

Submission to LRC in addition to email sent 15/7/17

By Angie Trehwella [REDACTED]

Private Guardian in NSW for adult with disability living in full-time supported accommodation.

### Question 7.1: Problems with the regulation of restrictive practices

What are the problems with the regulation of restrictive practices in NSW and what problems are likely to arise in future regulation?

No-one is capable of enforcing compliance with positive behaviour strategies *before* restricted practices are used. They are not being used as intended (i.e. a last resort).

In my sister's situation, there is a place for restraint (i.e. it would be more dangerous for her if I actively did *not* consent to restrictive practices) and yet, I know they are not complying with the positive aspects of behaviour management which would reduce the need for restraint in the first place (e.g. engaging her in meaningful activities, providing a consistent routine, using her augmented communication aids etc.).

The Ombudsman can't make them do anything and they always appear to do the right thing in front of a visitor (it's not hard to make it look like you're working in a 20 minute visit).

I think future regulation is at real risk of becoming another white elephant like the current Ombudsman.

### Question 7.2: Restrictive practices regulation in NSW

- (1) Should NSW pass legislation that explicitly deals with the use of restrictive practices?
- (2) If so, should that legislation sit within the *Guardianship Act* or somewhere else?
- (3) What other forms of regulation or control could be used to deal with the use of restrictive practices?

1. YES. The suggestions presented in the paper would not help my sister (e.g. the current policies on behavioural management are fine ***if they are followed***. We have crisis intervention management training galore and the problem seems to be compliance because it's human nature to take the easiest route (e.g. restraint is easier than taking the time to plan and execute a social story). We have OT's and therapists alerting the environment as I write this, but without authentic engagement (i.e. following the positive behaviour support advice), the modifications are superficial and limited in their capacity to modify behaviour).
2. I think it should fit within the guardianship act because as a guardian – I'm being ignored. I'm asking for information and not getting it. I'm asking them to follow

advice of clinicians and they're not. I've tried withholding funding from the NDIA on the basis they did not provide that support but had extreme difficulty and limited effectiveness in doing so because I had no real legal backing as guardian.

### **Question 7.3: Who should be regulated?**

Who should any NSW regulation of the use of restrictive practices apply to?

Disability supported accommodation providers and day program support providers.

### **Question 7.4: Defining restrictive practices**

How should restrictive practices be defined?

As outlined in paper.

### **Question 7.5: When restrictive practices should be permitted**

In what circumstances, if any, should restrictive practices be permitted?

Where it would be more dangerous to the person if it wasn't or puts others at foreseeable and unreasonable risk of harm.

### **Question 7.6: Consent and authorisation mechanisms**

- (1) Who should be able to consent to the use of restrictive practices?
- (2) What factors should a decision-maker have to consider before authorising a restrictive practice?
- (3) What should be the mechanism for authorising restrictive practices in urgent situations?
- (4) What changes, if any, should be made to NSW's consent and authorisation mechanisms for the use of restrictive practices?

1. Private guardians, provided they have a suitably trained clinician authorising and monitoring the use of the practice.
2. The safety and well-being of the person involved and focus on what can be done to reduce the need for it.
3. In my experience, providers will just restrain anyway without any regard for the law or whether there is an approval in place on the basis that they are acting as good Samaritans. Whatever the answer is, it has to be easy otherwise this behaviour will continue and could put people at risk.

4. I need the following clause in the guardianship act to be legally enforceable – “(2A) *For the purpose of exercising a function that an appointee is authorised to exercise by an instrument appointing the appointee as an enduring guardian, the appointee has the same right of access to information about the appointor as the appointor has.*” The biggest struggle as a guardian is getting access to information that would enable me to make informed decisions about the need for restricted practices. It is not uncommon for me to have to make applications to the privacy commissioner to get timely access to incident reports and related data for my sister that would help me to see if they are trying to prevent the behaviours from occurring in the first place. When I do find evidence of non-compliance, I’m literally powerless to stop the cycle.

### **Question 7.7: Safeguards for the use of restrictive practices**

What safeguards should be in place to ensure the appropriate use of restrictive practices in NSW?

When they ignore the BIS clinicians and doctors, we need to have some kind of legally enforceable penalty. The big wigs in large disability orgs only seem to care when it affects their bottom line or reputation. If a financial penalty can’t be imposed, then maybe a public ranking system where customers/clients/families and the public can provide honest and transparent feedback? They seem to care (at least intermittently) when someone speaks to the press!

### **Question 7.8: Requirements about the use of behaviour support plans**

- (1) Should the law include specific requirements about the use of behaviour support plans?
- (2) If so, what should those requirements be?

1. Yes
2. Access to relevant information/data and consequences for non-compliance for the people executing the plan. We have a good BIS plan but again – it’s only as good as the quality of data informing it and the willingness of support workers to comply with it!