
# Proposed National Framework on Restrictive Practices.

*Living a full and meaningful life.*

National Council on Intellectual Disability (NCID) has over 5,000 members representing all 8 states and territories. In addition to having people with intellectual disability on our Board, NCID receives policy advice from Our Voice. Our Voice is a committee of NCID's Board, the membership of which is exclusively people with intellectual disability representing all states and territories.

NCID is the recognised national peak body with the single focus on intellectual disability, ie, our actions and priorities centre on issues that affect the lives of people with intellectual disability and their families.

NCID's mission is *to work to make the Australian community one in which people with intellectual disability are involved and accepted as equal participating members*. We do this by:

- listening to people with intellectual disability and their families
- promoting and upholding the UN Convention on the Rights of Persons with Disabilities
- developing and promoting creative policies and practices
- speaking to politicians, public servants, business and community leaders about the lives of people with intellectual disability and their right to have equality of opportunity

National Council on Intellectual Disability is a social profit organisation. NCID was created in 1971 by parents and friends in an endeavour to improve the quality of life of people with intellectual disability and to fill the need for national unity and information.


# National Council on Intellectual Disability

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# Statement of Principles

- All people have inherent dignity and worth and equal and inalienable rights.
- All people are valued members of the Australian Community.
- People with intellectual disability as equal participating members of the Australian Community have the same rights:
  - to respect for their individual autonomy and independence
  - to make their own choices
  - to participate in decisions which affect their lives
  - to pursue any grievance which affects their lives
  - to diversity of choice for housing, education, work, recreation and leisure
  - to equity and justice
  - to be empowered to take their full place in the Australian Community
  - to dignity and privacy in all aspects of their lives

## National Council on Intellectual Disability will:

✓ work to make the Australian Community one in which people with intellectual disability have full and equal enjoyment of all human rights and fundamental freedoms and are involved and accepted as equal participating members.

✓ promote and protect the human rights of all persons with intellectual disability, including those who require more intensive support.

## Consultation Statement

National Council on Intellectual Disability consults people with intellectual disability and family members through our State and Territory Agency Members. In particular we:

➡ conduct an annual survey of members and stakeholders

➡ hold two meetings a year, rotating through all States and Territories

➡ present at the Having a Say Conference each year, attended by over a 1,000 delegates the majority of whom have a disability

➡ hold forums on specific issues

➡ sponsor actions and representations on issues of importance to people with disability

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# Introduction

In responding to this draft legislation NCID is using the lens of people with an intellectual disability and considering the way that restrictive practices impact upon their lives. It is important to remember that every person is a unique individual regardless of their ability difference.

As recognised in the draft paper, historically people living in institutional settings were regularly controlled using what is now, known as restrictive practices. As there is a growing knowledge and practice base that understands the complexity of human behaviour, the use of restrictive practices is seen as a last option, one that needs to be undertaken within the framework of a legal implementation and monitoring system. What has been increasingly understood is that ***Behaviour Is Communication***. Today it is widely understood that we can support a person with challenging behaviour to express themselves in socially appropriate ways, when we work at understanding what it is that they are telling us. In essence it is us (family members, professionals and support staff) that need to do the work of interpreting and accommodating a person's communication, when they face obstructions to being understood.

Additionally we would argue that before any restrictive practice is implemented a person undergoes a full physical and psychological assessment to eliminate that the challenging behaviour is the result of a health condition or associated mental disorder.

# Context

People with intellectual disability continue to be the largest group of citizens that live in small and large institutional settings. This means that the lives they lead are controlled and delimited by those who have power over them. For many people abuse is a constant in their lives[1]. This can be as simple as every day being subjected to a shower that is too cold or too hot, not having any choice about where you go and what you do, what you eat, when you eat, or when you go to bed. Often, institutional setting place the needs of staff and organisational process above those of the person living there. For instance a person who lives in a group home and becomes unwell and doesn't want to go to work one day, will be forced to go to work because the house will not be staffed and there is no option for them to stay at home. A problem in many current services is that people are reaching retirement age and no longer wanting to go to work, and they are forced to continue because of the

[1] Undercover Care: Panorama, BBC, 1 June 2011, http://www.bbc.co.uk/news/uk-13548222
Bribie Island Care, 2009, http://www.couriermail.com.au/news/bribie-island-care-facility-residents-need-voice/story-e6frerhf-1225771922563

structure and scheduling of staffing of a group home. This is because of the institutional needs (typically economic) of the running of the facility are placed before the best interest of the person.

When a person lives in an institutional setting very often health issues go under or undiagnosed and therefore untreated (for example side effects of medications, constipation, abdominal pain, tooth ache, ear infections and urinary tract infections)[2]. When a person has a dearth of language to describe emotions and pain they will typically display behaviours that can be constructed as challenging behaviour. Where a person has no language to communicate what they are feeling they will communicate using behaviour, it may be hitting their ear if they have an ear infection, punching a wall, screaming at another person, so they are seen as aggressive or dangerous person. Therefore we would advocate that before any restrictive practice is implemented that a person undergoes a comprehensive health screening to ensure that the cause of the behaviour is not a physical illness[3]. Full health screens and assessments should be undertaken on a yearly basis. It is important to remember that for a person living in an institutional setting the turnover of staff and movement within and across services often mean that there is a loss of memory of their life history, including medical history of the person. It is critical that the professional making assessments is skilled at collecting narrative information from a person with an intellectual disability. Having time to undertake a full assessment, and the appropriate screening tool is central to a successful health and behavioural outcome.

This is also imperative to assess the mental health of the person. Increasingly there is a literature on the over representation of mental illness among people with an intellectual disability. Bender (1993)[4] detailed that so rare was the consideration that a person with an intellectual disability may experience episodes of mental illness that they were not even given access to counselling. Thankfully there is an increased understanding that people live very stressful lives and the impact of this is episodes of mental disorders (depression; anxiety disorders and high rates of PTSD).

The first process in a National Framework on Restrictive Practices, must be to eliminate the physical and psychological causes of any challenging behaviour.

[2] Proffessor Nick Lennox 2012 Endeavour Foundation http://www.youtube.com/watch?feature=endscreen&v=SwqGGN2ibNY&NR=1

[3] CHAP tool, Professor Nick Lennox QCIDD April 2013. http://www.youtube.com/watch?v=zQj2_H6QQ1A

[4] Bender, M. 1993. The unoffered chair: the history of therapeutic disdain towards people with a learning difficulty. Clinical Psychology Forum: 54: 7-12.

It is imperative that restrictive practices are undertaken with the consent of the person and/or their guardian/ advocate; and the restrictive practice is managed by an external agency with the involvement of highly skilled multidisciplinary practitioners, and that regular reviews are undertaken. If there is no change in the behaviour then a new plan needs to be developed and implemented.

## What is missing in this draft

Around Australia the legislation relating to restrictive practices applies only within the environment of a disability funded service – a group home or a day centre for example. Increasingly we see that restrictive practices are applied to children in a range of settings, and are concerned that there are no regulations and compliance mechanisms to ensure these practices are developmental, rather than punitive. Therefore we advocate that any National Framework on Restrictive Practices address the use of restrictive practices with a child or children in educational, disability services and respite settings. In relation to this practice we would also advocate that:

- ✓ If a practice is unacceptable for general population then it is also for children with disabilities.
- ✓ We are keenly aware that at times children's behaviour may threaten their own safety, or that of other people and this exposes them to the use of a restrictive practice.
- ✓ Effective reduction of restrictive practices requires increased interagency/inter-professional collaboration, involving key disability and health professionals, include paediatricians
- ✓ Paediatricians have a key role in many aspects of the diagnosis and management of children with disabilities, including the management of challenging behaviour and are keen to participate more actively in policy development to improve health and wellbeing of these children and young people.
- ✓ It is often the case that the parents/carers understanding of and response to the diagnosis/disability can be a significant factor in their ability to implement positive behaviour plans.
- ✓ **A key component of any framework must include a comprehensive assessment of the behaviour that involves paediatrician/physician/psychiatrist, psychologist, social worker/case worker/educationalist as there may be physical health, emotional/mental health or disability related factors**

**influencing the presentation of challenging behaviour. Further it is through close collaboration that positive practices are effectively implemented.**

- ✓ Data collection should involve notifications to regulatory bodies e.g. Department Of Community Services and Department of Education.
- ✓ The National Children's Commissioner should be involved at a high level as the wellbeing of children with disabilities sits within her portfolio.
- ✓ There should be capacity for issues that arise from analysis of the data to be available to higher bodies National Children's Commissioner.

## Cautions

Where a restrictive practice is implemented it MUST not be a punishment of used to have control over a person. When a person is using communication that results in challenging behaviour it is the conversation that needs to be understood. As such implementing a restrictive practice must be DEVELOPMENTAL. That is, that it leads to the ongoing development of a person so that they be assisted to live a full and meaningful life. There are examples where people who lived secluded lives were provided with the necessary supports so that now they are able to move freely around their local community and are welcomed and accepted.

Often, staff who work in disability service are well meaning and dedicated people but do not have a high level of understanding relating to behaviour and communication; and the practical and technical ways to respond to challenging behaviours. Historically a restrictive practice has been used, (medication, mechanical or physical restraint, or seclusion) as the normal way to control a person. Where legislation has succeeded there has been intensive training of staff so that they understand the actions that they engage in, which are within the context of legislation, a restrictive practice. For example, tying someone into a bed is not keeping them safe, it is a restrictive practice, a better option may be a mattress on the floor next to a sensor mat – it reduces risk and maintains dignity and rights of the person.

There needs to be a clear process of applying for a restrictive practice – which will establish how this plan will lead to the development of a person and the withdrawal of the practice plan. While the order is in place, there needs to be regular monitoring and review of the application and a timeline for the withdraw of the plan.

## Recommendations

NCID supports the draft document with its focus on the involvement of the person and the spirit of person centred practice at the heart of the document, also the

acknowledgement that it is the workforce and system who will need to undertake the change and professional development in the use of restrictive practices. In responding appropriately to people with episodes of mental disorder we would make the recommendation to resolve national guidelines on the appropriate prescription of psychoactive medication for people with intellectual disability. This work should involve:

- ✓ Collaborative action between the RANZCP, RACGP, Australian Psychological Society, RACP and ACRRM, noting the importance of a multidisciplinary approach.
- ✓ Links to the development of a national strategy to reduce the use of restrictive practices in disability services.
- ✓ Consultation with the National Health and Medical Research Council.
- ✓ Noting in the proposed guidelines the importance of a formalised system for medication review e.g. by a multidisciplinary panel.
- ✓ Include a focus on mental health in the proposed national strategy to reduce the use of restrictive practices in disability services, including ensuring that decisions about use of psychoactive medication are based on the shared skills of appropriate health and disability professionals. There is a similar need for action on restrictive practices in schools and mental health services.

The process by which restrictive practices are applied for and are managed are central to the success for systemic reduction of restrictive practices. NCID advocates -

- ✓ To eliminate that the behaviour is a result of a physical or psychological disorder.
- ✓ That the person is a part of the decision making team
- ✓ A **skilled multidisciplinary** assessment team make the assessment and develop a plan that leads to the elimination of challenging behaviour by giving the person the scaffolding to express themselves in developmental and socially acceptable means.
- ✓ That there are provisions for ongoing evaluation and review of the plan.
    - A plan should not be developed for a life time but be time limited, a year, and then be reviewed.
- ✓ That a the workforces is supported with appropriate training and development
- ✓ That success is celebrated and a person sees themselves in positive ways.
- ✓ That people/ family members and advocates, have information on what services are doing best in reducing their use of restrictive practices as a means of measuring what services they may wish to enter.

## Specifically with in the document we recommend these changes

1. In the definition of ‘chemical restraint’, replace ‘mental illness’ with ‘mental disorder’.
2. In the core strategies, make the following changes:
    a. In ‘Person centred focus’, add two extra ‘key implementation areas’:
        i. Ensuring medical reviews to identify any physical or mental condition that contributes to challenging behaviour.
        ii. Ensuring that any prescription of psychotropic medication is based on a skilled multidisciplinary consideration of the behaviour.
3. In ‘leadership towards organisational change’, add a key implementation area:
    a. Development of good practice guidelines in relation to behaviour intervention and support and in relation to use of psychotropic medication, based on multidisciplinary and consumer input.

Thank you for the opportunity to comment on the draft paper.