



The Secretary
Parliamentary Joint Committee on Human Rights
PO Box 6100,
Parliament House
Canberra ACT 2600

Via email: human.rights@aph.gov.au

6 August 2019

Dear Secretary,

Re: Quality of Care Amendment (Minimising the Use of Restraints) Principles 2019 (principles).

I write to provide feedback regarding ADA Australia's human rights concerns in relation to the Quality of Care Amendment (Minimising the Use of Restraints) Principles 2019.

Aged & Disability Advocacy Australia (ADA Australia) is a not for profit, independent, community-based advocacy and education service with more than 25 years' experience in supporting and improving the wellbeing of older people and people with a disability.

ADA Australia provides individual advocacy support to users and potential users of Commonwealth funded aged care services and is a member of the Older Persons Advocacy Network (OPAN) delivering the National Aged Care Advocacy Program (NACAP) in Queensland.

ADA Australia also operates a Human Rights advocacy service in South-East Queensland supporting people with impaired capacity, including support as they engage with the Queensland Civil and Administrative Tribunal (QCAT).

ADA Australia has the benefit of reading the submissions of Human Rights Watch (HRW), dated 23 May 2019, the Office of the Public Advocate Victoria (OPA), dated 11 July 2019, and the draft report of the Queensland Office of the Public Guardian (OPG). We are in support of these submissions. We also welcome the opportunity to put the "consumer voice" to these previous submissions.

The inappropriate use of chemical restraint in aged care has been a matter of increasing concern raised by both aged care residents and family members supported by ADA Australia in recent years. Further, we would like to observe that the use of restraints in the aged care sector has been unregulated for a long time, and we welcome the Committee's scrutiny from the perspective of Australia's Human Rights obligations.

Breaches of United Nations Convention of the Rights of People with a Disability (UNCRPD)

ADA Australia is very concerned about breaches of the UNCRPD Articles 12, 14, 15 and 19.

Independent Oversight

In relation to Article 12, we are very concerned about the lack of independent oversight of the process, in particular regarding chemical restraint; along with there being no real mechanism in the principles to change care arrangements in order to reduce or extinguish use of restraints.

As raised in the OPA submission, it is also our experience that medical professionals are heavily reliant on aged care workers to report behavioural and health concerns of the residents, and therefore, have a divided loyalty. The relationship between prescriber and service provider is likely

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ADA Australia acknowledges the Traditional Custodians of this land and pays respect to Elders, past and present.

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to be much closer, in practical terms and business terms, than between the doctor and the patient in the facility. This has come about due to numerous factors that we have observed including:

- The resident of an aged care facility frequently has to terminate their relationship with their own General Practitioner (GP) and have the GP that the facility allocates, upon entry to the facility.
- It is often our experience that when residents of a facility are seeking an independent medical report most residents tell us that they do not trust the facility GP and ask for our assistance to provide lists of GPs in their area with whom they may seek an independent relationship with. (This task is made more difficult as people are often placed in suburbs or regions that they are unfamiliar with).

Due to the longer-term institutional nature of aged care and link with a regular medical professional not chosen by the resident, the requirements of an independent review of any mechanisms need to be stronger in residential aged care, not weaker, due to the possibility of a conflict of interest arising between the health professional and the aged care facility.

Article 12 (4) of the UNCRPD provides: “measures relating to the exercise of legal capacity respect the rights, will and preferences of the person, are free of conflict of interest and undue influence, are proportional and tailored to the person’s circumstances, apply for the shortest time possible and are subject to regular review by a competent, independent and impartial authority or judicial body. The safeguards shall be proportional to the degree to which such measures affect the person’s rights and interests. (emphasis added).

Article 14 (2) states that persons with disabilities are “not deprived of their liberty unlawfully or arbitrarily, and that any deprivation of liberty is in conformity with the law, and that the existence of a disability shall in no case justify a deprivation of liberty. (emphasis added)

Article 15

1. *No one shall be subjected to torture or to cruel, inhuman or degrading treatment or punishment.*

In particular, no one shall be subjected without his or her free consent to medical or scientific experimentation.

2. *States Parties shall take all effective legislative, administrative, judicial or other measures to prevent persons with disabilities, on an equal basis with others, from being subjected to torture or cruel, inhuman or degrading treatment or punishment. (emphasis added)*

Article 19:

b) Persons with disabilities have access to a range of in-home, residential and other community support services, including personal assistance necessary to support living and inclusion in the community, and to prevent isolation or segregation from the community; (emphasis added)

Chemical Restraint

In relation to Article 15, we refer to the Professional Practice Guideline 10, developed by the Royal Australian and New Zealand College of Psychiatrists on “Antipsychotic medications as a behavioural and psychological treatment for dementia”, 2016. This outlines the evidence of an increased risk of



death from the use of anti-psychotics, and the one anti-psychotic approved for use, is only approved for 12 weeks.¹

The guideline also notes that use of anti-psychotics should be targeted toward:

- People experiencing psychosis;
- People unresponsive to psychosocial interventions; or
- People exhibiting severe and complex risk of harm.

It also notes that:

- People with other anti-social behaviours are not indicated for use of anti-psychotics.
- Professionals are to seek informed consent from the person or their decision maker unless there is an emergency.

By outlining the key points in the guidelines, it appears that the “principles” go beyond the clinical framework by:

- Not acknowledging the increased mortality attached to the use of antipsychotics;
- No time restricted prescription;
- No specific behaviours targeted or a requirement for specialist review of medications; and
- No emphasis on informed consent.

By opening the door to use of chemical restraint outside the above guidelines, it enables residential aged care facilities to use chemical restraints (which have an increased risk of death) for other purposes, including possible punishment, inhumane and degrading treatment, along with usage as a measure of convenience. ADA Australia asserts that this is a breach UNCRPD Article 15.

Decision Making

We also refer to and endorse the OPA’s comments around the use of the term “representative”, as defined in section 5 of the Quality of Care Principles. It means:

- *a person nominated by the consumer to be told about matters affecting the consumer; or*
- *a person who nominates themselves as a person to be told about matters affecting a consumer, and who the provider is satisfied has a connection with the consumer and is concerned for the safety, health and well-being of the consumer.*
 - *A ‘representative’ includes a person who:*
 - *is a consumer’s partner, close relation or other relative;*
 - *holds an enduring power of attorney;*

¹ Professional Practice Guideline 10, Royal Australian and New Zealand College of Psychiatrists on “Antipsychotic medications as a behavioural and psychological treatment for dementia” 2016, p.2.



- *has been appointed by a State or Territory guardianship board; or*
- *represents the consumer in dealings with the provider.*

We have raised concerns previously (through Older Person’s Advocacy Network – OPAN) regarding the looseness of this definition of representative. It has no hierarchical structure to it, which therefore can allow providers to “cherry-pick” the representative who best fits their purpose, thus possibly creating a power imbalance. Also, it mixes or blurs decision making roles between formally appointed decision makers such as an (enduring power of attorney and guardian appointed by a State or Territory board or Tribunal), with family and also with that of a supporter or advocate. Tasks such as decision making are also blurred with advocacy, which involves supporting the person to express their views to a provider.

We regularly find that aged care facilities are very confused around decision making roles and the extent of the decisions which can be made. A common error we see is the person’s rights to be connected to friends, family and with the community more broadly, is often breached by the decision maker which goes unchallenged by the aged care facility.

The above definition of representative is not at all coherent with State based substitute or supported decision making regimes and as a result opens residents up to a range of social abuses resulting in cutting older people off from their community. Aged care facilities tend to enable human rights breaches by their lack of engagement with a practical understanding of decision making, capacity, and limitations of substitute decision making. This lack of understanding is enabled by the poor definition of a representative.

The principles in relation to chemical restraint do not allow for the person or their decision maker to consent to or refuse treatment. This treatment has been identified as use of medications without therapeutic benefit, and something that the Pharmaceutical Benefits Scheme could regulate to minimise or eliminate (by: at the minimum insisting on the 12 week maximum dose), rather than medications that are encouraged to be over-used without recourse to independent review.²

Voice of consumers

ADA Australia is currently reviewing the practical impact of chemical restraint with HRW. We have contacted past clients, and their families, with experience of the use of chemical restraint, to gain their consent for the HRW Research. As we re-contacted past and current clients, many common themes emerged.

- First, that they had never been approached by the treating Doctor or GP, or the aged care facility, about using the medications or indeed, the use of these medications.
- Commonly, it was not until the family member responsible for the payment of the fees received the accounts from the pharmacy, and then “googled” the names of the medications, they became aware of the medications being used.
- Once being made aware, and, also realising how their loved one had changed to becoming so drowsy that they could no longer mobilise or stay awake enough to complete a meal by

²From National Elder Abuse Conference, July 2019, Brisbane, 22nd July



themselves, family members would then often seek to meet with the appropriate staff in order for the medication to be reviewed or ceased.

- Often, when clear direction to cease the medication, the medication continued to be prescribed and administered.
 - Then, as a result of the chemical restraint being continually used, the family felt that they then had to remove the older person from care, or to another facility, because of this issue.
 - We also note OPA submissions that many residents (40%) have no visitors and no one to oversee or report the conduct of the aged care facility, and we remain extremely concerned for these residents.
- For some family members, although issues around chemical restraint occurred several years ago, the stressful impact of the decisions taken out of their hands to use chemical restraint was still very fresh in their memory.

Case Study

ADA Australia was contacted by a daughter, Rosie, of a lady (we shall call her Dianne) living in a residential facility, who was concerned (amongst other things) that her mother was being sedated.

We assisted Rosie to organize a meeting, which involved asking for a copy of the care plan, where they noted that a few strategies had been tried before sedation was prescribed. They stated at the meeting that the care plan be amended to state that they did not want chemical restraint to be used. It was also agreed that with any medication changes Rosie would be notified as she was the attorney under an EPOA.

Following review by behavior specialists, it was noted that music calmed Dianne. However, once the behaviour specialists left, the new measures were no longer used and chemical restraint was reinstated without any notice. A formal complaint was then made after the usual approaches were ignored. A conciliation meeting occurred with the Commission, and as a result, Rosie received an updated care plan (once again the advocate had to remind the facility to send this to the daughter), including the notation about use of chemical restraint.

Whilst this case study ended positively, it is interesting to note how persistent the daughter had to be in order to achieve the outcome she sought.

Closing Remarks

ADA Australia supports this review of the above principles. We remain concerned that the rushed introduction of the principles earlier in the year resulted in the adoption of principles that are inadvertently in breach of Australia's Human Rights obligations, namely Articles 12, 14 & 15 of the UNCRPD.

The effect of the principles and the breaches are that there is a "regression" of a rights focus in relation to consent, and decision making and independent review. The continued reliance on restraint that medical professionals have documented as harmful and likely to increase mortality is extremely concerning. This is lacking proportion to any original concern raised by the facility in responding to behaviours of concern.



We also want to take the opportunity to highlight to the committee, that generally, decision making around healthcare and community participation in aged care is poorly understood and emanates from an institutional perspective. The poor definition of representative, in our view, enables general personal and health decision making to be poorly understood in the aged care sector, making informed consent difficult to enforce. The difficulty for the aged care sector embracing state and territory decision making arrangements should not result in the adoption of these principles that breach human rights and overlook existing laws.

We suggest that any proposed laws engage with the existing clinical guidelines, medical research, current state and territory guardianship and restrictive practice laws, supported decision making and ensuring that there is an oversight body who can independently review disputes. This body would need to be able to review medical professionals who provide services in aged care facilities.

We **recommend that the principles be withdrawn**, and that the committee recommends a more formal debate canvassing the rights focus that HRW, OPA, OPG and ourselves have raised.

Thank you for the opportunity to respond to the work of this committee.

Yours Sincerely

Geoff Rowe
CHIEF EXECUTIVE OFFICER

