Submission to the Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability

Submission No.5: Response to Restrictive Practices Issues Paper

> *"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

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

April 2021

Acknowledgement: Family Advocacy would like to acknowledge the traditional custodians of the lands on which this report has been written, reviewed and produced, whose cultures and customs have nurtured and continue to nurture this land since the Dreamtime. We pay our respects to their Elders past, present and future. This is, was and always will be Aboriginal land.

Table of Contents

Summary of our Recommendations

1. The Disability Royal Commission explicitly recognise restrictive practices as violations of Article 15 of the CRPD and violations of the Convention against Torture and other Cruel, Inhuman or Degrading Treatment or Punishment.
2. The definition of restrictive practice be expanded beyond that provided in the issues paper to include: Mechanical, Seclusion, Environmental, Social, Chemical, Physical, Psycho-social, Organisational, Communication, Decision Making, Consequence driven.
3. The Disability Royal Commission adopts the Social Role Valorisation framework, acknowledging that when a person has valued roles in and out of the home, most behaviours and issues disappear, and thus the use of restrictive practices can be minimised.
4. The Disability Royal Commission acknowledge the importance of the right relationships as a critical factor to the reduction and elimination of restrictive practices.
5. The Disability Royal Commission recognise the process of supported decision making is essential. It is imperative that the person with disability be consulted in regards to any proposed restrictive practice, with clarity on how to communicate a process of supported decision making. 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.
6. The Disability Royal Commission to recognise and respond to intersectionality – the compounding disadvantage that occurs for those with disability that are part of other marginalised groups – and recognise these additional barriers.
7. The Disability Royal Commission recommend that all government departments expand the collection of data on the number of people with disabilities being subjected to restrictive practices in all settings.
8. To allow transparency in monitoring and reporting on the use of restrictive practices in all settings, the provision of data should be able to be used in such a way that allows for rigorous investigation of the use of restrictive practices.
9. The Disability Royal Commission acknowledge the need for a robust, independent and transparent complaints policy and procedures.
10. The Disability Royal Commission acknowledge the system/policy fragmentation and the need to strengthen the protocols around collaboration and the need to ensure a coordinated multi-agency response between government and non-government, between departments within NSW, between departments in NSW and the Commonwealth.
11. The Disability Royal Commission acknowledge the need for transparency of engagement between Commission’s and government departments.
12. 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; a family member /guardian/friend and their General Practitioner. Due to conflict of interests, the Service Provider should be kept at an arm's length in the process.

13. The Disability Royal Commission acknowledge that "family is the natural authority of the person with disability" and take this into account in its recommendations.
14. The Disability Royal Commission establish a nationally consistent legislative and administrative framework for the protection of all persons with disabilities, including children, from the use of psychotropic medications, physical restraints and seclusion under the guise of "behaviour modification", including corporal punishment, in all settings, including the home.
15. The Disability Royal Commission acknowledge the value of Inclusive Education to help influence community's attitudes. From a broad school system perspective, we recommend a schoolwide approach to social, emotional and wellbeing school policies are required to influence school culture and climate.
16. The Disability Royal Commission involve and engage people with lived experience of disability and those that support them. This must be genuine and deep engagement, not tokenistic.
17. We recommend a commitment be made at state and local levels for funding projects and initiatives focused on promoting inclusion and improved community attitudes towards disability, which also includes the evaluation of good practices.
18. We strongly advocate for an end to segregation of people with disability whereby 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.
19. The Disability Royal Commission endorse the recommendations in 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).
20. The Disability Royal Commission recognise the absolute necessity of providing for advocacy services when considering restrictive practices. Due to the higher risk of abuse of people with a disability in any setting, there will always be a need for independent disability advocacy.
21. The Disability Royal Commission make a recommendation that Federal, State and Territory governments provide funding in perpetuity for disability advocacy, representation and information services for people with disability.

About Family Advocacy

Family Advocacy is a state and federally funded disability advocacy organisation that works across New South Wales (NSW) and was founded 30 years ago by families who were concerned with the rights and interests of people with developmental disability[1] (hereinafter “disability”) over the span of their whole life. This includes Australian First Nations people and culturally and linguistically diverse people with disability.

We provide support in the following ways:

- Statewide Advocacy advice and advocacy information to individuals
- Advocacy development for family members of a person with disability - Advocacy is often undertaken by families and can be required over the lifetime of their family member.
- Systemic Advocacy - informing government regarding legislation, policy, funding, monitoring, and practice in areas that impact on the needs of people with disability.

Our goal is to advance and protect the rights and interests of people with disability so that meaningful lives can be enjoyed by experiencing the same opportunities and living conditions as the majority of Australians. This includes the right to live safely and with dignity, free from violence, abuse, neglect or exploitation. We recognise that the advocacy undertaken by families with or on behalf of their family member with disability can be the greatest safeguard in their family member’s lives.

Our Submission

Family Advocacy welcomes the opportunity to make a submission to the Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability (hereinafter, the ‘Disability Royal Commission’) in response to the Restrictive Practices Issues Paper.

Family Advocacy wholeheartedly agrees with the view of the UN Special Rapporteur on Torture and Other Cruel, Inhuman or Degrading Treatment or Punishment (Special Rapporteur on Torture) where it has been noted that restrictive practices "remain invisible or are being justified" as legitimate treatment, behaviour modification or management when "perpetrated against persons with disabilities". Instead, these practices should be recognised as torture or other cruel, inhuman *or* degrading treatment or punishment (torture and ill-treatment) and called for an “absolute ban on all coercive and non-consensual measures, including restraint and solitary confinement”[2]. We strongly urge the Disability Royal Commission to uphold the same viewpoint and zero-tolerance policy on restrictive practices.

We urge the Disability Royal Commission to be brave and bold in its approach to significantly improve the lives of people with disability and concretely work towards the reduction and elimination of restrictive practices towards a zero-tolerance policy. In this regard, we welcome the Disability Royal Commission’s reference to the United

---

[1] Developmental disability is a disability that occurs in the developmental period of a person’s life (in the period from conception to adulthood) and includes but is not limited to: autism, intellectual disability, cerebral palsy, spina bifida, and any combination of physical, intellectual or sensory disability.

[2] Manfred Nowak, Interim Report of the Special Rapporteur on Torture and Other Cruel, Inhuman or Degrading Treatment or Punishment, 63rd sess,UN Doc A/63/175 (28 July 2008) para 58.

Nations' *Convention on the Rights of Persons with Disabilities* (CPRD) and many of its principles in the Terms of Reference. As Australia has signed and ratified the CPRD, any recommendations made by the Disability Royal Commission concerning people with disability must be based on its principles with a human rights framework.

Family Advocacy is of the view that the Disability Royal Commission should explicitly recognise restrictive practices as violations of Article 15 of the CRPD and violations of the Convention against Torture and other Cruel, Inhuman or Degrading Treatment or Punishment.

However, we would be concerned if the Disability Royal Commission was to simply investigate solutions on how to enhance legislation/policy, complaints and oversight mechanisms, training and developing best practice management practices as this would provide only a limited examination and uphold the ongoing downplaying of torture and ill-treatment perpetrated against people with a disability. We invite the Disability Royal Commission to dig deeper and see in the context of reducing the need for restrictive practices, the critical nature of right relationships, getting one's basic human needs met, having supported decision making, the powerful impact of being in typical settings/environments, and the importance of independent advocacy.

We are providing comment and recommendations in relation to the use of restrictive practices in all settings in which it occurs, typically in traditional places of detention such as prisons and juvenile detention centres but also disability specific settings such as residential accommodation, day programs, Australian Disability Enterprises and education settings.

Q 1: What are restrictive practices? Does the explanation in this paper need to change?

Family Advocacy recommends the definition of restrictive practice should be expanded beyond that provided in the issues 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) [3]. The examples provided within each area of the definitions are based on anecdotal evidence provided by our families directly or stories 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, confined to makeshift cages
- ***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" or solitary confinement under the guise of a "sensory room"
- ***environmental***, such as preventing free access to all parts of a person's environment or house. For example, locking the refrigerators, or being restricted to fenced-off sections of a playground, locking the front door and having no key or way out
- ***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

---

[3] Purple Orange are a social profit organisation on a mission to create a world where people who live with disability get a fair go at what life has to offer. https://www.purpleorange.org.au/who-we-are/who-we-are

accommodation to go on an outing again, not being allowed to join a school extracurricula group or lunchtime group, being put in the library 'because they cannot cope with the playground', told to eat lunch separately in the classroom before joining their peers

- ***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, not allowing a person in a group home to go out as it does not fit in the staff schedule, not allowing visitors into their own group home
- ***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.

Q 2: What types of restrictive practices are applied to people with disability? Are certain types of restrictive practices more common than others?

People with disability are subjected to restrictive practices in all settings within society including the human service system such as group homes, Day Programs and Australian Disability Enterprises, as well as within government service settings such as schools, and hospitals.

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.

In the education space, students with disability face unacceptably high levels of abuse and violence at school, including restrictive practices, as a form of "behaviour management". 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 (NSW Parliament Budget Estimates September 2020 revealed 75% of students suspended in 2019/2020 had a disability).

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 recent 2017 Parliamentary Inquiry on Education of students with a disability or special needs in New South Wales reported serious concerns about 'harm caused to students when practices like restraint and seclusion' are used.[4] It was brought to light that advocacy groups 'are getting increasing reports of restraint and seclusion'[5]. Below are some de-identified examples of such reports. These examples have been written by Family Advocacy staff based on phone calls by those staff with parents:

Physical

My son came home from school very distressed. Once I finally managed to calm him down he told me he had been pinned to the ground in a prone position by multiple staff members at school. I was not informed that a restrictive practice had taken place. He did not have a behaviour support plan in place at the school. This is not acceptable. He has been traumatised ever since.

My son came home upset after school one day and told me the learning support teacher dragged him by the leg whilst hiding under a table. The school did not report this incident to me. Apparently, he was wanted access to the computers and was not allowed to. Rather than give him some space and time to accept this, he was boxed into a corner by the teacher which felt threatening so he hid under a table. Again rather than keeping calm and giving space to allow for reasoning and self-regulation, the teacher chose an antagonising approach which only made things worse. My son was grabbed by the leg and dragged along the floor. My son is a teenager. He felt ashamed and still does when in this teacher's company.

Chemical

After an incident occurred where my son "lashed out", I was told my son could not come back to school unless he took medication to calm him down. What they failed to tell me, and I subsequently found out, was that he was surrounded by four boys and he was being bullied. If the school had addressed the bullying, the behaviour would have stopped. Instead, my son was in fear of his life and he retaliated to protect himself. When I picked him up, he was laying on the floor in the foetal position, clearly distressed and traumatised

Mechanical

My son was not allowed to use his motorised wheelchair at recess in the name of "safety" and so the staff turned the power off to the chair and he was left without any way of moving.

Psycho-social

In Kindergarten, he had the most amazing teacher that understood different learning styles, really got to know him and my son would run out of class with a smile on his face. The next term he got a new teacher who was the polar opposite, rule oriented without flexibility and with a punitive approach. One day, he would not come out of class and I found him under the table, screaming. The next morning he got himself ready early saying he wanted to go to the bin. Turns out, the teacher had chastised him for not sitting still for one hour, ripped his sticker book rewards chart and told him he would have no friends if he kept behaving that way. I say again, this is in Kindergarten.

---

[4] 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,* Final Report, September 2017, p 106.
[5] 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,* Final Report, September 2017, p 24.

Social

In Year 7, my son who is in a wheelchair was placed in the "out of bounds" area with two teacher's aids and no one else around. It was at the top of a hill. All the Year 7's played at the bottom of the hill. So isolating. This went on every recess and lunch for a whole term before I found out. There was no discussion or problem solving, nothing.

In Year 10, all the students were to attend a tax seminar but the room it was scheduled in was upstairs so he could not attend. This was his fourth year in the school and this basic consideration was overlooked.

Organisational

My child was specifically asked not to attend the swimming carnival, athletics carnival, excursions, incursions or school camp. No inclusion happening at all. I believe this was the school's way to get us to leave. Often, permission notes would 'accidentally' not come home.

Communication

My child was never given support by someone that can communicate Auslan sign language with her, the language she can understand and respond to. The teacher's aide knew key word signing she had learned at a special school, this is very different to Auslan and my child could not communicate in this language. It's like having a Spanish speaking teacher when you speak English. Also, my child had an FM system, which is a microphone that would need to be attached to the teacher's lapel and feed into her hearing aide. This was sometimes used and sometimes not. The teacher was supposed to take it off during classwork time when she was going around to individuals but it would often be left on. This was very distracting and meant my child found it hard to concentrate to do classwork.

Seclusion

Use of sole confinement and time out placing my son away from their peers and natural supports and safeguards.

A child with autism was restrained by teachers and locked in a time-out room for more than an hour, and despite instructions that he was to be checked on after 3 minutes, a teacher standing outside the room ignored him, during which time he wrapped an electrical cord around his neck.

My child was being placed in their wheelchair in the out of bounds area of the school clearly away from their friends. His friends told me this, the school did not even consider changing this, I think it suited them

I dropped into school and saw my child facing a wall in a line with other students in wheelchairs. I decided right away that that was his last day in the school and we moved to the local regular class, much better.

Sent to 'planning room' for misbehaviour for specified periods of time - mostly gets into further trouble as inadequate supervision and he leaves. He's told he should not leave until teacher gives permission - mostly occurs during recess or lunchtime

Q 3: How often are people with disability subjected to restrictive practices?

On the basis of the examples provided from families in Question 1 and Question 2, we would say restrictive practices are too common and occur in all settings. Unfortunately, it is generally accepted within the disability sector that restrictive practices are seen as part of the fabric of the sector. Too often in schools, time-out rooms are being used in ways that are not consistent with the guidelines that have been issued by the NSW Department of Education. In group homes, restrictive practices are all too commonplace which then highlights the disability sectors reliance on restrictive practices and there is less likelihood of moving towards elimination and/or removal of such practices.

It is worth noting here, that as many restrictive practices are in place for years and don't move past this stage many people are blocked out of many domains of life and in some cases for decades.

Q 4: Where or in what circumstances are restrictive practices used?

All settings - including schools (government and non-government), hospitals, workplaces, Day Programs, Australian Disability Enterprises, group homes. This is due to the culture and mind set leading to these actions which is why it is across all settings including settings with so called "expertise and understanding towards people with disability. This stems from an approach of the medical model of disability and the mentality of 'fixing' the person rather than supporting them.

Q 5: Why are restrictive practices used?

The common justification for a restrictive practice is to protect the person or others from harm. We strongly disagree. Restrictive practices are a cruel and inhumane practice that often, create more harm. Due to people with disability being devalued, "less than" or "othered", restrictive practices are a way of managing a perceived problem. In other words, the person using the restrictive practices perceives the person with disability is the "problem". The real problem is that we don't understand enough about why people with disability are engaging in those behaviours we label as challenging.

In fact, people without a disability can also engage these behaviours but they are much more private. But people with disability have no privacy. Generally, someone is always present in their lives. It is mainly that people with disability are grouped together in very public settings such as under the watchful eye of support workers or group home staff or a special education teacher that these behaviours become under a microscope. The person with disability uses the behaviour as a form of communication, or a feeling and because we don't understand it, we go direct to punishment.

Instead, we need a system that is agile and willing to invest in the necessary considerations and changes to support the person with disability. We need to normalise a person's living conditions to normalise behaviour. It is when we keep a person in distorted concepts such as in a segregated school, or a group home or an ADE that maladaptive behaviour may arise. According to the Social Role Valorisation framework, when a person has valued roles in and out of the home, most behaviours and issues disappear. For example, a young man lived in a behaviour management house for 10 years and had a reputation as being violent and aggressive. With the right supports, he moved in with a non-disabled couple and got a job at Woolworths. He was really good at knowing where all the items were located. He ended up winning an Employee of the Month Award several times over the years. His reputation changed as he was known as a sweet and gentle man. As an aside, this man's support package reduced dramatically as he did not require support staff to manage his behaviour as it disappeared and he was also living independently with a few supports from his flatmates.

We strongly urge the Commissioners to watch these short videos that were taken after a workshop Ann Greer presented for Family Advocacy on “Responding well to people "labelled" as having challenging behaviour - Is it behaviour or is it communication?”

See https://www.family-advocacy.com/our-resources/responding-well-to-people-labelled-as-having-challenging-behaviour/.

The workshop encouraged people to:

- Determine a process that is respectful and non-punishing
- Discover how you can collaborate to find the motivations, effects and consequences
- Develop a range of strategies that can be used to minimise the effects of a person's actions

Ann Greer has over twenty years of formal experience in working with people who are labelled as having challenging behaviour and is a well-known and highly sought-after presenter in Australia and New Zealand. She has a deep commitment to assisting everyone to be part of their community as active members - receiving and contributing. We refer the Commissioners to Ann Greer. For those supporting a person with disability, apart from having a belief that a person with disability is a person to be valued, it would assist for them to be taught a suite of strategies to use to support people with disabilities. For example:

- Questioning what is the person trying to tell me? Not how do I stop this behaviour.
- How do we know when these behaviours are starting to build and can you adjust your expectations with what is happening today, your tone of voice? Then the moment you feel a person is on edge, you recognise that and change the things you might do and how you do them.

- Understanding the role of boredom. A person with disability does not have socially valued roles, and doesn't have real things to do other than "time-wasting" activities such as going to group bowling as that is what is scheduled for the Day Program that day. As a result, they generally have a low skill level and when skills are low is when behaviour can tend to happen.
- What are the good things in life for this person? Working on a meaningful life, getting plugged into the community is a critical part of the strategy.
- Motor movement differences – start, stop, transition, sequencing. Transitions seem to be the most problematic time for behaviour, usually mostly anxious, so we need to provide assistance to help a person understand what is happening now and what is happening next.
- Share power and control – if a person feels they have more control over their life, their behaviour will reduce. We need to stop saying 'no' all the time. The more we say "yes" the more a person is topped up and thus the more tolerant they would become when the word "no" is said to them.
- We should be taking the time to consider what are the conditions around that person that might be creating the reaction or "learned response" from the person with disability, and what can we do to change this learned response.

We know restrictive practices do not work well especially in the long term, and never fixes the problem. It is a very slippery and dangerous slope that places the most vulnerable at risk by placing a lot of power and trust, in the hands of the person carrying out the restrictive practice to be competent, compassionate, make a sincere effort to know and understand the person with disability really well, have a high ethical and moral compass, be compliant with reporting requirements. Also, a lack of direction or alternative approaches to support the person and address their needs so the person with disability can live a meaningful life. Without guidance, a support worker is left to manage the issue at hand and so it continues.

Q 6: What are the effects of restrictive practices?

We refer to the examples provided. Restrictive practices can have the effect of:

- Causing physical injury
- Causing psychological harm
- Causing a significant and traumatic impact
- Limiting the opportunity that a child/person has to interact with their peers
- Damaging relationships and trust between the person with disability and the person carrying out the restrictive practice
- Increasing feelings of isolation, othering, helplessness and deep wounding on multiple levels (physical, mental, emotional) due to being treated with a lack of dignity, being treated like a child, being seen as a menace.
- Minimising or reducing self-determination
- The use of restrictive practices desensitises both the person using it and the person subjected to it (for example, educational personnel and students with disability), undermining their ability to recognise these practices as unacceptable and as forms of violence, abuse. neglect and exploitation, and leads to acceptance of other forms violence and ill-treatment.

In the long run, these effects restrict a person with disability's access to sustainable relationships, gaining sustainable employment which we all know is an indicator that leads to poverty, lack of housing choices, and welfare dependence. That is, a very limiting life course.

Many people with disabilities are in segregated environments which reduces their social networks to only, or mainly, paid supports and this makes it more difficult to report unauthorised restrictive practices.

Physical seclusion and being surrounded by mainly paid supports grooms people with disabilities into a life of being socially isolated which ultimately reduces the safeguarding which comes inherently with freely given relationships.

All of the family examples provided throughout this submission share a common message of 'I didn't realise this was happening' which is a clear indication to this point that we can't rely on workers. In fact, in many of those examples it was the peers letting mum know what was going on.

Q 7: Is the use of restrictive practices different for particular groups of people with disability? If so, how?

A. How is the use of restrictive practices on people with disability of different age, sex, gender identity, sexual orientation and race different? Are restrictive practices used on them at higher rates?

B. How is the use of restrictive practices on First Nations people with disability different? Are restrictive practices used on First Nations people with disability at higher rates?

C. How is the use of restrictive practices different for culturally and linguistically diverse people with disability different? Are restrictive practices used on culturally and linguistically diverse people with disability at higher rates?

Acknowledging intersectionality

It is important to acknowledge the compounding disadvantage that occurs for those with disability that are part of other marginalised groups such as being of Aboriginal and Torres Strait Islander backgrounds, CALD backgrounds, LGBTQIA, and those living in out of home care, youth justice, as well as rural and remote communities. The Commission should provide particular consideration to and recognise these additional barriers, particularly in terms of determining whether an adjustment is reasonable.

Q 8: Does the use of restrictive practices lead to further violence and abuse, neglect and exploitation of people with disability? If so, how?

Yes! There is a very slippery slope between the use of a restrictive practice and abuse, violence, neglect and exploitation. The use of restrictive practices de-sensitises both the person using it and the person subjected to it (for example, educational personnel and students with disability), undermining their ability to recognise these practices as unacceptable and as forms of violence, abuse. neglect and exploitation, and leads to acceptance of other forms violence and ill-treatment

People with disability who are responded to in a certain way, can develop a strong response to their environment and at times, this leads to more violence as a means of lashing out as their rights are violated. In some respects, it can lead to learnt behaviours with only being shown punishment as a means to minimise. The data of reduction and elimination should talk to this very strongly.

We have heard of many examples where restrictive practices are in breach of existing policy and legislation. As previously stated, 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, and must be minimised and only ever used as a last resort. It also acts like a ‘get out of jail free’ card with the ‘last resort’ open to interpretation and varying levels of implementation and an open door for leadership to retain their unconscious bias and reactive measures towards the people they serve.

Q 9: Are current approaches to restrictive practices effective? This may include laws, policies, principles, standards and practices.

A. Are there any gaps in the current approaches?

B. If so, what are the impacts of these gaps?

There is no consistency amongst the States and Territories. Within NSW, there are large gaps between policy and practice. The policy is that restrictive practices need to be reduced and eventually eliminated and only used as a last resort. However, as we hear from families, this is not the case in reality. Processes can be legislated but beliefs and values cannot. Attitudinal change is an important component towards closing this gap. Another important component is appreciating the critical nature of relationships. Below are some suggestions of how to close these gaps.

Strengthen Accountability

To ensure the human rights approach of the Disability Royal Commission is not simply an aspiration statement, more accountability is necessary in relation to restrictive practices, as well as a structure to monitor progress. One of the impediments is the challenge posed by the silos within the multiple tiers of government in this country. There is a need for the implementation of a national framework with clearly defined roles and responsibilities for each level of government and other key stakeholders to overcome the inappropriate use of restrictive practice with the long term approach that will eventually eliminate the need for restrictive practices at all.

Clarity is required to set out key responsibilities, timeframes, targeted outcomes, key benchmarks and the role of key partners. As it stands, we urge the Disability Royal Commission to be clear about strategic planning around inclusion and to measure the success or otherwise of the rights of people with disability to be free from violence, abuse, torture, or cruel, inhumane or degrading treatment.

There are opportunities to build on the frameworks that exist to deliver better outcomes for people with a disability including building in more robust accountability, transparency, monitoring and oversight.

Accountability in the education sector

As a case study of one setting, we will look at this particularly in the light of the school setting due to its critical importance in shaping the adult experiences post school. Currently, there is an absence of oversight of actual and potential ill-treatment of students with disability in schools. The impact on students with disability, often those labelled as having challenging behaviour and complex needs, is significant.

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 UNCRPD as the DISABILITY ROYAL COMMISSION proposes, 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 been 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 (and other education sectors such as the independent and catholic schools) through the legislation regarding the reduction and elimination of restrictive practices.

Gap in data collection

Family Advocacy is concerned by the fact that there is no disaggregated data (in NSW or nationally) on students with disabilities, including on the use of restrictive practices, despite numerous recommendations to do so from inquiries over the last 5 years. It is essential for the Department of Education to **expand the collection of data on the number of students with disabilities on the use of restrictive practices.**

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

> *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.*

> *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.*

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. It is not uncommon to hear of a fundamental breakdown in communication, trust and respect between the school and the family/student. Often, the problem has escalated to a point where the issues in dispute become unresolvable, and the family is left with no option but to take legal action or leave the school. If an independent external body existed to resolve certain disputes before the family and the school become too entrenched in their positions, there could be a possibility of resolution.

We refer to a recent article in ABC News "Sydney School under investigation for locking child with autism in 'sensory room' dated 26 November, 2020 https://www.abc.net.au/news/2020-11-26/nsw-launches-investigation-into-school-locking-up-autistic-child/12924310. This article highlights there is not a robust, independent system for families. This lack of due process must be remedied 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 any 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.
- Have a process whereby it needs to be shown how other actions were taken that attempted to eliminate the need for any restrictive practice and used person centred understanding etc.
- Create an independent evidence centre for learning/awareness campaigns (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)[6]

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.

We would like to stress that we are only using the Department of Education as a case study but this issue of accountability and the requirement for an independent complaints processes is also relevant across many government departments but also in the human services sector.

In this regard, Family Advocacy recommends:

- further use of the role of the NSW Ombudsman or another independent body such as the Ageing and Disability Commissioner to externally review all allegations of ill-treatment or breach of restrictive practice guidelines, and 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) or Ageing and Disability Commissioner be empowered to intervene in cases of breach.

Transparency of monitoring and reporting

There must be transparency in monitoring and reporting on the use of restrictive practices in all settings. The provision of data should be used in such a way that allows for rigorous investigation of the use of restrictive practices. It needs to be 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.

Further, if repeated restrictive practices are used over a certain period of time, we urge the Commission to encapsulate triggers in the system to investigate why and work to bring in relevant specialists to minimise and eliminate these practices. This is similar to the guardianship approach where short to medium term guardianship are built into the system.

We recommend the inclusion of requirements around 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

---

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

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 an authorising panel on a regular basis 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. This comes with a caveat, that we have to be mindful as this could be just another 'tick the box' exercise and does not ensure an authorising panel is a good one, with a focus of reduction and elimination. If this is not present, there this is problematic.

The skills and experience of decision makers and implementers of restrictive practice

There needs to be a safeguard on who is the independent behaviour support practitioner on an authorisation panel, and those who are carrying out the restrictive practice. There is enormous variation in the skills of behaviour practitioners. Less conscientious providers/schools 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 and those carrying out a restrictive practice need to possess some or all of the following qualities:

- be independent and centred on the person with disability
- be aware of and continually challenge their own subconscious bias
- 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
- Have a successful track record with reducing and eliminating restrictive practices around a person with disability

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.

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. Hence, the need to ensure a coordinated multi-agency response between government and non-government, between departments within NSW, between departments in NSW and the Commonwealth.

Similarly, the NSW Department needs to get better at collaboration between departments 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 proposing a Draft Persons with Disability (Restrictive Practices) Bill 2021. It is absolutely imperative that there 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.

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 will 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, there is a need to allow for Commissions and government departments such as the NSW Ageing and Disability Commissioner and the NSW Ombudsman, to exchange information to relevant bodies, including the NDIS Quality and Safeguards Commission and government departments. There appears to be a gap in knowing 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.

Q 10: In what circumstances may restrictive practices be needed?

A. What rules and safeguards should be apply?

B. Should the same rules apply to all people?

Family advocacy asserts the following **principles** must be applied as a guide to restrictive practices authorisation, with consideration to the National Framework:

- **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 alternatives to restrictive practices - for the person with disability, their guardian or advocate, service provider and their staff.

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.

Authorisation Panel

We refer to the proposition for an authorisation panel in the proposed NSW Persons with Disability (Restrictive Practices) Bill 2021. Family Advocacy holds its position against having an NDIS provider or government department representative on a panel constitutes a massive conflict of interest. The provider/ government department 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 or government department. In addition, a person who has a close and ongoing relationship with the person with a disability 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.

Q 11: How can the use of restrictive practices be prevented, avoided or minimised?

A. What needs to change in laws and policies?

Family Advocacy are concerned with legislation, policies and practices that permit the use of psychotropic medications, physical restraints and seclusion under the guise of "behaviour modification" and restrictive practices against persons with disabilities, including children, in any setting, including in justice, education, health, psychosocial and aged care facilities. We urge the DISABILITY ROYAL COMMISSION to establish a nationally consistent legislative and administrative framework for the protection of all persons with disabilities, including children, from the use of psychotropic medications, physical restraints and seclusion under the guise of "behaviour modification" and the elimination of restrictive practices, including corporal punishment, in all settings, including the home.

Further, we endorse 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) and call for the Disability Royal Commission to endorse the recommendations in this report.

The report finds that the use of isolation with minimal oversight or guidance from the department or other school authorities, the use of physical restraints even when there is no real threat to teachers or other students, and the use of suspension or expulsion when other remedies would be better suited remain prevalent at both government and non-government schools.

B. What needs to change in the community and within organisations?

The Disability Royal Commission only needs to hear about the number of cases where restrictive practices are prevalent in schools to realise the problem goes beyond being controlled by legislation and policy and spills over into our broader cultural view that people with disability are devalued humans, and as such can be treated less favourably.

Acknowledge the value of Inclusive Education to help influence community's attitudes

> *Richard Rieser, academic, advocate and educator (2006a), sees a key role for schools:*
>
> *Prejudicial attitudes towards disabled people and indeed against all minority groups are not inherited. They are learned through contact with prejudice and ignorance of others. Therefore, to challenge discrimination against disabled people, we must begin in schools.*

Schools are a microcosm of wider society. If NSW is to be the multicultural, inclusive society it aspires or even claims to be, then all citizens need to be treated as equal and be visible. Children with a disability need to be allowed the same opportunities and experiences as children of different genders, language, ethnicity, socioeconomic status. Schools need to reflect this diversity. We need to see equity in employment of people with disability in schools and universities and education administration/organisations.

If all children grow up together and see inclusion as the norm; they will carry that forward to broader society. We need to recognise the assets that children with disability bring to the classroom, the social cohesion and the empathy that inclusion creates for all in a classroom. In this way, by making inclusive education a priority for children with disability, all of society will benefit over the long term, not just creating strong communities but also a competitive economy.

From a broad school system perspective, we recommend a schoolwide approach to social, emotional and wellbeing school policies are required to influence school culture and climate. Culture is shaped by the schools' values and expectations whereas climate tends to be associated with teaching practices, attitudes to diversity and the relationships with stakeholders.

Involve and engage people with lived experience of disability

There must be genuine and deep engagement and not a tokenistic consultation with the people who have the lived experience of disability (and those that support them). In our experience, we often find that the term "consultation" is applied by government departments in a knee jerk way and we are concerned that simply listening to the people with lived experience of disability is a shallow way to engage them. We have certainly experienced the situation where an agenda is predetermined by a government department and then information/input is sought with very rushed timeframes/deadlines and that is as far as it goes. In accordance with the CRPD, we advocate for a deeper engagement process where people with disability have shared responsibility, are active partners in co-design, making decisions and shaping policy/systems around restrictive practices. This also includes the review, monitoring and reporting processes.

C. What are the barriers to this change?

Community misunderstanding, stigma, prejudice and discrimination impact significantly on people with disabilities and allow the justification of bad decisions and hurtful acts. First and foremost, attitudes need to be addressed within each government department at the national/state/territory/council levels. We would assert that the NSW government need to "clean up its own backyard" on the topic. The NSW government needs to be a role model and lead the way for community. Having said this, some pockets of community may already be exercising good practices of inclusion and in this regard, we strongly encourage the NSW government to be prepared to learn from these good practices rather than reinventing the wheel.

For this reason, we recommend a commitment be made at state and local levels for funding projects and initiatives focused on promoting inclusion and improved community attitudes towards disability, which also includes evaluation of good practices. Such an investment must be across the life of the Disability Inclusion Plans and needs to recognise this goal will require an ongoing and sustained effort.

Any attempt to address both government and community attitudes needs to intentionally address the inherent devaluation of this group and the unconscious bias that exists in both community members and our systems.

For an in-depth discussion on how to tackle the unconscious bias within community and improve community attitudes, please refer to Family Advocacy's Submission to the Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability Submission No.3 - Rights and Attitudes Paper.[7]

Q 12: What alternatives to restrictive practices could be used to prevent or address behaviours of concern?

Adequately meet the needs of a person

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).

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.

---

[7] https://www.family-advocacy.com/assets/Submissions/c3348b0105/DRC-submission-rights-attitudes-paper.pdf

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 in any legislation or frameworks.

Further, legislation and policies 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

It is imperative that the person with disability must be consulted in regards to any proposed restrictive practice, with clarity on how to 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 being 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.

We refer to the short videos mentioned earlier, which were taken after a workshop Ann Greer presented for Family Advocacy on “Responding well to people "labelled" as having challenging behaviour - Is it behaviour or is it communication?”

See https://www.family-advocacy.com/our-resources/responding-well-to-people-labelled-as-having-challenging-behaviour/.

Ann Greer has a deep commitment to assisting everyone to be part of their community as active members - receiving and contributing. The videos speak to the importance of having agency, choice and control over one's life as well as the implications of the life course for an adult if we don't address this at school age first.

> *"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."*
>
> 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.

Right relationships

We have previously mentioned the importance of having the right relationship towards reducing the need for restrictive practices. In the context of the hierarchy of needs discussed above, it is critical to get to know a person really well, to understand what makes them tic, their motivations, interests, passions, and dislikes. In a group home, this can often be difficult to achieve, given the revolving door of staff coming and going.

One example we can share is about a man who would not let anyone into his house for 12 years. He would get very upset if anyone sat on the couch or touched the cups in the kitchen etc. Staff would often end up sitting in the car outside of the house until the man had calmed down and he could call them if he needed them. This was also the case when family wanted to visit. This was a learned response. Then one day a new support worker arrived, who took the time to get to know the man deeply and understand why this was happening. He discovered the man thought all of his stuff was going to be stolen and he was bothered that he had no privacy. The support worker taught the man that he could have total privacy in his own bedroom, but that the common area was for all of the rest of us to share and reassured him that all of his stuff would be safe. Once he accepted this different way of thinking about his space, the challenging behaviours disappeared and he was able to let family and staff enter the common areas of his house and touch things. This shows the importance of relationship and taking the time to get to know the person.

Q 13: Have we missed anything? What else should we know about restrictive practices?

We would like to draw the Disability Royal Commission's attention to a recent independent *'Inquiry into suspensions, exclusions and expulsion processes in South Australian Government Schools',* led by Centre for Inclusive Education's (C4IE) director Professor Linda Graham. We encourage the Disability Royal Commission to watch the *House of Assembly – December 2 2020 on Supporting students at risk of disengagement from schooling* as they discuss the report and find out more about the *South Australian Government's preliminary response.*

Given there are similar issues with an overrepresentation of marginalised groups making up the numbers of suspensions and expulsions in NSW, we see the recommendations of this independent inquiry as being highly relevant and applicable to NSW also. No doubt to all the jurisdictions within Australia would benefit from these recommendations "are made to support the Department's future roadmap for legislative, policy and practice reform to promote the rights, interests and outcomes of students and improve alignment with international human rights obligations."

The need for advocacy

We must highlight the absolute necessity of providing for advocacy services when considering restrictive practices. Due to the higher risk of abuse of people with a disability in any setting, there will always be a need for independent disability advocacy.

Our families who have a person with a disability in their life have expressed shock that so much advocacy is required on their part. Families want to be heard in relation to these systemic issues, but are frustrated and exhausted, hence the need for independent advocacy's organisations.

On an individual level, our advocacy, representation and information has provided essential supports to enable people with disability (and their family representative) to participate in society and to be included in the community. At a systems level, this consultation is one of many where we, and other disability advocacy organisations, have provided submissions to State and Federal governments as well as the Joint Standing Committee to the National Disability Insurance Agency (NDIA) and the NDIA directly.

Systemic advocacy can provide an alarm bell to warn where there are significant issues to enable the government department or NDIA to respond to failures, prevent unnecessary cost, time wasting, and avoid problems and preventable tragedies. Most importantly, it brings to the forefront the significant implications that current processes and practices are having directly on the people whom the system is there to support - the person with disability.

State and Federal Governments have a clear responsibility for ongoing funding to ensure that people with disability will always be able to turn to local, independent advocate when they need them, to support those who “fall through the cracks” and to feedback any unintended consequences that may follow from policy decisions.

Family Advocacy urges the Commission to make a recommendation that Federal, State and Territory governments provide funding in perpetuity for disability advocacy, representation and information services for people with disability.