Submission to the NSW Government Communities and Justice on Persons with Disability (Regulation of Restrictive Practices) Bill 2021

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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 with or on behalf of 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 to the NSW Department of Communities and Justice (DCJ) on behalf of people with disability and their families for this Consultation in relation to the Persons with Disability (Regulation of Restrictive Practices) Bill 2021 (hereinafter, the Bill).

Our concerns with the Persons with Disability (Regulation of Restrictive Practices) Bill 2021

At the outset, we are pleased with the NSW government's intention of working to reduce and eliminate restrictive practices. 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.

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 have some serious concerns regarding the proposed *Persons with Disability (Regulation of Restrictive Practices) Bill 2021*, which are discussed below.

Reduction or elimination of restrictive practice – How?

We fail to see how the proposed legislation drives the elimination of restrictive practice in all settings, including education environments. Rather, the Bill seeks to facilitate the authorisation of restrictive practices and merely focuses on process rather than setting up levers towards reduction and elimination of restrictive practice. This goes against the spirit of the United Nations Conventions aimed at safeguarding people with disability and leaves it open for breaches of their rights. We strongly recommend this be addressed in the Bill.

In our experience over 30 years, the experience of families that have a person with a disability is that behaviours of concern dissipate when a person with disability has a meaningful and engaged life. Behaviours of concern are generally a form of communication, the expression of an unmet need. It is relevant here to be cognisant of Maslow's hierarchy of human needs that dictate an individual's behaviour, the five basic needs:

- psychological (food, water, shelter, clothing)
- safety and security (health, job, financial)
- love and belonging (friendship, family, connection)
- esteem (respect, achievement, the need to be a unique individual); and
- self-actualisation (achieving one's fullest potential).

Needs lower down in the hierarchy must be satisfied before individuals can attend to needs higher up.

Unfortunately, too often, a person with disability does not have these basic needs met in the lower levels. The general picture is a segregated life from the rest of society, congregated with others that have disability which starts with their education setting, then being funnelled into a day care program and/or Australian Disability Enterprise, living in a group home with people who are not flat mates of their choosing. This usually entails filling their time with "activities" rather than having a sense of purpose in employment, where it is rare to have relationships beyond those of paid supports, where decisions are made on their behalf, being "done to" rather than "listened to", where self-advocacy, and supported decision making are absent.

Under these circumstances, most people would express their dissatisfaction at not having their basic/psychological/self-fulfillment needs met, and struggle to conform to the behaviours expected from our society, which our society has labelled "behaviours of concern".

Therefore, to properly address the goal to reduce and eliminate restrictive practices in all settings, we strongly advocate for an end to segregation of people with disability where they are genuinely included in our society, listened to through whatever form of communication or device that is needed in order to be heard, and supported in their decision making to have self-determination over their life. There must also be an allowance for innovative and contemporary practices that support meeting these needs. These concepts need to be expressly adopted by the Bill.

Further, the Bill must ensure the government invests in initiatives to educate service providers, schools, and other services about the rights of people with disability, including children and young people, the national/state commitment to reduction and elimination of restrictive practices, and the organisation's role and responsibility to make this happen.

Supported decision making

The Bill stipulates that the person with disability must be consulted in regards to any proposed restrictive practice, however, it does not communicate a process of supported decision making.

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 be involved in all matters relating to them being supported in relation to behaviors of concern and in this respect been seen as the primary person to consult with.

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.*
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> *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."*
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> Parent

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. Furthermore, the ability for congregated service provision adds more complexity around the ability or willingness for services to adapt the persons support considerations in a manner that would minimise and remove the need for restrictive practices over time. Often, this is simply due to the amount of people being supported in one environment.

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.

Transparency of monitoring and reporting

There must be transparency in monitoring and reporting on the use of restrictive practices in all settings. It is not all clear in the Bill how this will occur. The provision of data should be used in such a way that allows for rigorous investigation of the use of restrictive practices. It is not clear whether in each setting, who will do the reporting, what type data will be collected, how to ensure the data being collected is not just for the sake of it but to provide a clear picture of where there may be good practices/overuse of restrictive practices across all settings in the NSW, established targets to reduce restrictive practices, what mitigating strategies are being made to reduce restrictive practices, how this data will be reviewed, whether that data will be made publicly available.

We recommend to include in the Bill requirements that the type of data collected and the reporting of data be used as a mechanism to promote the reduction and elimination of restrictive practices in all settings. It is important to be able to establish where there may be clusters of poor practice and/or over reliance of restrictive practice in various settings/ geographical locations. It is equally important to be able to highlight where reductions of restrictive practice have occurred and to showcase these exemplars of practice, and bring awareness as to how this has occurred.

In addition, we suggest that these investigative questions be a requirement of the authorising panel at the 12 month plan review to ensure proper time be provided to allow for an in depth analysis of how the person with disability’s basic/psychological and self-fulfillment needs are being met, what works well, what is getting in the way, the way forward.

Authorisation Panel

Family Advocacy maintains that having the NDIS provider on the panel constitutes a massive conflict of interest. The provider has a real and perceived bias towards the provider needs over the interests of the person with disability and are therefore unable to act independently. It is a positive proposition that the behaviour support practitioner must not be employed by the NDIS provider as well as being a person different to the behaviour support specialist that wrote the behaviour plan.

In our experience, it is often difficult for the behaviour support specialist to be truly independent on the panel as often it is likely that the behaviour support specialist and provider already have a working relationship that is most likely has a financial benefit involved. Or there is the danger that the provider continues to select the behaviour support specialist that is more amenable and agreeable to their viewpoint. Worst case scenario is where a large provider contracts out to a small pool of behaviour support specialists and simply rotates between who writes the behaviour plan and who authorises the restrictive practice.

Often, once this mutually beneficial relationship has been established, the behaviour support specialist is less likely to consider the ‘actual’ needs of the person with disability as too much consideration is given to the possible constraints of the provider to adopt and implement a plan that will work towards eliminating a behaviour of concern. This conflict of interest, therefore, works against the interests of the person with disability.

Family Advocacy recommends that the authorisation panel be convened entirely independently of the provider. If the proposed authorisation panel suggestion is pushed through, at the very least, a trusted person should also be able to be on the panel or at least there must be a requirement that they have been consulted and their signature required.

As a general rule, the parent or family member has a natural authority for the person with disability in their life. 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/assets/Uploads/Downloadables/453f2744d5/10753-The-Natural-Authority-of-Families-MKendrick-CT06.pdf

Further to this point, the authorisation of restrictive practices should only be allowed by a person who has a clear understanding of what is an evidence-based approach to the mitigation of behaviours of concern and what is not, and acknowledge that the term last resort, commonly used by those excusing restrictive practices, means that every other approach has been used with fidelity, without success. To this point, last resort should be seen as a short-term measure.

Accountability

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. We are pleased the Bill attempts to cover all settings by referring to NDIS providers as well as government departments. However, we would like clarity as to some scenarios that may not be covered in the Bill:

Does the Bill extend to the non-government education sector such as Catholic schools and Independent schools?

Does the Bill extend to people who independent contractors to a government department or NDIS provider? For example, a teacher in a youth detention centre? a privately employed security guard in a prison or detention centre? a support worker in a group/ nursing home? an uber/taxi driver driving a person with disability to an activity/ hospital appointment?

Will some restrictive practices will be exempted from authorisation and consent by regulation and if so, which ones?

In the Bill, one glaring piece that is missing is there are much less rigorous obligations placed on NSW government agencies compared with those placed on NDIS providers. Whilst we are pleased that seclusion of all children has been prohibited in NDIS settings, why should this not apply in all settings? Especially in schools and out of home care? There must be consistency across all settings.

Accountability in the Education sector

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.

The education sector provides a good example of the real risks students with disability face on a daily basis when the reduction and elimination of restrictive practices are not clearly and expressly mandated from the government. In spite of the legal frameworks in place such as the *Disability Standards for Education* (2005), the National Safe Schools Framework, restrictive practices are being widely used in education settings.

For example, the 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), and reported serious concerns about ‘harm caused to students when practices like restraint and seclusion are used’.

Children and Young People with Disability Australia (CYDA 2017) has completed national education surveys consistently since 2015. Respondents to their 2019 survey reported:

31% of students with disability experienced restraint or seclusion at school in the last year and 11% experienced both.

21% of students with disability had experienced restraint in the last year, with the most common form being physical restraint, followed by psycho-social, mechanical and chemical restraint.

21% of students with disability experienced seclusion in the last year. The settings for seclusion included solitary confinement with and without supervision in a room, classroom or staff office.

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 reflect the same percentage as the national results (Poed et al. 2017).

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.

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.

To genuinely uphold the objects and guiding principles of the Bill, it is imperative that these real and longstanding issues in education environments (government and non-government schools) be expressly addressed in the legislation. It is essential for the safety of all children at school.

We also know that as a result of inappropriate restrictive practices in schools, children with disabilities are leaving the school system and transferring into adult services with difficulties that could have addressed in the education system. Behaviours of concern must have an early intervention focus and the Department of Education should take into account the trauma that children with disabilities are bringing into the adult disability services due to their school experience. Another good reason to be more clear with the Department of Education through the legislation regarding the reduction and elimination of restrictive practices.

The need for a robust, independent and transparent complaints policy and procedures

Students with disability face unacceptably high levels of abuse and violence at school, including restrictive practices. This can take many forms such as a student being told they cannot attend the school unless they take medication, being physically dragged along the ground by one leg, having one's motorised wheelchair turned off so they could not get out at recess (in the name of safety), not being provided the relevant communication device when that is their only way of communicating or being left in a wheelchair facing a wall, forced partial enrolments, suspensions/expulsions due to the school's failure to make reasonable adjustments (Budget Estimates September 2020 revealed 75% of students suspended last year had a disability).

> *Yes, I complained and I was told I was ungrateful. There is a lack of due process and a big power imbalance. We need an independent process with a body that has investigative powers.*
>
> Parent

> *There is no independence to complaint systems. The department of Education polices itself. Parents of students with disability and students with disability are very vulnerable to the consequences of lodging complaints. Therefore they tolerate harassment and victimisation that many others would not. The system is geared to the education staffer being presumed in the right, especially as the process is initially undertaken by the school itself. It could be vastly improved by an independent complaints process.*

Parent

In cases where a parent does complain in the education system, our recent survey revealed 70% of parents were not satisfied with the current complaints process (27% very dissatisfied and 43% dissatisfied), with only 17% stating they were satisfied. The current complaints mechanism lack objectivity, accountability, transparency and timeliness. The experiences shared by families tell of a system that investigates itself. The principal backs the teacher, the regional office backs the principal, and so it goes up the bureaucratic line within the Department. A big problem lies in the complaints process not being independent.

This has a flow on effect where students and their parents suffer harm and mental health issues such as low self-esteem, shame, depression, anxiety, PTSD.

The proposed Bill does not provide a robust, independent system for families. This lack of due process must be remedied. The Bill needs to:

- Ensure the Department of Education has clear policy with independent procedures and processes for responding to allegations of unauthorised use of restrictive practices and to appeal and consequent suspensions/expulsions to set clear guidelines and expectations for the benefit of external complaints. It is very important to ensure the school community understands how to make complaints of this nature and how the complaints will be investigated. It is critical that families and other also have a chance to feed into this.
- Ensure accessible online content in plain English or Easy Read advice is provided to parents about the right to complain about the unauthorised use of restrictive practices and how the complaint will be investigated, as well as the right to appeal (and this must be an external process).
- Ensure there is an independent complaints/review process for a school’s unauthorised use of restrictive practices.
- Acknowledge input from all stakeholders such as the principal, teacher, SLSO, allied health professional, parent, external expertise with evidence-based practices as to what constitutes a reasonable adjustment.
- Create an independent evidence centre for learning/awareness campaign (at State or Federal level) to guide schools/parents as to what constitutes a restrictive practice.
- Acknowledge that whilst guidance can come from evidence-based examples, students with disabilities are not a homogenous group and so to apply a “one size fits all” approach can be dangerous when it comes to restrictive practices. See the individual first not the diagnosis.
- Ensure no Principal investigates a complaint against themselves.
- Maintain the right to due process.

- Have an independent appeals process for suspensions/expulsions. (In Victoria, they now have an independent body for appeals of expulsions and the number of expulsions has dropped from 285 in 2018 to 185 in 2019)[1]

Additionally, while a complaints mechanism is usually the last resort for families, Family Advocacy suggest making further use of the role of the NSW Ombudsman or another type of independent body such as the Ageing and Disability Commissioner (that can be real-time responsive) to help track and provide a fuller picture of breaches of the Disability Standards in relation to restrictive practices. This would provide a less formal option for family complaints than the Human Rights Commission. Most parents are currently unaware of the Ombudsman's role in addressing complaints regarding schools.

In this regard, Family Advocacy recommends the Bill includes:

- further use of the role of the NSW Ombudsman or another independent body such as the Ageing and Disability Commissioner to help track and provide a fuller picture of breaches of the Standards in NSW, and that they be resourced to do so.
- that the Department of Education improve mechanisms to monitor compliance and that the Australian Human Rights Commission (AHRC) be empowered to intervene in cases of breach.

Strengthen the protocols around collaboration

Collaboration requires a commitment and a planned approach by all parties working towards a common goal by sharing responsibility and expertise. For successful inclusion of a student with disability (thereby significantly reducing the likelihood that behaviours of concern will appear), collaboration in schools takes many forms and involves multiple stakeholders working together to support the student such as the parent, teacher, teacher's aides and other professionals. For collaboration work to be effective, time and space need to be allocated for collaborators to develop a working relationship, establish roles, plan, implement, and reflect.

Similarly, the NSW Department needs to get better at collaboration between Department rather than being separate silos and prioritise the student at the centre of their decision and how they operate. It is worthy to note that the NSW Department of Education is currently reviewing its Student Behaviour Strategy and Policy at the same time as this Bill regarding Restrictive Practices. It is absolutely imperative that their be cross-departmental collaboration and communication to ensure there is consistency with the objective of the Bill to reduce and eliminate restrictive practices and the Department of Education's Student Behaviour Policy.

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[1] https://www.theage.com.au/politics/victoria/school-expulsion-rates-plunge-after-students-gain-new-power-to-appeal-20200819-p55n8l.html

We are concerned there is a real danger that collaboration will not occur. There are multiple layers of legislation/policy/strategy between state and federal parliaments, which makes this area of restrictive practices complex, and hard for a student with disability and their family member to navigate. With so many stakeholders involved, there is the real risk that each stakeholder with feel a limited sense of responsibility but no one with take an overall sense of responsibility to make sure the person with disabilities interests are protected.

Transparency of engagement between Commissions and Government departments

Further to this theme of collaboration and taking responsibility, the Bill allows for the NSW Ageing and Disability Commissioner to exchange information to relevant bodies, including the NDIS Quality and Safeguards Commission and government departments. It does not provide transparency of how it will engage with the *NDIS Quality and Safeguarding Framework* and the NDIS Quality and Safeguards Commission. Family Advocacy would like to see more clarity around how the legislation will interact with the NDIS Quality and Safeguards Commission and government departments.

Consent

Family Advocacy are concerned that there is no obligation to obtain consent for a practice that has an interim authorisation which can be as long as six months. We suggest this be reduced to three months as this should provide enough time for a comprehensive authorisation to be completed.

We take issue that the NDIS provider can decide whether or not a person can give their own consent. A person with disability should be able to seek review of this decision by the Ageing and Disability Commissioner.

We assert the term “trusted person” is inappropriate as it makes the assumption that the person with disability trusts the “trusted person” whereas in reality, that may not be the case. In some circumstances, people will not trust their guardians, carers or relatives. We suggest rather the term “person responsible”, not different to the term used under the Guardianship Act, would be more appropriate and accurate.

Family Advocacy is extremely concerned with the Bill allowing for the service provider to obtain consent from a person lower on the hierarchy of “trusted person” if the provider is satisfied that a higher person is not capable to fill the role or not suitable for the role taking into account the wishes of the participant. There is nothing to stop the provider bypassing a family member who is a strong advocate for the participant.

The skills and experience of decision makers

There needs to be a safeguard on who is the independent behaviour support practitioner on an authorisation panel. There is enormous variation in the skills of behaviour practitioners and less conscientious providers may choose a practitioner who will not challenge them. At present, the independent practitioner is allocated by the Department of Communities and Justice. The Ageing and Disability Commission should be given this role.

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.

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