

Submission – Cheryl McDonnell

- Why are more people using the NDIS than we thought there would be?

The government severely underestimated the number of people needing support because many people have been struggling along for a long time with no support, many of them having been told in the past they are not disabled enough, or do not fit the requirements. These people are now accessing help for the first time.

Also it is impossible for government to know how many people with disability there are if they do not actually ask that question. The most recent census had questions about carers but did not ask how many people in a household are disabled. In our house there were four people with disability. Government needs to phrase the question right.

- What kinds of things are making people's support cost more than was expected?

Support costs are higher for several reasons.

1) NDIA raised the price of everything.

2) when an OT says you need a \$30.00 set of cutlery to make it easier for you to be able to feed yourself, they can write down the brand etc and let you order it yourself, that is a part of the consultation. When NDIA require a \$300.00 report to justify the \$30.00 set of cutlery it has now cost for the initial consultation, the cost of the cutlery and the cost of the report. \$175.00 plus \$30.00 plus \$300.00 so the \$30 set of cutlery just cost \$505.00. This same scenario is repeated over and over in various situations and the result is that there are more costs and higher costs. There needs to be a way that people can purchase items up to \$1000.00 without the need for a report. Does anyone actually read those reports?

3) The government actually had little idea of the shortfall in the needed support and equipment. ADHC was providing much less than was required and people with disability were suffering because of that, with limited access to everyday things like access to transport, access to showers, and other ordinary supports that just were not happening for many people or were happening in a way that meant other family members became disabled themselves by suffering injuries caring for PWD.

4) Congregate settings were the cheap fix for what to do with PWD and it created more problems than it ever solved. Those created problems became expensive to resolve and so were left without resolution, fixing some of those problems will cost money now, but will later save money. I am pretty sure many service providers were satisfied that PWD would stay with them in the 'fun' day programs and instead PWD are wanting to exercise their right to be set free from congregate settings and live a real life.

- Do any changes need to be made to who is eligible for the the NDIS?

Access to NDIS should be based on need. If someone needs it they should get it.

- Is it clear what kinds of supports are the NDIS and what are other services, like health and education?

Clear as mud!

- Is the planning process working? What could make it better?

No. The planning process can be improved by having LACs who know about the various disabilities of the people they are planning for, also the ability and willingness to listen to what is required without them imposing their own opinions on that. LACs are insufficiently trained, insufficiently experienced, and having them fill in a tick and flick list does not equate to planning.

When my daughter had her planning meeting I described my daughter's disabilities and communication requirements to the LAC prior to them meeting my daughter, they came out to meet her a few days before the planning meeting and stated they would take all of the time required to work out a plan that suits my daughter's complex needs. Within the hour they were gone. They stated on their way out the door that LACs didn't have the training needed for this and we would need to wait until a planner could meet with us. LACS supervisor came out to complete the planning meeting. The supervisor showed us the plan and we had to correct a number of things in the plan that were not recorded accurately. This saved us and the NDIA the hassle cost and stress of a review. Others have been forbidden from seeing the plan before it was submitted and have had to go through a review session or two. It has got to be cheaper getting it right the first time than paying for reviews. We were very well prepared for planning having undergone pre-planning sessions and having worked on the plan for months prior to the planning meeting with LAC. Still the goals my daughter had identified were not the goals recorded in her plan! We have not asked for a review because we want to see how this works first and we want to understand the process of using the NDIS funding before asking for a review, and by the time that happens we will be close to needing an annual review so will leave it all til then. Auctioning the plan has been a nightmare!

- What sort of disability supports are included in the NDIS?
- What do people with disability want from disability workers in the NDIS?

A willingness to carry out the required work.

Reliability

Engagement with the PWD. Don't just mark time til the end of shift.

The ability to think and plan ahead.

DSWS that do not treat their job as 'babysitting' the PWD. Do not get judgemental about other household or family members.

DSWs that respect the human rights of PWD.

- What will happen to disability supports for people with disability in rural and remote areas or for people who need very specialist services?

So far these supports are falling apart. There is no guidance, no instructions in how to make the NDIS work in rural and remote settings nor for PWD with complex needs. I personally spent today crying about the fact we can not get DSWs hired to do the work of supporting my daughter. I am at my wits end. Today my laptop died

and so I could not do anything about fixing the situation until my daughter chilled out for a while so I could borrow the iPad she uses as a communication device to search for DSWs and then to submit this.

When I am dead and gone my daughter will need a full time coordinator to ensure everything in her life is attended to. At the moment she has me, a case manager, a support coordinator, and a plan manager. The other three don't do what I do, and I do some of what they do because there is only so much funding allocated for this, that is four people engaged in meeting the needs my daughter has that is not direct care work. Direct care work would be another four to five people. Most of the work I do is administrative in nature, following up emails, keeping everyone informed, as well as assisting her to manage her bank account, order things she needs, finding way to make DSWs understand their role is to help her make connections with other people in the community and not just drag her along to 'disability' standard activities. Case management is needed and has been phased out by NDIS, and Key Workers are needed and they too have been phased out. When a person has a significant and complex disability they require a lot of support from people who actually get to know them as human beings. Having it written in a file somewhere that you need DSWs to sit on your left hand side does not make sure the DSWs ever get to read that, or ever get made to do it. When you are left handed and only have vision in your left eye, this kind of information is extremely important and someone needs to know this and be in a position to enforce it. Key workers who get to know the person, derstand the complexity of needs and can show new staff how it is done is vital.

- Do people with disability have enough information and support to work with the NDIS?

No. We need a step by step guide. A clear list of who is who and who does what. What the heck is a support coordinator and what exactly can they achieve in an hour a week? I spend more time than that just reading and responding to emails from the DSW agency. Especially at the start of a plan, support coordinator needs to be much more active. And why is it so difficult and so expensive for sole traders to become registered with NDIS especially when they are already registered with their trade association?

- Do people with disability have enough say about the running of the NDIS?

No. The NDIS is being used as a political football for political purposes. PWD need to be directly engaged by the NDIA in as many roles as possible and should be on the board. There are plenty of talented people with disability in Australia who could perform the role of CEO, or board member. Having the withdrawal or reduction of the NDIS hanging over our heads scares me to death.