

Submission
No 217

**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

Partially
Confidential

To Portfolio Committee No.2 – Health and Community Services

Dear Members,

I wish to request that my name and contact details are protected.

Thank you for the opportunity to share our experiences/concerns with the hope that our voices are heard and acted upon. I have listed below some of the systematic shortfalls of the NDIS/NDIA processes and procedures that bear huge impacts on the services being provided.

While I appreciate the intention of the NDIS to provide the best outcome for the disabled people and their families, there are systematic failures in which the group home residents have little or no choice and control over some of their vital services. These include the following:

1) NDIA Planning Process:

Currently, planning meetings are organised with the disabled person and/or their guardian/ person responsible, their advocate and other responsible bodies. During the meeting all requirements for the disabled person needs are gathered and presumably noted by the planner to be included in the plan. However, a draft plan is not forwarded to the disabled person and or their guardian/person responsible to ensure its accuracy and completeness before being finalised. They only get to see the approved plan which often lacks important details which adversely affects the budgeting and required funding. In turn, this causes repetitive appeals and reviews.

These unnecessarily create stress, frustration, and worry in addition to the time and money that are wasted on multiple appeals, reviews and amendments. I personally had to go through many reviews over the last two years and with each review the same process has forced me to go through subsequent reviews. Another review/appeal is currently underway. With each new plan my daughter's vital services - Behaviour Management Plan, OT and speech Therapy – became on hold. One-year on still some of these therapies are in the developing process, for one therapist no funding was made available or the therapist couldn't access the fund. By the time the funding was made available the therapist timetables were filled up and the therapist refused to go ahead with implementing their recommendations due to their full schedule capacity.

I strongly recommend that a draft plan should be made available to the disabled person/guardian/person responsible/advocate for review and feedback before it is finalised. This will eliminate the unnecessary time, effort and resources that is required for each review and appeal and for the necessary therapies not to be interrupted and /or stopped.

2) Home and Service Provider's Contracts:

NDIS' goal of "providing our community with choice and control to get out and do the things we want to do" has been negated by the contracts formulated to keep the interests of the home and service providers over the needs of the disabled persons. The contracts have brought significant uncertainties and fact-based worries to people with disabilities and their families. These contracts are generic and take a blanket approach towards physical and mildly mental disabled persons. One size does not fit all and the contracts should be formulated to reflect this.

I am concerned about several clauses from the contracts I have been asked to sign for my adult non-verbal autistic daughter who also has a severe intellectual disability.

Accommodation Provider contract states: “the Accommodation Provider may end this Accommodation Agreement with less notice if ... you cannot be supported at the property without serious risk of harm to yourself, staff or other occupants.”

It also states that one of the client’s responsibilities is “to respect other occupants and their right to treat the property as their home.”

Additionally, the Service Provider can end their contract with a minimum of four weeks’ notice. It is also added:

“This agreement can be ended without a notice period as a result of a serious breach... A serious breach may include but are not limited to:

- Abusing or assaulting staff or other customers...
- Continually breaching the terms and conditions of this Agreement,
- Damaging... our property,
- Taking action which is intended, or would reasonably be expected to:
 - Harm us or our reputation,
 - Lead to unwanted or unfavourable publicity to us...
- This Agreement may also end immediately:
 - If you run out of funding before the end date of this agreement...
 - If you no longer receive funding.”

My daughter being intellectually disabled and non-verbal does not understand:

- Any terms and conditions,
- Hers and others’ rights
- What she should or shouldn’t do
- What is right or wrong

Her conditions and behaviours have been known to ADHC for a long time. They are fully aware of the disasters that have happened when her life needs were not met.

When her needs are not met, she will get frustrated and angry, resulting harm to herself, others and the property. She has destroyed clothes, shoes, other’s belongings, household items including kitchen and bathroom cupboards, fittings and furnishings. It is not a matter of ‘if/ but/ when’ she will meet all the contract conditions for eviction.

My daughter and people like her need a guaranteed home for life and not to be threatened with a contract that makes them homeless. NDIS promised that “nobody would be worse off under the NDIS”, but due to NDIS shortfall we live in an uncertain world with lots of worries and constant fear of our loved ones being homeless under these contracts and/or neglected and abused if the funding doesn’t cover their needs.

I urge the Committee to make sure these vulnerable citizens have permanent home and no one can force them out. Please do not take away from the disabled the security and choices over their lives.

Further, subject to the condition of the above contract that indicates a serious breach being taking action which harms their reputation or leads to unfavourable publicity, if a disabled person is abused

or mistreated how could we keep quiet? **Our concerns for the care of our loved ones should not be silenced in fear of immediate eviction.**

3) Lack of end of shift handover:

Currently when carers' shifts change, there is no handover process. One carer moves out and the next one comes in. For non-verbal person with severe intellectual disabilities and people with multiple disabilities, it is essential that carers report the details of their shift to the next shift carer. For example, if the resident (disabled person):

- has taken their medication or vomited it out.
- has had accidents, falls, injuries etc.
- had shower, food, drink and what time etc.
- has been to the toilet or not and what time.
- has had outdoor activities etc.
- has been sick, happy, unhappy etc
- how many times changed clothes etc.

The above details are quite relevant in order to understand the needs and expected behaviour of the non-verbal with intellectual disabilities persons and people with multiple disabilities. By doing so, the next shift carer would be more prepared to deal with the disabled person's needs and help them understand their behaviour/frustration. However, carers are not rostered for handover periods. The lack of a handover system means that there is no time for exchanging vital information and this has an enormous negative impact to the person being cared for.

For example, my daughter who is non-verbal with severe intellectual disability, is unable to communicate with any means of communications to let the next shift carer know of her day and needs. Hence, she gets frustrated when people do not understand what is needed for her. If the carer is aware of her daily issues and acts accordingly, it will mitigate the risk of her becoming unsettled and prevents her aggressive behaviour. Her behaviour ranges from crying to the extent of tearing off her clothes, shoes, damaging the property, putting herself and others in danger. Having time for handover would help carers to be more prepared.

4) Customised Training for the New Carers: (buddy shifts)

New carers are not trained to understand cues of intellectually disabled who are also non-verbal, therefore they fail to provide the required level of service, therefore contribute to unwanted behaviour of the disabled person.

New carers should be provided with detailed and personalised training to be able to understand the needs and wants of the disabled person, therefore mitigating the risks of unwanted behaviour and aggression. Buddy shifts would provide new carers with experience to the specific individuals and their needs.

5) Lack of representatives for autistic, non- verbal with severe mental disability people and people with multiple disabilities.

From my experience, I believe that this particular group of non – verbal autistic with severe mental disability and people with multiple disabilities haven't got representatives in the organisations to develop guidelines that accommodate and acknowledge their needs. Well educated and well-informed representatives are needed for this group of disabled persons to actively contribute while drafting their Home and Services Contracts and guidelines to the NDIA/NDIS funding board.

The NDIA/NDIS board need to have representatives that understand the needs of this group of people when planning for funding so that there is less of a need to have reviews and appeals.

The current situation without such representative has created enormous stress on top of the stress of daily living, because 'you have to prove how bad your situation is every single time you require assistance and reviews'.

At such stressful time to constantly prepare documents and attend meetings not just take toll on us, it is also draining NDIS budget unnecessarily and wastefully instead of where the fund is intended to be spent on. (for the disabled wellbeing, home, therapies and carers).

I hope to see the NDIS that we have hoped for under the committee's watchful-eye and an end to the uncertainties we are facing.

With regards,

08/08/2018