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Commissioner the Hon Richard Tracey AM RFD QC and Commissioner Lynelle Briggs AO
Royal Commission into Aged Care Quality and Safety
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Royal Commission into Aged Care Quality and Safety

Relationships Australia welcomes the opportunity to make a submission to the Royal Commission into Aged Care Quality and Safety. This submission is made on behalf of the eight State/Territory Relationships Australia organisations.

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.

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. In addition, services include:

- capacity building within families, mental health and transition support, family counselling and mediation[1]

[1] Relationships Australia notes that other service providers of aged care services are taking a 'whole of family' approach to support older people, and their families, through transitions related to ageing and to end of life care; see, for example, Opal Aged Care. The importance of high quality family relationships is emerging, through evidence, as a protective factor reducing the risk of abuse of older people and ameliorating its effects when it occurs: see A Dean, 'Elder abuse – Key issues and emerging evidence', CFCA Paper No. 51, 13.

- 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.

Relationships Australia is committed to:

- Working in regional, rural and remote areas, recognising that there are fewer resources available to people in these areas, and that they live with pressures, complexities and uncertainties not experienced by those living in cities and regional centres.
- Collaboration. We work collectively with local and peak body organisations to deliver a spectrum of prevention, early and tertiary intervention programs with older people, men, women, young people and children. We recognise that some families need a complex suite of supports (for example, family support programs, mental health services, gambling services, drug and alcohol services, and housing).
- Enriching family relationships, and encouraging clear and respectful communication.
- Ensuring that social and financial disadvantage is no barrier to accessing services.
- Contributing its practice evidence and skills to research projects, the development of public policy, and the provision of compassionate and effective supports to families.

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

- younger and older people
- 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.

The core of our work is relationships – through our programs we work with people to enhance and improve relationships in the family (whether or not the family is together), with friends and colleagues, and within communities. Relationships Australia believes that violence, coercion, control and inequality are unacceptable.

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 extensively to emerging 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.[2]

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 and even 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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[2] 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.

PART 1 – REVIEWS, REFORMS, AND THE PRESENT CHALLENGE

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:

- Chapter 14 of the Productivity Commission's *Report on Government Services* (2018)
- the report of the House of Representatives Standing Committee on Health, Aged Care and Sport (2018)
- the report of the Legislated Review of Aged Care (2017)
- the report of the Review of National Aged Care Quality Regulatory Processes ('Carnell-Paterson') (2017)
- the report of the Australian Law Reform Commission, *Elder Abuse – A National Legal Response* (ALRC Report 131) (2017)
- the *Aged Care Roadmap*, produced by the Aged Care Sector Committee (2016)
- the report of the Australian Law Reform Commission, *Equality, Capacity and Disability in Commonwealth Laws* (ALRC Report 124) (2014)
- the report of the Productivity Commission's inquiry into Caring for Older Australians ('Productivity Commission report'), (2011), and
- Australian National Audit Office, *Monitoring and compliance arrangements supporting quality of care in residential aged care homes*, Audit Report No. 48 (2010-11).

It is important to acknowledge the persistent commonality of themes, findings and recommendations which have emerged in each review. These have typically been followed by changes which can most politely be described as unambitious; in any event, the deep structural changes called for by diverse reviewers, researchers and commentators have not found favour with governments. It may be that review has become a proxy for reform.[3]

Relationships Australia acknowledges recent reforms and initiatives intended to improve aged care pending the final recommendations of the Royal Commission, including:

- the *National Plan to Respond to the Abuse of Older Australians*[4]
- the establishment and operation, as of 1 January 2019, of the single Aged Care Quality and Safety Commission
- the Aged Care Navigators Trial[5]
- the now mandatory status of the Single Quality Framework, and

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[3] We note that, in his testimony to the Commission on 7 August 2019, Professor Paterson expressed disappointment with the slow progress in implementing some recommendations made in the Carnell-Paterson Review, and his disappointment with the outright rejection of other recommendations.

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

[5] See https://www.cota.org.au/information/aged-care-navigators/

- the *Quality of Care Amendment (Minimising the Use of Restraints) Principles 2019*.[6]

Many people whose stories are being considered in this inquiry have, earlier in their lives, also suffered abuse and mistreatment by publicly funded institutions and providers who operate in the health care, aged care and disability service sectors. We express our concern and compassion for the numerous processes by which they are asked to tell and re-tell their stories – and for the lack of timely, effective action taken on recommendations made in the proliferation of reviews and inquiries. We acknowledge, too, that people who have lived in institutions, but not been abused, also have particular needs and concerns arising from this experience, and that service providers must be mindful of, and responsive to, these.

'Fit for purpose' – what is the purpose?

At the outset of its hearings, the Royal Commission set out its understanding of what a contemporary aged care system in Australia should be and do:

> ….A world class system in which those receiving aged care and their loved ones can have confidence. One that is simple to understand, easily navigated and accessible to all, a system which has services that are compassionate, fit for purpose, customised to individual needs and to the highest standards in terms of quality and safety, a system in which aged care services are delivered effectively and that can be sustained into the future.[7]

For the avoidance of doubt, in referring to an aged care system, Relationships Australia contemplates a system to provide services to all Australians aged 60-65 and over, and Aboriginal and Torres Strait Islander people aged 45-50 and over, the purpose of which is to:

- support the quality of life of users, including through embracing dignity of risk, as well as ensuring that services enable users to enjoy quality of life, according to their 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 meet the needs of ageing people, including community engagement, inclusion and participation, support to maintain valued family and social connections, access to health care and allied health services, nursing services, mental

[6] Currently the subject of an inquiry by the Parliamentary Joint Commission on Human Rights.

[7] Commissioner Briggs, 18 January 2019, 3.

[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.'

health services, and palliative care services in seamless, place-based and culturally safe formats

- for RACF – be truly 'residential' in terms of 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.[9]

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,[10] 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[11] 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[12]
    - Forgotten Australians,[13] and
    - Former Child Migrants

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[9] 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.

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

[11] 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'.

[12] 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.

[13] 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[14]

- 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.

PART 2 – THE CENTRALITY OF HUMAN RIGHTS TO 'FIT FOR PURPOSE' AGED CARE

Human rights do not stop at the doors of a residential aged care facility and are not diminished by impairment of cognitive or physical capacity

Relationships Australia considers that Australia's aged care system should be built on an explicit human rights framework which prioritises users' autonomy as the pre-eminent consideration.[15] The system should recognise that 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 expression, values 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 will, values and preferences, rather than by another's good intent and their own interpretation of good outcomes for the user.

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. Relationships Australia considers that current arrangements for the provision of services to older people are disconnected from the service users' human rights. The Carnell-Paterson Review observed that

> The Aged Care Act is a weak framework for promoting the rights of older people, including the right to be free from abuse and exploitation, since it only provides for the reporting of serious physical and sexual assaults.[16]

Accordingly, Relationships Australia considers that Australia should implement the recommendations made in Report 124 of the Australian Law Reform Commission, *Equality,*

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

[15] 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)

[16] Carnell-Paterson, 111.

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 decision-making in Commonwealth laws[17]
- recommendations 6-1, 6-2, 6-3 and 6-4
- recommendations 8-1 and 8-2, and
- recommendation 10-1.

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:

- segregation and isolation of older people from the broader community
- byzantine and dangerously timid[18] regulatory practices
- chronic underfunding
- opacity of information about aged care options, pathways, and provider performance,[19] and
- preventable deaths, and other serious incidents, occurring in aged care without rigorous scrutiny and effective responses.

This tolerance, in effect, 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.

In relation to preventable deaths, and the existing tolerance and lack of scrutiny, Relationships Australia notes the following observation made by Professor J Ibrahim in his testimony to the Royal Commission:

> I dare anyone to argue with me about death from an injury is a premature death which means someone has died before their time. If they're 90 or 95, I don't care. What I care about is they've died before they were supposed to. So if you're supposed to get to 95 and one month, and we've taken a month off you, that's not right. And every time I speak publicly and I ask – and again I ask anyone in this room, would you give me a week of

[17] Rather than substitute decision-making.

[18] 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).

[19] Paterson testimony 4604: transparency '…needs to become real rather than lip service.'

> your life? Now, for nothing? Would you give up a week of your life for me? And universally, no one would give up a week of their life. They wouldn't even give up a day. Yet, we accept people dying prematurely because we believe they're old and have no benefit to society, and that's just wrong.[20]

Relationships Australia agrees with the observation, set out in Background Paper 1, *Navigating the Maze*, of

> …a prevailing narrative that the ageing of the population is seen as a problem to be fixed and that older people are a burden facing the nation.[21]

Dean notes that

> The available evidence suggests that, for some older people, elder abuse is viewed [by them] as both a form of ageism that devalues their status and role in society and as an act of interpersonal abuse and neglect.[22]

It is not, in our view, drawing too long a bow to suggest that ageism and othering of older people contribute to the continued failure of a series of decision-makers to implement, in a timely manner, contemporary reform recommendations, preferring to deflect periodic calls for action by simply commissioning new reviews.

Relationships Australia considers that a key response to ageism must be to legally recognise and give effect to the agency of older people, supported by a human rights framework. Addressing discrimination is an important element of this, but must be reinforced by:

- positive public constructions of older people that embody them as whole persons with full agency in their lives
- deliberately making and holding space in public life – as a matter of rights, *not* generosity or tokenism - for the voices, images and actions of older people – understanding that 'ageing concerns' are not a niche issue, but universal, and
- strengths-based frameworks for service responses and interventions.

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[20] Testimony 16 May 2019, at p 1786.

[21] Background Paper 1, *Navigating the Maze*, 3. Although research has not, thus far, established a causative nexus between ageism and abuse of older people, there have been suggestions that ageism (or 'prejudice against our future selves') can adversely affect the health and wellbeing of older people and may exacerbate their vulnerability to abuse (see, for example, ALRC Report 131; S P Hirst, T Penney, S McNeill, V M Boscart, E Podnieks, S K Sinha, 'Best-practice guideline on the prevention of abuse and neglect of older adults,' *Canadian Journal on Aging*, 35(2), 242-260.

[22] Dean, CFCA 51, 8, citing Anand *et al* 2013; Dow and Joosten, 2012, Harbison *et al*, 2012; Killick *et al*, 2015, Taylor, Killick *et al*, 2014.

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 longing for interpersonal intimacy stays with every human being from infancy throughout life; and there is no human being who is not threatened by its loss…the human being is born with the need for contact and tenderness.[23]
>
> …it would appear that the establishment and maintenance of positive interpersonal relationships has become central to being human.[24]

In his opening remarks to the Royal Commission, Counsel Assisting noted that 'Loneliness and neglect is a major issue.'[25]

Social isolation and loneliness – prevalence and adverse health impacts

Recent research suggests that around one in four to one in six people report loneliness in any given year,[26] and

> …many situational determinants of loneliness have been identified, such as relocation, important others' temporary absences, social conflict, rejection, and exclusion, as well as inadequate transport, poverty and low income, unemployment, retirement, imprisonment, and hospitalization….[27]

Loneliness has been associated with poor mental health outcomes such as depression, low life satisfaction, low self-worth and poor subjective wellbeing, and suicide,[28] with a risk of early death consistent with other known health risks such as lack of physical activity, obesity, substance abuse and violence, and smoking 15 cigarettes a day.[29] Other poor health outcomes linked to loneliness include:

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[23] Fromm-Reichmann, 1959, 3.

[24] Liesl M Heinrich, Eleonora Gullon, 'The clinical significance of loneliness: A literature review', *Clinical Psychology Review* 26, (2006): 695-718, 697.

[25] Counsel Assisting, 18 January 2019, 9.

[26] Lim, 2018; Mance, 2018.

[27] Liesl M Heinrich, Eleonora Gullon, 'The clinical significance of loneliness: A literature review', *Clinical Psychology Review* 26, (2006): 695-718, 709, referring to Blai, 1989, Hymel *et al*, 1999, Killeen, 1998.

[28] Heinrich and Gullone further note that 'Loneliness may also be a vulnerability factor for suicide ideation, parasuicide (suicide attempts/self-inflicted injury) and suicide completion' (Liesl M Heinrich, Eleonora Gullon, 'The clinical significance of loneliness: A literature review', *Clinical Psychology Review* 26, (2006): 695-718, 702.)

[29] 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 Mance, P (2018), 'Is Australia experiencing an epidemic of loneliness? Findings from 16 waves of the Household Income and Labour Dynamics of Australia Survey (working paper)'.. Retrieved from <http://www.relationships.org.au/what-we-do/research/is-australia-experiencing-an-epidemic-of-

- nausea, headaches and eating disturbances (Page & Cole, 1991, Ponzetti, 1990)
- sleep disturbances (Cacioppo *et al*, 2000; Cacioppo, Hawkley, Berntson *et al*, 2002)
- fatigue (DiTommaso & Spinner, 1997)
- poorer immune functioning (Kiecolt-Glaser, Garner *et al*, 1984, Kiecolt-Glaser, Ricker *et al*, 1994)
- poorer cardiovascular functioning (Cacioppo, Hawkley, Crawford *et al*, 2002), and
- serious illness (Lynch, 1977).[30]

Isolation from the social scaffolding that has defined their identities for decades can be catastrophic for people moving into RACF or who remain in place but need help to maintain family and broader social connections.[31]

Forging, nurturing connections; combating isolation and loneliness

The benefits to older people of services and supports to maintain relationships have been well-recognised in the literature over the past decade, and are acknowledged throughout this submission.[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]

There is some evidence identifying particular services and supports that contribute to enhanced health and wellbeing among users of aged care services, including:

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loneliness. Masi, C, M, Chen, HY, Hawkley LC, & Cacioppo, J, T, (2011), 'Meta-Analysis of Interventions to Reduce Loneliness,' *Pers Soc Psychol Rev*., 15(3).

[30] As referred to in Liesl M Heinrich, Eleonora Gullon, 'The clinical significance of loneliness: A literature review', *Clinical Psychology Review* 26, (2006): 695-718, 703.

[31] See also Fernandez and Lee, 2018, 'Uprooted from everything that attaches you: Long term outcomes of former Child Migrants in the twentieth century in Australia', *British Journal of Social Work* volume 49, Issue 2, March 2019.

[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 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.

- participation in organised social activities[34]
- family friendly policies and practices[35]
- enabling residents to maintain links with their friends/confidants, social groups, communities and past times.[36] Relationships Australia draws to the Commission's attention research emphasising the essential individuality of these connections. It is not enough to enable participation in generic social activities; to have the desired therapeutic effect, it is necessary to enable continued participation in groups and activities with which an individual has a subjective identification and belonging[37]
- pet-friendly policies and strategies[38]
- plants and gardens[39]
- opportunities for engaging with children, as has been afforded – for example - by programs in which kindergarten students regularly visit RACF and 'buddy' programs.[40]

Busy, often over-burdened staff members[41] may not have the time, or the skills, to wraparound the new resident and support them, and their family, through and beyond the wrenching adjustments they are enduring.[42] This is a gap of psycho-social need that is not yet adequately

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[34] M Bajekal, *Health survey for England 2000: care homes and their residents*, 2000. See also Dean, CFCA 51, 20, Box 7, noting that '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.' (citing Acierno *et al*, 2017; Hamby *et al*, 2016; Pillemer *et al*, 2016).

[35] Grenade and Boldy, 2008, 473.

[36] Grenade and Boldy, 2008, 474, citing J Dragaset, 'The importance of activities of daily living and social contact for loneliness: a survey among residents in nursing homes,' *Scand J Caring Sci* 2004; 18: 65-71. There is considerable potential for use of technology in meeting these needs (eg enabling Skype conversations between residents and friends or family who are physically remote). Similarly, Relationships Australia notes the evidence of Professor Leon Flicker that telehealth has been evaluated as an effective model of care – this points to a broader application of technology to enable access to specialised clinical and allied health services (see transcript, 17 June 2019, 2040).

[37] T Cruwys, S Alexander Haslam *et al*, 'Feeling connected again: Interventions that increase social identification reduce depression symptoms in community and clinical settings', (2014) 159 *Journal of Affective Disorders*, 139.

[38] Grenade and Boldy, 2008, 473, citing M R Banks, W A Banks, 'The effects of animal-assisted therapy on loneliness in an elderly population in long-term care facilities,' *J Gerontol A Biol Sci Med Sci* 2002; 57: M428-M432, and C Keil, B Barba, 'The relationship of loneliness and stress to human-animal attachment in the elderly,' Paper presented at the 7th International Conference on Human-Animal Interactions, Animals, Health and Quality of Life, 6-9 September 1995, Geneva.

[39] Grenade and Boldy, 2008, 473.

[40] Grenade and Boldy, 2008, 473, citing L B Bearon, 'Quality of life in long-term care settings: a look at some of the trends in humanizing nursing homes,' *Forum* 1997: 2(4). See also https://iview.abc.net.au/show/old-people-s-home-for-4-year-olds.

[41] Whether in a RACF or providing home-based services.

[42] See, for example, Grenade and Boldy, 2008, noting the task focus of most staff-resident interactions: at 472, referring to R Marquis, 'Quality in aged care: a question of relational ethics?' *Australas J Ageing*, 2002; 21: 25-29.

recognised, researched or met. However, place-based individual and group work can offer a cost-effective therapeutic response, while building skills and capacity to thrive in a new community, and maintaining their sense of belonging to their old communities and connections.

Beneficial service responses include:

- access to individual, family and group counselling
- culturally safe and appropriate services (noting evidence before the Commission that attachment to Country, as well as lack of confidence that they will receive culturally safe and respectful service, lead many Aboriginal and Torres Strait Islanders to prefer community-based services to RACF)[43]
- support to build the service user's capacity, and capacity within the family, for effective problem solving and communication to help older people to:
    - prepare for, manage and move beyond the transitions into residential care and transitions between levels of intensity of assistance, and
    - maintain connections to family, neighbourhood and community (whether they remain at home or enter an RACF).

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[44]

Current initiatives

Relationships Australia strongly supports ongoing efforts to stop abuse of older people, in all settings and contexts, and welcomed the launch of the *National Plan to Respond to the Abuse of Older Australians* earlier this year as an important landmark. We look forward to the commencement of the first national prevalence study, and the public release of information about its methodology.[45] Building on its self-funded pilot of Senior Relationship Services earlier

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See also Sani *et al*, 2012, in which identification, rather than simply contact, was identified as being a better predictor of reduced depression: cited in Cruwys and Alexander Haslam, 2014, 140. Heinrich and Gullone suggest that 'One possible reason why quantitative measures, such as frequency of social contact, fail to be good predictors of loneliness may lie in their inability to capture the nature of the social relationships people engage in.' (Liesl M Heinrich, Eleonora Gullon, 'The clinical significance of loneliness: A literature review', *Clinical Psychology Review* 26, (2006): 695-718, 699).

[43] Testimony of Professor Leon Flicker, 17 June 2019, 2024-2025. Professor Flicker also noted that 'Virtually every Australian prefers community care to residential aged care. Aboriginal and Torres Strait Islander people have that preference more than non- Aboriginal and Torres Strait Islander people.' (at 2024) At 2025, Professor Flicker notes that culturally safe service delivery does 'not necessarily come intuitively' to service providers and their staff.

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

[45] The Commonwealth's first foray into research in this area was undertaken by Kaspiew, Carson and Rhoades: see Kaspiew *et al*, *Elder Abuse: Understanding Issues, Frameworks and Responses*, (Research Report No 35, Australian Institute of Family Studies, 2016). This was a precursor to the inquiry, undertaken by the Australian

this decade, Relationships Australia is also participating in the Elder Abuse Service Trials,[46] offering case management and mediation services.

Evidence base

The evidence base about prevalence of abuse of older people, risk and protective factors for victims and perpetrators, and the merits of interventions and service responses, is still nascent (internationally and domestically).[47] Of particular relevance to this inquiry, Relationships Australia notes observations that current

> …evidence suggests that most abuse of older people is intra-familial and intergenerational, making it challenging and complex to address.[48]

Relationships Australia respectfully suggests that the reference to 'most abuse' is unlikely to withstand future research into abuse of older people as it manifests in RACF. Indeed, 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.[49]

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.[50] 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.[51]

Current evidence suggests that institutional settings may carry an increased risk of certain forms of abuse, because of:

Law Reform Commission, into elder abuse and published in 2017 as Report 131, *Elder Abuse: A National Legal Response*.

[46] These trials form part of the 'More Choices for a Longer Life – Protecting the Rights of Older Australians' program and the National Plan to Respond to the Abuse of Older Australians 2019-2023.

[47] See, eg, Yon *et al*, 'The prevalence of elder abuse in institutional settings: a systematic review and meta-analysis', *European Journal of Public Health*, vol 29, no 1, 67-74 (2018), referring to Pillemer *et al*, 'Elder abuse: global situation, risk factors, and prevention strategies', *Gerontologist* 2016; 56:S194-205. See also Chesterman and Bedson, 2017; Castle, Ferguson-Rom, and Teresi, 2015; Dean, 2019 at 9.

[48] Attorney-General's Department, *Protecting the Rights of Older Australians*, www.ag.gov.au/ElderAbuseNationalPlan . It is for this reason that family members need to be counted as clients in their own right in addressing abuse of older people.

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

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

[51] 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.

- opportunities for resident to resident abuse
- unregulated restrictive practices
- inadequate institutional resources (including numbers of staff, staff qualifications and experience,[52] ratios of staff to residents)
- carer stress, emotional exhaustion and lack of training, education and/or clinical supervision for caregivers.[53]

Certainly, findings and recommendations of previous reviews, in addition to media reports, permit little confidence that abuse of older people in Australian RACF is detected, responded to, or reported to regulators or law enforcement agencies. This is the case irrespective of whether abuse occurs as between resident/resident; family members or carers/resident, or staff member/resident. Nor can we be confident that there are effective preventative measures in place. Oakden provided a powerful admonishment to this effect.

In light of this, Relationships Australia urges governments to invest in research into abuse of older people:

- in institutional settings
- that *includes* people with dementia or other cognitive impairment[54]
- that differentiates between:
    - different types of abuse[55]

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[52] Note, too, the recent comments of the Victorian Coroner inquiring into the death of Mr John Frederick Reimers, reported at https://www.theage.com.au/national/victoria/on-the-day-he-died-john-reimers-head-was-trapped-by-a-drawer-for-45-minutes-20190826-p52kr4.html. Coroner Audrey Jamieson is reported to have found that relevant staff did not have the 'competency, knowledge, skills or critical thinking" to manage Mr Reimers and his care was further compromised by the lack of a registered nurse on site.' (report 28 August 2019)

[53] See Dean CFCA 51, 15.

[54] Dementia and cognitive impairment contribute to dependency, which is recognised as a risk factor for the perpetration of abuse of older people, yet people affected by dementia or other cognitive impairment have seldom been included in research to date: see Bedson and Chesterman, *Are national elder abuse prevalence studies inclusive of the experiences of people with cognitive impairment? Findings and recommendations for future research*, Office of the Public Advocate (for the Australian Guardianship and Administration Council), 2017. Bedson and Chesterman note that people with dementia and other forms of cognitive impairment tend to be actively excluded from samples in prevalence studies (at 17), with only a few exceptions in existing literature (cf p 21; see also Bedson, Chesterman and Woods, 2018). While Bedson and Chesterman note that 'evidence supporting a relationships between dementia and elder abuse is mixed,' (at 8), this is a particular weakness in the evidence base which Relationships Australia considers, given predictions of increasing rates of dementia in the community, must be addressed urgently. See also Bedson, Chesterman and Woods, 'The Prevalence of Elder Abuse among Adult Guardianship Clients', [2018] *MqLawJl* 3; Bedson and Chesterman 2017 noted that 52% of people in Australian RACF have dementia (at 5).

[55] Bedson and Chesterman (2017) note that 'Studies also suggest that aggregating the various types of mistreatment, or seeing physical violence as part of a spectrum…is problematic and may mask risk factors for the various abuse types (at 13). Bedson, Chesterman and Woods (2018) note, in addition to the more

  - identifies patterns of co-occurring abuse,[56] and
  - different kinds of perpetrator (eg family members,[57] visitors, formal or informal carers, coercive controlling perpetrators)

- that takes into account the characteristics of institutions, including staffing profiles and ratios
- that takes into account cultural factors that may contribute to recognition, or masking, of abuse of older people, and
- that identifies protective and risk factors both for older people and for people who are at risk of becoming perpetrators.[58]

Not all who wander are lost - restrictive practices and human rights

A diagnosis of dementia or other cognitive impairment 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.[59]

The Carnell-Paterson Review noted that standards specific to dementia care are being developed in, for example, England and Ireland.[60] 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*.

Relationships Australia notes that the *Quality of Care Amendment (Minimising the Use of Restraints) Principles 2019* (Restraints Principles) instrument has been referred to the Parliamentary Joint Committee on Human Rights. Relationships Australia would welcome improved regulation of the use of restraints in aged care. This acknowledges important universal human rights recognised both in international law and in the common law. We have, however, had the opportunity to consider the correspondence received by the PJCHR from

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widely-recognised types of physical, social, psychological and financial abuse, as well as neglect, other categories can include impairment-related abuse, legal or civil abuse and acts of omission: cf footnote 52 of that article.

[56] A review of case files held by the Victorian Office of the Public Advocate in 2013-2014 'suggested that 71 per cent of elder abuse victims had experienced more than one form of abuse': Bedson, Chesterman and Woods, 2018.

[57] Noting that abuse within the family can be lateral and/or intergenerational. In our experience, too, there are often claims and counter-claims of abuse among multiple family members.

[58] See R Kaspiew, *Elder Abuse: Discussion paper about research on prevalence, dynamics and impact*, 2016; Bedson and Chesterman, 2017, 23-24. Yon *et al*, 2018, also make detailed recommendations about the design of research into institutional abuse of older people.

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

[60] At 64.

Human Rights Watch and the Victorian Office of the Public Advocate,[61] and share the concerns raised by these agencies; 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 relies on a substitute, not supported, decision-making model
- insofar as the instrument relies on a substitute decision-making model, it contains several significant gaps where it seeks to interact 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:

- 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 located 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,[62] or
    - as the instrument itself notes – that both physical and chemical restraints can themselves cause harm
- the instrument does not adequately address risks attendant upon polypharmacy[63]
- the definitions of both 'chemical restraint' and 'physical restraint' are sufficiently broad to facilitate continued use of medications such as antipsychotics to influence behaviour

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[61] 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

[62] As noted, for example, in the testimony, to the PJCHR, of Professor J Ibrahim. Relationships Australia notes that guidance on best practice in the use of restraints can be found in the *Decision Making Tool: Supporting a Restraint-Free Environment*

[63] See, for example, Carnell-Paterson at 141. Polypharmacy has also been well-documented in relation to older people living in the community. 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, pp 4600-4601. We note with concern evidence that the Government has been disinclined to accept recommendations around mandated points for RMMR.

under what may, in the absence of well-designed and enforced regulation, be seen as a confected veneer of therapeutic necessity to justify intrusive and harmful practices

- 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[64]
- 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 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, as well as human rights advocates.

Relationships Australia urges investment in:

- further research into the efficacy of supports to serve people with behavioural and psychological symptoms of dementia (BPSD), and which maximise exercise of their autonomy,[65] and
- research-informed training being given to service providers and care givers about supports for people affected by BPSD that maximise exercise of their autonomy.

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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[64] 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

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

Rights to health and wellbeing do not stop at the doors of a RACF and do not diminish with impairment of cognitive or physical capacity – access to health care services in RACF

Both Australian common law and public international law recognise universal rights to health and wellbeing.[66] Yet, too often, users of aged care services – in the community and in RACF - seem not to enjoy the freedom of access to health services that are enjoyed by people living in the community. This is inconsistent with a human rights framework. Examples of care which, Relationships Australia understands, can be difficult to access include:

- allied health services, like physiotherapy, pharmacy (particularly important to combat polypharmacy), speech therapy, occupational therapy, and podiatry[67]
- dental health care
- pain management
- wound care
- mental health and other psycho-social services, and
- palliative care services.

These difficulties are exacerbated for service users in regional or remote communities. Further, it is necessary to bear in mind that availability does not always equate to accessibility. This is particularly the case for people who have endured trauma in circumstances of vulnerability or dependency and who, as a consequence, may deeply fear and mistrust governments and service providers.

Facilitating access to these services could lighten the workload of unpaid carers and professional service providers, and reduce the isolation of users. As noted elsewhere in this submission, reduced isolation is, in itself, a protective factor against vulnerability to abuse that also enhances overall health and wellbeing.

To support better access, Relationships Australia also commends the value of cross-training between RACF staff and professionals offering other health services and accessible, well-promoted information for formal and informal carers outside RACF.

Right to health and wellbeing – aged-related transitions, conflict and connection

Ageing can be accompanied by the need for help with daily living activities. Acknowledging this is a profound, often deeply distressing, transition; with each incremental increase in assistance, this distress repeats itself. With increasing needs for help, from within and outside the family,

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[66] *Secretary of the Department of Health and Community Services v JWB and SMB* (1992) 175 CLR 218 ('*Re Marion*'); Art 12 of the International Covenant on Economic, Social and Cultural Rights; Article 25 of the Covenant on the Rights of Persons with Disability.

[67] Relationships Australia notes the evidence of Professor Leon Flicker, 17 June 2019, that 'The things that value-add to my practice are the use of allied health staff members and the multidisciplinary team', which includes a physiotherapist, occupational therapist and a social worker (see p 2044).

can come too an apparent reversal of the roles of parent, child and other family members. This can also give rise to existential fears and a sense of bereavement for parent and child. Moving into a RACF is a profound transition, yet our society does not currently support it as it does, for example, the birth of a child, marriage, family separation or bereavement. Yet it represents a pervasive loss of independence, of belonging, of physical and emotional intimacy with loved ones (as well as less frequent contact), of possessions, of community connections – a move away from all previously present and accessible protective features which have anchored a person throughout their life.[68] Further, lack of contact with a familiar environment has long been recognised as a predictor of loneliness,[69] with the negative implications that carries for physical and mental health.[70] Loving families, too, experience significant loss and grief when a beloved family member transitions into a RACF. This is often further complicated by guilt and fear for their loved one, and is compounded if, for example, travel distances make it difficult for family to visit.

These fears can paralyse older people and their families, dampening or silencing altogether discussions about the future, and about an older person's fears, wishes, values and preferences. Then, still more fear, anxiety and distress fills the void that could be occupied by safe and healthy communication.

Relationships Australia has seen distress attending age-related transitions eased by normalising early conversations between older people and their family members. These conversations could address the use of advance planning instruments, as well as creating space for other confronting conversations. We acknowledge and support the work being undertaken by the Australian Guardianship and Administration Council to develop resources for people contemplating the preparation of advance planning instruments. Such instruments can be a vital pillar to support ongoing exercise, by an older person, of their autonomy and ensuring that their will, values and preferences remain at the centre of decision-making about services.

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[68] Contact with family members can decrease by about a half following a move into a RACF: C L Port *et al*, 'Resident contact with family and friends following nursing home admission', *Gerontologist*, 2000; 41: 589-596. See also Grenade and Boldy, 2008, at 471-47, referring to a range of losses that often attend moving into a RACF, including home, family, friends, pets, local communities, opportunities for self-expression, and previous routines and lifestyles. See also R Findlay and C Cartwright, 'Social isolation and older people: a literature review,' 2002. The loss of valued social connections is a well-recognised as a specific precipitating factor for depression: cf Paykel, 1994; Tennant, 2002.

[69] C Proffitt, M Byrne, 'Predicting loneliness in the hospitalized elderly: what are the risk factors?', *Geriatr Nurs* 1993; 14: 311-314.

[70] 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 Mance, P. (2018). Is Australia experiencing an epidemic of loneliness? Findings from 16 waves of the Household Income and Labour Dynamics of Australia Survey (working paper). Kingston, ACT: Relationships Australia. Retrieved from <http://www.relationships.org.au/what-we-do/research/is-australia-experiencing-an-epidemic-of-loneliness. Masi, C., M., Chen, H.-Y., Hawkley, L., C., & Cacioppo, J., T., (2011), 'Meta-Analysis of Interventions to Reduce Loneliness,' *Pers Soc Psychol Rev*., 15(3). Further, social isolation has also been found to reduce response to treatment for depression, as well as being a trigger for people to suffer a relapse of depression: see Trivedi *et al*, 2005, George *et al*, 1989, Paykel *et al*, 1980.

We further acknowledge and support ongoing work to implement safeguards to prevent abuse of older people through misunderstanding, misuse or exploitation of such instruments.

Older people being cared for by family members (whether in a private household or in a RACF) can also be at increased risk of abuse if the family has a history of interfamilial abuse, violence or conflict, or simply of poor relationships and poor communication.[71] Further, evidence suggests a strong association between family conflict or poor family relationships and abuse of older family members.[72] Where these historical dynamics can be shifted through skilled therapeutic interventions, then this may have a protective effect – although it is too early as yet to be confident of this, and further research is required.

Senior Relationship Services provided by Relationships Australia offer older people the psychological space, safety and supports to initiate conversations about advance planning, scaffolded by individual, family and group counselling and mediation services where required.

An example of a service response to support older people and their families experiencing transitions – *Let's Talk* (Relationships Australia New South Wales)[73]

The *Let's Talk Elder Mediation and Support Service* is intended to help older people and their families tackle challenging issues such as finances, future planning and living arrangements before it escalates into extreme conflict or even elder abuse. The Let's Talk Service was launched in Sydney on 12 June 2019. It is available in Metropolitan Sydney, and regional New South Wales, including the Riverina, the South Coast and in Bathurst. In Metropolitan Sydney, the Service will be available to Mandarin and Cantonese speakers.

Family issues can arise at particular lifecycle points or be incremental in nature, with relationships deteriorating over time.

Older people and their families can find it difficult, painful and frightening to contemplate transitions that often accompany ageing and other changes in relationship dynamics that can, for example, attend increasing dependence to assist with the activities of daily life and the assumption of caring responsibilities.

'Let's Talk' rests on commitments to hear the voice of older people and uphold their rights. It provides a safe space in which older people and their families to work through subjects that may never have been the subject of open discussion, and enables capacity building within families to support clear and respectful communication and manage conflict in safe and healthy ways. It provides access to multi-disciplinary and tailored

[71] See Dean, CFCA 51, 13, citing Jackson & Hafemeister, 2016; Johannsen & LoGiudice, 2013; Kaspiew *et al*, 2016; McDonald & Thomas, 2013.

[72] See Dean, CFCA 51, 15, citing Johannsen & LoGiudice, 2013; von Heydrich *et al*, 2012.

[73] Relationships Australia acknowledges the investment of the New South Wales Government in this program.

support services to meet older people and their families where they are in their relationships, with all their strengths and vulnerabilities.[74]

Following initial consultation, users of the Service may be offered referrals to other service providers and agencies, including:

- the New South Wales Elder Abuse Helpline
- Seniors' Rights Services
- Dementia Australia
- general practitioners
- Carers New South Wales
- New South Wales police, and
- financial advisers.[75]

The Service offers Elder Mediation where family members can come together voluntarily to confidentially discuss these age-related issues, and other topics, if required, in a safe and private setting.[76]

Through providing this Service, Relationships Australia New South Wales hopes to achieve the following outcomes:

Short-term

- increasing respect for, and understanding of, the rights and wishes of older people
- reducing client distress
- improving family function and communication skills
- decreasing abusive behaviour
- reducing conflict
- increasing access to elder support services for clients who are geographically isolated or homebound

[74] See Dean, CFCA 51, 21, noting that while such interventions are relatively new, and not yet supported by a robust evidence base, 'given the importance of family relationships in moderating the risk of elder abuse', such interventions merit further exploration: citing Joosten *et al*, 2017.

[75] See https://www.relationships.org.au/news/stories/let2019s-talk

[76] Agreements reached in these mediation are not, of their own force, legally binding.

Medium term

- sustaining and/or improving the older person's health, welfare, wellbeing and safety
- preserving and enhancing family relationships valued by the older person
- responding to legal and other issues, and
- minimising barriers to accessing services.

There are some groups of older people for whom age-related transitions 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,[77] 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.[78]

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

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

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 attention of the Royal Commission.[79]

Service delivery for care leavers must be co-designed with care leavers' organisations.[80] 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.[81] 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.

Relationships Australia is aware that the Commission has heard from Aboriginal and Torres Strait Islander people about why they 'shun' aged care services, and we note, too, the testimony of Professor Leon Flicker, about why Aboriginal and Torres Strait Islander people are under-represented in RACF:

> There's probably several reasons. One reason is the fact that Aboriginal and Torres Strait Islander peoples are more likely to develop age-related syndromes at a younger age and therefore don't find residential care that suitable. The other thing is that Aboriginal and Torres Strait Islander people are much more likely to live in regional and remote areas, and therefore access to appropriate 25 residential care is less. And thirdly - and I don't list these in any order of priority, but thirdly, Aboriginal and Torres Strait Islander people often do not believe that residential care is culturally safe for them, and therefore they shun it and do not use the service as much as they could.[82]

In connection with the Stolen Generations, Professor Flicker referred in his testimony to

> …the trauma of that early upbringing and uprooting….The – the distrust of institutions and services that that has resulted in may produce a particular problem for when people are going into residential care.[83]

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[79] 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.

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

[81] 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, 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)

[82] Transcript, 17 June 2019, 2024. See also p 2026, where Professor Flicker noted that 'We know that the disability rates for Aboriginal and Torres Strait Islander people are much greater and they occur at an earlier age,' and pp 2028-2029. See also L Flicker and K Holdsworth, *Aboriginal and Torres Strait Islander People and Dementia: A Review of the Research – A Report for Alzheimer's Australia*, Paper 41, October 2014. This review notes the significantly greater prevalence of dementia among Aboriginal and Torres Strait Islander people. See also Radford *et al* (2017), 'Childhood Stress and Adversity is Associated with Late-Life Dementia in Aboriginal Australians', *Am J Geriatric Psychiatry* 10: 1097-1106.

[83] Transcript, 17 June 2019, 2038.

And while the financial and clinical care complexities of moving into a RACF are well-known (and have been canvassed by many witnesses from whom the Royal Commission has already heard), these psycho-social complexities can be under-played, their grievous impact notwithstanding.

PART 3 – SYSTEMIC OBSTACLES TO DELIVERING PERSON-CENTRED SERVICES

This Part describes some systemic obstacles to the delivery of genuinely person-centred services that:

- respect human rights, including by honouring the individuality and agency of older people and eschewing ageism
- can be trusted by current and prospective users who have experienced polyvictimisation
- mitigate structural inequities and asymmetry of information, and
- are provided by carers (unpaid and paid) who are acknowledged, valued and equipped with resources, knowledge and skills.

From scattered kaleidoscope to ordered mosaic – overcoming bureaucratic, regulatory, funding and service fragmentation

Fragmentation bedevils many of the policy and programmes with which the clients of Relationships Australia engage, including:

- the aged care 'system'
- the family law 'system'
- the child protection 'system'
- disability services, and
- mental health services.

The Royal Commission has acknowledged the complexities arising from 'the interface between health, aged care and disability services in urban, regional and rural areas.'[84] In its first Background Paper, the Commission noted that

> …the system is complex and fragmented, and reform has been difficult to implement.[85]

People approaching the aged care 'system' are confronted with a disorienting kaleidoscope of scattered, ever-shifting pieces where the burden is on them to identify and navigate a coherent array of services to meet their needs, or the needs of their loved ones. Some people will have the means to pay for someone to do this; for others, it can be an insuperable obstacle that further entrenches existing inequities of service provision and inclusion.

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[84] Royal Commission, 18 January 2019, 2.

[85] Background Paper 1, *Navigating the Maze*, 1.

Families presenting to Relationships Australia often report, or are identified as having, complex multi-faceted needs, which cannot be met by a single service provider, or within a discrete funding bucket available to a provider. It is not uncommon for Relationships Australia to have to 'patch together' a service response for a single family from multiple funding sources, and through collaborating with other providers, to meet that family's needs. While we have the size and geographic coverage to facilitate this, we are acutely mindful that this can be a significant obstacle for families, and smaller providers, to navigate.

Some groups of prospective service users face particular structural deterrents to obtain even the most basic information and perfunctory engagement with the system. As noted in testimony by Professor Leon Flicker, for example, My Aged Care is

> …torturous for literate middle-class Melbournians. It's impossible for a remote Kimberley Aboriginal person. They might not be literate, they might not even own a computer or a landline or a mobile phone that can wait 35 minutes. The idea that this is a system that is navigable by the average client is basically absurd.[86]

Earlier in his evidence, Professor Flicker described the Lungurra Ngoora trial in the Kimberley, and noted that

> The important thing was to have an independent broker for the various services because otherwise the divisions between each of those services, the mental health versus disability versus aged care can become overwhelming.[87]

Some of this fragmentation is innate to a federal system of government. It is a responsibility of *governments*, however, to manage those complexities, and to minimise the extent to which the burden falls to those least equipped to shoulder it – service users and their families. Relationships Australia notes Professor Flicker's testimony that

> There's very little interest in community members on where the money is coming from to provide the service. They just want the service provided and the trouble is there are arcane and numerous pathways for the sources of funds and these mechanisms are of no interest in people receiving the funds and the resources.[88]

Despite this, the responsibility of managing fragmentation of funding, governance and regulation and service delivery has not been well taken up by governments, and the horrific consequences of unchecked fragmentation were exposed (surely beyond further debate) by the events at Oakden.[89]

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[86] Testimony, 17 June 2019, 2035.

[87] Testimony, 17 June 2019, 2029.

[88] Testimony, 17 June 2019, 2031.

[89] In addition to inquiries initiated by the Government of South Australia, Carnell-Paterson also described how fragmentation of oversight and accountability facilitated shamefully long-tolerated failures. Professor Flicker also drew attention to the effect of funding fragmentation in limiting the possibility of achieving economies of scale in service delivery: see testimony, 17 June 2019, 2032.

Fragmentation of existing aged care arrangements also presents:

- within and between government agencies, both within the portfolio of aged care and between aged care and other related agencies such as health and social services[90]
- between providers of different kinds of services
- within larger service providers
- between providers and regulators, and
- between various professional disciplines involved in delivering services (including vertical fragmentation within professional hierarchies).

Thus, fragmentation pervades every aspect of that heterogeneous collection of agencies, facilities and services (optimistically) referred to as an aged care 'system': research, policy formulation, program design and delivery, data collection and sharing, regulation and enforcement/sanctions.

Relationships Australia supports advocacy for multi-disciplinary and co-ordinated approaches to support older people, and their families and caregivers.[91] Such approaches offer a person-centred response that could be the difference between a person ageing in their home and amidst their familiar networks and supports, and that person having to move to institutional care.

A well-functioning aged care system should be one in which interfaces within and between the 'moving parts' of the system are imperceptible to service users and which adopts a 'whole of ageing' approach. It requires, among other things:

- timely sharing of high quality information and intelligence - between agencies, consistency with privacy protections; especially (but not only) in relation to sentinel events
- shared training among various specialisations and disciplines, and
- easy to access, easy to understand information presented in a variety of formats, to all participants in the system – service users, providers, funders, regulators, policy-makers and the community at large.

In 2011, the Productivity Commission found that

> The aged care system suffers key weaknesses. It is difficult to navigate. Services are limited, as is consumer choice. Quality is variable. Coverage of needs, pricing,

[90] Carnell-Paterson, 2017, 53: 'For aged care facilities that are also health facilities, Australia lacks jurisdictional clarity in its regulatory system.' See also Carnell-Paterson, 2017, 77, 82-82ff.

[91] See, for example, Chesterman, 2016.

subsidies and user co-contributions are inconsistent or inequitable. Workforce shortages are exacerbated by low wages and some workers have insufficient skills.[92]

There has been little progress in fixing these weaknesses, with the exception of the establishment of the single-body regulator earlier this year, and the Aged Care Navigator Trial.[93] This trial is funded to run nationally until 2020. There is no guarantee of ongoing support – or, indeed, of governments producing a solution to the fragmentation issue by 2020. Indeed, the trial implies acceptance by governments of fragmentation as an inevitability which *users* must work around (or at best, helped to work around), rather than as a phenomenon that is within the power of governments, with the application of political will and focus, to alleviate.

Relationships Australia would welcome a more robust approach that sees governments manage fragmentation in a way that is imperceptible to users of all human services.

Responding to polyvictimisation and preventing re-traumatisation

Aged care services must be acutely sensitive and responsive to the vulnerabilities of at risk cohorts; particularly when intersectionality and polyvictimisation are present.[94] Many providers of aged care services have been involved in other systemic failures, including abuse, neglect and mistreatment, of vulnerable people, including:

- children in out of home care
- people with disability
- people affected by mental illness
- Aboriginal and Torres Strait Islander people, including members of the Stolen Generations
- Former Child Migrants
- people affected by forced adoptions
- Forgotten Australians, and
- people who identify as members of the LGBTIQ communities.

Relationships Australia clients who identify with one or more of these cohorts have expressed to us their (wholly justifiable) deep anger – and fear - that some of the organisations that abused

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[92] Productivity Commission, *Caring for older Australians*, 2011, Report No 53, Vol 1, 2. See also Carnell-Paterson, 2017, vii.

[93] See https://www.cota.org.au/information/aged-care-navigators/

[94] A Dean notes that '…the recognition that different forms of abuse can co-occur as a form of poly-victimisation…Recent focus on poly-victimisation has highlighted the intersection of multiple forms of abuse as a pattern of victimization as well as the cumulative effects over the life course that can lead to abuse in older age', citing Heisler, 2017; Ramsey-Klawsnik & Heisler, 2014 and Hamby *et al*, 2016; A Dean, CFCA 51, 7.

them are now aged providers. Some client groups have told us that they would prefer to die by suicide rather than to again be at the mercy of institutions who have abused, neglected and exploited them in the past.[95]

Accordingly, current and aspiring providers with these histories must undertake a serious and public reckoning of their responses to those whom they harmed and their accommodation and facilitation of the individuals who perpetrated that harm. They must interrogate their history with unsparing eyes to form a rational view as to whether they are or ever can become suitable and trusted providers of services to vulnerable members of our community.

Governments and other funders should pay close attention to organisations whose service of vulnerable people has fallen so lamentably short in other contexts. As a starting point, close attention should be paid to how providers have taken up the guidance provided in the information booklet, *Caring for Forgotten Australians, Former Child Migrants and Stolen Generations*.[96]

People who have endured the compounding trauma and disadvantage of, for example, adverse childhood experiences and institutional abuse *must* receive services that entrench autonomy, choice and control. Freedom of movement, freedom of choice in the activities of day to day life, control over medical interventions and the provision of intimate care services, for example, are particularly to be cherished where one's early life has been made despairing and desolate by coercion and violent control.

Person-centred large scale delivery[97] – structural inequities and asymmetry of information – market forces of limited utility

That the Australian aged care system should deliver person-centred care was acknowledged at the outset of the hearings for this inquiry.[98] Counsel Assisting submitted that aged care

> …must be centred on and tailored to the needs[99] and choice of the person receiving aged care services, whether this is in a nursing home or in their own home. This is what is meant when the terms of references [sic] speak of person-centred aged care services. All this must occur in partnership with family and with other carers.[100]

Personalised large scale service delivery, predicated on choice and control, was a key objective of the 2012 reforms to the aged care system. However, this objective is unlikely to be achieved

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[95] See, for example, comment from 'Cynthia', quoted in presentation of Professor Elizabeth Fernandez, *Addressing the Complex Needs of Forgotten Australians in Aged Care*, Relationships Australia NSW, 6 June 2019: 'I've told my kids I want a bullet first. There is no way I'm going into a nursing home and if I have to, I'll take my own life before I go into a nursing home. I'm not going to be institutionalised ever again.'

[96] Australian Government, Department of Health, 2016.

[97] See Yon *et al*, 2018, arguing that 'person-centred and integrated care' is a necessary element of a human rights-informed aged care system.

[98] See, for example, the opening remarks of Commissioner Briggs, 18 January 2019, 3; Counsel Assisting, Mr P Gray QC, 18 January 2019, 10. See also the evidence of Professor R Paterson at 4579.

[99] To be determined by the resident's values, wishes and preferences.

[100] Counsel Assisting, Mr P Gray QC, 18 January 2019, 10.

without mitigating pre-existing structural inequities;[101] indeed, the risk is that those inequities may be even further entrenched. This risk is the subject of significant commentary around the role of social determinants of health and is reflected in Hart's 'inverse care law'.[102]

The challenge for Australia is to hold fast to affording choice and control, which is linked to positive health outcomes, while designing policy and programmes to immediately remediate, and for the future prevent, structural inequalities.[103] For example, aged care reforms should, to be fit for purpose in Australia, enable Aboriginal and Torres Strait Islander users to retain their connections with family, culture and country.[104]

In this connection, Relationships Australia again emphasises the importance of giving service users, their caregivers and advocates, and their loved ones, access to clear, comprehensible and contemporary information – including comparative information. The system will fail its objectives around autonomy, choice and control unless it acknowledges and remediates the vast asymmetry of knowledge between users and providers (and between regulators and providers). Further, the system will fail its objectives around caring for vulnerable people, because asymmetry of knowledge enables predation and exploitation by bad actors.

In this context, adherence to ordinary principles of consumer law and market forces cannot deliver quality and safety. This was noted by Carnell and Paterson in their review of the aged care system.[105] There are perverse incentives that arise when human services operate as businesses that are required to prioritise generating profits for owners/shareholders by minimising expenditure and costs over quality of life for users. This has been apparent in relation to health services, child care services, and corrective services; the 'profit motive' can confidently be assumed to have contributed to some of the egregious examples of substandard services in aged care that were the subject of the *Four Corners* investigations aired in 2018.

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[101] For example, poverty, reduced literacy, language barriers, cultural safety barriers, access to good nutrition and physical activity, and psycho-social and cultural factors that contribute to increased risk of chronic disease burden. Relationships Australia notes that in 2011, according to the Australian Institute of Health and Welfare, Aboriginal and Torres Strait Islander people bore a burden of chronic disease that is 2.5 times greater than the general Australian population: AIHW, 2011. Radford *et al*, 2017, however, refer to research suggesting a rate of 3-5 times higher: see Li *et al*, 2014; Radford *et al*, 2015; Smith *et al*, 2008.

[102] This provides essentially that 'the availability of good medical care tends to vary inversely with the need for it in the population served. This inverse care law operates more completely where medical care is most exposed to market forces, and less so where such exposure is reduced. The market distribution of medical care is a primitive and historically outdated social form, and any return to it would further exaggerate the maldistribution of medical resources.' (see https://www.thelancet.com/journals/lancet/article/PIIS0140-6736(71)92410-X/fulltext).

[103] See Malbon et al, *Personalisation schemes in social care: are they growing social and health inequalities?* BMC Public Health, accessed at https://bmcpublichealth.biomedcentral.com/articles/10.1186/s12889-019-7168-4

[104] See presentation of Professor Elizabeth Fernandez, *Addressing the Complex Needs of Forgotten Australians in Aged Care*, Relationships Australia NSW, 6 June 2019. See also the testimony of Professor Flicker, 17 June 2019, 2034-2035, where he refers to the life course approach to dementia described by Professor Tony Broe. Professor Flicker noted that the rates of dementia among people in the Kimberley 'are only found in communities like, for example, an Arab population in Israel, other communities that are relatively deprived and have life course factors associated, risk factors associated with cognitive impairment.'

[105] See pp ivff; p 100. Carnell-Paterson observed that quality consumer information is essential to a mature market (see pp 93, 101).

A further issue in strict application of consumer law and market forces assumptions and principles was adverted to by Professor Flicker, in his testimony to the Commission:

> One of the problems we have is, for example, in both the NDIS and the home care packages, is that they are funded for individuals. But if there's no service there [eg in smaller communities], those individual packages can't be provided. So somehow there has to be a pooling of funds to allow for those services to be provided.[106]

Relationships Australia therefore supports work to ensure that the personalised service delivery does not exacerbate structural inequities and enables service delivery that is both available and accessible.

Unpaid workforce

'Carer' is not a synonym for 'perpetrator'. The Australian Law Reform Commission, in its inquiry into abuse of older people, heard from a range of submitters emphasising the loving and supportive intent and actions of the majority of carers.

Relationships Australia notes that in 2015, according to the Australian Bureau of Statistics:

- there were 2.7 million unpaid carers in Australia[107]
- around 856,000 carers were primary carers (ie those who provide the most informal assistance to another person)
- more than two thirds of primary carers were female
- while the average age of a primary carer was 55, 272,000 carers were under the age of 25 (ie around 10%)
- almost all primary carers (96%) were caring for a family member
- more than half of primary carers provided care for at least 20 hours per week, and
- 56% of primary carers aged 15-64 also participated in the paid workforce, compared to 80% of non-carers.[108]

Also for 2015, Deloitte Access Economics identified that:

- the replacement value of the unpaid care provided in that year was $60.3 billion, and
- it is estimated that carers provided 1.9 billion hours of unpaid care.[109]

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[106] Transcript, 17 June 2019, 2032.

[107] This figure is acknowledged by the Department of Social Services: see https://www.dss.gov.au/disability-and-carers/carers

[108] Australian Bureau of Statistics, *Survey of Disability, Ageing and Carers*, 2015, cited by Carers Australia, https://www.carersaustralia.com.au/about-carers/statistics/

[109] Deloitte Access Economics, *The Economic Value of Informal Care in Australia*, 2015, cited by Carers Australia, https://www.carersaustralia.com.au/about-carers/statistics/. In 2017, there were 3.8 million people in Australia aged 65 years or over and there were around 200,000 RACF or flexible living places. Thus, only a small fraction

Each major review of the Australian aged care system has rightly acknowledged the magnitude and human (as well as economic) value of the efforts undertaken 24 hours a day, seven days a week and 365 days a year by the very large unpaid workforce.[110] Husbands, wives and other intimate partners, children, grandchildren and other family and friends assume responsibilities, often amid trauma and crisis, for which they have little or no training, and which they must somehow balance with other family, professional and social responsibilities. Additional complexities arise for families affected by histories of conflict, violence, and poor relationships; caring responsibilities can present opportunities for, and risks of, abuse, revenge and perpetuation of existing coercive-controlling relationships. This may also be bi-directional between the older person and the carer.

While bearing their own burdens of grief, loss, guilt and fear, and their own needs and limitations, family members take on confronting tasks the performance of which can subvert cherished and long-standing relationship dynamics. Lovers become nurses; children become jailers, in their own eyes if not in the eyes of others. In some instances, carers can become the fearful and isolated victims of abuse at the unintentional hands of the person for whom they are caring.

To better support carers in navigating new relationship dynamics, Relationships Australia recommends:

- increased investment in psycho-social supports for unpaid carers
- investment to make training and skills development available to unpaid carers, and
- regular collection, and timely publication, of data about:
    - the numbers of unpaid carers
    - the kinds of support and care they provide
    - experience of 'carer stress' and carers' accounts of the challenges they face (including co-morbidities such as substance abuse or poor mental health),[111]
    - the supports they are eligible to receive, and
    - the value of their unpaid labour to the economy.

Relationships Australia would also like to take the opportunity to emphasise the need for investment in service responses that are available to the family as a whole, regardless of who

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of older people live in RACF; most live in private households. Sources: https://www.gen-agedcaredata.gov.au/; https://www.aihw.gov.au/reports/older-people/older-australia-at-a-glance/contents/health-and-aged-care-service-use/aged-care

[110] In its 2011 report, the Productivity Commission reported in Report No 53, *Caring for Older Australians*, 326-327, that around 350,000 people provided primary care to people aged 65 years or over.

[111] Keeping in mind, for example, that dependency and/or carer stress are also risk factors in abuse of older people. Carer stress was, in the 1970s, thought to be the dominant cause of abuse of older people: see Dean, CFCA 51, 14, citing S L Jackson, 'All elder abuse perpetrators are not alike: The heterogeneity of elder abuse perpetrators and implications for intervention,' *International Journal of Offender Therapy and Comparative Criminology*, 60(3), 265-285. Over time, other factors have been recognised, and characterological work is now emerging to develop a more nuanced understanding of abuse of older people.

approaches the service providers. There are instances where adult children approach Relationships Australia for help to deal with abuse, neglect or exploitation that is being perpetrated by their parent's intimate partner or a sibling or other family member. Sometimes, the older person is unable or unwilling to seek support on their own initiative, but provision of services to the family member who raised the alarm can ameliorate the situation for the family as a whole and lay solid foundations for subsequent therapeutic intervention.

> For example, one of our services was approached by the adult daughter of a mother with dementia. 'Mary' was one of three siblings, but most of the caring responsibilities had fallen to her, with her siblings and her mother's intimate partner not engaged with the caring role. Mary was struggling to cope, practically and emotionally. Our service worked with Dementia Australia to arrange mediation and group work to support Mary to have a safe and constructive conversation with her step-father and formerly disengaged siblings about future planning about her mother's care. The family has reported that intervention has had a significant positive impact on their relationships, as well as facilitating support being made available to Mary's mother in her transition to residential aged care.

Relationships Australia notes that, without ongoing investment, the invaluable work undertaken by unpaid carers may be unsustainable, and the responsibilities which they shoulder would then fall upon government or be neglected entirely. Not only would this be more expensive, it would undermine broader policy priorities to enable people to age in place, and maintain all the protective features of their familiar environments.

In this regard, Relationships Australia welcomed the funding initiatives announced in 2018-2019 of $85.6 million over four years for the introduction of new services for carers, as part of an Integrated Carer Support Service model. We particularly welcome the emphasis on early intervention supports in that measure. Further, the 2019-2020 Budget included a further $84.3 million over four years to increase these services, and provide additional support to young carers.[112] These amounts are, of course, very modest in light of the carer hours and replacement value of carer work mentioned at the outset of this section. They are also very modest compared to the amount of funding for RACF and community care services. Further, we note that the inclusion criteria refer to the 'frail aged'. It is our view that investment should be extended in relation to all people aged 60-65 and over, and Aboriginal and Torres Strait Islander people aged 45-50 and over.

Paid workforce

Similarly, it must be acknowledged that neglect and abuse are not universal experiences of people receiving care in the community or in RACF. There are home and community service providers of RACF, and many staff who work within them, who offer highly skilled, compassionately delivered services. It is vital also to acknowledge and express gratitude for the courage of staff who have come forward as whistleblowers.

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[112] See https://www.dss.gov.au/disability-and-carers/carers

The Royal Commission recognises that

> …there are many positive examples of high quality care within the aged care sector. We recognise that the sector engages thousands of dedicated people who provide quality and compassionate aged care services every day, often in difficult circumstances whose work is complemented by the important contribution of families and volunteers.[113]

We concur broadly with the point made by the Royal Commission in this regard but would, with respect, suggest that available data demonstrates that it is more the case that the paid workforce complements the work of the unpaid workforce.

To better support the paid workforce, and foster high quality services, Relationships Australia recommends:

- structured workforce planning to ensure that staffing profiles correspond to need and risk[114]
- providing increased remuneration for all staff employed in RACF and community-based aged care services
- providers be required to employ staff (eg 'social inclusion officers') whose job it is to offer that kind of contact and care, and facilitate residents to pursue family and social activities and connections that have previously nourished them, as well as facilitating exposure to new social activities and connections that interest users[115]
- support for community visitors programmes, along the lines of the programme run by the Office of the Public Advocate (Victoria)
- that service providers be required to offer professional training,[116] 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,'[117] and

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[113] Commissioner Briggs, 18 January 2019, 3. Counsel Assisting, Mr P Gray QC, noted that the Royal Commission had, at its earliest stages, received examples of good aged care service models: 18 January 2019, 11.

[114] See also Carnell-Paterson 75.

[115] For example, by arranging visits to facilities by social and other interest groups, as well as providers of other services that users have previously enjoyed (eg music lessons, hairdressers, sporting clubs, beauty therapists, clothes shops etc).

[116] 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.

[117] 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

- inter-jurisdictional working with vulnerable people.

PART 4 – REGULATION, GOVERNANCE, ACCOUNTABILITY

> The ultimate test of the regulatory framework is its ability to respond to issues in a timely and appropriately calibrated manner. Past incidents in the sector serve as a reminder of the potential impact of non-compliance on frail and elderly residents, and the importance of adopting a proactive and flexible approach to the administration of the framework, including the timely reporting and assessment of information collected by the Department and Agency staff.[118]

Multiple reviewers, researchers, practitioners and commentators have expended considerable effort exploring the regulatory, governance and accountability settings on which the aged care system relies, and how these might be improved.

In 2011, the Productivity Commission identified the following best practice principles for RACF which included:

- good governance, including separating policy advice from regulation and interactions between individual users[119]
- standards[120]
- role clarity among regulators, and
- responsive regulation to encourage and enforce compliance.[121]

The regulatory failures at 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.[122]

We note the testimony of Professor Paterson that

> I think there has been a total lack of curiousity. I think there has been a mechanistic approach to the [complaints] role.[123]

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and health practitioners to understand the impact of exposure to maltreatment on psychosocial problems across the life course is crucial.'

[118] Australian National Audit Office, *Monitoring and compliance arrangements supporting quality of care in residential aged care homes*, Audit Report No. 48 2010-11; see also Carnell-Paterson at 62.

[119] As also noted by Carnell-Paterson, 56ff. See also Productivity Commission, *Caring for Older Australians*, 2011, vol 2, 15.2.

[120] Carnell-Paterson, 61ff.

[121] See Productivity Commission, *Caring for Older Australians*, 2011, vol 2, Chapter 15. Carnell-Paterson, 66ff. See also the testimony of Professor R Paterson to the Royal Commission: 4584-4585.

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

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

Moreover, even the best-intentioned and most highly skilled regulators and providers are constrained by funding envelopes that force them to rely on measures and processes that do not take much time or expense to collect, interpret and disseminate to other concerned stakeholders. Thus, the kinds of silos mentioned previously in this submission may not be created with the intention of increasing opacity, plausible deniability and bureaucratic obstruction, but simply to try and do the best job possible with chronically inadequate funding. Unsophisticated budget practices have real life impacts on those whom government should be serving; this includes trying to regulate a $22 billion aged care system on chewing gum and wishful thinking.

Hence, for example:

- the 'default' three year accreditation cycle, rather than accreditation periods purposefully calibrated with reference to risk profiles that are informed by real time data[124]
- the use of announced visits to facilities in place of unannounced visits[125]
- the '10%' rule for consultation with service users[126]
- reliance on a binary measure – met/not met – in place of more nuanced and informative standards developed in genuine engagement with service users,[127] and
- resistance among policy and programme designers, regulators and providers to useful, publicly accessible comparative information to enable the choice and control which is the aspiration for the Australian aged care systems.

Relationships Australia supports:

- separating policy responsibility from regulation/compliance[128]
- through co-design with service users, developing outcomes that are valued by older people (ie move away from 'process/output' measures to quality of life measures defined by users)[129]

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[124] For more discussion on weaknesses of risk profiling, see Carnell-Paterson, Box 3, at p 87; see the evidence of Professor R Paterson, 7 August 2019, 4584, 4588, 4594.

[125] Relationships Australia understands that this setting has been changed, implementing a recommendation from the Carnell-Paterson review (see recommendation 8(ii).

[126] For discussion of work concerning the collection and use of feedback from service users to inform more effective regulation, see Productivity Commission, *Caring for Older Australians*, 2011, vol 2, 399, citing Braithwaite 2001 and Braithwaite *et al*, 2007, Chapter 10. Carnell-Paterson recommended that assessment contact visits must seek the views of 20% of residents and their representatives: recommendation 2(iii). It appears that the Government has rejected this recommendation as being too prescriptive; Relationships Australia notes that Professor Paterson, however, does not resile from that recommendation: see transcript at 4595-4596.

[127] See Carnell-Paterson at 91, noting the crucial importance of nuanced risk screening, assessment and profiling.

[128] See Carnell-Paterson, 77.

[129] 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,

- an accreditation process which is outcomes-focused, and stratified according to risk profile[130]
- 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)
- a publicly searchable complaints register[131]
- applying an Open Disclosure Framework to RACF and providers of home and community-based services, and
- consideration of mandatory reporting where abuse is suspected to be perpetrated by staff employed by aged care providers, or by individuals and other entities receiving a fee for providing a service to an older person.

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 evidence that the Commission has received to date that, too often, discussions about accreditation and compliance are conceptualised within a dyad comprising only (or, at best, dominated by) government and providers. This is incompatible with a human rights based, person-centred system.[132]

Relationships Australia emphasises the need for quality measures that demonstrate person-centred care, where the service user is supported to enjoy a quality life as defined by them. We welcome the Royal Commission's recognition of this, in asking providers about instances of substandard care since 2013, concerning

> …dignity, choice and control', as well as instances relating to 'clinical care, medication management, mental health, loneliness, disengagement, disconnection, or boredom,

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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).

[130] 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.

[131] Relationships Australia is aware that the Department of Health rejected this recommendation which was made in the Carnell-Paterson Review. The Department's reasoning for rejecting this recommendation was put to Professor Paterson by Counsel Assisting, and described as being based on the need for information to be kept confidential, in accordance with the secrecy provisions of the *Aged Care Act 1997* and the *Privacy Act 1988*. We note that Professor Paterson disagrees: 'I don't accept that. I accept that it might be more difficult. I've seen it described as prescriptive. Well, you know, actually, that's part of regulation sometimes and we quite deliberately said, "No, we've got to be more ambitious here". Providers and agencies will come up with all sorts of reasons why it's too difficult to get 20 per cent. Ultimately that, it seems to me, is a way in which we end up diminishing the voices of the people who we need to hear from. So I think that was an important recommendation and I'd be disappointed if it's put in the too-hard basket

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

> personal care, nutrition, restrictive practices, end of life care, governance and management and any other area that the service provider may have identified.[133]

Right touch or light touch?

Relationships Australia shares public concerns about the extent to which regulators in aged care have relied on managing providers back to compliance, and have flinched from imposing timely and meaningful sanctions.[134] This is not 'right touch' regulation, but an abnegation of responsibility. Perhaps this has been forced on regulators because of inadequate resources to engage in right touch regulation – that is a matter to be considered by the Royal Commission – but it has clearly allowed less competent or conscientious providers too much latitude to offer services that have, too often, been so substandard as to be lethal.

Centrality of the user's voice – transparency, complaints, advocacy

A genuinely person-centred aged care system will proactively seek a diverse array of intelligence – especially from users of the system - and make public that intelligence to enable users to exercise control and choice. This includes recording, acting on and making public information about complaints. As envisaged by Professor Paterson:

> COUNSEL [foreshadowing evidence to be given by a Commonwealth official]: But, Professor, this online register that you were making recommendations about, was that intended to be information at an aggregated level or at an individual level?
>
> PROF PATERSON: Of course it was intended to be at an aggregate level. So – I mean, the thinking behind – it seems to me that too often we strike the balance in favour of privacy at the expense of transparency and openness of information. I say that partly having, as parliamentary ombudsman, also been our Freedom of Information Commissioner, and it seemed to me important that a complaints body makes it visible to people who are looking; what are the nature of the complaints they are receiving, how many have they got, how have they been resolved, which ones are being escalated and so forth. Of course we're not talking about – that you should identify the name of the resident or the family member complainant, nor even the name of the provider. So we're not talking about that. We're talking about aggregated information but something that would give you a *much better picture than the sort of vanilla information that one tends to find in the annual reports of complaints bodies*.[135] [emphasis added]

[133] Commissioner Briggs, 18 January 2019, 4.

[134] See also the testimony of Professor R Paterson, 4585.

[135] At 4602.

Similarly important to supporting exercise of choice and control through quality information is, in the view of Relationships Australia:

- access to systemic and individual advocacy , including through community visitors programmes,[136] and
- protections for complainants and their caregivers/loved ones.[137]

In this connection, the Government's rejection of the Carnell-Paterson recommendation that assessment contact visits seek the views of 20% of service users and their representatives seems to bode ill for the aspiration of a person-centred aged care system. Certainly, when Counsel Assisting put this position to Professor Paterson, he was concerned:

> I don't accept that. I accept that it might be more difficult. I've seen it described as prescriptive. Well, you know, actually, that's part of regulation sometimes and we quite deliberately said, "No, we've got to be more ambitious here". Providers and agencies will come up with all sorts of reasons why it's too difficult to get 20 per cent. Ultimately that, it seems to me, is a way in which we end up diminishing the voices of the people who we need to hear from. So I think that was an important recommendation and I'd be disappointed if it's put in the too-hard basket.[138]

PART 5 – RESEARCH AND ACCESS TO DATA

Throughout this submission, Relationships Australia has identified research needs that must be supported for the Australian aged care system to meet the objectives identified by the Government and the Royal Commission. Collectively, we consider research is needed 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[139]
- risk and protective factors for different types of abuse, as well as relating to differentiated cohorts of perpetrators[140] and people at risk of abuse

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[136] 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.

[137] 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.

[138] At 4595.

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

[140] 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.

- the efficacy of supports to serve people with BPSD, and which maximise exercise of their autonomy[141]
- the availability and quality of training for people who care for and serve people with BPSD
- 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 impact of place-based approaches in the community and in RACFs
- palliative care needs of users of aged care services, including particular needs of Aboriginal and Torres Strait Islander people in this context[142]
- 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.

Access to data held by governments

High quality research relies on timely and affordable access to data. In this regard, Relationships Australia notes the observation in the Carnell-Paterson report that

> Despite the importance of ongoing data sharing by regulators, there is currently no connectivity between the databases used by the Department [of Health], the Quality Agency and the Complaints Commission. Ironically, the Department and the Complaints Commissioner both use the National Complaints and Compliance Information Management System database, yet neither agency can access the data held by the other. The Quality Agency uses different systems.
>
> Criteria for transmittal of information among the agencies mean that only a fraction of the data collected by each one is available to the other regulators…[143]

In reflecting on the necessity for, and current inaccessibility of, data, Relationships Australia has had the benefit of considering the evidence given by Professor J Ibrahim, in response to a question from Counsel:

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

[142] Flicker and Holdsworth, 2014, recommend that 'Education and awareness of palliative care be provided to Aboriginal [and] Torres Strait Islander health workers and communities to ensure a greater understanding of the services provided,' and that 'Further research should be conducted to gain a greater understanding of the palliative care needs of Aboriginal and Torres Strait Islander people and communities:' see p 21.

[143] At 84-85; see also 87-8, 91.

> MR BOLSTER: Just pausing there, there's legislative reporting requirements in the Commonwealth system for both physical assaults and sexual assaults. What happens with that data?
>
> PROF IBRAHIM: I don't know. I've asked for the last two years and I've not heard an answer that would satisfy me as a citizen, let alone as a researcher. I – I – all I know is what is in the annual reporting requirements the Department has to do according to legislation, and they provide a one paragraph summary saying the 30 number of incidents that have occurred. There's no state breakdown. There's no breakdown of nature. There's no breakdown, whether it's resident or staff perpetrated. There's no explanation as to whether they've used that data or fed it back. There's – I don't know. I would happily analyse that data for free if it was provided to our team.
>
> MR BOLSTER: There are also carve-outs for reporting in the case of people who have a cognitive impairment. How useful is that when it comes to identifying the extent of this problem?
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> PROF IBRAHIM: Well, I think carve-out is the wrong term. So it's not – it would be better to say carved in. The only thing that's carved in, is if you've got someone that's cognitively intact and given that two-thirds of the residents have some form of cognitive impairment, that eliminates two-thirds of the population already. Then the onus is on the provider because the responsibility sits with the provider to report so there's not an obligation there. You then have interpretation of the staff about your willingness to report and if you report an incident, are you going to be rewarded for reporting it, or are you going to be faced with two or three days of work, and then complaints about what you're doing which means it's going to be underreported. So the system does not work. The exclusion for people with dementia makes no sense because the people with dementia are the ones at the greatest risk, and so we set up a system which is not accountable to anyone. So there has been no accounting by the Department of what they've done with that data for 10 years now, and no one seems interested in that fact. And so we're not using that data. We've carved in only for people with cognitive – who are cognitively intact. For staff that have the guts to report is what comes through. And so I, you know, it doesn't work for me.[144]

Of course, such blockages in the regulatory aspects of the aged care system not only hinder research, but have dangerous implications for service users. These blockages hinder the collection of intelligence that is a necessary enabler of responsive, right touch regulation, that might provide timely alerts of changes to the risk profile of an activity or provider, and thus put a regulator on notice that more intensive scrutiny is required.

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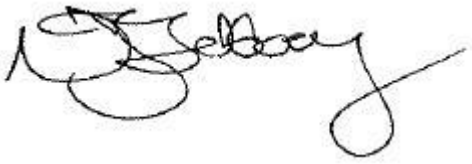
[144] Transcript of evidence, 16 May 2019, at 1795-1796; see also Professor Ibrahim's evidence at 1781-1782. The passage of testimony at 1795-1796 provides another example of effective exclusion from data collection of people with cognitive impairment in a reporting/regulatory context, as they are also excluded from data collection about abuse of older people across all settings: Bedson and Chesterman, *Are national elder abuse prevalence studies inclusive of the experiences of people with cognitive impairment? Findings and recommendations for future research*, Office of the Public Advocate (for the Australian Guardianship and Administration Council), 2017.

CONCLUSION

We thank the Royal Commission for the opportunity to contribute to its work, 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,



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