



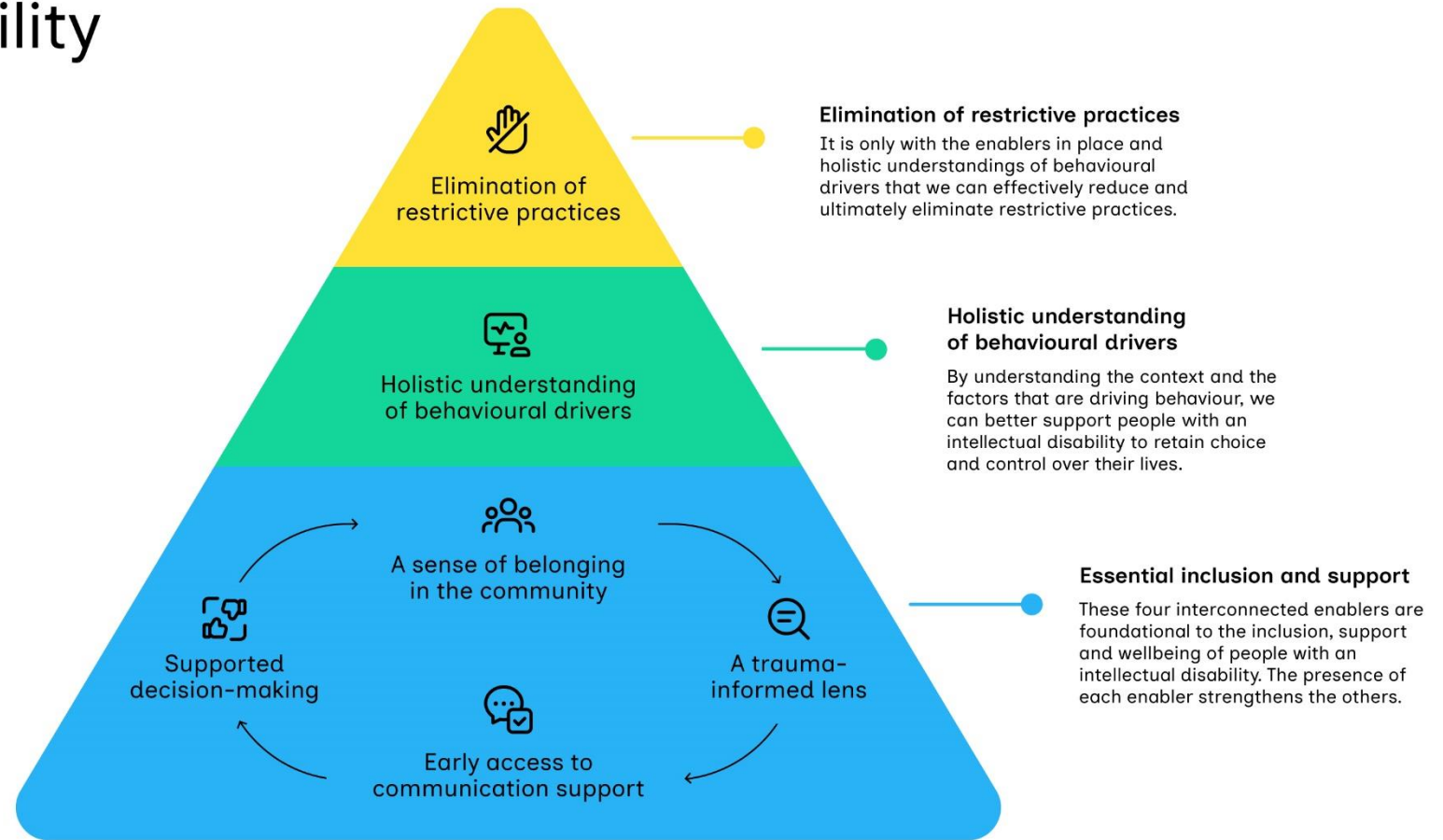
A model for eliminating the use of restrictive practices against people with an intellectual disability

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A model for eliminating restrictive practices for people with an intellectual disability



Text alternative of the image above

A model for eliminating restrictive practices for people with an intellectual disability.

Essential inclusion and support

These four interconnected enablers are foundational to the inclusion, support and wellbeing of people with an intellectual disability. The presence of each enabler strengthens the other.

The enablers are: (1) A sense of belonging, (2) A trauma-informed lens, (3) Early access to communication support, (4) Supported decisions-making.

Holistic understanding of behavioural drivers

By understanding the context and the factors that are driving behaviour, we can better support people with an intellectual disability to retain choice and control over their lives.

Elimination of restrictive practices

It is only with the enablers in place and holistic understandings of behavioural drivers that we can effectively reduce and ultimately eliminate restrictive practices.

Background

This model has been developed by Inclusion Australia to demonstrate the factors that may contribute to a reduction and, ultimately, elimination of restrictive practices, particularly as they are experienced by people with an intellectual disability.

It has been formulated through an extensive review of current research literature and evidence from people with lived experience.

This document is intended to accompany our model and provide further detail on its elements.

Thank you very much to our member organisations, Dr Paul Ramcharan, and colleagues across the sector for your feedback on the model as it was developed.

The use and impact of restrictive practices: a brief review of current evidence

The *NDIS Act 2013* defines a restrictive practice as ‘any practice or intervention that has the effect of restricting the rights or freedoms of movement of a person with disability’. There are five restrictive practices that are subject to regulation and oversight by the NDIS Quality and Safeguards Commission: chemical restraint; mechanical restraint; physical restraint; environmental restraint; and seclusion.

Restrictive practices, and especially chemical restraint, are disproportionately used on people with intellectual disability in Australia. There is extensive evidence that restrictive practices do not address the underlying factors that have prompted the use of a restrictive practice, and often result in significant human rights breaches. Evidence also shows:

Restrictive practices are at odds with international human rights obligations

There is an absolute prohibition on torture and cruel, inhuman or degrading treatment or punishment under international law, which is monitored through instruments such as the Optional Protocol on the Convention against Torture and other Cruel, Inhuman or Degrading Treatment or Punishment (OPCAT).¹ This means that restrictive practices that rise to the level of torture and cruel, inhuman or degrading treatment or punishment must be prohibited.

Given this, there has been a growing consensus that has pointed to restrictive practices in health and disability contexts specifically as being at odds with international human rights obligations. For example, in 2013 the Special Rapporteur on Torture and Other Cruel, Inhuman or Degrading Treatment or Punishment states “it is essential that an absolute ban on people with psychological or intellectual disabilities should apply in all places of deprivation of liberty, including psychiatric and social care institutions”.²

Given that restrictive practices often represent a form of violence that is applied on a disproportionate basis toward people with disability, these practices, even where they do not rise to the level of torture and cruel, inhuman or degrading treatment or punishment, are at odds with international law.³

Restrictive practices strip people with disability of dignity

The principle of dignity is at the core of international human rights obligations to prevent torture and ill-treatment and to protect people from violence, and promote equality and non-discrimination. Using restrictive practices fails to respect the inherent dignity of people with disability. Research shows that people with disability may experience restrictive practices in the following interconnected ways:

- Trauma, pain, harm and violence
- Abandonment and neglect
- Fear and a real and/or perceived lack of safety

- Disempowering, humiliating and dehumanising experiences
- Cruel and punishing treatment
- Lifelong trauma and life-altering effects.⁴

People with an intellectual disability disproportionately experience restrictive practices, especially chemical restraint.

The use of medication to restrain people with disability is one form of restrictive practice that is enabled by the health system and is common in mental health settings.⁵ Research indicates medication can be given to people with disability as a matter of routine, without any or sufficient therapeutic purpose to explain its use.⁶ In the Disability Royal Commission's sixth public hearing, Commissioners heard that the number and dosage levels of such medications administered to people with an intellectual disability are sometimes so significant, they constitute abuse.⁷

Lessons from the Disability Royal Commission

Evidence from the Disability Royal Commission showed that people with an intellectual disability, especially people with complex support needs, are among the most likely to experience restrictive practices, especially chemical restraint.⁸

Research indicates that restrictive practices are routinely used in group homes,⁹ and the Disability Royal Commission heard that their use in group homes is increasing.¹⁰

Restrictive practices may also be used in the community, such as in day programs or other disability service settings.

People with disability in detention settings, which includes a high number of First Nations people with an intellectual disability, are also at a high risk of restrictive practices. Prisoners and youth detainees with disability, particularly people with an intellectual disability, are disproportionately secluded in solitary confinement for long periods of time.¹¹

In an extensive research report commissioned by the Disability Royal Commission, it was found that:

The research literature is unequivocal: people with disability are subject to the greatest use of restrictive practice in segregated and congregated contexts where people with disability are clustered together.¹²

The report suggested that people with disability's lack of choice and autonomy within those settings is a distinguishing factor that contributes to the increased use of restrictive practices. We also know that people with an intellectual disability are more likely than other people to experience such settings.

Unfortunately, there was a dearth of recommendations or discussion related to behaviour support in the Disability Royal Commission's Final Report. This is despite the significant evidence about the need and prerequisites of good quality behaviour support

heard across a range of the Disability Royal Commission’s hearings, submissions and research program, including:

- Public hearing 6—psychotropic medication, behaviour support and behaviours of concern
- Safeguards and Quality Issues Paper
- Restrictive Practices Issues Paper
- The University of Melbourne, University of Technology Sydney, and the University of Sydney: Restrictive practices: a pathway to elimination, a research report commissioned by the Disability Royal Commission.

However, the NDIS Review recommended government should “reinvigorate efforts to urgently drive reduction and elimination in the use of restrictive practices”, including that:

- All Australian governments should agree a joint action plan for meaningful collaboration and a stronger focus on corrective actions against providers to reduce and eliminate restrictive practices, and review interventions and practices that may be harmful;
- The new National Disability Supports Quality and Safeguards Commission (the Commission) should work with practitioners and providers to improve the quality of behaviour support plans, enhance quality of life for participants and eliminate poor provider practices; and
- The Commission should work with states and territories to better support providers to deliver on their role in reducing and eliminating restrictive practices.¹³

Noting this, as well as the evidence from the Disability Royal Commission, there is a clear need for targeted strategies that work to address the pathologisation of ‘behaviour’ and the ways this incentivises the use, and in many cases over-use,¹⁴ of restrictive practices.

At the same time, it is important to note there has been very little scholarly research into the experiences of people with disability who are subject to restrictive practices. In their research report for the Disability Royal Commission, Claire Spivakovsky and her colleagues describe the extent of the limitations of current research:

There has also been little to no research into the specific experiences of restrictive practices for LGBTQIA+ people with disability, or culturally and linguistically diverse people with disability. Only a few studies consider the experiences of First Nations people with disability. Additionally, while people with disability’s experiences of some forms of restrictive practices are well explored—such as experiences of seclusion or involuntary mental health treatment—experiences of other forms of restrictive practice such as guardianship or financial management are rarely considered. This disparity in accounts is at least in part reflective of the opportunities that have and have not been provided to people with different types of disability to articulate experiences of restrictive practices over the years. Very few researchers venture into group homes to speak with people with disability, and, to the best

*of our knowledge, little to no attempts have been made to capture the accounts of people with disability subject to restrictive practices in the context of Australian Disability Enterprises, day programs, out-of-home-care, immigration detention, and in the family home.*¹⁵

These limitations mean that the evidence-base for behaviour support, including Positive Behaviour Support, can be considered ‘emerging’ rather than ‘established’.¹⁶

It is also important to note that many of the ‘high level’ frameworks and principles for reducing and/or eliminating restrictive practices that exist in Australia across a range of settings are sorely under researched in terms of their effectiveness.¹⁷ Any evaluation or consideration of these frameworks have occurred in the context of mental health settings alone.

Changing understandings of ‘behaviours of concern’

The research literature highlights the need to shift understandings of behaviour—and especially so-called ‘behaviours of concern’—to recognise them as both a product of the interactions between the person and their environment, and as socially constructed.¹⁸

The terms ‘challenging behaviours’ or ‘behaviours of concern’ are generally used to describe behaviours that are perceived as being disruptive, threatening or damaging to the wellbeing, safety or day-to-day activities of a person or those around them.

These terms create a tendency to focus exclusively on behaviour itself, where interpretations of and responses are about ‘managing the behaviour’ alone. This can lead to overlooking the wider context in which the behaviour is happening.

It is becoming increasingly accepted that the concept of ‘behaviours of concern’ or ‘challenging behaviour’ is culturally and socially constructed, reflecting dominant social attitudes towards people with disability.¹⁹

Importantly, labelling some behaviours as ‘concerning’ or ‘challenging’ relies on an interpretation or judgement by *someone else*, who is declaring this behaviour to be “dangerous, frightening, distressing or annoying”,²⁰ rather than centring the person with disability themselves or considering their needs—particularly their unmet needs. There is also substantial literature establishing ‘behaviours of concern’ as an important and valid part of a person’s communication—this is true for people with and without disability.²¹

As such, it is becoming more broadly accepted to recognise ‘behaviour’ as dysregulation or an expression of unmet needs and/or overwhelm, and that these are valid responses that should not be pathologised.

For example, as we understand more about our nervous systems and the brain-body connection, we can now identify that what might be termed a ‘behaviour of concern’ is actually an involuntary physiological response to external stimuli which has become too difficult for the brain to process. This is known as an ‘automatic storm’, where an overload of information from sensory or cognitive stimuli triggers the automatic nervous system, which creates

a feeling of fear, threat or danger within the person. This can result in intense distress or dysregulation (the 'behaviour'), which in this instance is an involuntary physical response to an overloaded or overwhelmed brain.²²

Paul Ramcharan and colleagues also note that 'behaviours of concern' may equally define the service a person may be receiving or a setting a person is experiencing life in, rather than being pathologically and unidirectionally attributed to people with disabilities.²³ They suggest:

A behaviour of concern is likely to be produced by 'an environment of concern' ... behaviours seen as being 'of concern' can be understood better as adaptive behaviours to maladaptive environments ... and should be seen as legitimate responses to difficult environments and situations, and not a reason for restrictions designed to change the person and their behaviour.²⁴

Research has also shown that "restrictive practices may form part of a 'vicious cycle' in which the psychological instability and distress they generate leads to more behaviours that in turn result in further restrictive practices".²⁵ This was also key finding of a research report commissioned by the Disability Royal Commission, which found that restrictive practices (as responses to 'behaviours of concern') take place within an "ecological system of violence, coercion, and control".²⁶

A holistic understanding of behavioural drivers

In our model, we show how important it is to have a holistic understanding of the factors that drive someone's behaviour. This means bringing an understanding of behaviour that considers the situation at that moment in time as well as the person's unique experiences and whole-of-life context to the greatest extent possible.

This approach means seeing 'behaviour' as a legitimate response to a difficult situation and interpreting this in the context of the person's current life and past experiences. That situation may be one in which the person is disempowered, have a range of unmet needs, feel unsafe, and is expressing themselves according to their own ways of communicating

Importantly, this process is not unique to people with an intellectual disability: this is how we all experience and express what is happening to us.

This approach moves us away from seeing 'behaviours' as isolated events or things that happen in a vacuum, that need to be 'managed' according to a pre-determined procedure, rather than addressing the underlying causes within a person's whole-of-life context.

We have identified four factors which we believe are necessary to develop these holistic understandings of behaviour.

Supported decision-making

Supported decision-making is a fundamental human right given effect by Article 12 of the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD), which guarantees every person's right to legal capacity—to make one's own decisions and have those decisions legally recognised. It specifically requires governments to provide people with disability the supports they may need to exercise legal capacity, meaning support for decision-making.

There is increasing evidence that the elimination of restrictive practices is contingent on people with disability having access to the supports and empowerment to exercise (and build capacity to exercise) these rights. Research commissioned by the Disability Royal Commission was clear that:

- Legal systems and service systems must facilitate autonomy
- Legislation and court jurisdictions enabling substituted decision-making must be replaced with those that are not disability-specific and additionally enable supported decision-making
- Service and health systems need to be educated and resourced to implement supported decision-making
- Systems of supported decision-making should not over-regulate the lives of people with disability.²⁷

Early access to communication support

Today, there are many adults and older adults with an intellectual disability with communication support needs who did not receive communication support as children or young people. This is because of what is known as the 'candidacy model', which dominated approaches to delivering communication support up until early 2000s.²⁸

This model was based on a range of 'criteria' it was believe a person needed to fulfil to demonstrate 'candidacy' for communication support. Because of these ideas, many children with an intellectual disability were deprived of communication support based on perceptions they were "too something ... too 'young', too 'socially withdrawn', too 'intellectual disabled' or 'too linguistically delayed'".²⁹

This model has been replaced with the 'participation model', which is a human rights- and strengths-based approach that considers all the research we have demonstrating that the use of early, ongoing communication support has a positive effect on communication abilities. This has moved practitioners away from focusing on a list of criteria to 'qualify' for access to communication support in the first instance.

This is a big shift, and it has taken place relatively recently. This means that many people with complex communication needs (especially if they are older) may have never had access to communication supports. Access to meaningful, ongoing supported decision-making is therefore extremely limited, meaning ongoing communication support is crucial for many people who are experiencing, or at risk of experiencing, restrictive practices.³⁰

A trauma-informed lens

The Disability Royal Commission clearly demonstrated that experiences of violence, abuse, neglect, and exploitation are frequently and disproportionately experienced by people with disability. We know that those experiences are more likely to (though do not solely) take place in segregated settings, separate from the community.³¹ The impact and trauma caused by these experiences is enormous and can be life-long.

Becoming trauma-informed is increasingly considered good practice in a range of fields. Now that the extent of abuse and neglect experienced by people with disability has been exposed by the Royal Commission, there is an obvious need for governments and support service systems to facilitate trauma-informed approaches to delivering relevant supports.

Notably, the benefits of using a trauma-informed lens to understand behaviours—as well as trauma-informed approaches more generally—has only very recently been considered in the context of people with disability and disability services.³²

Blue Knot Foundation's *Disability Guidelines for Trauma-Informed Practice*³³ describe a trauma-informed practice as one that:

- Is not clinical treatment
- Recognises that many issues are trauma-related and requires people to be trained to act on this awareness
- Follows the principle of 'do no harm'
- Understands the effects of stress and trauma on the brain and body
- Considers what trauma has happened to a person and not what is 'wrong' with a person
- Regards 'symptoms' as expressions of coping strategies
- Is sensitive to the person's comfort levels and to the way in which a service is delivered, not just what a service is
- Works with the person rather than doing something 'to' or 'for' the person.³⁴

The *Disability Guidelines for Trauma-Informed Practice* also states:

*Trauma-informed support means seeing the person who has experienced trauma as the expert. It means working with a person's strengths. Not focussing on what is wrong with a person or trying to 'fix' the person. Being trauma-informed changes how we think and respond to people ...It helps us notice what is going on for someone. We can then support the person to recognise their strengths as well.*³⁵

A trauma-informed lens may also promote deeper understandings of safety, and what makes a person feel safe or unsafe according to their unique life context. It is about understanding the way different people cope with trauma, and how trauma responses and adaptations can become barriers to connection and participation. This understanding supports those within a person's life to more meaningfully and effectively respond to a person.

Belonging in ordinary community life

Through the thousands of testimonies of evidence given at public hearings, private sessions, community engagements, in submissions, and through its robust research program, the Disability Royal Commission showed that inclusion is most evident where:

An individual is made welcome, where they feel welcome, where they know they belong, where they know they are safe, and where their voice is heard and acted upon ... it is where people live ... in close personal relationships with others, where they have friends and advocates and where they are free to express their philosophical/religious beliefs, sexual and cultural identities, that people can live a quality life free from violence, abuse, neglect and exploitation. ³⁶

We refer to this as ‘belonging in ordinary community life’ to highlight the *unremarkable yet essential* human need to have access to meaningful, freely entered interpersonal connections, and the *ordinariness* of being in positive relationship with one’s surroundings.

This is often the aim of ‘informal supports’ or ‘natural safeguards’, which are the social support networks that provide protection and support human rights by increasing connections, relationships and visibility in the wider community. They are a key preventative measure against the risks of violence, abuse, neglect and exploitation.

Research commissioned by the Disability Royal Commission³⁷ argued that in exploring the policy and practice directions needed for people with disability to live in an inclusive society, we need to consider the ways this can and does take place through:

- Community belonging
- Visibility and feeling valued within one’s community
- Unpaid, freely entered social connections.

The researchers suggested that there is a need to move beyond simplistic notions of physical location or dichotomies of inclusion versus segregation, and towards what is sometimes called ‘psychological inclusion’.

This concept is aligned with our notion of ‘belonging in ordinary community life’ in that it focuses on the extent to which an individual perceives membership in their community, expresses an emotional connection with their neighbours, and can fulfil their needs (physical, emotional, spiritual) through community connections. This is arguably among the most poorly acknowledged in policy and most under-addressed in service and practice.

Yet that felt sense of belonging within one’s community is a powerful and robust natural safeguard that prevents violence, abuse, neglect and exploitation—including those experiences which happen because of restrictive practices.

Appendix A

¹ United Nations Human Rights Office of the High Commissioner. 2002. Optional Protocol to the Convention against Torture and other Cruel, Inhuman or Degrading Treatment or Punishment. Retrieved from: <https://www.ohchr.org/en/instruments-mechanisms/instruments/optional-protocol-convention-against-torture-and-other-cruel>

² Human Rights Council, Report of the Special Rapporteur on torture and other cruel, inhuman or degrading treatment or punishment, Juan E. Méndez, UN HRC 22nd sess, UN Doc A/HRC/22/53 (1 February 2013), p 15.

³ Spivakovsky, Claire., Steele, Linda., and Wadiwel, Dinesh. 2023. Restrictive practices: a pathway to elimination. A research report commissioned by the Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability. University of Melbourne, Australia.

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⁹ Claire Spivakovsky, 'Governing Freedom through Risk: Locating the Group Home in the Archipelago of Confinement and Control' (2017) 19(3) *Punishment & Society* 374; Lynne Weber, Keith McVilly and Jeffry Chan, 'Restrictive Interventions for People with Intellectual Disability Exhibiting Challenging Behaviours: Analyses of a Population Database' (2011) 24(6) *Journal of Applied Research in Intellectual Disabilities*, pp 495-507.

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¹² Spivakovsky, Claire., Steele, Linda., and Wadiwel, Dinesh. 2023. Restrictive practices: a pathway to elimination. A research report commissioned by the Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability. University of Melbourne, Australia.

¹³ NDIS Review. 2023. Recommendations and actions. Retrieved from: <https://www.ndisreview.gov.au/resources/reports/working-together-deliver-ndis/preface/recommendations-and-actions>

¹⁴ Ibid.

¹⁵ Spivakovsky, Claire., Steele, Linda., and Wadiwel, Dinesh. 2023. Restrictive practices: a pathway to elimination. A research report commissioned by the Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability. University of Melbourne, Australia. Page 3.

¹⁶ Claire Spivakovsky, 'Governing Freedom through Risk: Locating the Group Home in the Archipelago of Confinement and Control' (2017) 19(3) *Punishment & Society* 374; Lynne Weber, Keith McVilly and Jeffry Chan, 'Restrictive Interventions for People with Intellectual Disability Exhibiting Challenging Behaviours: Analyses of a Population Database' (2011) 24(6) *Journal of Applied Research in Intellectual Disabilities*.

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¹⁸ Louise Denne, Nick Gore, Carl Hughes, Sandy Toogood, Edwin Jones & Freddy Jackson Brown, 'Implementing evidence-based practice: The challenge of delivering what works for people with learning disabilities at risk of behaviours that challenge', (2020), vol 25 (3), *Tizard Learning Disability Review*, p 3; Stella Koritsas & Teresa Iacono, 'Predictors of challenging behaviour in adults with intellectual disability', (2015), vol 9 (6), *Advances in Mental Health and Intellectual Disabilities*, pp 312-326.

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²⁶ Claire Spivakovsky, 'Governing Freedom through Risk: Locating the Group Home in the Archipelago of Confinement and Control' (2017) 19(3) *Punishment & Society* 374; Lynne Weber, Keith McVilly and Jeffry Chan, 'Restrictive Interventions for People with Intellectual Disability Exhibiting Challenging Behaviours: Analyses of a Population Database' (2011) 24(b) *Journal of Applied Research in Intellectual Disabilities*, pp 495-507.

²⁷ Spivakovsky, Claire., Steele, Linda., and Wadiwel, Dinesh. 2023. Restrictive practices: a pathway to elimination. A research report commissioned by the Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability. University of Melbourne, Australia.

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³⁰ <https://disability.royalcommission.gov.au/system/files/2023-09/Final%20Report%20-%20Volume%206%2C%20Enabling%20autonomy%20and%20access.pdf> p. 270.

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