

People with Disabilities WA
individual & systemic advocacy



Submission

Issues Paper: Restrictive Practices

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

People with Disabilities (WA) Inc. (PWdWA) would like to thank the Disability Royal Commission for the opportunity to provide comment about restrictive practices.

PWdWA is the peak disability consumer organisation representing the rights, needs and equity of all Western Australians with disabilities via individual and systemic advocacy.

PWdWA is run BY and FOR people with disabilities and, as such, strives to be the voice for all people with disabilities in Western Australia.

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People with disabilities WA (PWdWA)

Since 1981 PWdWA has been the peak disability consumer organisation representing the rights, needs, and equity of all Western Australians with a physical, intellectual, neurological, psychosocial, or sensory disability via individual and systemic advocacy. We provide access to information, and independent individual and systemic advocacy with a focus on those who are most vulnerable.

PWdWA is run by and for people with disabilities and aims to empower the voices of all people with disabilities in Western Australia.

Introduction

PWdWA welcomes the opportunity to provide comment to the Disability Royal Commission on restrictive practices. PWdWA receives both state and federal funding to provide advocacy around issues experienced by the community concerning abuse, neglect and violence – including restrictive practices. We also have specific funding from the Department of Social Services to provide Individual Advocacy to assist individuals to engage with the Disability Royal Commission and make submissions.

As the peak consumer voice for people with disability in Western Australia (WA), our submission is compiled on the experiences of people with disability, their families, and carers. Our responses are also informed through PWdWA collaboration with other advocacy and disability organisations. We have provided case studies where appropriate to furnish our statements.

Addressing issues around the misuse of restrictive practices is an important aspect of PWdWA's advocacy work at both a systemic and individual level. People with disabilities continue to experience restrictive practices in our community, some on a daily basis. Our work includes advocating with and on behalf of individuals who have experienced restrictive practices and who are seeking assistance in having issues and complaints resolved. We work with individuals who have often been labelled as 'difficult' or having 'behaviours', and who by engaging the services of Advocates are seeking to have their basic human rights realised.

Submission Format

This submission will answer the questions posed as part of the Restrictive Practices Issues Paper.

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

The current explanation does not highlight that restrictive practices should be time limited with appropriate plans in place to eliminate them. The use of 'challenging behaviours' or 'behaviours of concern' is also problematic as it places the focus on the behaviour itself as a 'symptom' of the disability and the impact on others rather than the person with a disability. It pathologizes normal expressions of human emotion and assumes that the person and their behaviour is the problem.

Often, behaviours are a way for the person with a disability to communicate. They could be experiencing unmet needs or challenges to their wellbeing, sensory changes, responding to their environment or it could be a perfectly normal reaction to a set of circumstances. It is important to ensure that terminology used supports a focus on understanding what the person with a disability is trying to communicate and meeting any unmet needs.

There have recently been changes in nomenclature in the dementia space including options such as 'unmet needs' and 'changed behaviours.' We also note that the Royal Commission into Aged Care have adopted the term 'changed behaviours' in their reports.

PWdWA recommends that the Commission adopt the term 'unmet needs' in place of 'challenging behaviours' or 'behaviours of concern'.

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

Despite the introduction of the *Voluntary Code of Practice for the Elimination of Restrictive Practice* introduced in 2012 in WA, the endorsement of the *National Framework for Reducing and Eliminating the Use of Restrictive Practices in the Disability Services Sector* in 2014, and the subsequent *Code of Practice: A Guide for*

the Elimination of Restrictive Practices (2019) there continues to be cases of restrictive practice experienced in WA, some required, many not. PWdWA notes that all the types of restrictive practice included in the Commission's definition have been experienced by people with a disability in the WA community. As an advocacy service we usually encounter issues where a restrictive practice is being misused. That is, that restrictions have been put in place without there being a risk of harm, or without less restrictive options being explored.

Common restrictive practices that we are aware of through our Individual and Systemic advocacy work include:

Locking doors

It is common for group homes in WA to lock front doors or internal doors to prevent residents from leaving the home or accessing specific rooms. It is more common for residents who have intellectual or cognitive disabilities. Often staff are the only ones who have keys, and this means that residents cannot leave without 'permission' and cannot invite guests over. This effectively makes the group home a 'locked facility' although it is not formally classified as such. Similar situations can be found in some family homes. The reasoning for locked front doors is often that the person with a disability will wander, get lost, end up on the road or be otherwise harmed. However, there may be no history of this behaviour for a person, rather an assumption that based on their intellectual/cognitive ability they will come to harm. Where these problems do exist, there is often limited 'out of the box' thinking to support the person's right to freedom of movement.

Locking cupboards and fridges/controlling diet

It is common for cupboards and fridges to be locked in group or family homes, especially for people with intellectual or cognitive disabilities. This is often to restrict access to food, but also to prevent destruction of property. In some homes this may only be a small cupboard of specific food, however in others it is all food cupboards and fridges. The reasoning behind restricting access to food is often around healthy eating. However, there is a difference between these restrictions being required, and people acting in a 'best interest' capacity. It is not uncommon for service providers and families to make decisions about a person's diet based on the rationale that a person with capacity would 'choose' to be healthy. This is a false assumption and

speaks to the tendency for people to hold a person with a disability to a different standard to the rest of society. Advocates have worked with people who have been told they are not allowed to consume junk food, soft drink etc because it is not healthy. For example, we would not presume to tell a person without a disability they cannot drink more than one soft drink a day, or they cannot have takeaway more than one night a week. However, this is not an uncommon occurrence for people with intellectual or cognitive disabilities who rely on support workers to shop for them or support them with their meals.

Families or service providers may also decide that a person needs to go on a diet. In some cases, these are people with no specific diet related medical conditions. There are situations where it may be necessary to restrict diet, such as diabetes, where there is imminent risk of harm based on diet. However, we would expect that education, supported decision making and creative problem solving be used before locks are put on cupboards/fridges.

Use of medication for unintended purposes or to control behaviour

Advocates have seen examples of medication being used to control behaviour, reproductive functions, and expression of sexuality. It is not uncommon in WA for women with intellectual disabilities to be placed on birth control without their consent or in some cases their knowledge. Anecdotally there are a number of reasons for this including the elimination of menstruation, so staff do not have to assist with personal hygiene and prevention of pregnancy in case of sexual assault. It is also common for men with intellectual disabilities to be chemically castrated. Men with intellectual disabilities are often labelled as sex offenders when they express sexual desire or an interest in sex (e.g. watching porn and masturbation). Some families view chemical castration as a protective measure to prevent individuals from encountering the justice system for sexual related crimes. Essentially for many men and women with an intellectual disability, others find it is easier for their sexuality to be repressed rather than supporting safe expression. A human rights approach to this area would see more funding and increased services for education and support around sexuality, relationships, and protective behaviour. However, in WA there is limited services offering this and waitlists are over nine months.

People with unmet needs resulting in changed behaviours and those with mental health diagnosis are much more likely to experience chemical restraint. This includes people with intellectual disabilities and a diagnosis of dementia. Advocates are aware of widespread misuse of medication, such as risperidone, in aged care facilities to control behaviours. Similarly, Advocates have seen epilepsy medication used as a behaviour management tool for people without an epilepsy diagnosis, and anti-anxiety and sleeping medication which is supposed to be PRN used daily to keep people 'docile'. Sleeping medication has been used as a way to decrease the level of support required overnight as it is more expensive for 'active' overnight shifts.

Applications for state ordered guardianship

Guardianship is a legal means of restricting a person's right to make decisions about their lives. It is intended to be used where the person does not have legal decision-making capacity. The experience of Advocates is that there is a rising trend of Guardianship being used to control 'behaviour' and implement restrictive practices, especially where a person with a disability is considered 'difficult'. Examples include decisions about where a person lives, what services they access, what medication they take, whether they are allowed out without a support person.

For example, a gentleman who had an Acquired Brain Injury was living in an aged care facility. He had vastly improved in health since he acquired his condition and was wanting to leave the facility to go to the shops. His Guardian determined that the risk to his safety was too high, despite no medical evidence to support this. The Guardian had told facility staff to prevent the man from leaving the facility. An Advocate was able to work with the man to have his Guardianship order turned from plenary to restricted and he was able to leave the facility as and when he wanted to.

Case Study: Danny

Danny lived in community housing, that also provided disability supports, for a number of years. Danny was having issues with his housing provider and they sent him an eviction notice stating he did not meet the criteria for their housing program. Danny felt they were evicting him because he complained about how they treated him, and he was fighting the eviction. An application for Guardianship was made on the grounds that Danny could not manage his accommodation. A Guardianship order

was granted despite there being no clear evidence that Danny could not manage his own affairs. Danny was able to have the order removed but not without considerable time and effort.

Physical restraints

We have heard many instances of people with disabilities, especially those with mental health diagnosis, being physically restrained in medical settings such as hospitals. This includes being tied to hospital beds or chairs and being restrained by a person. Children with Autism also experience physical restraint in education settings.

A large service provider told the Inquiry that their clients, who are not restrained in disability settings, are often 'restrained for weeks on four point restraints' in health and mental health settings, or chemically restrained. This differs significantly from the way a person with disability would be supported in a disability service setting or at home and the perception is that the person is being restrained as a consequence of their disability, not their mental health needs, due to a failure of the system or process to cater for their disability support requirements.

Behind Closed Doors Report, 2015, PWdWA

Removing aids and assistive technology to restrict movement or communication

Removing aids and communication devices can be done for a number of reasons but can come down to staff convenience or punitive responses. In some cases, the rationale for removing movement aids is around perceived falls risks, or to prevent wandering. However, the root cause of the falls or wandering may not have been addressed. We are aware of situations where communications devices have been removed where a person is seen to be 'pestering' staff, or the device is distracting to others.

Seclusion

Seclusion has been experienced by people with a disability in many settings including, mental health, health, education, and disability services. This includes use of 'time out' rooms for children in schools and being locked in rooms alone for adults in care settings.

Telling people they cannot do things without a reasonable justification

Psychosocial restrictions are very prevalent in the disability sector. It is common for families and services providers to take a paternalistic, best interest approach to people with a disability, especially those with an intellectual or cognitive disability. The experience of PWdWA Advocates has been that there is a culture of risk aversion and assumptions made about what a person with a disability can and cannot do. In some ways people with a disability are held to a higher standard in that people apply the presumption that a person would want to make the 'right' or least risky decision. The reality is that we all make risky or 'bad' decisions, but don't necessarily allow people with disabilities this same opportunity. In some cases, people may not realise that what they are doing constitutes a restrictive practice or will believe that they are justified in their actions (best interest). The example of restricting diet above is both a physical and psychosocial restriction. Historically, people with disabilities have had limited power to make their own decisions and have been in systems where they don't have choice or control. For many, they do not question what they are told.

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

How often a person is subjected to a restrictive practice depends on the type of disability, their education level, cultural background, informal supports, access to community and how well they can communicate. For some people they may be subject to restrictive practices multiple times a day, for others it may be once off. For example, a person with an intellectual disability who lives in a group home is more likely to experience restrictive practices daily compared to a person with a physical disability who is well educated and able to articulate themselves.

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

Restrictive practice is being used in multiple settings in WA including Disability services, health services, education, and home settings. Please see the excerpt from Behind Closed Doors included with this submission, which details the restrictive practices experienced in specific settings in WA.

Question 5: Why are restrictive practices used?

Restrictive practices should, in theory, only be used if the person is at risk of harm and all other less restrictive options to meet the persons needs have been exhausted. The restrictive practice should be proportional to both the type of harm, and the risk of it occurring.

While there are certain situations where a restrictive practice will be necessary, we often see them being used in formal services settings due to organisational or staff convenience, to overcome a lack of staff, inadequate staff training or knowledge, and lack of staff support and/or supervision.

In the home it can be the result of a lack of awareness around restrictive practices, lack of skills/knowledge to support person without resorting to restrictive practice, for convenience, or to overcome a lack of funded supports.

Restrictive practices are also implemented under the banner of 'Duty of Care'. As mentioned above there is a 'risk averse' culture in disability settings. There is a tendency to approach risk with an all-or-none attitude focusing on preventing the worst possible outcome, no matter how small the possibility. The result of this is often a restrictive practice that is not proportional to the probability of the risk occurring.

Question 6: What are the effects of restrictive practices?

Where used correctly a restrictive practice will prevent harm to a person or others. However, ultimately the impact of using a restrictive practice is to deny the person with a disability their basic human rights. Where restrictive practice is implemented without understanding, or addressing an unmet need, it invalidates and ignores the voice of the person with a disability and breaches their human rights.

In some cases, the use of restrictive practice leads to physical injury. Please see the examples provided on page 41 of the Behind Closed Doors report attached to this submission. For many it can also lead to issues with mental health and wellbeing.

Restrictive practices can lead to isolation and decreased opportunities for social participation. We have also seen that restrictive practices can lead to an escalation of 'behaviours' and increasingly restrictive and punitive responses. Individuals may

be labelled as 'difficult' or 'aggressive' which is not only dehumanising but means that providers do not want to engage with them. These outcomes further impact on a person's mental health.

Putting restrictions in place based on 'what if' and for the purpose of removing risk denies people with a disability the natural right to engage in risky behaviour. Risk is fundamental to the human experience, and the ability to make risky decisions (dignity of risk) an inherent human right. We know that risk is also an important factor in growth and learning. As such restrictive practices, when used unnecessarily, restrict the opportunities for people with disability to grow, learn and experience the world in the same way as everyone else.

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

People with Intellectual, Cognitive and Psychosocial Disability

People with intellectual, cognitive, and psychosocial disability are more likely to experience restrictive practices. These groups are commonly assumed to be incapable of safe decision-making and so restrictive practices are used under the auspices of protecting the individual and those around them. These restrictive practices are often treated as standard methods of addressing changed behaviour before exploring alternatives or seeking to address the unmet needs of the person with disability.

Younger people with disability

Parents of people with disability may continue to use restrictive practices with their adult children more so than parents of other young people. While this often comes from a mindset of wanting to protect people with a disability, this does act to limit people with a disability from gaining experience, making important decisions and gauge risks appropriately. Additionally, service providers will often adopt this attitude with young people reinforcing the use of restrictive practice. This does disproportionately impact people with intellectual, cognitive and psychosocial disabilities however younger people with physical disability do present for advocacy for support in having their choices listened to.

Culturally and Linguistically Diverse (CaLD) and First Nations populations

Culturally and Linguistically Diverse (CaLD) and First Nations populations may experience cultural differences that impact the way restrictive practices are used. This can impact family expectations for how people with disability are treated, as well as how people with disability engage with service providers. The specific cultural and spiritual needs of CaLD and First Nations populations have also been the subject of restrictive practices in the past. These have included limiting engagement in traditional ceremonies, disallowing specific foods of cultural significance, or limiting engaging with other members of a particular cultural identity or spiritual belief.

People in Rural and Remote locations

People with disability in rural and remote areas face unique challenges when engaging support. In Western Australia, outside of the metropolitan zone of Perth, even large towns can have few options when it comes to transport with little public transport and only one or no taxi service. People with disability who rely on transport from family and formal support services have been refused transport in a punitive manner or to restrict who they can engage with. The lack of choice of disability service providers can also deter individuals from complaining about the unnecessary use of restrictive practice for fear of losing support and reinforce the use of restrictive practices. Without oversight, service providers who might otherwise be forced to change their practices due to market forces in a more competitive environment are less likely to update their practices to reflect best practice.

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

The recurrent and ongoing use of unnecessary restrictive practices limit the opportunities for people with disability to gain experience and encourages the development of dependence on support providers. Additionally, recurrent use of restrictive practices will normalise the restriction of freedoms and rights for individuals. We know that people with disability are more likely to experience family violence and more likely to stay in violent relationships for longer. The same is true for individuals in professional relationships with abusive service providers or working with abusive support workers.

Restrictive practices that isolate a person place them at increased risk of abuse, neglect and exploitation. We know that the more isolated a person is and the less connections/safeguards they have in their lives the higher their risk. Their exposure to other, non-abusive, relationships is reduced. The person with disability then learns that all relationships are violent and abusive and making them vulnerable to abuse in future relationships.

It is important to note that changed behaviours can be a result of restrictive practices. As the person with a disability tries to communicate their unmet need their behaviour is increasingly met with more restrictive practices, until the restrictive practice is indistinguishable from abuse. This is even more concerning as the underlying cause of the initial behaviour is never addressed.

Where restrictive practice is used without appropriate oversight the use of, and even the threat of, restrictive practices can be exploited by perpetrators of abuse to silence individuals or blackmail them into taking part in situations they would not otherwise choose to. If bad actors must account for their actions and restrictive practices are regulated, approved by a panel involving the individual their ability to use such practices as tool of manipulation would be restricted.

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

The current system in place in WA until the rollout of the NDIS Quality and Safeguards Commission is the *Voluntary Code of Practice for the Elimination of Restrictive Practice* introduced in 2012 and the subsequent *Code of Practice: A Guide for the Elimination of Restrictive Practices (2019)*. As the name suggests, this is a voluntary process and as such, there is currently no registration or monitoring of restrictive practices in WA. It is unclear how many WA disability providers have implemented the Voluntary Code, but the continued use of unnecessary restrictive practices suggests that it has not been successful in reducing or eliminating restrictive practices.

The introduction of the NDIS Quality and Safeguards scheme has seen the WA Government look to legislating the use of restrictive practices in disability services to ensure that both state and NDIS service providers are legally obliged to register and report the use of restrictive practices. This approach relies on services to know what

a restrictive practice is and proactively report them. It is also unclear if/how the use of restrictive practices in family settings will be monitored and reviewed under the legislation.

The legislation also only applies to restrictive practices implemented by disability service providers. It does not relate to schools, hospitals/health settings, mental health institutions or aged care facilities etc. Many of these other settings do not have policies or guidelines around the full range of restrictive practices. For example, the WA Disability Health Framework 2015–2025 does not explicitly reference restrictive practices. Seclusion and Restraint are the only notifiable restrictive practice in the WA Mental Health setting. This only includes physical or mechanical restraint, not chemical restraint which is commonly used in mental health settings. Seclusion is specific to confinement alone, rather than restricting access to areas such as outdoors etc. In Western Australia, education regulations specifically permit the use of restraints but provide little guidance for its use. It also permits seclusion/time out as a planned intervention. The use of restrictive practice is, however, not a reportable incident and therefore there is no monitoring of its use. We are aware that many unnecessary restrictive practices happen in these settings. Any approach to reducing and eliminating restrictive practices must work across disability, health, education, and other relevant sectors. Until there is a consistent approach to education, elimination and reporting across all settings people with a disability will continue to be subject to restrictive practices.

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

Restrictive practices should only be used where there is a demonstrated risk of harm to a person/s and where all alternatives to the restriction have been exhausted. It should be a last resort. It should also be proportional to the likelihood and consequences of the risk.

Where a restrictive practice is intended to be part of regular practice there must be a plan in place to try to reduce or eliminate the restrictive practice. This plan should be developed with the person with a disability, and their human rights, front-and-centre. This means that plans should be individualised based on the person with a disability and their circumstances. Best practice would be an independent panel assessing,

approving and monitoring the use of restrictive practices. All plans should be time limited and be regularly monitored and reviewed (no longer than 12 months).

Where an unauthorised restrictive practice is used there must be nationally consistent reporting requirements to ensure that trends and issues can be identified and responded to in a timely manner. Best practice would be to require organisations to review the incident, identify why the restrictive practice was used and whether there were alternative actions available as well as areas for improvement and include this information in required reports.

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

Education

Education is a key factor in ensuring restrictive practices are prevented, avoided and minimised. Many support workers and families are unaware of what constitutes a restrictive practice as well as any reporting requirements there may be. There should be mandatory training across disability, health, education, and justice settings for staff about not only restrictive practices, but the UNCRDP. Training and support should also be funded for families to ensure they can recognise restrictive practices and implement alternative options.

Education should also be provided for people with a disability themselves as to what is a restrictive practice, their rights and how they can complain if they experience a restrictive practice that they do not consent to.

Attitudes and culture

Historically the community has taken a paternalistic, risk averse approach to supporting people with a disability. If we are to reduce or eliminate restrictive practices, we must create a community that values dignity of risk and the right for people with a disability to make both good and bad decisions.

Adequate funding of services

While education is important, we must also ensure that there is adequate funding for services to support alternatives to restrictive practice. This includes funding supported decision making and being able to explore and trial various supports to

find a non-restrictive option which meets a person's needs. This includes funding to appropriately support students with disabilities when they are in school to address unmet needs early on.

Increased funding needs to be provided to disability advocacy services to ensure people with a disability who want to complain about restrictive practices have access to an independent Advocate to assist with their complaint.

Trauma informed support

Many people with a disability have experienced abuse, neglect or exploitation which has resulted in trauma. It is important to take a trauma informed approach to the support of people with a disability where abuse, neglect or violence has been experienced to ensure that strategies to address unmet needs are appropriate. This would require training for disability staff in trauma informed practices. Trauma informed approaches may meet needs in a way that do not lead to the use of restrictive practices.

Nationally consistent reporting

There should be national mandatory reporting of restrictive practices regardless of the setting in which it occurs. Mandatory reporting on a national scale ensure that trends and issues are identified in a timely manner and the government can respond to issues as they arise.

Strengthening informal support networks

In addition to the formal mechanisms discussed, casual mechanisms of oversight afforded by informal support networks for people with disability could also be encouraged and developed. When people are isolated, they are easy targets for violence, abuse, neglect, exploitation, and the inappropriate use of restrictive practices. By encouraging, developing, and funding programs that assist people with disability to develop wide informal support networks, less people will fall through the gaps, and the use of inappropriate restrictive practices will not go unnoticed.

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

The alternatives to restrictive practices will depend on the individual and their specific situation. Whatever the approach taken it should:

- Recognise that behaviours are usually a form of communication
- Seek to understand what the behaviour is trying to communicate/what is the unmet need
- Look at ways to meet the need of the person that promotes their human rights, dignity of risk and right to freedom
- Be trauma informed where appropriate

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

There should be consequences for the abuse of restrictive practices. Where appropriate this should include laying criminal charges. We know that historically there have been limited criminal or civil penalties for abuses and neglect which have resulted from abuse of restrictive practices. Ensuring that people who have experienced abuse of restrictive practices have access to justice sends a strong message that restrictive practices are a last resort and should be carefully considered before they are implemented.