

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

**Name:** Name suppressed  
**Date Received:** 29 July 2018

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Partially  
Confidential

29.7.18

Portfolio Committee 2

Dear Members,

I hereunder tender my submission to your inquiry into Privatisation of the State Government Disability Sector.

I am the mother of a 32 year old man with very severe Autism and very challenging behaviours.

I would like my personal information ie contact details to remain private please.

My name and this letter may be posted minus those things stated above.

The purpose of having government and of paying taxes is to devise and operate systems which are for the public good, things which advance our civilisation but things that do not necessarily generate a monetary profit. Things such as Education, Health, Law and Order and care for our vulnerable ie – Departments like ADHC.

Private enterprise does not function at this altruistic level.

Companies devise and operate systems which create monetary wealth for the owners, shareholders and CEOs of that enterprise.

The so called “not for profit” NGOs are in that same basket unfortunately. They are happy to spend funds advertising to generate more funds, they pay executives large amounts of money and they invariably cut spending and tighten belts at the “coal face”. They would never countenance running at a loss.

They are there to make at least some money and any “profits” are used to enhance and expand the company and its top brass.

With the advent of the NDIS, it seems that the state government of NSW saw an opportunity to rid itself of the cumbersome bundle of care for our aging and disabled population. (NGOs have historically cared for a portion, but the state was always a dominant provider.) They have sold them down the creek without a conscience or caring.

Lots of “pretty words” of comfort and reassurance have accompanied this sell out but in reality, for those of us who have family at the very challenging end of the spectrum, these words are just hollow propaganda.

My son has severe Autism and Global Developmental Delay. He is physically like any other young man of 32, rather handsome in fact.

BUT he cannot communicate verbally, he cannot view the world as “normal” people do and his sensory system takes in stimuli in exaggerated ways. He has no understanding of socially acceptable behaviour. His behaviour is odd, annoying, embarrassing and can be fraught with danger for himself. He can also become aggressive when frustrated and therefore dangerous to others. His behaviour is often inexplicable to “us” and he cannot be reasoned with.

ADHC spent many patient years sourcing expert personnel – both behavioural and medical, devising plans and working with my son to give him a reasonable quality of life and some happiness.

Therapists and specialists behavioural teams were all able to communicate and plan seamlessly because they all worked for ADHC. Now these people are often disjointed and everything is charged at an hourly rate (which by the way, for people like my son, is just shy of \$200 per hour.)

Staff with years of experience (and high qualifications) in mental health knew the best medical specialists to get on board as well. (Please don't lose these people through employers that do not value them and their expertise.)

All this assistance was previously not done within a rigid budget constraint, but rather on a needs basis with compassion as the driving force. (In the end, this usually turns out to be the most cost effective way to act in the long term anyway.)

Private Enterprise do not have this mindset. Please don't insult me by trying to cite examples of wonderful, benevolent private providers.

As a general rule – please see my opening paragraphs.

For the really difficult to manage and therefore also highly “costly” people, the NGOs would really much rather they go elsewhere (just where is that NOW ?)... or they try to cut, change, rearrange services which ultimately leads to a breakdown.

Staff working in group homes which are complex should also be paid accordingly.

Someone who cooks meals, chats with, goes on an outing in public or for a coffee and ensures medications are taken should really not be receiving the same pay rate as someone who does all of that **plus** needs to have the skill and experience to deal with people who have extremely challenging, unpredictable behaviours. They actually work in an emotionally draining and potentially dangerous environment. Outings need to be planned almost like a military operation. They deserve a specialist pay rate.

A happy, supported and valued staff makes for a happy and well running workplace which enhances life for the clients.

Since the privatisation of my son's group home I have seen staff morale dip. Things that have been running smoothly for years under ADHC are being changed for no apparent reason rather than to make all houses standardized.

In difficult environments morale needs to be maintained and bolstered, not torn down by bureaucrats who think they know better and who really know nothing at all about the specifics of each individual

home. They don't really want to know because things run more smoothly (for them) when all is mandated from above and it's all uniform.

When are people (I mean ALL people) going to realise that what is good for some or even most people with disability is NOT necessarily good for all?

Disability does not fit into a couple of well filled buckets. Many buckets might contain only a few people or even just ONE. The disabled population is as varied as the general one and if you really want to HELP them the 'good' of anything must be measured against the individual.

I thought NDIS was supposed to give choice and control to the people in its care, but Privatisation takes that all away. The choice and control seems to be dictated from the top down in group homes.

We know that people fall through the cracks but at least ADHC was there to catch them. The ADHC homes in this area had the people that NGOs refused.

No longer will people fall through the cracks because Privatisation is systematically removing the floor for the most difficult cases.

I also worry that it will come to a point where only big providers remain. I have seen that happening here where the original plan was a 5 service conglomerate, Mid North Coast Disability Services. One of these 5 – Ability Options - is a large state wide provider. It now seems the octopus of this largest one is smothering all the others.

My major concern is, that with no state provider for group homes, the people who 'fail' (get 'kicked out of') these private concerns have nowhere to go. Stories about this are emerging already.

Parents are too old – and we won't outlive our children in any case. What is to become of them when there is no one there to fight their case?

Since NDIS/Privatisation, this fight has become a weekly/daily one again – much as before we got our 'hard to manage' children into ADHC care. When that was finally achieved we thought we could at least go to our graves in relative peace because the state would always be there to look after them (ha, ha, ha) – Boy! Were we in for a shock!

My son cannot speak, he cannot look after himself.

He will never have a job, drive a car, have a family (wife and children), go where he wants when he wants, choose to do or not to do many things. He doesn't really understand the world we live in. Who is going to look out for his welfare in a private system?

What is to ultimately become of the state owned properties which were ADHC group homes and institutions?

Families in this area asked this question at the beginning of the takeover and protested any sell off because hope of a return to some NSW Government homes of last resort would be even further out of reach if this happened. Will they all ultimately be sold "under the table" and we won't know until it's a done deal ?

Please, before it is too late, make NSW government retain the care of those people who are lost to the private sector and have nowhere.

Retain places of "last resort" for the most vulnerable and needy in our disabled community.

A few great people throughout history have been attributed with saying words to the effect, "The greatness of a nation can be judged by how it treats its weakest and most vulnerable members." - those being the children, the aged and the incapacitated.

We know that Australia is a great nation. Let us include NSW completely in that by showing we are a State full of greatness too.

Please let us look after our disabled to the BEST of our ability, particularly the most vulnerable of them.

Keep NSW Government as a provider of last resort for those who are cast adrift without any other hope of safe rescue.

Yours Sincerely,