4 September 2019

Mr Ian Goodenough MP
Chair
Joint Parliamentary Committee on Human Rights
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CANBERRA ACT 2600

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Dear Chair

Inquiry into *Quality of Care Amendment (Minimising the Use of Restraints) Principles 2019*

Relationships Australia welcomes the Committee's current inquiry into the *Quality of Care Amendment (Minimising the Use of Restraints) Principles 2019* ('the Principles'). The federation of Relationships Australia recently made a submission to the Royal Commission into Aged Care Quality and Safety ('the Royal Commission'), in which we canvassed general concerns about the use of restrictive practices in aged care, as well as specific concerns about the Principles. We wish to put our concerns to the Committee, for consideration in its inquiry.

Relationships Australia welcomes the Commonwealth's move to better protect the human rights of older people by regulating restrictive practices in residential aged care facilities (RACF). However, we are concerned that the Principles, in their current form:

- permit breaches of human rights and infringements of long-established common law rights, inhering to all individuals, to personal liberty and bodily integrity
- lack rudimentary safeguards to protect human rights
- do not acknowledge that restrictive practices, physical or chemical, are intrinsically harmful[1] and that they are, in any event, unlikely to achieve even the behavioural management and safety objectives for which they are applied[2]

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[1] Being associated with risks such as increased mortality, heart attack, stroke, pneumonia, falls, and as acknowledged, for example, in the submission to this inquiry from the Aged Care Quality and Safety Commission, the submission from ADA Australia. See also Background Paper 4 of the Royal Commission into Aged Care Quality and Safety, *Chemical and Physical Restraint.* In his evidence to this inquiry, Professor J Ibrahim noted that the consequences of physical restraint include 'pressure injury, malnutrition, confusion, delirium.' (at p 18)

[2] Relationships Australia notes testimony to this inquiry as to when a 'pharmaceutical aid' is administered for a therapeutic purpose and when it has been administered as a chemical restraint: see, for example, testimony of Dr Colleen Pearce, Public Advocate of Victoria, p 5 of transcript. We further note the testimony of Professor J Ibrahim to this inquiry that '…there is a misperception that physical restrain improves safety, that it

- do not acknowledge that these inherent harms are compounded by so subduing residents that they reinforce isolation and othering of older people, and undermine older people's capacity to nurture and enjoy connections with family and friends, and
- do not acknowledge:
  - the well-established physical and mental health benefits of connection,[3] and
  - the equally well-established physical and mental health risks of isolation and loneliness.[4]

For these reasons, Relationships Australia considers that the Principles allow for ongoing abuse of older people in RACF. We support the calls from other submitters and witnesses to this inquiry to disallow the Principles.

This would create the opportunity for well-considered development of evidence-based regulation that is genuinely co-designed with:

- users of aged care
- human rights advocates (particularly those with a focus on advocating for older people)
- professionals with expertise in the use of restrictive practices, and
- relevant state and territory office-holders the performance of whose functions and powers are purportedly engaged by the Principles.[5]

The work of Relationships Australia

Relationships Australia is a federation of community-based, not-for-profit organisations with no religious affiliations. Our services are for all members of the community, regardless of religious belief, age, gender, sexual orientation, lifestyle choice, living arrangements, cultural background or economic circumstances.

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stops people from falling over, stops them acting impulsively, stops them injuring themselves, other staff and other residents. ….there is more harm that occurs from physical restraint to the individual.' (at p 18)

[3] See, for example, L Grenade and D Boldy, 'Social isolation and loneliness among older people: issues and future challenges in community and residential settings', *Australian Health Review*, August 2008, vol 32 no 3, 468.

[4] See, eg, Liesl M Heinrich, Eleonora Gullon, 'The clinical significance of loneliness: A literature review', *Clinical Psychology Review* 26, (2006): 695-718. A Dean, 'Elder abuse – Key issues and emerging evidence', CFCA Paper No. 51, 1, 12-13, citing Dong, 2015; Dow & Joosten, 2012; Jackson & Hafemeister, 2016; Johannesen & LoGiudice, 2013; Kaspiew *et al*, 2016; Pillemer *et al*, 2016; von Heydrich *et al*, 2012. Holt-Lunstad, J, Smith, T B, Baker, M, Harris, T, & Stephenson, D (2015). Loneliness and Social Isolation as Risk Factors for Mortality: A Meta-Analytic Review, *Perspectives on Psychological Science*, 10(2), 227 –237. Lim, M (2018), 'Is loneliness Australia's next public health epidemic?' *InPsych* 2018; 40(4). Retrieved from https://www.psychology.org.au/for-members/publications/inpsych/2018/August-Issue-4/Is-loneliness-Australia-next-public-health-epide

[5] Office of the Public Guardian, Queensland, *Quality of Care Amendment (Minimising the Use of Restraints) Principles 2019 – Submission to the Parliamentary Joint Committee on Human Rights*, 2019, 3, 6, 9. Relationships Australia understand that there may be some doubt in law as to the extent to which the Principles can affect the exercise, by State statutory officeholders, of their powers and functions.

Relationships Australia has, for over 70 years, provided a range of relationship services to Australian families, including individual, couple and family group counselling, dispute resolution, services to older people, children's services, services for victims and perpetrators of family violence, and relationship and professional education. We aim to support all people in Australia to live with positive and respectful relationships, and believe that people have the capacity to change how they relate to others and develop better health and wellbeing.

From 2016, Relationships Australia has provided targeted services to individuals and families with age-related issues and who are experiencing difficulties coping with life course transitions, conflict, family violence and abuse of older people, grief and loss, poor mental health, intergenerational trauma, or who need professional support to have difficult conversations with family members around end of life decisions. Our services also include:

- capacity building within families, mental health and transition support, family counselling and mediation
- supported referral to police or other specialist legal services
- family meetings co-facilitated with a counsellor and a mediator, and
- training and clinical supervision for service providers and their staff.

Relationships Australia State and Territory organisations, along with our consortium partners, operate around one third of the 66 Family Relationship Centres across the country. In addition, Relationships Australia Queensland operates the national Family Relationships Advice Line and the Telephone Dispute Resolution Service.

We respect the rights of all people, in all their diversity, to live life fully and meaningfully within their families and communities with dignity and safety, and to enjoy healthy relationships. A commitment to fundamental human rights, to be recognised universally and without discrimination, underpins our work.

This submission draws upon our experience in delivering, and continually refining, evidence-based programs in a range of family and community settings, including:

- people who come from culturally and linguistically diverse backgrounds
- Aboriginal and Torres Strait Islander people
- people adversely affected by adoption practices, including post-adoption and forced adoption support services
- people who have suffered from abuse within institutions, out of home care, and under wardship arrangements
- people who identify as members of the LGBTIQ communities
- people affected by intergenerational trauma, and
- people affected by intersecting disadvantage and polyvictimisation.

Relationships Australia contextualises its service, research and advocacy energies within imperatives to strengthen connections between people, scaffolded by a robust commitment to human rights. Accordingly, this submission refers to evidence indicating:

- the adverse impacts of social isolation and loneliness, which include increased risk of becoming a victim *or* perpetrator of abuse, as well as pervasive negative effects on mental and physical health, and

- the protective impacts of safe and healthy family relationships, and of social belonging and connection in both preventing abuse and mitigating its impacts.

The potential for interventions to strengthen connections and reduce isolation is one of the most promising avenues for reducing the risk of abuse and exploitation of older people. Certainly, it is one of the most modifiable factors as yet known, and should therefore be embedded in services and supports offered to older people, and other vulnerable members of our community:

> Social support has emerged as one of the strongest protective factors identified in elder abuse studies….Social support in response to social isolation and poor quality relationships has also been identified as a promising focus of intervention because, unlike some other risk factors (eg disability, cognitive impairment), there is greater potential to improve the negative effects of social isolation.[6]

Practices, such as physical and chemical restraint, that impinge upon residents' capacity to participate in activities that are meaningful to them, and to connect with other people, are practices that, in the view of Relationships Australia, should be discarded. They should be replaced with responses to unmet need and BPSD that support and nurture users' capacity to connect with other people and guard against isolation and loneliness.

Notes on language

Relationships Australia uses:

- 'abuse of older people' rather than 'elder abuse' because of the implications of 'elder' for Aboriginal and Torres Strait Islander people

- where context allows - 'service' rather than 'care' to underscore the autonomy of people who receive aged care services; 'care' licenses paternalism which is rooted in ageism, and

- 'user' rather than 'recipient' because 'user' is more autonomy-friendly and active; 'recipient' is more passive. 'User' can also include an older person's loved ones and representatives.

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[6] See Dean, CFCA 51, 20, Box 7, citing the United States of America population study described in Acierno *et al*, 2017; citing also Hamby *et al*, 2016; Pillemer *et al*, 2016.

Relevant initiatives

Relationships Australia notes the proliferation of inquiries and reports concerning quality and safety in aged care. This submission is informed by observations, findings and recommendations in reports and other documents, including testimony and submissions made to this Committee. Relationships Australia acknowledges recent reforms and initiatives intended to improve aged care pending the final recommendations of the Royal Commission into Aged Care Quality and Safety ('the Royal Commission'), in addition to the Principles, including:

- the *National Plan to Respond to the Abuse of Older Australians*[7]
- the establishment and operation, as of 1 January 2019, of the single Aged Care Quality and Safety Commission, and
- the now mandatory status of the Single Quality Framework.

Purpose of aged care

It is important, at the outset of this submission, to consider whether and, if so, how the use of restraints serves the purpose of Australia's aged care system, which Relationships Australia considers is to:

- support the quality of life of users, including through embracing dignity of risk, according to their individual wishes, preferences, values and capacities
- offer services and support that empower users to express their individuality and draw on their own strengths/abilities as they see fit, including through defining and achieving a quality and meaningful life; including by enabling users to:
  - maintain existing family and social relationships,[8] and
  - belong to and participate in group activities that are valued by the user
- offer high quality services that support users to access their preferred health care[9] and allied health services, nursing services, mental health services, and palliative care services in seamless, place-based and culturally safe formats

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[7] See https://www.ag.gov.au/RightsAndProtections/protecting-the-rights-of-older-australians/Pages/default.aspx

[8] As noted by Dean CFCA 51, 15, Johannesen & LoGiudice, 2013, suggested that 'Formal social supports or networks for older people have been suggested as a key protective factor for older adults at risk of social isolation.'

[9] Relationships Australia notes evidence to this inquiry to the effect that users of RACF must often relinquish their relationships with their own GPs, and use GPs retained by the RACF, and the risks that this can expose residents to: see, eg, the evidence of Ms Siegel-Brown, Queensland Public Guardian, at pp 6-7; the evidence of Dr Nespolon, President of the Royal Australian College of General Practitioners, p 32.

- for RACF – be truly 'residential' by providing a home, not an institution, allowing freedom of movement within and outside the facility, independence, choice of activities, ability to attend activities that they previously enjoyed, and engage with risk.[10]

Accordingly, Relationships Australia considers that a 'fit for purpose' aged care system would:

- ensure that service providers meet and work to exceed standards relating to:
  - human rights considerations,[11] and
  - clear prudential and governance requirements, based on purposefully calibrated risk stratification, and supported by responsive regulatory mechanism administered by adequately resourced regulators
- ensure that staff have requisite qualifications, skill and expertise and access to self-care supports, and are afforded sufficient time to spend on providing quality services to individual users
- acknowledge the association of adverse childhood experiences with adult health outcomes[12] and, as a consequence, nurture service models that enable ageing in place and other non-institutional forms of service provision. This is particularly important to older people who, earlier in their lives, experienced the trauma, loss and hardship of institutional 'care', including:
  - members of the Stolen Generations[13]
  - Forgotten Australians,[14] and
  - Former Child Migrants

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[10] See Chesterman, arguing that service responses to abuse of older people should prioritise the wishes of the older person, *including* the wishes of people with 'significant cognitive impairment': J Chesterman, 'Taking Control: Putting Older People at the Centre of Elder Abuse Response Strategies' (2016) *Australian Social Work* 115, 117.

[11] Relationships Australia notes the United Nations *Principles for Older Persons*, adopted by the United Nations General Assembly on 16 December 1991.

[12] See, in particular, Felitti *et al,* 2002. Note also that Radford *et al*, 2017, concluded that 'Childhood adversity is a likely independent contributor to high rates of all-cause dementia [and] Alzheimer's disease in Aboriginal Australians'.

[13] To enable this, it will be necessary to review federally funded home care packages to identify the number of Forgotten Australians, Former Child Migrants, and the Stolen Generations who are accessing these, and whether (and, if so, how) ACAT assessments have taken into account the particular concerns and needs of individual service users in these cohorts. See presentation of Professor Elizabeth Fernandez, *Addressing the Complex Needs of Forgotten Australians in Aged Care*, Relationships Australia NSW, 6 June 2019.

[14] Forgotten Australians include people who were harmed in state and institutional care during their childhood, former wards of the state, former child migrants, care leavers and the Stolen Generations. Relationships Australia respects that not everyone will identify with this terminology.

- continually review and refine reportable outcomes, as co-designed with users to ensure they reflect outcomes that are valued by service users[15]

- ensure that service users, and the broader community as the ultimate funders and prospective users, have ready access to clear, timely and reliable comparative information about service providers

- establish regulatory mechanisms as a tripartite activities between service user, funder and provider, that are carried out in accordance with responsive regulation principles, and

- empower, through legislation and culture change, regulators to enforce, as well as encourage.

As a consequence, and as will be set out in the following pages of this submission, Relationships Australia considers that the use of restrictive practices should be very rare, and should only occur as permitted by a human rights-informed regulatory approach.

Rights to bodily integrity, personal liberty – the primacy of autonomy as a universal principle

In common law, it is well-established that all people have a right to bodily integrity. This right has been vindicated, for centuries, in criminal and civil law and remains good law in Australia. This right is based on the primacy of the moral principle of autonomy and finds expression, too, in international human rights instruments to which Australia is a party.[16] For present purposes, this right operates so that lawmakers who wish to permit, to any degree, the use of restrictive practices must take as their starting point that people cannot be subjected to physical or chemical restraint without lawful authority. That authority ought not, because of the gravity of impinging on the right to bodily integrity, be exercised lightly.[17]

Similarly, personal liberty, the 'bedrock value' which is 'the birthright of every individual under the common law' can 'only be restrained where this is authorised by law.'[18] Personal liberty has long been vindicated at common law through the writ of *habeus corpus* and the tort of false imprisonment.[19]

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[15] In place, for example, of outputs relating to process.

[16] Including the *Convention of the Rights of Persons with Disabilities*, the *International Covenant on Civil and Political Rights*, the *Optional Protocol to the Convention Against Torture and Other Cruel, Inhuman or Degrading Treatment or Punishment*, the *International Covenant on Economic, Social and Cultural Rights*.

[17] See M Williams, J Chesterman, R Laufer, 'Consent versus Scrutiny: Restricting liberties in post-Bournewood Victoria', (2014) 21 *Journal of Law and Medicine* 641, especially 651.

[18] *Antunovic v Dawson* (2010) VR 355 at [195], per Bell J.

[19] See, for example, *Darcy v State of NSW* [2011] NSWCA 413; *State of SA v Lampard-Trevorrow* (2010) 106 SASR 331.

Relationships Australia agrees that

> Every person is entitled to respect under the fundamental principles of dignity and personal integrity that underpins the legal framework. They do not lose this dignity or right to personal integrity because their capacity is diminished. Rather, the impairment calls for a deeper reflection of what is required on the part of those who have capacity to properly uphold both values.[20]

Specifically, diagnosis of dementia or other cognitive impairment, or the manifestation of BPSD does not, in any way, diminish the entitlement of a person to enjoy all the human rights that attend on personhood. This was recognised nearly 30 years ago in the Burdekin Report:

> ...dementia, like other mental illnesses, can be managed successfully without compromising protection of human rights.[21]

These statements are by no means radical; they are entirely consistent with the position taken by the High Court in 1992 in the case of *Re Marion*,[22] in which the Court clearly accepted the universality of the dignity and right to bodily integrity, irrespective of existing decision-making capacity, the loss of decision-making capacity, or (which was enlivened in *Re Marion*) the potential of a person ever to acquire that, or other, capacities.

Relationships Australia further considers that Australia's aged care system should explicitly prioritise users' autonomy as the pre-eminent consideration in a human rights based framework.[23] Within that system, notions of 'care', deriving from the moral principle of beneficence, should take substance from the service user's autonomy and thus focus on supporting individual values, preferences and wishes. Put another way: beneficence should be understood as reactive to autonomy in the sense that beneficent conduct towards the user is defined by the user's wishes, values and preferences, and not by another's good intent and their own interpretation, however well meaning, of good outcomes for the user.

Benevolent intent does not cure infringement of bodily integrity, which is why medical treatment is, with limited exceptions, subject to a precondition of consent.[24] This precondition reflects also

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[20] M Williams, J Chesterman, R Laufer, 'Consent versus Scrutiny: Restricting liberties in post-Bournewood Victoria', (2014) 21 *Journal of Law and Medicine* 641, 657.

[21] Carnell-Paterson at 111, citing B Burdekin, *Human rights and mental illness*, 1993.

[22] *Department of Health and Community Services (NT) v JWB and SMB* ('*Re Marion*') (1992) 175 CLR 21.

[23] See World Health Organization, *Multisectoral Action for a Life Course Approach to Healthy Ageing: Draft Global Strategy and Plan of Action on Ageing and Health*, (2016-2020); World Health Organization Regional Office for Europe, Strategy and Action plan for Healthy Ageing in Europe (2012-2020). Yon *et al*, 2018, argue that affirmation of human rights is 'crucial to elder abuse prevention.' (at 59)

[24] *Rogers v Whitaker* (1992) 175 CLR 479. See also M Williams, J Chesterman, R Laufer, 'Consent versus Scrutiny: Restricting liberties in post-Bournewood Victoria', (2014) 21 *Journal of Law and Medicine* 641, 647. In the context of public international law, we note that the United Nations Special Rapporteur has stated that informed consent 'is a core element of the right to health, both as a freedom and an integral safeguard to its enjoyment': Human Rights Council, Report of the special rapporteur on the right of everyone to the enjoyment of the highest attainable standard of physical and mental health, Dainius Puras A/HRC/35/21, 28 March 2017, para 63, cited in the submission of Human Rights Watch to this inquiry, 2.

the precept that objectives valued by a clinician (or, by way of analogy, any other provider of health and related services) can diverge from objectives valued by the person for whom treatment is intended.[25] Where there is divergence between the objectives valued by that person and the objectives valued by a clinician, then the primacy of autonomy requires that the person's view must prevail.[26]

On this approach, autonomy (choice) and beneficence (safeguarding and protection) should be seen not as in a state of conflict or tension, with one principle prioritised over the other, but in a relationship of complementarity.

Accordingly, Relationships Australia considers that Australia should implement the recommendations made in Report 124 of the Australian Law Reform Commission, *Equality, Capacity and Disability in Commonwealth Laws* as far as they relate to the provision of aged care services and, in particular, recommendations relating to:

- the National Decision-Making Principles
- supported, *not* substitute, decision-making in Commonwealth laws
- recommendations 6-1, 6-2, 6-3 and 6-4
- recommendations 8-1 and 8-2, and
- recommendation 10-1.

The Commonwealth should also implement pertinent recommendations from Chapter 4 of Report 131 of the Australian Law Reform Commission, *Elder Abuse – A National Legal Abuse*, noting in particular recommendations 4-10 and 4-11, which set out the elements of regulatory arrangements for use of restrictive practices in RACF that would give primacy to the human rights and common law rights of RACF users.

Ageism in aged care

In a similar vein, Relationships Australia considers that it is imperative for governments, service providers and community advocates and allies to provide leadership in rejecting, forcefully and frequently, ageist attitudes that lead to our society's tolerance of a range of practices and circumstances that disregard and disvalue the full humanity of older people. These practices and circumstances include:

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[25] Similarly, the High Court imposed a requirement for judicial authorisation – rather than parental consent – for certain kinds of medical treatment, in *Department of Health and Community Services (NT) v JWB and SMB* ('*Re Marion*') (1992) 175 CLR 218, because it recognised the potential for divergence of interests between a person for whom treatment is intended and a substitute decision-maker, such as a parent. The potential for conflicts of interest in 'complying' with the Principles was emphasised also in the submission to this inquiry from ADA Australia.

[26] There are exceptions, including emergency, the so-called 'therapeutic privilege', and where the safety of a third party might be compromised by, for example, refusal of medical treatment. These exceptions are unlikely to be of concern in the circumstances under consideration by this inquiry.

- segregation and isolation of older people – *including* people affected by behavioural and psychological symptoms of dementia (BPSD) - from the broader community
- byzantine and dangerously timid[27] regulatory practices
- chronic underfunding
- opacity of information about aged care options, pathways, and provider performance, and
- preventable deaths, and other serious incidents, occurring in aged care without rigorous scrutiny, accountability and effective responses.

Most notable for the purposes of this inquiry is society's tolerance for the all but unregulated use of restrictive practices for users of aged care services, whose most fundamental human rights to bodily integrity, dignity, health and well-being and social connection, are breached as a matter of routine. The largely *laissez-faire* approach taken until very recently by Commonwealth legislators differs starkly from the approach taken to restrictive practices in other sectors; notably, the disability sector. We acknowledge the observation by the Queensland Public Guardian that the Principles

> …fall significantly short of industry practice and minimum standards in comparable sectors, in particular the national standards in the National Disability Insurance Scheme (NDIS) and disability sector regarding regulation of restrictive practices.[28]

This otherwise inexplicable differential treatment accorded to older people emerges from ageism in our public institutions. This is not good enough if every age does, indeed, count. It is (or should be) self-evidently invidious that the protection of fundamental rights is weaker simply if one has attained (an arbitrarily determined) birthday.[29]

Community tolerance for the use of restrictive practices in RACF gives licence to governments and service providers to be passive in the face of serial revelations of egregious harm and abuse of older people. There is, we respectfully suggest, an unstated cross-party assumption that 'there are no votes in aged care'. This passivity leads to the piecemeal, sporadic and reactive ('let's do another review') approach to reforms and chronic under-investment to support the unpaid and paid workforce and the services they provide to older people.

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[27] That is, dangerous to users who have been left at the mercy of substandard service providers because of unwillingness to impose coercive sanctions (for example, Oakden – see Carnell-Paterson Review).

[28] Office of the Public Guardian, Queensland, *Quality of Care Amendment (Minimising the Use of Restraints) Principles 2019 – Submission to the Parliamentary Joint Committee on Human Rights*, 2019, 3. See also recommendation 2 of that submission, at 4, 13. We note that this disparity has been remarked upon by other participants in this discussion: see, for example, the statement to the inquiry from Older Persons Advocacy Network, the response from the Australian College of Nurse Practitioners

[29] Relationships Australia notes that concerns about this divergence of protection has been expressed in various contexts over some years; see, for example, M Williams, J Chesterman, R Laufer, 'Consent versus Scrutiny: Restricting liberties in post-Bournewood Victoria', (2014) 21 *Journal of Law and Medicine* 641, 654.

Relationships Australia considers that ongoing tolerance for barely regulated use of restrictive practices in aged care services is sanctioned abuse of older people. It is more than simply incongruous in light of government initiatives such as, for example, the National Plan to Respond to Abuse of Older Australians – it is immoral.

Relationships Australia considers that the agency of older people who use aged care services must be robustly supported by an explicit human rights framework. This must include:

- a legal presumption prohibiting the use of innately dangerous restrictive practices, rebuttable in only carefully constrained circumstances
- evidence-based practices to respond to BPSD and other challenging behaviours that:
    - are premised on robust recognition of the full humanity of all older people, and their rights to dignity, bodily integrity, health and wellbeing
    - support their personal liberty and maintaining social connections
- adequate resourcing, training and education (including dementia-specific training and education) for all caregivers and regulators, and
- adequate resourcing for regulators, as well as a transformation of 'tick a box' mechanistic regulation which has been explored in testimony to the Royal Commission.[30]

The Carnell-Paterson Review noted that standards specific to dementia care are being developed in, for example, England and Ireland.[31] Australia should learn from these. Relationships Australia acknowledges the work done in this area by Dementia Australia, reflected in its report *Our Solution: Quality Care for people living with dementia*

The human needs for, and rights to, social inclusion and public participation do not stop at the doors of a residential aged care facility and are not diminished by impairment of cognitive or physical capacity - supporting continued inclusion and participation

The benefits to older people of services and supports to maintain relationships have been well-recognised in the literature over the past decade.[32] Accordingly, Relationships Australia considers that reforms of the aged care system should prioritise investment in service responses that mitigate against stigma, segregation, loneliness and social isolation, and that actively promote ongoing user-centred participation in outside (as well as on-site) activities and public life. It is well-understood that stigma, segregation and isolation each poses significant risks to physical and mental health and that healthy family and broader social relationships are protective factors against abuse and neglect.[33]

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[30] See, for example, the evidence of Professor R Paterson.

[31] At 64.

[32] See, for example, L Grenade and D Boldy, 'Social isolation and loneliness among older people: issues and future challenges in community and residential settings', *Australian Health Review*, August 2008, vol 32 no 3, 468.

[33] See, eg, Liesl M Heinrich, Eleonora Gullon, 'The clinical significance of loneliness: A literature review', *Clinical Psychology Review* 26, (2006): 695-718. A Dean, 'Elder abuse – Key issues and emerging evidence', CFCA

The use of restrictive practices that isolate and other, and that dull people's capacities to enjoy the company of others, is untenable.

Abuse of older people – the right to freedom from violence and coercion does not stop at the doors of RACFs and does not diminish with impairment of cognitive or physical capacity[34]

The evidence base about prevalence of abuse of older people, risk and protective factors for victims and perpetrators, prevalence in different settings, and the merits of interventions and service responses, is still nascent (internationally and domestically. However, a meta-analysis published in 2018 observed that

> …research has shown that elder abuse occurs in every country with nursing and residential facilities and anecdotal evidence suggests that abuse may be very prevalent.[35]

The researchers who undertook that meta-analysis contemplated that prevalence of abuse of older people may be higher in institutional settings than in the community.[36] Of particular note in this context was the finding of

> …significant correlation…between abuse and high ratio of residents to registered nurses. It was further found that an increased presence of qualified nurses was associated with a reduction in resident abuse risk.[37]

It may be that future research may identify association between staff ratios and prevalence of the use of restrictive practices in RACF.

Certainly, findings and recommendations of previous reviews, in addition to media reports, permit little confidence that abuse of older people in Australian RACF – including through unjustified and unsafe use of restrictive practices - is detected, responded to, or reported to regulators or law enforcement agencies.

Paper No. 51, 1, 12-13, citing Dong, 2015; Dow & Joosten, 2012; Jackson & Hafemeister, 2016; Johannesen & LoGiudice, 2013; Kaspiew *et al*, 2016; Pillemer *et al*, 2016; von Heydrich *et al*, 2012.

[34] For the avoidance of doubt, in this context, 'abuse' includes neglect.

[35] Yon *et al*, 2018, 59.

[36] Yon *et al*, 2018, 61.

[37] Yon *et al*, 2018, 62, citing T Goergen, 'A multi-method study on elder abuse and neglect in nursing homes, *J Adult Prot* 2004; 6:15-25.

Specific concerns about the Principles

Relationships Australia has considered the correspondence received by the PJCHR from Human Rights Watch and the Victorian Office of the Public Advocate,[38] and share the concerns raised by these agencies;[39] in particular, that:

- in light of the importance of the human rights they impinge upon and the grave implications of the breach of those rights for older people, restrictive practices should be regulated through primary, not delegated, legislation
- the regulatory approach taken in the instrument is inconsistent with Article 12 of the *Convention on Rights of Persons with Disability*, because it is premised upon a substitute, not supported, decision-making model
- insofar as the instrument relies on a substitute decision-making model, it contains several significant gaps and anomalies where it seeks to engage with various kinds of substitute and representative decision-making, and
- the incongruous weakness of the protections offered to the bodily integrity, dignity and other human rights of people in RACF relative to the protections offered to people receiving services through the National Disability Insurance Scheme.

Further, Relationships Australia considers that:

- as foreshadowed - the approach taken in this instrument is inconsistent not only with human rights defined in public international law instruments, but also with the rights long-vindicated at common law through the torts of assault, battery and false imprisonment
- the use of restraints remains firmly fixed in a medicalised 'beneficence' framework, rather than in a human rights framework that maximises autonomy
- the definition of 'chemical restraint' does not reflect either:
    - the absence of an evidence base establishing therapeutic value of chemical restraints,[40] or
    - as the instrument itself notes – that both physical and chemical restraints can themselves cause harm[41]
- the instrument does not acknowledge, much less address, well-known risks attendant upon polypharmacy[42]

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[38] Copies of these items of correspondence can be found on the Committee's website: https://www.aph.gov.au/Parliamentary_Business/Committees/Joint/Human_Rights/QualityCareAmendment.

[39] We support also the concerns expressed in correspondence from Public Advocates and Public Guardians of Victoria, Tasmania, New South Wales, the Australian Capital Territory, Queensland, South Australia and the Northern Territory.

[40] As noted, for example, in the testimony, to the PJCHR, of Dr Breen and Professor J Ibrahim.

[41] See the testimony to this inquiry of Professor J Ibrahim, p 18.

[42] See, for example, the Carnell-Paterson Report at 141. Relationships Australia shares Professor Paterson's concern at what appears to be ongoing bureaucratic resistance to measures to vigorously combat polypharmacy: see testimony of Professor R Paterson to the Royal Commission, pp 4600-4601. We note with concern evidence

- the definitions of both 'chemical restraint' and 'physical restraint' are sufficiently broad to facilitate continued use of medications to influence behaviour under what may, in the absence of well-designed and enforced regulation, be a confected veneer of therapeutic necessity to justify intrusive and harmful practices[43]
- the Principles not only prescribe unacceptably permissive regulatory arrangements for the use of physical restraints, but draw a false dichotomy between physical and chemical restraints, the effect of which is likely to be increased use of therapeutically unjustified – and harmful - chemical restraints[44]
- there is a lack of clarity about what constitutes 'informed consent' for the purposes of this instrument – informed consent, properly understood and respected, is a key enabler of the exercise of autonomy in health and personal care contexts[45]
- there is an over-reliance on consent/approval/authorisation which will support a 'mechanistic' (ie 'I've ticked the box') approach to use of restrictive practices, rather than thoughtful responses to users' individual needs
- there is a lack of clarity about what constitutes an emergency for the purposes of the Principles; we are concerned that this, too, creates potential for abuse and a medicalised construct that breaches users' human rights[46]
- the range of potential decision-makers (through the defined concept of 'consumer representative') is so broad as to:

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that the Government has been disinclined thus far to accept recommendations around mandated points for RMMR. We note that the Chief Clinical Advisor is currently engaged in work 'aimed at minimising the inappropriate use of medications in aged care': see submission from the Aged Care Quality and Safety Commission, paragraph 34. We acknowledge the contribution to addressing this problem made by other initiatives, such as the 'RedUse Project' (see submission from Leading Age Services Australia).

[43] As noted in evidence to this inquiry, for example, by Ms Siegel-Brown, Queensland Public Guardian, p 5 of transcript. Freckelton has noted that '…[t]here is a problematic tradition in the provision of care and treatment to persons with disabilities that decision-making has too often been paternalistic and variously justified by convenience, necessity and what have been asserted to be the best interests of the person concerned.: I Freckelton, , 'Habeus Corpus and the Involuntary Detention of Patients with Psychiatric Disorders' (2011) 18(4) *Psychiatry, Psychology and Law*, 473 at 480.

[44] Relationships Australia notes testimony to this inquiry from Dr Breen (p 17) and that this differentiation also operates under the Single Quality Framework. Dr Breen observed that '…by making chemical restraints the easier or preferable restraint, it could well increase use further as other restraint methods are made more restrictive.' See also the evidence of Ms Mary Burgess, Queensland Public Advocate, and Ms Siegel-Brown, Queensland Public Guardian, to this inquiry, at pp 6, 9.

[45] We note and support the recent testimony of Professor J Ibrahim to the Parliamentary Joint Committee on Human Rights about the unreality of 'consent' given by family members, under the impression that they are acting in a way that protects and helps the person whose restraint is proposed: see transcript, pp 18ff, https://parlinfo.aph.gov.au/parlInfo/download/committees/commjnt/b4dbc95f-9bca-48fd-8e98-de0c521c660a/toc_pdf/Parliamentary%20Joint%20Committee%20on%20Human%20Rights_2019_08_20_7110.pdf;fileType=application%2Fpdf#search=%22Parliamentary%20Joint%20committee%20on%20human%20rights%22

[46] We note similar concerns have been expressed by OPAN, in its statement to this inquiry.

  - enable, at best, restrictive practices to be imposed on a person by a well-meaning decision-maker with no insight into that person's circumstances, wishes, values or preferences
  - enable, at worst, the perpetration of abuse for gain,[47] and
  - exacerbate the vulnerability of those residents who do not have a loving family member or friend, or a vigilant visitor or other advocate, to detect inappropriately authorised and used restraints and to act upon this to ensure accountability;[48] the plight of such residents is deeply concerning
- the safeguards described in the instrument are process driven; they are about documentation, not achieving person-centred outcomes. The reliance on process-driven safeguards to ensure quality and safety in aged care was demonstrated, in the Carnell-Paterson Review, to be misconceived and utterly inadequate to protect residents' rights
- the vulnerability of potential decision-makers, such as family members, to pressure from RACF to implement restrictive practices in respect of a user; for example, under threat of refusal of service provision,[49] and
- inadequate reporting requirements.[50]

The Explanatory Statement accompanying the instrument offers no greater comfort about the ability of the instrument to protect the human rights of older people. In particular, Relationships Australia notes with concern that the stakeholder consultation described in the Explanatory Statement seems dominated by clinicians, providers and regulators. Relationships Australia would hope that future consultations about regulation of restrictive practices give a greater voice to those whom the practices are said to serve,[51] as well as human rights advocates.

Relationships Australia recognises that a human rights based approach to restrictive practices would have a substantial impact on the cost of providing aged care. Yet if Australia takes seriously its human rights obligations to our older community members, then this is what is required.

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[47] We acknowledge similar concerns have been expressed by ADA Australia in its submissions to this inquiry.

[48] See M Williams, J Chesterman, R Laufer, 'Consent versus Scrutiny: Restricting liberties in post-Bournewood Victoria', (2014) 21 *Journal of Law and Medicine* 641.

[49] Noted also, for example, in OPAN's statement and in testimony to the public hearings of this inquiry (see evidence of Professor J Ibrahim, p 18, where he also observes that 'Family members still think that restraint is useful and protective, when it's not.').

[50] See also the OPAN's statement and the response to this inquiry from the Australian College of Nurse Practitioners. A similar observation was made by Counsel Assisting the Royal Commission into Aged Care Quality and Safety, in his submissions to that Commission concerning testimony given by Mr Graeme Head AO, the NDIS Quality and Safety Commissioner: see transcript for 9 August 2019, p 4804.

[51] Noting, for example, the observation by the Public Guardian of Queensland that it 'first became aware of the existence of the Principles when several aged care service providers contacted by OPG on 2 July, seeking consent from guardians to the use of physical restraint on guardianship clients in aged care.' It is perplexing that providers were aware, but that the Commonwealth had not reached out to the state and territory instrumentalities that were contemplated, by the Principles, as exercising key functions for the purposes of the Principles.

Restrictive practices and risks of re-traumatising particular groups

There are some groups of older people for whom age-related transitions, such as admission into a RACF, pose life-threatening threats. These groups include people who have suffered previous trauma and abuse, particularly in an institutional setting. This includes people who are Forgotten Australians, Child Migrants, members of the Stolen Generations, people affected by forced adoption, and survivors of institutional child sexual abuse – and who, too often, belong to a combination of these groups. Relationships Australia clients who have had these experiences have told us of plans to kill themselves rather than enter institutional aged care, or anything that resembles the institutions where they were preyed upon. As a provider of services to members of these groups (although not a provider of RACF, homecare or past out of home care), Relationships Australia is deeply mindful that, for people who have experienced perpetually compounding, life-long suffering as a result of institutional abuse, the prospect of being re-institutionalised is terrifying. Daily life in even the best RACF is saturated, down to the tiniest detail, with triggers for re-traumatisation. At the worst, for example, where physical premises in which people were once abused have actually been re-purposed as RACF,[52] the menace is self-evident, grotesque and utterly intolerable.

A key priority for system reform must be to ensure that there is no replication in later life of the oppressive policies, practices and environments that engendered trauma earlier in life. For example, the aged care system must:

- listen and respond to the voices of care leavers, who are the experts in their own lives, experiences and needs
- acknowledge that care leavers hold fears about their future that are real and life-threatening
- afford high levels of privacy, respect and recognition, explicitly embracing the individuality of each person, and
- provide transparency, choice, access to support and information about rights.[53]

The use of restrictive practices to 'manage' members of these cohorts is highly dangerous.

Work is ongoing to develop guidance for reforms that acknowledge and respond to the needs of older people who have experienced abuse and trauma in early life. We commend this work to the Committee's attention.[54]

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[52] For example, Wesley/Uniting in Parramatta and Nazareth in Ballarat.

[53] See Diana O'Neil, 'Listening and Responding to Forgotten Australians – Real Care the Second Time Around', Wattle Place Forum 2019.

[54] For example, the Helping Hand Project, funded by the Commonwealth for two years from July 2019. Flinders University is undertaking a study of 'Inclusive Care for Older Trauma Survivors', which will finish in mid 2020.

Service delivery for care leavers must be co-designed with care leavers' organisations;[55] this includes processes to regulate the use of restrictive practices. It is also vital to enable Aboriginal controlled organisations to offer services, as well as to employ Aboriginal and Torres Strait Islander liaison staff and 'in service' advocates.[56] For example, Elm Place at Relationships Australia South Australia is working with Helping Hand to provide Forgotten Australians with aged care services that provide 'Real Care the Second Time Around', including through talking to service providers about the particular needs of this cohort.

Workforce considerations

Relationships Australia acknowledges that restrictive practices can only be eradicated if caregivers are properly supported within a safe work environment. We note the evidence to this inquiry of Professor J Ibrahim that

> Staff restrain residents to get through their day because they don't have enough hands to get through what is needed or they don't have the skills, knowledge or ability to assess why a person has responsive behaviours or unmet needs to address that….We don't have the staff campaign around education and training. Personal care workers are not obligated to undertake any training in dementia care of any level of sophistication, and the supports provided by mental health services and specialty services and by the public hospitals are insufficient and slow, generally speaking, to assist resident aged-care facilities. So what we're doing is beating the aged-care workforce around the head on a practice that we all want out, but we're not actually helping them by saying: 'If you have problems, the severe-behaviour response team will be there shortly; the local hospital will help you look after this person in the meantime; you are able to get additional staff, and we will reward that.[57]

To this end, we recommend:

- structured workforce planning to ensure that staffing profiles correspond to need and risk[58]
- providing increased remuneration for all staff employed in RACF and community-based aged care services

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[55] As well as by drawing on the expertise of entities like Find and Connect service providers.

[56] See the presentation of Professor Elizabeth Fernandez, *Addressing the Complex Needs of Forgotten Australians in Aged Care*, Relationships Australia NSW, 6 June 2019. See also Diana O'Neil, 'Listening and Responding to Forgotten Australians – Real Care the Second Time Around', Wattle Place Forum 2019. See also the evidence of Professor Leon Flicker to the Royal Commission, 17 June 2019, 2042-2044, 2046. Flicker and Holdsworth, 2014, recommended that 'Mainstream aged care and community care services should work with Aboriginal Community Controlled Health organisations where possible when providing services for Aboriginal and Torres Strait Islander clients.' (at 20)

[57] At p 18.

[58] See also Carnell-Paterson Report, 75.

- support for community visitors programmes, along the lines, for example, of the programme run by the Office of the Public Advocate (Victoria),[59] with a legislative mandate to monitor the use of restricted practices
- that service providers be required to offer professional training,[60] clinical supervision and psycho-social support to staff; optimally, providers should seek out 'suitably trained people with a lived experience of childhood institutionalisation… to conduct training and awareness raising.'[61]

Regulation, governance, accountability

Oakden and Earle Haven have recently underscored the dangerous shortcomings of systems that rely on process and outputs designed, one may suspect, with more of an eye to lighten regulatory and compliance burdens on regulators and the regulated, than to ensure high quality outcomes that are valued by service users themselves.[62] Relationships Australia notes Professor Paterson's testimony to the Royal Commission:

> I think there has been a mechanistic approach to the [complaints] role.[63]

We consider that the Principles exemplify a mechanistic approach to regularising, rather than regulating or deterring, the use of restrictive practices.

To remedy this, Relationships Australia supports:

- separating policy responsibility from regulation/compliance[64]

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[59] This should be accompanied by a report on findings of visitors, tabled in Parliament; for a precedent, see the volunteer-based Community Visitor programme run by the Office of the Public Advocate (Victoria): https://www.publicadvocate.vic.gov.au/our-services/community-visitors. In this regard, we note also the observations by the Queensland Office of the Public Guardian, identifying community visitors, with a legislated mandate, as essential to human rights compliant regulation of restrictive practices in RACF: see Office of the Public Guardian, Queensland, *Quality of Care Amendment (Minimising the Use of Restraints) Principles 2019 – Submission to the Parliamentary Joint Committee on Human Rights*, 2019, 10, 13-14.

[60] Including mandatory training in working with care leavers and trauma-informed practice. In this regard, we draw to the Commission's attention the recommendations emerging from the study of *Long-term Outcomes of Forgotten Australians* (UNSW, 2016). These included that service providers and assessors, ACATs, RAS undertake mandatory training in working with care leavers to enhance holistic management and care planning, and case management. Training must include the specific cultural awareness and cultural safety training for those survivors working with Stolen Generations survivors and other Aboriginal and Torres Strait Islander care leavers, their families and carers. See also presentation of Professor Elizabeth Fernandez, *Addressing the Complex Needs of Forgotten Australians in Aged Care*, Relationships Australia NSW, 6 June 2019.

[61] See presentation of Professor Elizabeth Fernandez, *Addressing the Complex Needs of Forgotten Australians in Aged Care*, Relationships Australia NSW, 6 June 2019. Fernandez also observes that 'Training for social workers and health practitioners to understand the impact of exposure to maltreatment on psychosocial problems across the life course is crucial.'

[62] See also Carnell-Paterson at 71, 73, 94, and the description of the approach being taken in The Netherlands.

[63] Transcript of testimony, at 4592. See also Carnell-Paterson, 62.

[64] See Carnell-Paterson, 77.

- through co-design with service users, developing outcomes that are valued by older people and that support the fullest exercise by older people of their human rights (ie move away from tick a box 'process/output' measures to quality of life measures defined by users)[65]
- an accreditation process which is outcomes-focused, and stratified according to risk profile[66]
- transforming service provision culture from a beneficence/safeguarding approach to a human rights-informed approach that gives primacy to users' autonomy
- transforming regulator culture to make considered use of sanctions and enforcement measures that are informed by responsive regulation principles (rather than responding to problems by multiple extensions of approval and a predictable 'default' accreditation period), and
- protections for complainants and their caregivers/loved ones.[67]

Most importantly, Relationships Australia considers that it is vital to re-conceptualise accreditation, regulation and compliance as activities emanating from a tripartite relationship between service users, accrediting agencies/regulators and providers –with users having primacy. It would appear from the Explanatory Statement accompanying these Principles that consultation was dominated by government and providers. This is incompatible with a human rights based, person-centred system.[68]

Research and data

In its submission to the Royal Commission, Relationships Australia identified a range of research needs that must be supported for the Australian aged care system to meet the objectives identified by the Government and the Royal Commission. Of relevance to this inquiry, we recommend:

- systematic national collection and analysis of data about the use of all restrictive processes across the health, ageing, and disability sectors

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[65] Carnell-Paterson observed that 'Risk factors may not be sufficiently aligned with outcomes for consumers. Of the 23 risk factors listed in the [visit prioritisation and risk ratings] policy, only one relates to the care needs of consumers (number 17 "high-risk demographic care recipients")…': at 71 (see also Carnell-Paterson at 69). Relationships Australia notes the testimony of Professor R Paterson to the Royal Commission that 'At some point, you have to get on and do it…and it does seem as if the consultation is dominated by the provider groups.' (at 4584; see also 4586 and 4603).

[66] See Carnell-Paterson, Box 4, 90, endorsing proposals that had been developed by Nous Group, commissioned by the Quality Agency. We also note the discussion of accreditation, quality review and monitoring in the Commission's Background Paper No. 7, *Legislative Framework for Aged Care Quality and Safety Regulation*, at 13.

[67] Relationships Australia is, from its practice experience, very conscious that fears of retribution and reprisal are strong deterrents from raising concerns and making complaints. See also Carnell-Paterson at 89.

[68] See also the evidence of Professor Paterson at 4595-4596.

- further research into the efficacy of supports to serve people with BPSD, and which maximise exercise of their autonomy[69]
- research-informed education and training being given to service providers and care givers about supports for people affected by BPSD that maximise exercise of their autonomy
- research into prevalence of abuse of older people and the impacts of abuse, in both community and institutional settings; this must be inclusive of people affected by dementia or with cognitive impairment[70]
- risk and protective factors for different types of abuse, as well as relating to differentiated cohorts of perpetrators[71] and people at risk of abuse
- the prevalence of isolation and loneliness among older people (ideally, prospective and longitudinal), as well as research into the relative efficacy of interventions to reduce isolation and loneliness for older people living in the community and in RACF
- the impacts of abuse of older people in the community and in RACF, and
- preventable deaths of older people living in the community and in RACF.

Further, governments must commit to supporting robust evaluation of interventions.

CONCLUSION

We thank the Committee for considering this submission, and would be happy to discuss further the contents of this submission if this would be of assistance. I can be contacted directly on (02) 6162 9301. Alternatively, you can contact Dr Susan Cochrane, National Policy Manager, Relationships Australia National, on (02) 6162 9309 or by email: scochrane@relationships.org.au.

Yours sincerely,

Nick Tebbey
National Executive Officer

[69] Noting that these issues have been under consideration for several years; see, for example, literature establishing and commenting on the Brodaty Triangle (2003).

[70] As noted previously in this submission. See also Dean, CFCA 51, 10, citing Hamby *et al*, 2016

[71] For example, distinguishing risk and protective factors, and effective interventions, for people who may perpetrate for financial gain and in circumstances of opportunism and people who may perpetrate in circumstances of carer stress. See Dean, CFCA 51, 14, on the paucity of knowledge of risk factors associated with perpetrators, noting that existing evidence has identified caregiver burden, dependency/interdependency, a sense of entitlement in the carer, substance abuse, poor mental health, or a history of family violence and conflict.