

Submission To The Parliamentary Standing Committee On The NDIS

Good morning I'm Wendy Cuneo, parent of three disabled children, advocate for another gentleman and Vice President of the Stockton Hospital Welfare Association.

We all want the National Disability Insurance scheme to work but there are some flaws that I believe need to be corrected before the full roll-out.

My son has benefited from his plan and it has definitely improved his quality-of-life however there are modifications that need to be addressed.

While the plans for our people at Hunter Residences have been very positive in some cases and negative in others, **unfortunately we have not had the two reviews that should have been done**, due, I suspect to the amount of people in the residences, however this makes it difficult to address any line items that may have been missed or to fix any problems with service providers etc.

We have been told no review will be done until June and this has created some difficulties as some plan's like my son's need additions and corrections.

After a very rocky start I have also had some very positive results for the gentleman whose Advocate I am.

Unfortunately when a plan is developed you then have to choose a service provider to meet the requirements of that plan and there can be many hold-ups in this process **due, for example, to the service provider either moving too slowly or changing case workers frequently so that for some considerable time nothing actually is achieved.**

Part of this problem is caused by carers only being given a 3 month contract and often only getting 25hours a week, this is not enough money to live on.

This scenario was responsible for the waste of practically the whole first year of my Gentlemen's plan, I simply could not get them moving and they were promising him things that were not part of the plan.

Obviously we made a different choice for the second year and things have worked very well for him since then, however the constant change over of staff and the Time taken to implement services is a problem that I and others have experienced, I don't know what the answer is however the problem needs to be addressed.

Many families find the whole process difficult and stressful.

There are many hurdles in creating a plan that covers all aspects of a persons life and **it often depends on how good the planner is in helping families and people with a disability to negotiate and insert all that the person with a disability** requires and many people have complained to me that **it is not easy to get this reviewed before the next scheduled review when things have been omitted all miscalculated.**

An example of this is the estimating of continence aids, many people have run through their allowance as it is almost impossible to estimate the normal requirements, let alone estimating things like gastric attacks or urinary tract infections (a common problem), one woman was told that she should have thought about it more carefully.

After having negotiated the plan many families then find that choosing Service providers for the different line items across the portal can be extremely difficult, some providers only deal with certain firms and this can cause unacceptable waiting times for goods and parts.

Where before a person would require a caseworker now they are called Service support coordinators so even the language you use makes it difficult to include everything the person with a disability requires.

Another problem that Friends have asked me to mention has been due to the fact that the residents in their son or daughter's house who had families to advocate for them get more in their plan than those without families and there is little we can do to correct this situation because due to the privacy regulations and the fact that we are not person responsible for these other residents **so we have no say in correcting this situation which creates a type of class system within the house, it is unfair and needs to be addressed.**

Another problem is that **people with disabilities do not have tenancy rights** and a service provider can and do remove a person they consider difficult from one residence to another without risk assessments or compatibility assessments being done, causing upheaval in the houses concerned and damage both emotional and mental to the life of the person with a disability.

I speak with experience about this, as my daughter has been the victim of just such a situation where she has been moved three times in three months, her behaviour management plan was ignored and she has only had those belongings that are essential with her, the damage this has caused is extensive.

The shortage of beds should not be an excuse to avoid doing proper assessments before making decisions about to where the person with a disability should live or who with, we need to come up with a much better System that protects both the person being rehoused and the impact it will have on other residents in the houses.

Previously risk assessments, compatibility assessments and allocation of caseworkers was done by trained workers from the Department of disability ageing and home care, if you intend to disband that department then some arrangement should be made for someone other than the service provider involved to choose the services who will fulfil this role otherwise there is a conflict of interest.

My next point relates to the fact that all the money that is going into the NDIS provides for services and carer hours however the very limited funds that people with disabilities have accessible to then after they pay 75% of their pension in board and accommodation leaves them with little funds to actually make all these lifestyle choices that are supposedly open to them.

The cost of Doctors, Psychologists, Psychiatrists and other therapists are prohibitive and even with the one care plan a person is allowed per year there is just not enough money to go around. **My daughter's last appointment with the psychiatrist was \$426 due to the urgent state of her emotional distress, the waiting time to see him in the public system was five months and she couldn't wait that long.**

A planner told a person with the disability that if you are physically capable of getting on a bus or a train then you do not get transport costs, your carer can catch the bus or train with you to keep your appointment with a doctor or other therapist, this can add at least one or two hours of carer time, that would appear

to me to be more expensive and time consuming than too be transported in a car.

There are many reasons other than physical that necessitate transport by service providers.

Transport has been greatly depleted since the introduction of the NDIS and where public transport is not easily accessed it is very difficult and it is a continuing problem.

A planner also told another person who had been placed in a group home that was quite a distance from her specialist that it was up to her wether she spent her transport allowance going to the specialist of her choice or changing to another specialist closer to her accomadation, to me this is unreasonable as specialists who understand disabilities and relate well to that person are difficult to find.

These are a few of the problems facing families and people with a disability and we appreciate the opportunity to bring them to your notice.

Wendy Cuneo

Parent, Advocate, Vice President and Publicity Officer

Stockton Hospital Welfare Association