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12 September 2019

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

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

Dear Secretary,

Re: Quality of Care Amendment (Minimising the Use of Restraints) Principles 2019 – Department of Health Response to Questions from Committee

I am writing regarding the response the Parliamentary Joint Committee received to questions it raised with the Department of Health in correspondence dated 28 August 2019. The questions were raised with the Department by the Committee resulting from its inquiry into the *Quality of Care Amendment (Minimising the Use of Restraints) Principles 2019*. The response from the Department of Health was published on the Committee's website on 10 September 2019.[1]

As the Public Advocate for Queensland, I have significant concerns about the responses from the Department to a number of the Committee's questions and the possibility for the responses to lead to misunderstandings about the potential operation of the amended Principles.

Accordingly, I trust the Committee will accept this further submission addressing a number of the issues arising from the Department of Health's response.

Question A (Hansard Page 71, Tuesday, 20 August 2019)

Comment on Department of Health response

I note the response provided by the Department of Health. I concur with the information contained in the first seven paragraphs of that response.

The response then states:

> Before a medical practitioner or nurse practitioner prescribes a medication for the purposes of managing the behavioural and psychological symptoms of dementia, he or she must assess the consumer as requiring the medication.
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> During the assessment, the medical practitioner or nurse practitioner must satisfy themselves that other non-pharmacological methods have been tried to the fullest extent possible, and those methods have not been successful. The consumer must be experiencing symptoms which are likely to be alleviated by the proposed medication.
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> The medical practitioner or nurse practitioner would then make a clinical judgement. For example, some behavioural symptoms of dementia do not respond to medications; therefore, it would not be appropriate to prescribe for these behaviours. However, for some behaviours

[1] Department of Health (Cth), Answers to Question on Notice, Health Portfolio, Inquiry into Quality of Care Amendment (Minimising the Use of Restraints) Principles 2019 Ref No1, accessed online 11/9/2019 <https://www.aph.gov.au/Parliamentary_Business/Committees/Joint/Human_Rights/QualityCareAmendment>

e.g., aggressive or psychotic behaviours, including people who have distressing hallucinations or delusions, medication can be of benefit.

The practitioner must satisfy themselves that the person is sufficiently adversely affected and that other methods have not worked or worked sufficiently.

The practitioner would make a clinical judgement about the person's capacity to provide informed consent to the medication and seek informed consent, either from the person, or their representative if they do not have capacity to consent. Informed consent involves providing information about the reason for the medication, the options and alternatives, the risks and benefits, how long it may be used for and making sure the person and/or their representative understands this information.

Then the practitioner would trial the medication for those specific behaviours, and monitor for any impact. If the symptoms get worse, the medication would be stopped. However, if the symptoms improve, the practitioner may trial taking the person off the medication completely to see if those symptoms return. Some persons may need to stay on medication as their symptoms return if the medication is ceased.[2]

The paragraphs above describe how the system of assessment of residents for medication to manage challenging behaviours should operate in practice. In particular, I would respectfully request that Committee members note the comment that the 'practitioner would make a clinical judgement about the person's capacity to provide informed consent to the medication and seek informed consent, either from the person, or their representative if they do not have capacity to consent.'

However, the Department's response fails to explain how the approach they have described can actually be reconciled with the procedures provided for the administration of chemical restraint under the amendment to the Principles.

Section 15G of the *Quality of Care Amendment (Minimising the Use of Restraints) Principles 2019* states:

> (1) An approved provider must not use a chemical restraint in relation to a consumer unless:
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> (a) a medical practitioner or nurse practitioner has assessed the consumer as requiring the restraint and has prescribed the medication the use of which is, or is involved in, the restraint; and
> (b) the practitioner's decision to use the restraint has been recorded in the care and services plan documented for the consumer in accordance with the Aged Care Quality Standards set out in Schedule 2; and
> (c) the consumer's representative is informed before the restraint is used if it is practicable to do so. [Emphasis added]
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> (2) If an approved provider uses a chemical restraint in relation to a consumer, the approved provider must:
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> (a) if the consumer's representative has not been informed of the use of the restraint—inform the consumer's representative as soon as practicable after the restraint starts to be used. [Emphasis added]

The amended Principles do not address the very relevant issue of the medical practitioner obtaining consent to the administration of medical treatment, but instead, due to the way

[2] Ibid

they are drafted, seem to be suggesting that all the law now provides is that 'the consumer's representative is informed before the restraint is used if it is practicable to do so'.

This is not consistent with the law relating to medical treatment nor with the Medical Board of Australia *Code of Conduct* dealing with informed consent, which states:

> **3.5 Informed consent**
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> Informed consent is a person's voluntary decision about medical care that is made with knowledge and understanding of the benefits and risks involved. The information that doctors need to give to patients is detailed in guidelines issued by the National Health and Medical Research Council (NHMRC). Good medical practice involves:
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> 1. Providing information to patients in a way that they can understand before asking for their consent.
> 2. Obtaining informed consent or other valid authority before you undertake any examination, investigation or provide treatment (except in an emergency), or before involving patients in teaching or research.
> 3. Ensuring that your patients are informed about your fees and charges.
> 4. When referring a patient for investigation or treatment, advising the patient that there may be additional costs, which patients may wish to clarify before proceeding. [3]

There is nothing in the Principles that relieves medical practitioners of their legal obligations in relation to informed consent. Further, the way the Principles are drafted in relation to chemical restraint appear to suggest to aged care providers and medical practitioners (dangerously) that their obligations to residents, in terms of obtaining informed consent to the administration of chemical restraint, is met if the person's representative is 'informed' after the event.

Such misleading drafting will lead to aged care residents' rights being routinely breached and will expose medical practitioners, believing that they can rely on government legislation to clearly outline their responsibilities in this area of practice, to significant professional risk.

All of these outcomes would be avoidable if the Commonwealth Government were prepared to produce a comprehensive document, informed by appropriate consultation with the relevant stakeholders and potential decision-makers, that clearly outlined the law and the appropriate processes.

There are also significant issues around the Commonwealth's informal representative scheme. It is unclear under what head of power the Commonwealth Government is purporting to authorise people to be a person's 'representative' under the *Aged Care Act* for these types of significant decisions. The power to appoint guardians, financial administrators and powers of attorney sits with the Australian states and territories.

The purported authorisation of people to be substitute decision-makers under the *Aged Care Act* is also a process without reviews, checks or balances. Such a system leaves older people who need decision-making support potentially vulnerable to inappropriate people assuming these functions with little oversight or accountability. This is likely to lead to serious breaches of people's rights.

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[3] Medical Board of Australia, Good Medical Practice: a code of conduct for doctors in Australia < https://www.medicalboard.gov.au/Codes-Guidelines-Policies/Code-of-conduct.aspx>, accessed online 11/9/2019

The representative provisions in the *Aged Care Act* and the attempt to use them to use informal 'representatives' to consent to restrictive practices under the Principles, breaches the human rights of vulnerable older Australians to recognition and equality before the law.

Question B (Hansard Page 74 Tuesday, 20 August 2019)

Comment on Department of Health response

In terms of the groups and agencies that were consulted by the Department of Health in the Key Stakeholder Working Group, there appears to be no representative on that group who would bring a legal or human rights perspective to this issue, nor were there representatives from the various Public Guardians or Public Advocates in each state or territory who would be required to make decisions about consent to these treatments on behalf of many aged care residents. It is important to acknowledge that a proposal to amend the law and practice around the use of restraints in aged care, including the use of physical and chemical restraints, involves treatment that, without the appropriate legal and decision-making frameworks in place, would amount to criminal acts against the person.

Of necessity, consultation around such matters must involve lawyers, guardians and advocates with expertise in these matters. It is the absence of these perspectives that has resulted in the amendments to the Principles being inadequate and misleading about the law and potentially exposing vulnerable older Australians to unlawful treatment and breaches of their human rights.

Question C (Hansard Page 75 Tuesday, 20 August 2019)

Comment on Department of Health response

I respectfully submit to the Committee that the Department of Health's response to your question about whether the instrument engages Australia's obligations under the Convention against Torture also could lead to a misunderstanding about whether the instrument engages significant human rights.

The Convention Against Torture and Other Cruel, Inhuman or Degrading Treatment or Punishment does not deal with the non-consensual administration of medical treatment or other restraints on a person's liberty and right to bodily integrity. That Convention is limited to the very specific definition of torture under that document, which is:

> any act by which severe pain or suffering, whether physical or mental, is intentionally inflicted on a person for such purposes as obtaining from him or a third person information or a confession, **punishing him for an act he or a third person has committed or is suspected of having committed,** or intimidating or coercing him or a third person, or for a any reason based on discrimination of any kind, when such pain or suffering is inflicted by or at the instigation of or with the consent or acquiescence of a public official or other person acting in an official capacity.[4]

It is patently clear that the Convention against Torture is not applicable in these circumstances. However, I would submit that it is potentially misleading for the Department to not acknowledge the other key human rights under international conventions that <u>are</u> breached by this instrument.

Specifically I refer to the United Nations Convention on the Rights of Persons with Disabilities, under which Article 4 requires States Parties to:

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[4] *Convention Against Torture and Other Cruel, Inhuman or Degrading Treatment or Punishment*, opened for signature 10 December 1984 (entered into force 26 June 1987) ('*Convention Against Torture and Other Cruel, Inhuman or Degrading Treatment or Punishment*), art 27.

> ensure and promote the full realisation of all human rights and fundamental freedoms for all persons with disabilities without discrimination of any kind on the basis of disability.[5]

The Convention it operates to protect the rights of older Australians with disabilities such as dementia and other conditions that may affect their cognitive function, as well as those with physical disabilities.

Article 12 of the Convention requires that:

1. States Parties reaffirm that persons with disabilities have the right to recognition everywhere as persons before the law.
2. States Parties shall recognize that persons with disabilities enjoy legal capacity on an equal basis with others in all aspects of life.
3. States Parties shall take appropriate measures to provide access by persons with disabilities to the support they may require in exercising their legal capacity.
4. States Parties shall ensure that all measures that relate to the exercise of legal capacity provide for appropriate and effective safeguards to prevent abuse in accordance with international human rights law. Such safeguards shall ensure that 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.
5. Subject to the provisions of this article, States Parties shall take all appropriate and effective measures to ensure the equal right of persons with disabilities to own or inherit property, to control their own financial affairs and to have equal access to bank loans, mortgages and other forms of financial credit, and shall ensure that persons with disabilities are not arbitrarily deprived of their property.[6]

Article 17 of the Convention states that:

> Every person with disabilities has a right to respect for his or her physical and mental integrity on an equal basis with others.[7]

Article 25 of the Convention provides that:

> Persons with disabilities have the right to the enjoyment of the highest attainable standard of health without discrimination on the basis of disability ... In particular, States Parties shall:
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> ...
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> (d) Require health professionals to provide care of the same quality to persons with disabilities as to others, including on the basis of free and informed consent by, inter alia, raising awareness of the human rights, dignity, autonomy and needs of persons with disabilities through training and the promulgation of ethical standards for public and private health care.[8]

Clearly, all of these human rights are engaged by the instrument under consideration by the Committee. The Statement of Compatibility provided by the Department of Health to the Committee failed to adequately acknowledge the range of human rights being impacted by the amendments to the Principles and to provide the necessary justification of those breaches of the rights of older people who are subjected to restrictive practices.

For the benefit of the Committee, I also include a quote from the Australian Law Reform Commission Discussion Paper No 81, *Equality, Capacity and Disability in Commonwealth*

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[5] *Convention on the Rights of Persons with Disabilities*, opened for signature 30 March 2007 [2008] ATS 12 (entered into force 3 May 2008) ('*Convention on the Rights of Persons with Disabilities*') art 9.

[6] Ibid.
[7] Ibid.
[8] Ibid.

Laws[9]. This quote specifically addresses the issue of informed consent to medical treatment and the role of guardians and advocates in making health and other decisions for an adult who is not capable of giving consent:

> 10.47 At common law, all competent adults can consent to and refuse medical treatment. If consent is not established, there may be legal consequences for health professionals. Under the law of trespass, patients have a right not be subjected to an invasive procedure without consent or other lawful justification, such as an emergency or necessity. At the international level, the CRPD expresses this in terms of a 'right to respect for his or her physical and mental integrity on an equal basis with others'.[35]
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> 10.48 'Informed consent' refers to consent to medical treatment and the requirement to warn of material risk prior to treatment. As part of their duty of care, health professionals must provide such information as is necessary for the patient to give consent to treatment, including information on all material risks of the proposed treatment. Failure to do so may lead to civil liability for an adverse outcome, even if the treatment itself was not negligent.[36]
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> 10.49 The common law recognises that there are circumstances where an individual may not be capable of giving informed consent (for example, due to impaired decision-making ability) or where consent to treatment may not be required, as in the case of emergency. However, except in the case of children—where the High Court has recognised the courts' *parens patriae* jurisdiction in authorising treatment[37]—it does not provide significant guidance on supported decision-making in health care settings.
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> 10.50 State and territory guardianship and mental health legislation (discussed below) does provide detailed rules for substitute decision-making concerning the medical treatment of adults who are deemed incapable of giving consent.[38]
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> 10.51 Guardianship legislation outlines criteria for appointing substitute decision-makers, the hierarchy of possible decision-makers and the scope of their powers, which depend on the age of the patient and the type of treatment proposed.
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> 10.52 In all jurisdictions, except the Northern Territory, guardianship legislation provides for a decision-maker who is chosen (for example, an enduring guardian), assigned by the legislation (for example, a spouse, close friend or relative) or appointed (for example, by a court) to make health decisions for an adult who is not capable of giving consent.[39]
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> 10.53 In exercising their powers, substitute decision-makers are required to adopt one of two tests (or a combination of both in some jurisdictions) in reaching their decision for the person with impaired decision-making capacity. One is the best interests test, which requires a balancing of the benefit to the patient against the risks of the proposed treatment, and the other is the substituted judgment test, which involves making a decision which is consistent with what the person would have decided if they had the capacity to do so. Evidence of such wishes may be provided by advance care directives, religious beliefs and previous history of treatment.[40]

I trust that this information assists the Committee to understand the full range of human rights engaged by the provisions of the instrument under consideration and that it is inadequate, in terms of providing a framework of appropriate safeguards, review and accountability to protect the human rights of older Australians in aged care who may be subject to restrictive practices.

Question 1(Written Question on Notice – The Committee)

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[9] Australian Law Reform Commission, Equality, Capacity and Disability in Commonwealth Laws, Discussion Paper No.81, accessed online 11/9/2019 < https://www.alrc.gov.au/publication/equality-capacity-and-disability-in-commonwealth-laws-dp-81/10-review-of-state-and-territory-legislation/informed-consent-to-medical-treatment/#_ftn36>

Comment on Department of Health response

a) I note the statement by the Department that 'the meaning of "representative" within the instrument is intended to provide for the operation of 'practical decision-making arrangements'.

It is unclear how this can actually be legally and practically achieved. I also remind the Committee of the points I made in relation to the Department's response to Question A, including that it is unclear under what head of power the Commonwealth Government is purporting to authorise people to be a person's 'representative' under the *Aged Care Act* when the power to appoint guardians, financial administrators and powers of attorney sits with the states and territories.

It is also questionable whether a decision of this type is appropriately made by an informal decision-maker who has no legal or other guidance for their decision-making and who is not formally accountable, nor are their actions or decisions reviewable or overseen by another authority.

In the circumstances, I submit with respect to the Committee that the Department's response does not adequately address the issues raised by the Committee's question.

b) The Department's response to this question is also particularly disturbing in the context of its response to the previous question. In answer to the previous question the Department was defending the appointment of informal 'representatives' as providing for 'practical decision-making arrangements'. This response, and the way the instrument is drafted, would suggest that providers will have met their legal and compliance obligations if they obtain consent from a 'representative', even an informal one authorised under the *Aged Care Act*.

However, in response to the Committee's question about the circumstances when consent is obtained from a 'representative' appointed under the Act who does not have legal authority under relevant state and territory laws, the Department states that 'where a provider meets its responsibilities under the Act, this does not excuse it from complying with state and territory laws' and that 'legal action may be taken against the provider if it does not comply with state or territory law.'

This response is confusing and unreasonable on the part of the Department. If there is an expectation that the provider must comply with state and territory laws in relation to guardianship and decision-making, why does the instrument provide for informal representatives under the *Aged Care Act* to have authority to consent to restrictive practices? Further, why does the instrument not clearly state that compliance with the requirements of the Principles will not exempt medical practitioners and providers from their other legal obligations relating to consent to restrictive practices?

Based on the responses of the Department, the amended Principles appear deceptive and dangerous and are likely to result in providers unwittingly breaching the law while believing they have fully complied with their obligations in terms of standards and quality of care under the *Aged Care Act*. The Principles as drafted are exposing aged care providers, medical practitioners and residents to significant risks (albeit of different types). This is an untenable situation, and I respectfully request the Committee to disallow the instrument and direct the Department to amend the Principles to protect residents from breaches of their human rights and medical practitioners and providers from inadvertently breaking the law.

c) This response from the Department is also potentially misleading about the period for which a consent to a restrictive practice is valid, in that it does not actually answer the Committee's question about this issue. By using an example involving a restrictive practice that is only applied for a short time, the response appears to be suggesting that the consents to restrictive practices will only have a short life. However, the instrument is unclear about how long a consent, for example, to the administration of anti-psychotic medication would be valid. It appears to be implied under the instrument that the consent is valid until the use of the restrictive practice is no longer required. In the case of chemical restraint, we know from the research, that unless family members or other supporters challenge the administration of these medications, they are being administered to large numbers of aged care residents, without much clinical evidence to support the treatment, without obtaining consent and without review.

   Notionally under the instrument, a person could be administered chemical restraint from the time of their admission to a residential aged care facility and remain on that treatment until their death some years later, without anyone reviewing the appropriateness of the treatment, or its on-going effectiveness, or reconsidering alternative approaches after the residents' behaviour has stabilised.

Question 2 (Written Question on Notice – The Committee)

Comment on Department response

I respectfully submit to the Committee that the Department's response to the Committee's question is wholly unacceptable, especially in terms of ensuring that aged care providers, medical practitioners and nurse navigators fulfil their legal and statutory responsibilities and the rights of aged care residents are protected.

There is no reasonable basis on which the Department can justify not drafting the instrument to ensure that it is clear to providers, medical practitioners and nurses that the obligations under the Principles are in addition to their other statutory and legal obligations and do not replace those obligations.

In its current form, the instrument is misleading and is likely to have the effect of encouraging providers, medical practitioners and nurses to inadvertently breach their legal obligations. It therefore exposes them to the risk of disciplinary action or criminal prosecution and aged care residents to human rights abuses.

Question 3 (Written Question on Notice – The Committee)

Comment on Department response

In its response, the Department does not adequately explain why the Minister did not, on his own initiative, adopt the recommendations of his own Carnell/Patterson review, nor why the short-term Working Group appointed by him did not recommend adoption of the recommendations of the Australian Law Reform Commission 2017 Report, *Elder Abuse – A National Legal Response,* or the Carnell/Peterson review, or the National Disability Insurance Scheme restrictive practice model.

Each of those reviews were led by highly regarded experts who gathered and synthesised key views on the issues, including the use of restrictive practices. It is concerning that following those very comprehensive and competent reviews, and their consistent recommendations, the Department of Health, instead of adopting those recommendations and introducing the appropriate recommended restrictive practice model, chose to establish yet another short-term Working Group to re-visit the results and recommendations from those extensive processes and take another course.

Conclusion
I thank the Committee for its thorough inquiry into this instrument and trust that this submission will be of assistance to members in their deliberations.

In the circumstances, I reiterate my original request that the Committee disallow the instrument and direct the Department to consult with legal experts and state and territory guardians and advocates and redraft the Principles to avoid ambiguity and ensure the protection of the rights and interests of vulnerable older Australians in residential aged care.

Yours sincerely

Mary Burgess
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