning meeting until October 2017- 10 months later- not the 4 weeks we were originally advised. Despite a detailed planning meeting with our LAC with information provided about the existing services my son had been accessing for the preceding 3 years, when his plan was finally approved- in April 2018- a very long six months after our planning meeting, and 16 months after initial contact form NDIS. The approved plan does not meet his needs at all. It has reduced substantially his previous supports and removed some of them completely. He is no longer able to access the community with a support worker to increase his independence and ability to participate in group activities as his plan does not include any funding at all for this. We rarely are able to leave the house with him as he requires 2:1 support for his own safety and that of others due to extremely unpredictable behaviour and flight risk. He also has no funding for assistive technology he needs. The providers he has worked with previously are no longer able to continue with his therapy as due to the changing landscape of the disability sector, they have seen it as more profitable to apply for NDIS contracts as ECEI partners. This has resulted in us needing to find new therapy teams, many I have contacted have long waiting lists. There is no choice and control if PWD's are limited by availability of suitable providers.

2. My husband (D) has a number of conditions which result in physical disability and limited mobility. His functional capacity is reduced due to this, and he needs to access regular therapy as well as assistive technology to maintain his ability to work and support our family, as well as to maintain movement in his joints as they degenerate. All medical and surgical options have been exhausted. The impact if he is not able to access adequate supports will be substantial as he is the sole income earner for our family. His application for NDIS access was declined. The burden of providing more evidence is exhausting and expensive with no guarantee of access to support.

3. My now 14 month old son (K) has a congenital undiagnosed genetic condition with complex care needs.
His condition results in him being permanently fed through a PEG and connected to a feeding pump 24 hours a day. He takes regular medication in an attempt to control his epilepsy. He has CVI (Cortical vision impairment) which is a neurologically driven type of vision impairment. He has Hypotonia which means he is unable to hold his body up due to low muscle tone. He has a severe global developmental delay. He also has severe reflux causing his to aspirate. . He requires 24/7 nursing care- 1:1 care at all times, equipment to position him safely in bed as well as to support him correctly in a sitting and standing position, to safely transport him and bathe him. He also requires many hours of early intervention therapy to give him the best possible chance of independent movement.

K's disability became clearly apparent when he was 4 months old, and it was at this time in October 2017 that I made initial contact with NDIS regarding an access request. I was referred to our local ECEI partner who told me that while K was eligible for NDIS, he would not be able to have a planning meeting until all the participants with existing services had had their planning meetings (as per COAG agreement) We were advised to contact ADHC

which I did, only to be told that Better Start funding had been shut down (K would have been eligible for this for his Vision impairment alone) and there were no services available through ADHC, it was the responsibility of the NDIS to provide supports for K.
Given his young age, and profound disability, surely it is not reasonable to expect a child to go without supports for the first few years of his life!
I made contact with the Federal Minister for Disability (Christian Porter at this time) as well as our State MLA (Lee Evans) and Federal MP (Sharon Bird) to request assistance to access supports for our son in a timely manner. After waiting for access we were finally contacted in December 2017 by an NDIA representative after a Ministerial Directive to give K access to NDIS immediately. A planning meeting was arranged in December 2017 with our LAC, however despite what we thought was a good understanding of K's needs by our LAC, we did not receive an approved plan until April 2018-6 months after initial contact.
This meant that for 6 months we had no access to any supports or equipment to meet our child's needs. Now, another 4 months later we still do not have services or equipment to meet his needs as the NDIA planner put together a plan that does not at all suit his requirements or allow for the highly specialised paediatric mobility equipment he needs.

He has been confined to his bed for up to 23 hours a day for the first 14 months of his life as we have been unable to get him access to this equipment to meet his basic human rights.

We were unable to access the supports he needed through the Health system as due to a number of factors, he did not meet the bureaucratic criteria to access appropriate outpatient allied health services or equipment loan pools. Instead of the health and disability sectors working together to meet his needs, we were left in the middle with no services at all.
Due to his complex needs we are not able to access childcare except In Home Care. Even then, our educators are not allowed to attend to his nursing needs requiring me to be present at all times and available to do this. I am not able to leave our home or attend to the needs of our other two children, let alone my own basic needs such as eating, sleeping and showering.

The multiple disabilities affecting 3 members of our family have exponentially increased the demand on me as a mother, wife and carer. The intersecting needs of my husband and two sons have meant that for the last year, I have been unable to sleep for more than a couple of hours a day due to our 14 month old's needs. Most days I have to choose between sleep, showering or eating as there is not enough time to attend to all of my own basic needs due to their needs. There is no choice in this if our son is to remain safe. Our eight year old daughter suffers considerably as she is often on the receiving end of her brother's aggression, or misses out on the care she needs. We are unable to leave our home as a family of five without extra assistance. My husband is not physically able to attend to our younger son's needs, he is also unable to maintain our 6 year old's safety due to his physical impairment.

Usual household tasks which are usually shared between family members all fall to me as due to my husband’s disabilities her is unable to do them, on top of this attempting to provide nursing care for our youngest child 24/7, care for our 6 year old and manage his behaviour and access to therapy for his Autism, as well as be a mother to our daughter. It must be remembered that she is only 8 years old. She should not be expected to be a carer to both her brothers and her father, yet that is often the situation she finds herself in.
This burden of care is too much for any one person.

Even when we were finally able to access some funds (albeit inadequate) I have had a lot of trouble finding providers who are able to meet his needs due to his age, and complexity. There is no “safety net” for those who fall through the gaps since services have been privatised.
There is no choice and control for PWD in service providers- we are limited by where we live as due to K’s very young age, it is best practice to have his therapy delivered at home. This involves travel time from providers to our home eating into his therapy budget which does not adequately allow for this.

Overall, my experience navigating disability services in NSW has been traumatic, exhausting, and disappointing. I would be happy to provide any more information you may require to assist in this inquiry.

Sincerely,