Co-designing a Framework for Listening to People with Disabilities Experiences of Restrictive Practices

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Acknowledgement of Country

I acknowledge that we are meeting on the land of the Gadigal people of the Eora Nation, I pay my respects to this land, its people, and to the elders past and present.

I extend this respect to any Aboriginal and/or Torres Strait Islander people present today.

Always was, always will be Aboriginal Land.

We also acknowledge all people with a lived experience of disability here with us today.

PWDA commissioned artwork by Paul Constable Calcott, Wiradjuri Elder and PWDA member.

Eliminating Restrictive Practices by Listening to People with Disability's Experiences

Linda Steele, University of Technology Sydney

Dinesh Wadiwel, The University of Sydney

Restrictive Practices: A Pathway to Elimination

- Claire Spivakovsky, Linda Steele and Dinesh Wadiwel asked by Disability Royal Commission to research eliminating restrictive practices.
- Comprehensive survey of the human rights concerns and drivers of restrictive practices.
- Examined current research on eliminating restrictive practices, including available evidence on effectiveness or ineffectiveness of positive behaviour support approaches.
- Report published by the Disability Royal Commission: Spivakovsky, C., Steele, L., & Wadiwel, D. (2023). *Restrictive Practices: A Pathway to Elimination*. Australia: Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability.
- Report + Easy Read Summary: https://disability.royalcommission.gov.au/publications/restrictive-practices-pathway-elimination

Defining restrictive practices

“Restrictive practices are legally authorised and/or socially and professionally sanctioned violence that targets people with disability on a discriminatory basis and are at odds with the human rights of people with disability.

Restrictive practices include, but are not limited to, chemical, mechanical, physical and environmental restraint and seclusion, guardianship, forced sterilisation, menstrual suppression and anti-libidinal medication, financial management, involuntary mental health treatment, and other non-consensual or coercive interventions said to be undertaken for protective, behavioural or medical reasons.”

Why eliminate restrictive practices?

- There are many reasons why restrictive practices are problematic and should be eliminated.
- Restrictive practices strip people with disability of dignity, are painful and harmful, disempower people, and can produce trauma and life altering harm.
- Restrictive practices do not comply with our human rights obligations to prevent ill-treatment and prohibit discrimination against people with disability.

Examples of lived experiences of restrictive practices

‘The lady who told me to shut up, one of the nurses, she pushed my face in like that. I say, **‘I can’t breathe; you’re hurting my neck**. Let me go. You people are hateful the way you treat me.’ After I was tied up, she **just gave me the finger**. The policeman who was nice to me, he just looked at her like he knows she’s doing something wrong, but they **don’t say anything**.’ – person with disability, restraint in emergency department

‘[there] was a **huge cage** in the middle of school, the school was padlocked once kids were in and parents were not allowed to be involved in their education. I **cried every day** I dropped him there.’ – parent of child with disability, restraint in school setting

‘I feel **alone and isolated**.’

‘Because I have had important parts of my body taken away it is **hard to find out what is really going on** in my body.’

‘It has resulted in **loss of my identity** as a woman, as a sexual being.’

- women with disability, sterilisation

Research gaps on restrictive practices

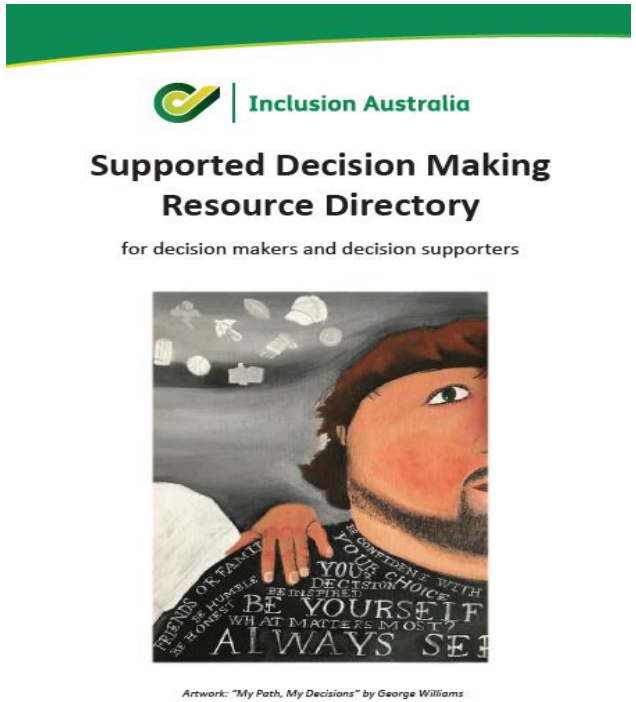
- There are limitations and gaps in current research on restrictive practices.
- A lot of faith has been placed in positive behaviour support, but the research only shows little evidence or uncertain results about its effectiveness in eliminating restrictive practices.
- There is a lack of studies on the lived experiences of people with disability who are subject to restrictive practices, including people with intellectual disability.
- The lack of lived experiences in the research is highly problematic because the voices of people with disability have not been involved in research about them.

Individualised Engagement

In the context of inclusive disability research

Individualised Engagement

- Drawing from the suggested tools/approaches to effectively supported decision making.



Individualised Engagement

- What does an individualised engagement approach look like?
  - Allowing the appropriate time for the person to be prepare for the engagement session and allow for more than one attempt at engagement
  - Assistive technology
  - Video messaging unique to the person
  - Using environments where the person feels safe
  - Consult with communication partners or those who know and interact with the person regularly

Why include those with complex communication support needs in research?

If the stories from those with complex communication support needs are not included, we are not getting the real picture regarding the use of restrictive practice for people with intellectual disability.

We already know they are at the highest risk and their stories should be one of the drivers of what will lead to the elimination of restrictive practices.

Luke Nelson, Policy Officer, Inclusion Australia

My views

- Restrictive practices should not be used as much as possible.
- They should only be used as the last resort and in extreme situations.
- Positive behavior supports should be put in place and the person should be given positive prompts.
- Before using restrictive practices, permission must be given from the senior practitioner and must be written down.

My views

- I would like to see restricted practices removed and not having to use them at all.

- They should be removed because I believe it is sometimes dangerous for people living with disabilities, it can be harmful and restrictive towards their movement.

- It also restricts individuals' free will and right to act.

Moving forward together

2024 Interagency restrictive practices workshops

Collaborating for change in a way that is rights affirming

A recognition of the power of people stories

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Informed by lived experience: Building awareness of rights and restrictive practices

Convention on the Rights of Persons with Disabilities

Articles 3 & 4: Dignity and autonomy

Articles 14, 15 & 16: Right to liberty & protection from violence

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Identified areas for change

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Shared priorities for systemic advocacy

- Most workshop/roundtable participants voted for community education as their first priority, and for targeting settings which affect most people as their second priority.

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