

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

Name: Name suppressed
Date Received: 23 June 2018

Partially
Confidential

22/06/2018

The Hon. Greg Donnelly MLC

Committee Chair

Re: Private submission to Legislative Council regarding Inquiry into the National Disability Insurance Scheme in New South Wales.

Dear Sir,

I am a stakeholder in this issue as a legal Guardian, Financial Manager, NDIS Plan Nominee and sibling to a young adult with complex disability and challenging behaviour. Due to a family history of domestic violence, it is in my sibling's interests to refer to them only as "PWD" and their whereabouts have been suppressed to ensure estranged members of their family can do no harm. My sibling is a NSW resident and has the mental capacity of a 3 year old; they are completely reliant on others to communicate and make decisions on their behalf. Due to the complexity of their condition and behaviours, it became no longer safe for my sibling to reside at home and our mother had to make the heart-breaking decision (if you can call it a choice) to relinquish her to the state government in 2010, in order to get the 24/7 care, she desperately required.

My sibling currently lives in a property with 3 other clients, purpose built for their needs by FACS. Upon transitioning to the NDIS, we collectively requested this house be run by [redacted] from May 2017. Prior to signing our contracts, [redacted] had advertised supported accommodation services would involve families in decision making (as the clients did not have capacity themselves) and that clients would not lose their service if they (i.e. we) made complaints. A number of positive discussions were had around this, however when it came time to sign the agreements, we were told we were not allowed to negotiate these terms and the promises we were made were not valid because they weren't included in the standardised unable-to-be-modified agreement. We were forced into signing as there were no other providers willing or able to take this house on, and we really did not have a choice now that there is no government provider of last resort.

My sibling has very intensive and specific support needs, and there is simply a paucity of services and accommodation available that have the capacity to cater to them. We are so grateful for the NSW government for providing them with the perfect house that was literally built to their specifications. But now, with the NDIS, a hidden clause in the contract apparently enables providers like [redacted] to evict PWDs with 90 days' notice, without reason.

[redacted] eventually did provide a reason, and the reason was that I had made a number of complaints on my sibling's behalf. Many of which were not addressed properly or at all, and when I sought the assistance of the NSW Ombudsman, I discovered that they had no powers to make

providers comply with their recommendations or even force them to conciliate. adamantly rejected invitations to conciliate with them or with the Community Justice Centre and made it extremely difficult for me to discuss issues in person or via video conference, preferring to deal with everything via email – a medium which is fraught with miscommunication. Despite being reassured by the NSW Ombudsman that providers cannot take retaliatory action against complainants under section 47 of the *Community Services (Complaints, Reviews and Monitoring) Act 1993 (CS-CRAMA)*, have done exactly that. And it would appear that the only way this act can be enforced is through the NSW Police.

However, upon discussing this problem with the NSW Police, I was informed that this matter that would be incredibly difficult to prosecute given that there is no one individual who is responsible and that it seems like an issue better suited to civil court. I was further informed that issues like this tend to become a game of handball between agencies who are not entirely equipped to deal with such matters.

With no finance to take legal action and no free agency that can hold to account, I am now faced with an unscrupulous eviction notice for my sibling (attached). are aware that I have no capacity to physically care for my sibling. Neither I, nor my Support Coordinator, nor my advocate can find a vacancy or suitable place for my sibling, despite approaching multiple (+15) alternative services. Despite the outrageous reason under which the eviction has been given in the first place, we have asked for leniency to retain her accommodation until we can find an alternative and been denied. This effectively means that come the 5th September at 5PM, a 3-year-old in a young adult's body is going to be put out on the street by . To date, there is literally nothing or no-one out of the following agencies I have approached that can assure me with confidence that this will not happen: NSW and Commonwealth Ombudsman, Advocate, Support Coordinator, NSW Fair Trading, NSW Police, IDRS, Law Access, OAIC, Council for Intellectual Disability, State and Federal members of Parliament, and the NDIA.

With this context in mind, I would like to provide a submission for your consideration particularly in reference to the following terms of reference (a, b, d, and f) highlighted in bold:

(a) the implementation of the National Disability Insurance Scheme and its success or otherwise in providing choice and control for people with disability,

There is no choice and control unless it can be legally enforced. After denied me the opportunity to have input into the development of my siblings NDIS plan and individualised SIL tool (the document where the provider identifies what success looks like for the participant), I approached the NDIA for help and was ignored. I then complained the Commonwealth Ombudsman who investigated it and said that even though all the documentation and wording says we should be involved and have some choice and control, it ultimately is up to the NDIA's discretion to apply it as it's not a part of any legislation.

What this meant for my sibling is that there was critical advice from their psychiatrist that didn't get any opportunity to be implemented and their challenging behaviour has not improved as a result. refused (twice) to attend the appointments, wouldn't accept the advice from me, wouldn't respond to complaints regarding same and all the while the NDIA were not listening and I couldn't enforce any of them to stick by their own policies and procedures. Unless there is legislation

forcing providers and the NDIA to include legal guardians in the process and allow them to have their say, there is no choice and control.

(b) the experience of people with complex care and support needs in developing, enacting and reviewing NDIS plans,

My sibling has complicated and high care needs involving restricted practices. I chose to self-manage after it was advertised to me that this would result in faster results and greater choice for my sibling (e.g. if a transport harness breaks, I can just order another – as it would always be allocated for in her plan; or if I can't find a registered NDIA provider, I can use anyone who has the necessary qualifications to get the job done).

When the NDIS rolled in, we no longer had our long-time case manager from FACS. I had to explain everything to completely new people which quite frankly, is impossible to do. It takes months for new people to get their head around how complicated and interconnected the problems my PWD faces. This is an inherent problem with the call-centre model. It does not work because it is impossible to communicate and comprehend such a large volume of information to someone who will only deal with you for a handful of times before they handball you to someone else and you need to start again.

Then the NDIA started restricting my choices and control over the plan (e.g. SIL and Assistive Technology are now agency managed because my sibling is "high risk"). In other words, the NDIA's solution to this is to remove me, the lay/unpaid person, without justification or evidence that my choices are or have been remotely detrimental and put this responsibility in the hands of faceless NDIA people who have never even met my sibling. To demonstrate how ridiculous this is, I will use the initial example about my sibling's harness breaking. In reality, this is a simple order and replacement for an item that has been used and required since 2004. The paperwork on it has all been provided to NDIA upon rollover. But now, the NDIA are insisting on more paperwork which means more money being used from the plan that would have been otherwise spent on things that would advance the PWDs interests. In a less complicated situation, it is not unreasonable to request such documents. However, it is unreasonable when you can't find a relevant clinician in the private market that is competent and available to complete it.

Someone that has challenging behaviour, requires restricted practices and lives in a group home needs regular reviews and recommendations by a psychologist and psychiatrist to prevent them from hurting themselves or others. But this only works if the group home a) attend the appointments, b) listen and understand the advice, c) attempt to implement the advice, d) provide accurate feedback and e) genuinely want to use the least restrictive options to manage behaviour. There is currently no regulatory body with power to oversight this so the Behavioural Support Plans are often not worth the paper they are written on.

If a SIL provider insist on using more restrictive practices (e.g. lifting the PWD to their room when they would not comply or falsely report that behaviour improved under heavy sedation), and you, as a Guardian, object, you may get some lip service in response but you won't get any objective assurances that your loved one isn't being treated improperly as they have arses to cover. Even if something went wrong and the PWD is hurt, there is often no way to tell what happened and no way to investigate it (no capacity for the victim, no honesty from the provider, no CCTV). If you raise a complaint or request for explanation of injuries, you will be tarred and feathered by the organisation as a serial complainant, blamed for inflicting the injuries yourself (if they can't blame it on the PWD

themselves) or worse – paint you as someone who is out to blame staff for things they did not do – rather than get an impartial and balanced internal investigation/response to your concerns.

In short, I have a big expensive plan for my sibling that's not being used effectively because I have a SIL provider that won't play fair, no actual control over the game and there is no objective referee.

(d) the effectiveness and impact of privatising government-run disability services,

The impact for us is, if the government doesn't step in, my sibling will be homeless by 5th September. I cannot physically look after them and they will literally be put out on the street according to as I will not be there to pick them up because I have nowhere to take them. I'm terrified about what may happen to them for something that is of no fault of their own.

(f) the adequacy of current regulations and oversight mechanisms in relation to disability service providers,

As previously described, the NDIA don't listen and if they did, what penalties could they impose? Deregistration is not even a threat for an organisation like who cater to hundreds of clients. No other org as previously listed have been able to force to change their behaviour.

I would really like to see providers like this forced into conciliation and mediation. If an objective party could see both sides and advise on a solution, that would be the best and most reasonable outcome for clients and providers.

Thanks for taking the time to consider this and I hope you can help. Please find eviction correspondence attached, redacted to protect privacy.

Sincerely,