

**Submission
No 180**

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

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Portfolio Committee No.2- Health and Community Services- NSW Parliament, Legislative Council

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I refer to your Inquiry into the implementation of the National Disability Insurance Scheme (NDIS) and the provision of disability services in New South Wales.

I wish to make a submission as a Carer, and on behalf of my child, a 14 year old with an diagnosed syndrome that encompasses severe intellectual disability, sensory issues and medical issues. I am the child's mother. The child lives at home with 2 older siblings and my husband, the child's father. I sibling is a university student, 1 sibling is in year 11 at school and my husband works full time, while I work as a Registered Nurse in a NSW public hospital 32 hours per week.

I believe an inquiry into the implementation of the NDIS and the provision of disability services within NSW would not be complete without the voice of the Carers of children with disabilities in NSW. I am just one of those carers and can only refer to my own situation but in this close circle of parents of children with disabilities I know there is a level of stress and frustration.

I was a strong supporter of the NDIS prior to its implementation and I remain a strong supporter of it today. I do believe that there are some issues related to its implementation as well as some issues related to remaining NSW disability services. Without exposure of these issues resolution cannot be sought.

I will address each term of reference as it is relevant to myself as a carer or to my child as a participant. I recognise that this is not a platform to solve individual cases, but it through my individual examples that I can demonstrate the NDIS in action.

(a) The NDIS and choice and control for people with a disability.

The NDIS is an excellent concept and in the long run will be of great benefit to all, however its implementation has been rushed and there are many issues, all of which filter down to carers and participants. For example, the planner constructing my child's plan had no experience in disability let alone with children and disability, the information that came from me then went to the planner and was inputted to the data base, in order to build the plan was somewhat misinterpreted or incorrect, so much so that I declined the first plan on the spot knowing that it was severely underfunded. A new appointment with a new planner and a new plan had to be done which is very time consuming- meaning explaining the whole story again from the beginning, more time off work to meet and more stress. It seems we as carers

don't really have control over what data is being inputted. My child has had funding built into the plan from day 1 for assistive technology to purchase software and an iPad (iPad is the device that the child knows how to navigate). We are now more than 18 months into NDIS and I still have not been able to get the NDIA to successfully make the service booking and allow for purchase of these items by the speech pathologist. I heard just two days ago from a NDIA call center person that the planner had incorrectly built the plan which is preventing the system from allowing the speech pathologist to make the service booking. For me to find this out has taken many phone calls, emails, being kept on hold- this all takes more time and more stress. The speech pathologist has also made many phone calls about this. This is not choice and control in action.

At the start of the process I had an NDIA planner, visualise my child and make an assumption that the lowest level of continence aids was what should be provided for....until I stopped this person and explained that the child was actually wearing two incontinence products at once and was fully incontinent day and night. It became clear to me that assumptions were easily made and that I had to look at every fine detail twice to make sure it was captured correctly.

(b) The Experience of people with complex care and support needs in developing, enacting and reviewing NDIS plans.

My child is not able and will never be able to manage an NDIS plan. I or someone else will always be managing it. My child has complex support needs, requiring a mix of, overnight respite care, personal care, therapies, and recreational programs. The process of predicting for a year what the child might need and then gathering all the quotes from in my case, 6 different providers is quite daunting and very time consuming, however I don't mind completing this process if all the documents are reviewed while building the plan for the child. In my case I can say that during the planning process for the current plan, quotes were submitted and justification for why my child had become 1:1 care rather than 1:4 care. It was obvious when I received the plan that these quotes and letters had not been looked and, consequently I will require a plan review prior to this current plan ending. That seems to be a waste of everyone's time when the evidence was produced at the initial planning stage. As a carer the planning and managing the NDIS plan is difficult in terms of time spent. I have a job and a family and now find myself negotiating contracts and reviewing plans, identifying errors, calling hotlines etc. In reality, I spend around 6 hours a week just managing aspects of the plan. I feel grateful that being an experienced nurse I have developed skills in complex care management and advocacy, I feel for those without these skills.

(c) Not relevant to myself or my child

(d) The effectiveness of privatising government- run disability services.

The privatisation of disability services seems to equate to a significant increase in price for the service. For example, my child attended FACS overnight respite service

at around \$550 per night. The respite house is now run by Cerebral Palsy Alliance and care is now between \$860 and \$1200 per night depending on the day of the week. These prices came into play on July 1 this year, unfortunately my child's plan was finalised in February of this year so the plan will have a significant short fall in funding toward the end of it. I am hoping for a quick plan review so as not to have to go without overnight respite services through no fault of ours. Plan review times are extraordinarily long so I'm not hopeful of a smooth process. Supported School Transport is looking at transfer to the NDIS, effectively privatizing the service. This is not a good idea for so many reasons but most importantly the safety of the kids. For many the Supported School Transport driver is a constant in the child's day a point of reference and reassurance. If supported school travel was to move from a state based system to NDIS, the kids could be put into cars or buses with anyone that wants to be a driver, it could become very expensive just as the overnight respite has and it would require parents to negotiate yet another contract for a service that affects them daily and often twice per day. Parents are already overwhelmed with the NDIS process. Transport should remain as a State government service. Given the issues with the implementation of the NDIS, some services should remain with the state government to ensure safety and security of the most vulnerable members of the community.

(e) The provision of support services.

My child is an eligible NDIS participant so all support services are now via the NDIS. For the most part the provision of services has been good, however as mentioned previously, the plan is underfunded in relation to quotes submitted. Consequently, for the last 3 months of the plan, my child will be very limited with support services while I wait in line for a plan review...which is a lengthy process. I have been told as a rule the NDIS will only provide funding for a maximum of 30 nights a year overnight respite. In some cases, this is just far too little. As a child becomes an adolescent and needs to learn to live without the support of family and become independent, 30 nights is inadequate. This really is not giving people choice and control. My child will use each of the 30 nights...we would like more but as mentioned earlier the plan has not been topped up in response to the NDIA price guide for overnight respite. Overnight respite is not a break for the parents, it's a time to teach adolescent children skills to aim to become more independent. 30 nights does not allow for continuity of staff and for children to become familiar with respite house staff and routines. The NSW government needs to be careful not to transfer services to the NDIS too early. The NDIS has inherent problems with inadequate computer systems and under staffing. The cost of transferring a service too early and the NDIS not being ready for the service is too great...it is the safety and wellbeing of children with disabilities and their carers and families.

(f) Not Relevant to my child

(g) Workforce issues impacting on the delivery of disability services

It seems that as the NDIS has been implemented and taken over the services the demand for those services has grown. Some providers are not able to provide the workforce to meet the demand. For example, my child receives support for 3 hours every Monday afternoon. The child's provider was requesting to constantly send a new worker, until I explained that a child needs continuity and familiarity. It defeats the person to have the carer train a new worker constantly. I requested that a small group of familiar carers rotate the shift if needs be rather than new workers coming in all the time.

(h) Challenges facing disability service providers and their sustainability

Not relevant for me to answer

(i) Incidents where inadequate disability supports result in greater strain on other community supports

If adequate disability supports are not in place, the strain and pressure put on carers is enormous. As a parent, I work hard to maintain my employment both for financial and mental health reasons. The constant sorting, asking, managing supports is draining and makes it difficult. If adequate supports are not in place, there is a future of parent burn out, under or unemployment and health issues as we age. These issues will put a strain on financial and health systems eventually. Inadequate Supported School Transport services will lead to a strain on carers as well as teaching staff. The privatisation of school transport services will lead to increased cars/ buses on the roads at school drop off and pick up times. The new NDIS Quality and safeguards Commission has not been in operation long enough to establish a proven track record, and as such the children of NSW need to be guarded by state bodies until the Safeguard Commission proves itself.

(j) Policies, Regulation and Oversight

As mentioned above the newly formed NDIS Quality and Safeguards Commission does not yet have a proven track record so NSW needs to maintain some oversight during the overlapping period. The State disability service funding seems to stop suddenly while it is expected that the NDIS funding for the same service has been implemented but this is not always the case, everyone's plan has a start and stop date that is a random date throughout the year, the start and stop dates are not aligned to start of a calendar year or financial year. It seems a more sensible way to transition the funding would be to slowly withdraw state services and funding as each participant receives the plan and puts it to use. There seems to be little

discussion between state and commonwealth services to ensure smooth transition. For example, School Supported Transport has now declined to transport children between school and respite houses, the respite houses or some other independent operator is to take over this service, however participants don't have the funding for this in their plan as this transfer was not predicted. It seems sensible to transfer the service gradually as each participant receives the funding in their plan rather than leave the participant with no funding for a privatised service.

As carers, of children with disability we don't choose to put our children into overnight care services but we need to. The oversight, policies and regulation of these services is paramount to the safety of the children. I personally would have hoped for a Royal Commission into the alleged abuse of people in out of home care before the transition to privatisation of these services, so that the private operators could build their policies on the recommendations from such a commission.

(k) Other related matters

Once again I would like to say that I am a great supporter of the NDIS and its mantra of choice and control. Choice and Control should not be the aim at the expense of the safety and wellbeing of children with a disability.

The transfer of services from NSW government to NDIS will be excellent in the long run. However, at the moment, for me as a Carer it has meant an enormous workload of management, review, coordination. My husband and I do this on top of caring for a 14-year-old, who can't toilet, feed, dress himself or talk but is very independently mobile. It is overwhelming at times. We are also people who work to pay a mortgage and care for other children.

The NDIS needs to iron out all its issues, including an up to date IT system and adequate staff in terms of numbers and training and until this happens Carers of children with disabilities are going to continue to feel increased pressure. Until this happens I'm not sure that the NDIS should absorb any more NSW government disability services.

I hope that I have been able to demonstrate some of the challenges faced as a result of the implementation of the NDIS and the transfer of NSW Disability Services. I am a carer who can see the potential of the NDIS for my child. I am happy to be part of the solution to the problems. I also urge the NSW government to consider the appropriateness of the transfer of the remaining disability services and the impact of the most vulnerable children with disabilities and their carers.

I thank you for your time and consideration of my submission.

Jo Hovian