Submission: Consultation on draft Aged Care Visitor Access Code

1. What is Capacity Australia?
Capacity Australia (capacityaustralia.org.au) is a not-for-profit, medico-legal organisation with charity DGR status, led by senior legal and health academics and practitioners. We are committed to supporting the human rights of people with decision-making disability.

2. How do we do this?
One of the ways we do this is by providing education regarding capacity (decision making ability) and human rights across medical, allied health, legal, financial and community sectors across Australia and internationally.¹ We join international advocates for the promotion of the equal enjoyment of human rights of older persons, particularly those with disability such as dementia living in residential care. These rights are articulated by the United Nations Convention of the Rights of Persons with Disabilities (CRPD),² they key ideas underpinning such being equality, autonomy and independence. Of the CRPD’s 50 Articles, the most salient for advocacy in residential care are:
1) Article 12: Equal recognition before the law including the right to equal legal capacity, support in exercising that capacity, expression of will and preferences and the right to be safeguarded against undue influence and abuse;
2) Article 14: Liberty and security of the person;
3) Article 16: Freedom from exploitation, violence and abuse;
4) Article 19: Living independently and being included in the community;
5) Article 22: Respect for privacy;
6) Article 23: Respect for home and the family, and relationships; and

7) Article 25: Enjoyment of the highest attainable standard of health without discrimination, including respecting specific needs that arise on account of disability.

We note that these dual, sometimes competing priorities are asserted in Articles 12 and 16 relating to the rights of older people under United Nations human rights conventions to which Australia is a party. Another equally important priority is to ensure that when decisions are made, people with disability are afforded access to the highest attainable standard of health without discrimination on the basis of disability, as asserted in Article 25 of CRPD. These issues are extremely relevant to the question of aged care quality and safety.

3. Comments on the Visitation Code
3.1 General
We applaud Aged Services for the timely development of this Code, and strongly encourage its rapid publication, notwithstanding the tragedy of the recent spate of nursing home deaths in NSW. It is perhaps one of the strengths of this Code, that it highlights the dual importance of achieving “the right balance between protecting residents from COVID-19 and providing them with vital social connections and support from loved ones” as you have outlined in the Background to the Code. We also applaud the prioritisation of the first Principle being: “Providers must actively facilitate connections between residents and family, families of choice and friends, consistent with the Charter of Aged Care Rights”.

3.2 Suggestions
We make these suggestions mindful of the excellent brevity of the Code which increases its readability and impact. We suggest only one or two lines addressing the following issues:

- We suggest, in the opening lines of the second paragraph, that reference to higher order human rights preface discussion of Aged Care Quality Standards and Rights. The human rights “anaemia” in Australian aged care frameworks and policies has been a focus of concern for some time. This is not unique to Australia. Invisibility of older persons in human rights systems and the implementation gap between the articulation of human rights values and principles in human rights frameworks, and the actual

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enjoyment of such \(^8\) has led to discussions by the UN Open Ended Working Group about a new UN treaty on the rights of older people. We therefore feel that explicitly acknowledging the human rights to (i) the highest attainable standard of health without discrimination, on the basis of free and informed consent, with respect for specific needs that arise on account of disability (Article 25); (ii) the expression of will and preferences (Article 12); (iii) liberty and security of the person (Article 14); and (iv) the family, relationships and connectedness (Article 23) should preface the rationale for the Code. This is especially important for the edification of families and carer advocates.

- We recommend the addition of a Principle regarding the implications of the Code and the complexity of achieving these objectives for people with cognitive impairment or dementia. This would recognize the specific vulnerabilities of these residents and the multiple human rights at stake. Implicit in this is helping staff, families and carers understand that violations of the human rights to the expression of will and preferences (Article 12) and the meeting of unmet needs (Article 25) associated with pandemic-imposed social isolation, loneliness and deprivation of intimacy (Article 23) are likely to drive changed behaviours in dementia. At the same time, there needs to be an acknowledgement of the difficulty in enforcing social distancing and hand hygiene in people with cognitive impairment, challenging the equitable rights to health (Article 25) and to liberty and security (Article 14). In line with additional support that may be required in the instance of changed behaviours, we would suggest reference in the Code to the encouragement that facilities seek specialist input from available services such the DBMAS/ SBRT (with contact details) and/or their local specialist mental health services for older people. Telehealth means that access to these services continues.

On a final note, we congratulate the consortia on a Code that stands out amongst global initiatives for supporting human rights of older people in the pandemic and we look forward to disseminating this Code internationally as soon as it is finalised. We also might be of assistance in implementation of the Code locally in Australia.

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For Capacity Australia