Submission to the New South Wales Government on Restrictive Practices Authorisation (RPA) in New South Wales

Cecile Sullivan Elder
Executive Officer, Family Advocacy
cecile@family-advocacy.com

Leanne Varga
Systemic Advocate
leanne@family-advocacy.com

Family Advocacy
(02) 9869 0866
Suite 704, 88-90 George Street,
Hornsby, NSW 2077, Australia

30 August 2019

Table of Contents

Introduction

Family Advocacy is a not for profit disability advocacy organisation whose objective is to advance and protect the rights of people with developmental disability. We do this by supporting families to advocate for their family member with disability, so they can achieve meaningful lives and enjoy the same opportunities and living conditions as the majority of Australians. For example, being included at their local school, having a job, a place to call home, and a valued place in the community amongst friends and family, with the necessary supports (both informal and paid), to enable this to happen.

Family Advocacy was founded by families of people with developmental disability almost 30 years ago and is funded by New South Wales (NSW) and the Commonwealth (Cth) governments. We appreciate the opportunity to be able to provide input on behalf of people with disability and their families for this Consultation discussion paper on Restrictive Practices Authorisation (RPA) in NSW.

At the outset, we are pleased with the Minister's suggestion to "be brave and bold" in our approach to "significantly improve the lives of people with disability and work towards the reduction and elimination of restrictive practices". Family Advocacy is of the view that restrictive practices constitute a breach of human rights under a number of United Nations conventions relating to torture, the rights of the child, and the rights of persons with disabilities, to which the Australian Government is a signatory.

We are providing comment and recommendations in relation to the regulation of restrictive practices with NDIS service providers, but we are also concerned about all settings in which it occurs. One setting of particular concern is education and the use of restraints and seclusion on children with disability in schools.

Recent research has demonstrated that, in practice, restraint and seclusion are used in school settings for a variety of purposes beyond or in addition to a protective purpose, including as a means of coercion, discipline, convenience or retaliation, and to prevent damage to property. The use of restraint or seclusion for non-protective purposes is inconsistent with human rights norms.

Family Advocacy's position on restrictive interventions in all settings is that it would be better protected by establishing a system with independent oversight for reporting and monitoring. Independent, transparent data and analysis, combined with continuous quality improvement review mechanisms should be put in place to support service providers, regardless of the setting, to manage behaviours of concern while protecting the rights and dignity of people in their care.

What are restrictive practices?

The definition of restrictive practice should be expanded beyond that provided in the consultation discussion paper. This expanded definition is a combination of what was suggested in the *National Framework for Reducing and Eliminating the Use of Restrictive Practices in the Disability Service Sector* (the "National Framework" 2014) as well as the JFA Purple Orange report "Minimising and Eliminating Restrictive Practices: A Consultation for the ACT Government: Final Report" (2017). The examples provided are based on anecdotal evidence provided by our families or reported in the media.

- ***mechanical***, such as devices that limit a person's movements (and this includes the removal and/ or disengagement of mechanical supports that assist the person's movements). For example, tying a child down to a seat with a belt
- ***seclusion***, such as the sole confinement of a person at any time in any room where the doors and windows cannot be opened by that person, such as a 'time out"
- ***environmental***, such as preventing free access to all parts of a person's environment or house. For example, locking the refrigerators
- ***social***, such as the imposition of sanctions that restrict the person's access to relationships/opportunities they value. For example, not allowing a friend to come over and take them out of their group accommodation to go on an outing
- ***chemical***, such as medications that blunt the person's emotions, cognition, and motor activity. For example, schools that refuse to allow a child access to school unless they take a certain medication
- ***physical***, such as holding or 'pinning down' by another person
- ***psycho-social***, such as power control strategies which might include threats, intimidation, fear, coercion, discipline, or retaliation

- ***organisational***, such as excluding the person from activities, and restrictions to the person's choice. For example, not allowing a child to attend excursions or school camp
- ***communication,*** such as switching off someone's communication device
- ***decision making***, such as failing to provide options for supported decision making
- ***consequence driven***, usually involving the withdrawal of activities or items.

What principles should guide RPA?

Q1. What principles should guide Restrict RPA in NSW?

The six principles proposed in this consultation discussion paper to guide restrictive practices authorisation are sound but not complete. With consideration to the National Framework, we recommend the principles be:

- **Reduce and eliminate restrictive practice** - as the overarching principle underpinned by the following principles below
- Human rights focused - should only occur in very limited and specific circumstances, as a last resort
- Person centred - Self-determination over their lives and an individualised approach
- Supported decision making
- Least restrictive
- For the shortest time
- Evidence - based best practice
- Consistent approach across settings
- Accountability and transparency through documentation, benchmarking and evaluation
- Monitored
- Reviewed regularly
- Raise awareness, provide education and accessible information about restrictive practices - for the person with disability, their guardian or advocate, service provider and their staff.

How should people participate in RPA?

Q3: How should people with disability participate in RPA decisions?

Q4: How should people with disability be supported to participate in decisions?

Q5: How should families and carers participate in RPA?

Q6: How should families and carers be supported to participate in RPA?

People with disability have equal rights to all members of society and deserve the right to respect for inherent dignity, equality before the law, freedom from torture, and inhumane treatment. Where possible, self-determination and self-advocacy are always the preferred option when making decisions about one's quality of life. It is the person with disability's right to tell decision makers how they want to be supported to manage their behaviours of concern. There must be proper consideration given as to how a person with disability can have a voice or some agency in this process, particularly if the person is nonverbal and/or uses a communication device.

Where this is not possible, it is absolutely vital that the person with disability has access to advocacy services to assist them in supported decision making. Adherence to the supported decision making model ought to be the preference where the parent/guardian/friend or advocate support the person with disability to have their say.

As a general rule, the parent or family member of the person with disability know the person well, and have a historical knowledge of their personality, interests, passions, choices, preferences, dislikes, and fears. This is important as behaviour is a form of communication and people do things for a reason. By having a deeper insight to the person, this can expose the extent to which the person's current daily life is missing opportunities that are meaningful to the person. Getting to know the person and their story will assist in finding alternatives to restrictive practices.

Restrictive practices, by their very nature, completely undermine a person's choices and preferences, or their opportunity to a self-determined life. Alternatives to restrictive practices might include making changes to the person's environment such as support arrangements or home arrangements that better reflect the person's choices and preferences. The focus should be more about improving the quality of a person's life rather than the reduction of the behaviour of concern (Carr et al. 2002).

> *"There is a significant imbalance of power experienced in all settings for person with disability receiving services and supports. Of course, I would like my son to have a say in his behaviour support plan that includes using restrictive practice but he has an acquired brain injury and cannot verbally communicate. So to the best of my ability and with my son's best interests at heart, I advocate for him. My son has a very particular passion for newspapers. If Derek carries a newspaper under his arm, it makes him feel stable and confident in the world.*
>
> *If he does not do this, the need would arise for restrictive practice, as his anxiety would rise and behaviours of concern would follow. Often, if given the chance, the person with disability themselves knows the solution as to what stabilises them. Rather than having a theoretical, broad brushed approach, really knowing the person and tapping into an individual's true desire, however unusual it may seem, is the key to reducing the need for restrictive practices."*
>
> Alan, father of Derek

On this note, many mainstream services and disability services strategies for supporting a person to manage any behaviours of concern do not individualise their responses in a manner that reduces or removes the incidence of behaviours or adapts adequately their supports and environments to accommodate the person. Thus, creating a feedback loop to the continued use of a restrictive practice response.

Many times, the parent/guardian also requires support to ensure they are fully informed and have the skills to be able to protect and promote the rights of the person with disability. This highlights the absolute necessity for advocacy services to be available, both at the individual and systemic level.

Q7a: Have you been involved in consent for a restrictive practice?
Q7b: If yes, in what ways was the experience good or bad?
Q8: How should consent be part of RPA?
Q9: What support do you need to give consent on a person's behalf?

In the first instance, and in formulating the process of consent in relation to authorising a restrictive practice upon a person with disability, we strongly recommend that the person with disability and/or their family member or guardian are able to attend any RPA panel meeting; and that this forms part of the essential make up of relevant decision makers on the RPA panel. It also imperative that written consent be obtained regarding strategies and outcomes of this meeting.

As a general rule, the parent or family member has a natural authority. They tend to care more, have greater responsibility over their family member's wellbeing, they know them the most fully and for the longest period of time, have a stake in outcomes, and are granted a degree of independence being free of the vested interests which call into question the credibility of other parties.

In addition, families are often best positioned to see how everything, in its entirety, adds up to a person's life and for this reason, they can often see the incongruences of different interventions. Utilising this relationship and familiarity with the person enables all options to be explored prior to the use of restrictive practice. In this regard, we refer to "The Natural Authority of Families" by Michael Kendrick:

https://www.family-advocacy.com/our-resources/the-natural-authority-of-families/ .

Where should RPA be required?

Q10: In what settings should restrictive practices need to be authorised before they can be used?
Q11: N/A
Q12: In what settings should we use the same RPA principles for people with disability?
Q13: In what settings should we use the same RPA processes for people with disability?
Q14: When should one authorisation for a restrictive practice apply across settings?
Q15: How should we make RPA more consistent across settings?

To be effective, the regulation of restrictive practices needs to cover the use of restrictive practices in a range of settings. Especially given that people with disability may be subjected to restrictive practices in a variety of contexts, including: supported accommodation and group homes; residential aged care facilities; mental health facilities; hospitals; transport; prisons; and schools.

Broad application of any national or nationally consistent approach would address one of the key shortcomings of current approaches to restrictive practices, including The National Framework, which is limited to the disability services context, and not all settings. In addition, one of the ongoing challenges is that there is no consistent data collected on the rates of restraint and seclusion.

Education provides a good example of the gaps as to why this is necessary. Currently, we have the *Disability Standards for Education* (2005) to provide guidance to education and training providers regarding their obligations to ensure students with disabilities have equal access to education (Department of Education and Training (Cth) 2005). The National Safe Schools Framework provides guiding principles to ensure safe and supportive school communities (Department of Education and Training (Cth), National Safe Schools Framework (2010) 2). The implementation of the National Disability Insurance Scheme (NDIS), and the National Disability Insurance Scheme Quality and Safeguarding Framework have provided an opportunity to develop a consistent Framework but this is only limited to the regulation of NDIS-funded supports and providers.

Therefore, restrictive practice in the education system is not regulated specifically by any of these frameworks and we recommend that this is necessary, particularly in light of the evidence which suggests it is on the rise. For example, a recent Parliamentary Inquiry in New South Wales on Education (2016) heard that advocacy groups ‘are getting increasing reports of restraint and seclusion’ (Legislative Council Portfolio Committee No 3 — Education, above n 14, 24; and 106) where the same inquiry reported serious concerns about ‘harm caused to students when practices like restraint and seclusion are used’. This demonstrates that just having guidelines, and not mandatory requirements such as is the case with the Disability Standards for Education 2005, are not enough to motivate all schools to reduce and ultimately eliminate restrictive practice.

In addition, a survey of 771 students with disability conducted by Children and Young People with Disability Australia (CYDA 2017) identified that 19% of all respondents had experienced restraint at school, and 21% of respondents had experienced seclusion. CYDA is only part way through completing their 2019 national education survey in August and September

2019, and already the results for NSW (n=75) show 15% of children with disability experienced restraint and 21% experienced seclusion in the last year.

Further, the data from a 2017 Australia-wide survey of 745 families (parents, carers, and students with disability) showed over 70% report experiencing one or more examples of gatekeeping used to minimise the enrolment into mainstream, and/or restrictive practice. NSW figures reflects the same percentage as the national results (Poed et al. 2017).

More broadly, these statistics coupled with the anecdotal evidence received from families across NSW, also illustrate some of the systemic issues relating to the use of restraint in schools. This was highlighted in the New South Wales Ombudsman's report to Parliament, "Inquiry into Behaviour Management in Schools: A Special Report to Parliament Under s 31 of the Ombudsman Act 1974" (2017). The report includes proposals for reform that are relevant to this matter which endorse, including:

- Proposal 15, which includes the need for the department to develop clear and comprehensive guidance that strengthens the processes relating to actions that schools are required to take prior to adverse action being taken against a student in relation to their behaviour, and following any instance of the use of physical restraint
- Proposal 26, which includes the need for guidelines regarding the treatment of students – including students with disability – insofar as behaviour management and support strategies are concerned, and
- Proposal 28, which includes the need for the department to focus on ways in which it can enhance its complaint and reportable conduct practices to better identify and track the use of restrictive practices; consistently examine complaints and reportable conduct matters relating to the use of these practices; and where restrictive practices are used, ensuring that their use is consistently and competently reviewed against 'best practice' policies and procedures.

Who should make decisions about RPA?

Q16: Who should authorise use of a restrictive practice?

We recommend the authorisation of restrictive practice have a central panel or Tribunal of independent experts to make all decisions concerning the use of restrictive practice. This should include a properly qualified behaviour analysis experts (general feedback from our families is that they are not very competent in their experience); a person that knows the person with disability very well and has a good relationship with them such as a family member /guardian/friend. Another suggestion for an independent person should be a doctor. This should be their General Practitioner, not a specialist, as they will tend to know the person with disability, having seen them more regularly and as such, have taken the time to form a relationship.

Due to the conflict of interest that exists between what is best for the person with disability and what may be in the best interests of the organisation, the service provider should be kept at “arm’s length” in this process. If this does not occur there is significant risk that the process of approval will both minimise the opportunity to reduce or remove the use of restrictive practice and not seek alternative and adaptive practices within the service context.

This safeguard also acts as a means to mitigate the use of historical responses to supporting people with behaviours of concern which in many cases has not proven to be effective or in the best interests of the person. Moreover, disability services and mainstream services currently work within a principle of expectancy and assumption, whereby the person or people with disability is broadly labelled as being inherently violent and thus not seeking avenues to adapt and modify structures, environments and supports to accommodate the person appropriately.

We recommend the establishment and maintenance of a confidential register of restrictive practices, and that regular reporting on this data is released.

Q17: What skills and experience should decision makers have?

Decision makers need to possess some or all of the following qualities:

- be independent

- understand the disability
- know the person with disability well
- know and understand the Positive Behaviour Support program
- know and understand that behaviour is a form of communication
- a deeper look into the structures/environment/staff/ and responsiveness of the system surrounding the person with disability is also required.

Due to the importance of the individualist approach, one of the skills should be open-mindedness, an ability to think outside the box, and to be creative. One of our family members shared that a “cookie cutter approach would not work for his son as what works is highly individualised”. Again stressing the conflict of interest of decision makers is critical to this point.

This question also raises the broader issue of providing awareness through education for those who are implementing the restrictive practice. In any setting, while the use of restrictive practice is intended to protect the person and others from harm, they also pose significant risks to a person’s wellbeing and implicate fundamental human rights. In any setting, staff/personnel must navigate these complex ethical scenarios, often in very resource- and time-constrained circumstances, and attempt to strike a balance between competing values or rights. It is therefore critical that staff/personnel are provided clear guidance about the use of these practices and the human rights implications of their use.

Q18: What conditions should be met to authorise use of a restrictive practice?
Q19: What information should decision makers use when deciding whether to authorise use of a restrictive practice?
Q20: What support and advice do decision makers need to do their job well?

All avenues available must have been explored in the behaviour support plan prior to applying a restrictive practice. It must genuinely be a “last resort” rather than a convenience, or the status quo. It is vital that the person with disability and their parent/guardian give informed consent.

> *I was not informed of any behaviour support plan in place at school, nor that a restrictive practice took place. I found out because my son was distressed and he told me that two teachers pinned him to the ground face-down and he didn’t understand why. This approach is simply not acceptable.*
>
> Dana, mother of James

Q21a: Should authorisation decisions be subject to review or appeal?
Q21b: If yes, how often should this happen?
Q21c: If yes, who should consider the appeal or review?

Yes, an independent central review panel should consider appeals in the first instance. Timeliness would be critical to this process. In the event that the decision in unsatisfactory to the person with disability or their parent/guardian/advocate, then appeal options should form part of this process through current structures such as the NSW Civil and Administrative Tribunal. This will require legislation. Whilst it may take longer, this is preferred pathway as it critical that this process be both independent and rigorous.

Q22: How should the quality and consistency of RPA decisions be monitored?
Q23: What enforcement powers should this include?

We agree that benchmarking and quality controls are essential and that this should occur in each setting that the person accesses. This is critical as the structure, environments and supports are significantly different in each setting and so strategies to reduce behaviours of concern should therefore be adapted to each environment. Furthermore, behaviours of concern are often not experienced across different settings.

However, there may be some benefit to undertaking an independent audit if the same behaviours of concern are being experienced by the person. An audit process could take place to provide checks and balances as to the quality of the decision making. For example, to check decision makers have the right skills and information to make good decisions or check some decisions and make sure they were made in the right way.

The enforcement powers ought to be able to have sanctions or compulsory orders aimed at deterring the use of unauthorised or unnecessary restrictive practice.

Q24 What form should RPA regulation take?

Any regulation must ensure higher standards of treatment and very tight regulation of restrictive practices. Any regulation needs to reflect the principles reflected in the UNCRPD and the Human Rights Principles.

There should be nationally consistent legislation governing restrictive practices, including seclusion and restraint, and be developed and adopted across all states and territories. This legislation should include standardised terminology and definitions; and set clear and effective practice standards. A national or nationally consistent approach may provide a vehicle through which some of the systemic concerns of stakeholders, for example in relation to data collection, might be addressed.

In NSW, the rules for authorising restrictive practice are in a policy. We do not believe there is enough motivation in policy for service providers to make the necessary changes towards eliminating restrictive practice. We would advocate that legislation be established to provide clear authority and enforcement powers combined with policy to support the legislation with guidance on how to make decisions.

Our experience has taught us that service providers cannot be relied on to make the necessary changes to structures, environments and supports unless they are forced to through legislation, and that this legislation has strong enforcement powers. History has shown us that service providers, whatever their perceived good intentions might be, are motivated by profit or self-preservation using the path of least resistance, most convenience, and will only take positive action when they are forced to.

An example to this point: While positive behaviour supports have been demonstrated to reduce the incidence of restraint and seclusion practices, and are strongly supported at a national level, they have not been adopted universally. In 2017, only approximately half of all schools in New South Wales had adopted a positive behaviour support approach to behaviour management (NSW Ombudsman 2017). As such, while positive behaviour support programs are important, it remains critical that regulatory frameworks through legislation provide clear guidance on the acceptable use of restraint and seclusion in schools with strong enforcement powers.

Given the scarcity of consistent data in NSW, we recommend that provisions in legislation require the collection and reporting of comprehensive data on the use of restrictive practices in NSW, including established targets to reduce restrictive practices. Further to this that agencies involved in restrictive practices should be required to supply relevant data. The point should also be made that any regulatory function must be designed and implemented in a way that does not duplicate nor encroach on processes such as those which already provide an established regulatory function.

Recommendations

1. Restrictive practices should only ever be authorised if they are a genuine “last resort” after all alternatives have been explored, considered and implemented.
2. The NSW government legislate (preferably a nationally consistent approach) to reduce and eliminate restrictive practice which covers all settings where restrictive practices occur, in alignment with Human Rights principles.
3. The person with disability has the right to have some agency over the process of Restrictive Practice Authorisation. Where this is not possible, advocacy is essential to support decision making.
4. Restrictive Practice Authorisation panel decisions should have involvement and authorisation of the person with disability’s family member/guardian and be open to an appeals process.
5. Benchmarking and quality controls are essential and that this should occur in each setting that the person accesses.
6. To improve accountability and transparency, we recommend the establishment and maintenance of a confidential register of restrictive practices, and that regular reporting on this data is released.

Acknowledgement of References

Carr et al. 2002, ‘Positive Behaviour Supports: Evolution of Applied Science’, *Journal of Positive Behaviour Interventions*, Volume 4, Number 1, Winter 2002, pages 4-16, 20.

Convention on the Rights of Persons with Disabilities, opened for signature 30 March 2007, A/RES/61/106 (entered into force 24 January 2007) (‘CRPD’)

Convention on the Rights of the Child, opened for signature 20 November 1989, GA/RES/44/25 (entered into force 2 September 1990) (‘CRC’)

Children and Young People with Disability Australia, CYDA Education Survey 2017

Deloitte 2017, ‘Review of Education for Students with Disability in Queensland State Schools

Disability Standards for Education 2005

JFA Purple Orange 2017, ‘An Overview of Restrictive Practices, and the Key Issues for Consideration in Relation to the Establishment of an Office of the Senior Practitioner: A Public Discussion Paper Prepared for the ACT Government to Assist Public Consultation’

Kendrik, M. 1996, ‘The Natural Authority of Families’, https://www.family-advocacy.com/our-resources/the-natural-authority-of-families/

Legislative Council Portfolio Committee No 3 — Education, Parliament of New South Wales, Education of Students with a Disability or Special Needs in New South Wales Report No 37 (2017).

McCarthy, T. 2018, ‘Regulating restraint and seclusion in Australian Government Schools, A Comparative Human Rights Analysis’, *QUT Law Review*, vol. 18, no. 2, pp. 194–228

National Framework for Reducing and Eliminating the Use of Restrictive Practices in the Disability Service Sector 2014

National Safe Schools Framework 2010

National Disability Insurance Scheme (NDIS)

National Disability Insurance Scheme Quality and Safeguarding Framework

New South Wales Ombudsman 2017, Inquiry into Behaviour Management in Schools: A Special Report to Parliament Under s 31 of the Ombudsman Act 1974

Poed, S., Cologon, K. and Jackson, R. 2017, ‘Gatekeeping and Restrictive Practices with Students with Disability: Results of an Australian Survey’, paper presented at *The Inclusive Education Summit*, Adelaide, October 2017

Weissbrodt D. et al 2012, ‘Applying International Human Rights Standards to the Restraint and Seclusion of Students with Disabilities’ *Law and Inequality: A Journal of Theory and Practice,* no. 30, pp. 287, 288