Capacity Australia Response:
Draft Psychotropic Medicines in Cognitive Disability or Impairment Clinical Care Standard Public Consultation

Conjoint Professor Anne Duggan,
Chief Executive Officer
Australian Commission on Safety and Quality in Health Care
Level 5,
255 Elizabeth Street
Sydney NSW 2000

Dear Professor Duggan,

We wish to thank you for providing Capacity Australia the opportunity to comment on the draft Clinical Care Standards. Congratulations on a well-put-together document with attention brought to critical issues around the use of psychotropic medicines for people with Cognitive Disability or Impairment. The Capacity Australia Board has reviewed the document and primary concerns relate to the following:

- The generalist nature of the document - We understand that this guideline aims to cover Psychotropic medicine use in cognitive disability or impairment that will traverse both the disability and aged care sectors. It is neither customary nor best practise to conflate the needs of two different patient/client groups in a single Clinical Standard. The apparent efficiency of this approach comes at a cost to critical details that are either missing from the document or the misapplication of details that do not apply to one group or the other. A highly relevant example is in relation to the legal and ethical issues (including but not limited to Informed consent) where there is great nuance across the lifespan and clinical context. The issue of capacity should be front and centre and acknowledging the need for capacity assessments to be undertaken by trained professionals is not clarified fully. In addition, the requirement for documentation of consent and for this consent to be fully informed is mentioned but the standards enforced across disability and aged care are again quite different;

- Staff training standards and competency – we have made comment on the need to strengthen availability and quality of training for clinicians in non-drug approaches to behavioural challenges or unmet needs and related behaviour support plans. This

should be reflected in the standards. This is another area where there are glaring differences between the disability and aged care sectors.

We hope that you will consider these issues and our comments below in response to your specific questions and will be happy to review a revised specific aged care document (where our expertise lies) in the future with consideration for endorsement of the final Clinical Care Standards.

Our responses to the questions posed are as follows:

1. **Questions about each quality statement and indicators (1-8)**

Does the quality statement adequately describe the quality of care that should be provided? a. How could the quality statement be improved?

Capacity Australia Responses

1. *Person- and family-centred care*: We suggest to change human and legal rights to "human rights and legal rights". This may seem a minor point, but abbreviating human rights means this absolutely crucial concept - rarely understood or acknowledged by clinicians on the ground - gets lost. We do, however, resoundingly applaud the Commission for making human rights front and centre of this document.

2. *Informed consent for psychotropic medicine*. We note the presumption of capacity. You cannot suggest that clinicians automatically "inform the person and their family" before determination of capacity. Also, the family may not be the individual's proxy decision maker, please do not refer to the family here, as while they may fit the criteria in some circumstances, this is not the correct terminology for proxy decision-makers.[1] [2] The language around consent should also be strengthened to avoid passivity. Consent MUST be obtained – or not. Suggest change to: If a psychotropic medicine is being considered, the person's consent (or their proxy, if they lack capacity) must be obtained. Consent must be obtained by informing the person first before they consent or not consent, and only if they lack capacity (which should be appropriately determined by a qualified professional), their proxy, about the reason for prescribing, and its potential benefits and harms and alternative treatments.

[1] O'Neill N., Peisah C. (2021) Capacity and the law. 4th Edition Australasian Legal Information Institute (AustLII) Communities http://austlii.community/wiki/Books/CapacityAndTheLaw/.

[2] Peisah C, Jessop T. (2021) Australia's problem with obtaining consent for psychotropic use in older people Internal Medicine Journal. Intern Med J.;51(4):604-607

Where use of psychotropic medicine is agreed, informed consent must be obtained and documented before use. If the person's decision-making capacity is impaired, processes for supported decision making, proxy consent or exemptions under relevant legislation are followed as appropriate. The option for an individual not to consent to treatment with a psychotropic medicine is not made clear and again the language could be strengthened. Page 23, line 17 states "You will be asked to give informed consent to have the medicine." Suggest that a sentence following clarify that upon receipt of all information, the individual or their proxy may choose not to consent.

3. *Assessing a person with behaviours of concern*. We suggest that the first time behaviours of concern are mentioned, an explanation is provided in brackets after (formerly behavioural and psychological symptoms of dementia or BPSD) i.e. "Assessing a person with behaviours of concern (formerly behavioural and psychological symptoms of dementia or BPSD). The way new terms have been linked to the old terms and explanations provided on Page 13 'Terminology' is excellent. As we know, the term "BPSD" is still in common parlance among clinicians on the ground, even senior ones, and needs to be rectified as you have done. We have concerns about the use of the word 'unexpected' when referring to behaviours of concern. Any and all behaviours of concern should be assessed by a qualified clinician, documented and interventions scheduled for review as appropriate.

4. *Non-drug strategies* re: Non-drug strategies are used first-line when responding to behaviours of concern. Please add "unless the behaviour causes significant distress to the person or poses urgent and serious risk to the safety of the person or others". The consensus from the scientific community is that this statement must always be qualified.[3,4]

5. *Behaviour Support Plans.* Regarding the section "For clinicians" page 34 line 36 where it's stated " A behaviour support plan is a written document prepared in collaboration with the person with cognitive disability or impairment, their family and other support people that brings together important information…" It is our

[3] Peisah C. (2014) The use of restraints and psychotropic medications in people with dementia Paper 38: A report for Alzheimer's Australia. Alzheimer's Australia. https://www.dementia.org.au/files/NATIONAL/documents/Alzheimers-Australia-Numbered-Publication-38.pdf

[4] O'Neill N., Peisah C. (2021) Capacity and the law. 4th Edition Australasian Legal Information Institute (AustLII) Communities http://austlii.community/wiki/Books/CapacityAndTheLaw/.

experience this is not the way that support behaviour support plans are developed, particularly in aged care, however it should be. Secondly it is stated in lines 39 and 40 it is often written by an authorised allied health or nursing staff member who knows the person. Again, this is not our experience and the quality varies greatly between behaviour support practitioners. There is currently no indicator under Quality Statement 5 regarding qualifications or training in developing behaviour support plans, only considerations for plans that already exist. We suggest that accreditation for behaviour support practitioners should be included in the standards.

Comments on indicators:

- Indicator 3a. Assessing a person with behaviours of concern:
  - Process to assess adherence to the policy. Please change to Process to assess understanding, use of and adherence to the policy. We have too many policies that sit in drawers.
  - Please add: Processes to support people with behaviours of concern after hours, which is often the context for initiating psychotropic use, particularly in aged care. The Dementia Behaviour Management Advisory Services https://www.dementia.com.au/dbmas provide 24hour on the ground support, clinical advice Australia-wide, to persons living with dementia and their carers. This is referred to later in the document, but we consider that this is worthy of an indicator as it is the context for initiation and in our experience clinically, is under-utilised with dire consequences.[5]

- Indicator 4a Non-Drug strategies. The document acknowledges that the workforce must be trained in non-drug strategies but it is not this simple. We need to move away from the tick-box approach to training, emphasising the need for in-depth understanding and competency. Non-drug strategies must be developed and implemented by clinicians who are trained in behavioural interventions and must meet ethical standards and be informed by evidence-based practice.[6]

[5] Peisah C., Jessop T., Brodaty H. (2018) Nursing homes "no-returns" policy, when residents are discharged to the Emergency Department at 4am: what does the law say Medical Journal Australia. 209(7):324
[6] McGrath, J.C. (2007). Ethical practice in brain injury rehabilitation. New York: Oxford University Press.

2. **Questions about the clinical care standard.**

The quality statements focus on areas identified by the Commission as being a priority for quality improvement. Are there additional areas or aspects of care that should be included? a. If so, please provide further detail.

Capacity Australia Response

We suggest another one, possibly two Quality Statements are added:-

Quality Statement 9: Supporting behaviours of concern for people with cognitive disability or impairment who are approaching the end of life. We suggest you define, in Terminology, "end of life" using the UK Gold Standard Surprise Question.[7] See empoweredproject.org.au for resources.

Quality Statement 10: Provision of appropriate resources for people living with cognitive impairment or disability to enhance shared decision-making. The Commonwealth Government invested just under $1million for Capacity Australia to empower the Australian public over the issue of de-prescribing and quality prescribing within the context of cognitive impairment and dementia. The resources developed (see empoweredproject.org.au) need to be used, and were, while the NPS MedicineWise existed. A statement concerning provision of resources and shared decision making could stand alone or be incorporated as an indicator under *Quality Statement 2 Informed Consent for Psychotropic Medicine*.

2.1 Scope Page 10. "The standard recognises existing legislation [3, 4, 6, 7] which identifies psychotropic medicines... Please add as reference 8 here: O'Neill N., Peisah C. (2021) Capacity and the law. 4th Edition Australasian Legal Information Institute (AustLII) Communities http://austlii.community/wiki/Books/CapacityAndTheLaw/. This is the only text available in Australia that comprehensively addresses the legislation and common law on these issues (ie both Consent and Restrictive Practices) in plain language and is used by all of the Courts and Guardianship and Administration Tribunals, and is the standard reference text.

[7] Thomas K, Armstrong Wilson J, GSF Team. Proactive Identification Guidance (PIG) National Gold Standards Framework Centre in End of Life Care. 2016. http://www.goldstandardsframework.org.uk/

2.2 Healthcare settings. We applaud the inclusiveness of the stakeholders within scope - too often the issue of psychotropic use is restricted to, and focused on, residential care settings at the expense of Community[8] and Hospital settings.

2.3 *The distinction between use as treatment and use to influence behaviour.* It is time at least here, if not earlier, to start specifying what we mean by a "diagnosed mental health or other condition." Scientific consensus, teaching and best practice suggests that this refers to psychosis (eg delusions or hallucinations) or mood disorder, including that complicating dementia. [9] We suggest that this be added following "Regulation typically makes a distinction between a medicine used for a therapeutic indication such as a diagnosed mental health or other condition, as opposed to a medicine prescribed for the primary purpose of influencing a person's behaviour. "

I.e. "Regulation typically makes a distinction between a medicine used for a therapeutic indication such as a diagnosed mental health or other condition, as opposed to a medicine prescribed for the primary purpose of influencing a person's behaviour. Scientific consensus, teaching and best practice suggests that a diagnosed mental health or other condition refers to psychosis (eg delusions or hallucinations) or mood disorder, including that complicating dementia. [10] It is absolutely crucial that these standards do not interfere with best practice and quality patient care.

2.4 *Terminology*

As stated above, we endorse and support the behaviours of concern definition.

The following statement is nonsensical and offensive to human rights, including but not limited to autonomy (We never conflate the person with their family). Please delete this sentence: In this standard, when the word 'person' is used, it is intended to include significant others who are involved in the person's healthcare and decision-making either by virtue of being family or through more formal arrangements for substitute decision-making.

Please correct the definition of cognitive disability provided in the document: *An umbrella term for people whose level of cognitive function generally causes difficulty with things such*

[8] Loftus K, Wand A, Breen J, Peisah C. Factors associated with psychotropic medication use in people living with dementia in the community: A systematic review. Emerging Researchers in Ageing, Australia. 4 Nov 2021

[9] O'Neill N., Peisah C. (2021) Capacity and the law. 4th Edition Australasian Legal Information Institute (AustLII) Communities http://austlii.community/wiki/Books/CapacityAndTheLaw/.

[10] O'Neill N., Peisah C. (2021) Capacity and the law. 4th Edition Australasian Legal Information Institute (AustLII) Communities http://austlii.community/wiki/Books/CapacityAndTheLaw/.

as completing day-to-day tasks, decision-making, and communication. It is tautological to talk about cognitive function level and then difficulty with decision-making, and communication. It is also unusual to specifically single out these cognitive functions, which to the lay person reading this document will exclude anyone with predominantly memory problems (i.e. Alzheimer's disease). Perhaps simply define cognition and disability.

2.5 How to use this clinical care standard.

Please note this useful reference for supported decision-making for clinicians.[11]

2.6 Quality statement 2 Informed consent for psychotropic medicine.

Please ensure that the O'Neill and Peisah Capacity and the Law (as above) is used.

3. Do the proposed indicator(s) capture information that can be used to support local clinical quality improvement activities? a. How could the indicator(s) be improved?

Some direction should be provided to stakeholders regarding measuring awareness and use of policies. Time and effort invested in the development of "local policies" that sit in drawers and are never used is both a major risk and opportunity loss. It is suggested that a Quality Improvement project be undertaken to measure of the use of or compliance with local policy/ies such as an annual audit return of activities compliant with their own policy/ies.

4. Are you aware of any current or planned initiatives that could support implementation of this clinical care standard? a. If so, please provide further detail.

4.1 See above 1.2. The Commonwealth Government invested just under $1million for Capacity Australia to empower the Australian public over the issue of de-prescribing and quality prescribing. The resources developed (see empoweredproject.org.au) need to be used, and were, while NPS MedicineWise existed. Note resources with regards to psychotropics, consent, plus a video concerning end of life in this context.

4.2 Capacity Australia is available for funded education provision to support implementation of this clinical care standard, as we have done since our inception.

[11] Peisah C., Sorinmadeayo D. Mitchell L., Hertogh C., (2013) Decisional capacity: towards an inclusionary approach The International Psychogeriatric Association Task Force on Capacity International Psychogeriatrics 25 (10): 1571-9.

Questions about cultural safety and equity considerations

6. *Do you agree with the suggestions relating to cultural safety and equity? a. If not, how could this be improved?*

No comment

Questions about the supporting resources

7. *Is the Consumer Guide useful? a. If not, how could this resource be improved?*

No comment

8. *Is the Easy Read Consumer Guide resource useful? a. If not, how could this resource be improved?*

The sheer length of this document would not make it an easy read. Can we suggest content be reduced and key messages articulated clearly.

We look forward to the opportunity to review the revised Clinical Care Standards when available and will hold our decision regarding endorsement until that time.

Thanking you again,
Capacity Australia