

Submission to Royal Commission into Aged Care Quality and Safety

September 2019



**Seniors Rights
Service**



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List of Acronyms

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| ACAT | Aged Care Assessment Team |
| ACQSC | Aged Care Quality and Safety Commission |
| ACS | Aged Care Standards |
| CALD | Culturally and Linguistically Diverse |
| CHSP | Commonwealth Home Support Program |
| COTA | Council on the Ageing |
| CVS | Community Visitors Scheme |
| DVA | Department of Veteran's Affairs |
| EPG | Enduring Power of Guardianship |
| HACC | Home and Community Care |
| HCP | Home Care Package |
| NACAP | National Aged Care Advocacy Program |
| NCAT | New South Wales Civil and Administrative Appeals Tribunal |
| OPAN | Older Person Advocacy Network |
| POA | Power of Attorney |
| RACF | Residential Aged Care Facility |
| RAS | Regional Assessment Service |
| SRS | Seniors Rights Service |

Seniors Rights Service recognises and acknowledges Aboriginal and Torres Strait Islander peoples as Australia's First Peoples. We pay our respects to Elders - past, present and emerging - and to the Aboriginal and Torres Strait Islander peoples and communities on whose lands we work.

About Seniors Rights Service

Seniors Rights Service (SRS) has been assisting older Australians across New South Wales (NSW) since 1986 and is recognised by the NSW government as the leading older persons (aged) rights Peak Body for NSW. SRS provides information and education to older people to make them aware of their rights, and resources and advocates for them to insist on the enactment of their individual rights.

SRS has offices in Sydney, the NSW Mid-North Coast, NSW South Coast, NSW Central West (Dubbo), and the NSW Far North Coast (Northern Rivers). These sites were carefully selected to provide SRS with optimal access to population groups described under the Aged Care Act 1997 as groups of people who have special needs.¹

The NSW and Commonwealth Governments support us in these aims by providing a range of funding to deliver various services and projects. Services include:

Legal services

Provision of free legal advice to older people in NSW, linked to a comprehensive referral service. We offer general legal advice, as well as advice on retirement villages and strata living.

We provide free education sessions to older people, their family and friends on legal topics pertinent to seniors.

We have delivered legal education sessions in sports and service clubs, retirement villages and aged care facilities. These sessions are delivered by solicitors.

We also provide free education sessions to staff who work with older people. Our focus is to assist workers to identify possible elder abuse and to access appropriate services that can assist the older person. These sessions are delivered by solicitors.

Advocacy

SRS provides free, confidential and independent Individual aged care Advocacy services, delivered to people using, or wishing to access Commonwealth-subsidised in-home or residential aged care services. Our Advocates are highly trained and very experienced. Coming from a rights perspective, Advocates listen to the concerns of older persons, provide information on rights and responsibilities, and support and/or empower older persons to enforce their rights. If the older person wishes it, our Advocates can speak on the older person's behalf. Our Advocates always have the express permission and instruction of the older person before taking any action.

In 2018/19 our advocates also attended 21 meetings at aged care homes where the Department has notified residents and their families of sanctions being imposed on their facility.²

Education

The SRS Education Service plays a key role in raising awareness about the rights of older people across NSW. Our staff are well networked and are invited to hold information sessions with community groups, clubs, social and professional groups, residential aged care homes and retirement villages.

SRS also provides information sessions to service providers, relatives, carers, professional groups and others.

Each year we reach around 28,000 people through various education events, including approximately 5,000 who identify as being of Culturally and Linguistically Diverse (CALD) backgrounds and 1,700 who identify as being Aboriginal or Torres Strait Islander.

More recently, SRS has delivered World Elder Abuse Awareness Day webinars and on-line information seminars which have greatly expanded our reach to 'tech-savvy' older people and to a greater number of aged care professionals.

¹ Aged Care Act, 1997 (Commonwealth), Sect 11.c accessed from http://classic.austlii.edu.au/au/legis/cth/consol_act/aca199757/s11.3.html on 22/8/19.

² Seniors Rights Service (2019), Annual Report, Advocacy Manager's Report, currently Unpublished.

Systemic Advocacy

SRS has a long history of representing older residents of NSW in voicing their issues and concerns to governments and to the aged care industry. SRS is a founding member of the Older Person's Advocacy Network (OPAN), founding member and co-chair of Elder Abuse Action Australia, member of the National Aged Care Alliance (NACA) and member of the Global Alliance for the rights of Older People. SRS has been a long-time supporter of movements to establish an international convention on the rights of older people and each July, SRS sends representatives to the United Nations Open Ended Work Group on Ageing to work towards achieving this.

Projects

In addition to the delivery of the above services, SRS delivers or contributes to many projects and outreach activities. Examples of these types of activities over in 2018 and 2019 include:

- Partnering with COTA to deliver aspects of the Aged Care System Navigator Trials.
 - Collaborating with Older Person's Advocacy Network (OPAN) to deliver the Charter of Aged Care Rights Promotion Project in NSW.
 - Assisting the Aged Care Quality and Safety Commission Consumer Experience Report (CER) testing questions Project.
 - Contributing to OPAN's initiatives in fields such as national consistency, improved data collection, staff development and the provision of webinars to promote the new Charter of Aged Care Rights to aged care recipients and staff.
 - Contributions to the discussions on supported decision-making with the Cognitive Decline Partnership Centre (which are now included in the Quality Standards).
- Working with Aged Care Roundtable, Carers NSW, Relationships Australia and the NSW Police Force, as well as with many elder abuse prevention collaboratives and interagency networks to implement community projects and forums to further educate and inform the community and workforce about consumer and human rights for the vulnerable elderly.
 - Hosting the 5th National Elder Abuse Conference and developing extensive (free) resource materials to support community and industry awareness.
 - Developing the Seniors Rights Service Reconciliation Action Plan (RAP).



1. Executive Summary

This submission will address the many ways in which the rights of older persons are not upheld across NSW. The failure to uphold and protect the rights of older persons is the primary cause of substandard care, particularly in many residential care settings but also in care services delivered in-home. SRS has heard stories from thousands of older people whose human rights have been ignored or violated, sometimes to the point where criminal laws have been violated by staff, by other Residential Aged Care Facility (RACF) residents, or by the older person's own family.

Seniors Rights Service will present evidence of fundamental imbalances of power between the aged care system and older persons that must be addressed. These imbalances are evident in Institutional systems and practices that consistently work against individual choice and control (e.g. routines, rosters, provider-centred risk management systems etc.). In other circumstances, the power imbalance is expressed through unfair contracts, or in the failure of society to extend the protections of the law to older people. These imbalances are perpetuated by inadequate access to rights information for older people and their families, and inadequate aged care staff training about the rights of older people (as enshrined in the Charter of Aged Care Rights, but also in the law generally).

A framework is available to help restore (or more correctly, to uphold and enact) the rights of older people, particularly in aged care. This framework consists of the Aged Care Quality Standards; quality assurance systems; the Charter of Aged Care Rights; aged care advocacy information and services; and consumer and criminal laws. And yet, this submission will demonstrate that in practice, the framework is not fully utilised, as SRS Board Chair Margaret Duckett says:

“Service providers, and sometimes society at large, still seem to reject or ignore the rights of older people.”

And as Russell Westacott, CEO of SRS says,

“...recognition that the Crimes Act and tort law actually do extend to aged care seems to be an almost universally held blind spot. Too often, internal procedures and aged care complaints handling processes are used when it would have been more appropriate for the police to be called and for the older person to be offered the full protection of the law.”

Therefore, this submission argues that further efforts are needed to ensure these frameworks and power rebalancing mechanisms are applied to their fullest extent. The recommendations on the following pages are offered by SRS as suggestions to this end.

2. Recommendations

2.1 On the Charter of Aged Care Rights and Advocacy Training, Information and Guidelines

- Rights and Advocacy training should be compulsory for aged care providers, and should be conducted annually. Also, managers as well as front line staff should be required to attend sessions.
- That the quality review process more explicitly and extensively should require service providers to provide evidence of access to advocacy and advocates by residents/consumers.
- That the quality review process more explicitly and extensively should require service providers to provide evidence of compulsory annual training on rights, advocacy and person-centred care to all staff.
- That Guidelines be developed for interpreting and applying the Charter of Aged Care Rights from a person-centred and culturally appropriate perspective.
- That information to older persons be delivered by non-government agencies, preferably that are independent of market-based aged care service delivery.

2.2 On the Community Visitors Scheme Links to National Aged Care Advocacy Program

- The CVS Guidelines be reviewed to require standardised policies and procedures linking CVS and NACAP when a CVS client raises issues about their choice and control not being respected. These Guidelines should be consistent with the requirements of the various Aged Care Diversity Frameworks and related Action Plans.
- CVS volunteers, auspices and auspice coordinators receive annual information and/or training on Rights, the role of aged care Advocates and how to access advocates.
- CVS volunteers receive a standard range of orientation materials that includes information on Rights, the role of aged care Advocates and how to access advocates.

2.3 On Home Care Packages and residential aged care homes

- Residential Aged Care Agreements be mandated to include defined standards of service, and that failure to meet that standard be a civil offence for which compensation is to be paid.
- Security of tenure be established with a limited number of explicit reasons why a resident's contract can be terminated and that the service provider must obtain the approval of a Tribunal before this can take place.
- There be standard clauses in aged care service contracts, and further that Statutory warranties be promulgated establishing that a standard of care must be met.
- The full protection of consumer law be applied in real terms to older people receiving aged care services under a residential aged care or Home Care Package contract.
- The Council of Australian Governments (COAG) negotiate with states and territories to extend Civil and Administrative Tribunals' powers to enable aged care recipients to have consumer rights restored in real terms. Tribunals should be mobile, and able to have 'bedside hearings.' Also, older people should have access to representation at the Tribunal (in the form of support persons or legal representatives) for this type of matter.
- Any interested person may make an application to enforce the standards for an individual.

2.4 On the Supply of Home Care Packages

SRS supports the recommendations of the Legislated Review of Aged Care (Tune Report 2017)³ in addressing the issues of:

- Insufficient Home Care Packages, particularly the need for more Level 3 & 4 Packages.
- Cost disparities between CHSP and HCP Level 1, and the disproportionate fees paid by HCP recipients of HCPs Levels 1 & 2.

2.5 On Recognition of Carers' Needs

- That pilot programs be developed to explore an evidence base on how transitions from home to a RACF can be better managed and how the older person and their former carer (where this is wanted by both parties) can be involved in planning the transition.
- ACQSC compliance systems should require providers to give evidence for how Guardians always involved in the care planning process and, with the consent of the older person, how former carers can assist to develop care plans.

2.6 Stopping the Abuse of Older Persons

In relation to preventing and responding to the abuse of older persons, SRS offers the following recommendations, that:

- Awareness campaigns relating to elder abuse include explicit statements that the laws and protections of federal, state and common law are equally applicable to older people living in RACF or home-based settings. People should be informed of the right and, in some circumstances their obligation, to call the police if they have witnessed or been subjected to a crime.

- Legal penalties be applied to those found to have perpetrated elder abuse.
- The recommendations of the following be implemented:
 - Australian Law Reform Commission (2017), Elder Abuse – A National Legal Response (Report 131)⁴
 - 'Abuse of Older People: A Community Response, Final Report' (2018)⁵, by the Community Led Strategies for Change group, to Commonwealth Attorney-General's Department) and
 - Carnell and Paterson (2017)⁶ recommendations to establish a new Serious Incidents Response Scheme.
- Aggression and abuse between consumers in residential aged care settings be included in definitions of serious incidents.
- Unexplained serious injury in residential aged care settings be included in definitions of serious incidents.

2.7 On Access to Formal Advocacy

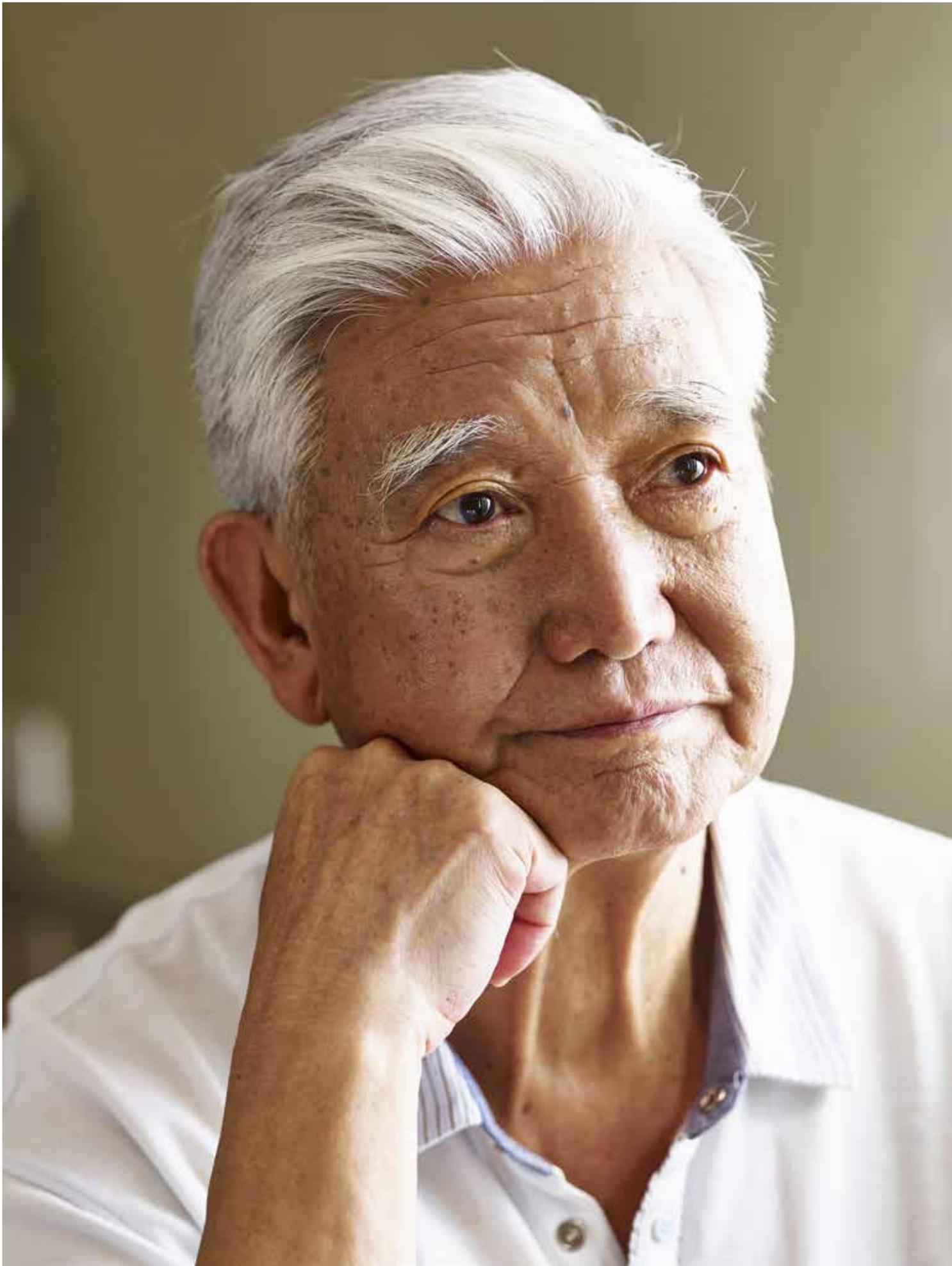
- That the Older Persons Advocacy Network (OPAN) be strengthened Australia-wide so older people can be made aware of their rights and choices.
- That the NACAP be increased to enable greater provision of information and advocacy services, to keep pace with the expected increase in the number of older Australians who are eligible for aged care.
- Increased funding for specialist lawyers be made available and that formal guidelines and referral protocols be developed between the NACAP providers and these legal specialist services.

³ Tune, D. (2017), Legislated Review of Aged Care, accessed from (REF DOH Single quality framework: focus on consumers <https://agedcare.health.gov.au/quality/single-quality-framework-focus-on-consumers> on 22/8/19.

⁴ ALRC (2017), Report 131.

⁵ Senior's Rights Service (lead) and National Work Group of concerned community advocates throughout Australia (2018), Abuse of Older People: A Community Response, Final Report, accessed from https://seniorsrightsservice.org.au/wp-content/uploads/2019/07/COMMUNITY-RESPONSE_Web-min.pdf on 22/8/19.

⁶ Carnell, K. & Prof Paterson, R. (2017), Review of Aged Care Quality Regulatory Processes accessed from <https://agedcare.health.gov.au/quality/review-of-national-aged-care-quality-regulatory-processes-report> on 1/8/19



3. Perspective and Scope

3.1 Stakeholder Perspective of Seniors Rights Service

Seniors Rights Service (SRS) offers a unique and independent perspective to the considerations of the Royal Commission. As a provider of advocacy services for more than 30 years, SRS has empowered and/or assisted tens of thousands of older persons in NSW to be informed of their rights, and supported or assisted them to insist on the enactment of those rights. Moreover, SRS has long-standing relationships with communities across NSW and with the many sectors and services that support them. SRS does not just liaise with agencies in the aged care industry, we also work with partners in health, legal services, housing, social security, human rights – wherever the issues and concerns of older people require us to be. Thus SRS has significant understanding of the issues and concerns of older people across NSW, as well as a depth of experience, and data, to reflect on how these issues and concerns have changed over time, as Australia's population profile has changed and as government (and industry) policy and practice have changed.

Whilst SRS has a significant 'footprint' in the aged care industry, it is crucial to state that SRS is not a service provider of aged care. Our only interest is informing and supporting older people to know of and enact their rights. We have no financial interest in the decisions made by the individuals who use our service, and while we support the aged care industry to become more person-centred, we do so from a rights perspective and mostly under the direction of individual older persons who are using the support of our Advocates to implement their rights.

3.2. Scope of the Submission

This submission will address the many ways in which the rights of older persons are not across NSW. The failure to uphold and protect the rights of older people is the primary cause of substandard care, particularly in many residential care settings but also home care settings.

This submission does not detail the additional challenges that many older people experience in aged care because the system does not adequately cater to characteristics such as culture, language, cognitive disability, gender identity, sexual preference or other characteristics described under the Aged Care Act 1997 as relating to special needs groups. SRS is acutely aware of the additional barriers encountered by many older people who are marginalised by systems that are not culturally safe, culturally and socially competent, geographically equitable, or trauma aware. Of the 4,451 advocacy services delivered in the financial year 2018-2019, more than 33% were to people in our priority target groups.⁷ Rather, to better address these issues, SRS has contributed to, authored or co-authored papers submitted to the Royal Commission by the Older Person's Advocacy Network (on Abuse of Older People and Aged Care; Special Needs Groups in Aged Care; and Aged Care and Advocacy in Rural and Remote areas), and SRS is co-authoring submissions with other partners (e.g. with Ethnic Communities Council of NSW; the National Association of People with HIV Australia; and the Australasian Society for HIV Medicine – ASHM).

⁷ Seniors Rights Service (2019), Annual Report 2018-2019.



4. Systems and Supports to Address Power Imbalances

4.1 Institutionally Based Power Imbalances

A fundamental power imbalance exists within residential aged care facilities (RACFs). The economic realities of delivering care in congregate environments often, and perhaps usually, results in care that is fundamentally service-oriented or business-oriented. The rights of the older person to choose the timing of simple activities of daily life such as when to shower, when to eat, and when to get a cup of tea, are usually constrained by rosters and staff availability. In this context the “good” service user is the “compliant” person. The older person who requests a change or a preference outside of the costed routine is labelled as “difficult” or “demanding”. Even the act of refusing to take medication is often termed “non-compliant” rather than “consent withdrawn”. Advocates of SRS are frequently told by older people living in residential care that when the older person requests a change to care, or makes a complaint, they are “made to feel like ... a problem, or a nuisance.”

Fred's Experience⁸

Fred, a resident of an aged care home, called SRS requesting an advocate to visit him to discuss some concerns he had. He had requested the advocate not to disclose any of his affairs to the staff there. Both Fred and the advocate were questioned by several staff members who demanded to know why the advocate was there and who they were speaking to. Three staff members confronted Fred about his visitor. Fred told his advocate that this made him feel quite frightened.

Fred had capacity and his concerns did not relate to his care, but to another matter which did not concern the staff. A family member had been financially abusing him and he wanted confidential, sensitive understanding and advice about his options to stop the abuse. SRS assisted him to access a solicitor from our service.

The care home manager told Fred to not be a “trouble-maker”. Fred said he considered withdrawing his request for advocacy support because he feared further ridicule and retribution for speaking up.

The economic aspects of residential care facilities impacting on the lives of the older people living in them are a reality. The weight and momentum behind every RACF routine is in itself an operation of power over individuals, albeit perhaps to some extent an economically inevitable one. As a result, the right for choice and control over one’s body and routines, within whatever scope may be possible, becomes an even greater marker of dignity and humanity. And yet, the power imbalance is compounded by the fact that the individual resident is usually physically frail and dependent on those they need to negotiate with. This is a fact not lost on those living in RACFs. SRS Advocates have reported that when they inform individuals of their right to “be free from reprisal, or well-founded fear of reprisal, in any form for acting to enforce his or her rights”⁹ the response from some is “who will be here to ensure that when complaints officers go home?”.

The reach of the institutional control over individuals also extends to lack of privacy and a pervasive message that complaints should not leave the confines of the facility. If the older person does so, pressure can be brought upon them by the facility staff to provide details of the discussion with Advocates or external complaints bodies. Several older people have told our Advocates that after they raise a complaint or ask for an advocate, it is not uncommon for staff to “harass them for information” about what was discussed.

In rare but troubling circumstances, SRS Advocates have been prevented from seeing residents who contacted our service wishing to discuss their concerns confidentially. Advocates have also been obstructed from entering RACFs to provide education sessions on consumer rights, standards, advocacy and external complaints processes. One SRS Advocate had a RACF manager “shadow” (follow) them down the corridor, repeatedly asking for identification (which had been given at reception) and asking, “what are they (the resident) complaining about?” The Advocate described this manager’s behaviour as “aggressive” and

⁸ All client names and identifying details have been changed to preserve confidentiality.

⁹ Charter of Care Recipients’ Rights and Responsibilities – Residential (now replaced by the Charter of Aged Care Rights) see <https://agedcare.health.gov.au/quality/single-charter-of-aged-care-rights>, accessed on 22/8/19.

“intimidating”. It is disturbing to consider how a frail and dependent resident would have experienced similar behaviour.

4.2 Legal and Aged Care Rights, Legal and Aged Care Advocacy - Addressing Power Imbalances

SRS maintains that multiple and connected strategies are required to address the power imbalances in aged care - particularly care delivered in RACFs. The first strategy is to ensure RACFs are appropriately funded but also, that hidden poverty is not occurring in them, whereby the facility is well funded but residents do not experience enhanced care. Currently, it is not uncommon for previous carers and family members to tell us they feel the need to visit often - even daily - for the purpose of supplementing the care, food, activities and emotional support, otherwise their loved one would feel isolated and alone. Compliance checking systems are also a critical component (Aged Care Quality and Safety Commission). However, many RACFs visited by SRS Advocates have achieved compliance under such systems and yet significant numbers of individual older people still tell us their experience in those services is not one of shared power, choice and control.

Greater choice and independence for some older people is only possible when they have access to a person to represent their views and decisions, that is, by way of an advocate. Thus SRS supports the new Charter of Aged Care Rights which includes the right to an advocate. However, SRS recommends that Guidelines be developed for interpreting and applying the Charter of Aged Care Rights from a person-centred perspective. It is the experience of many SRS Advocates that too often, providers apply interpretations that inevitably support the service-centred perspective. Invariably these relate to the “duty of care” of the provider to remove all risk which, equally invariably, equates to the only option being to comply with the institutionalised option already in place.

SRS also supports the new Aged Care Quality Standards, particularly the person-centred focus in which they are framed. However, compliance reviews should seek more extensive evidence of how the person-centred and rights based elements of the Standards are implemented in

practice. Compliance assessments should also more strongly interrogate how the Charter, the Standards and person-centred practice are supported by annual information to residents and compulsory annual training to all staff.

However, the ultimate guarantor of the individual having a voice and insisting on their rights, is advocacy. This advocacy could be formal (NACAP funded individual aged care advocacy, or group advocacy or legal advocacy) or informal (self-advocacy, peer-advocacy, family-advocacy). However all forms require a knowledge of the older person’s rights and of the options available to the person should those rights not be respected and upheld. SRS is of the view that awareness of the previous Charter of Rights and Responsibilities among older people and their representatives was low. SRS applauds the new emphasis on the Charter of Aged Care Rights and the requirement for services to be more proactive in ensuring consumers know about it. However, SRS is also of the view that knowledge about the role of advocates, or the availability of independent aged care advocates who could support older people to raise and resolve issues is not as well promoted. SRS can provide free education and training for community members, residents of aged care facilities. Currently, this training can only be provided when SRS is invited to come to RACFs (or community based events). But in our experience, many residential care providers do not access this free training. In 2017/18 for example, SRS promoted free training to 60 providers and only 20 accepted the training. When SRS does provide training to residential care providers, we find managers often do not attend, yet our experience shows it is mostly managers who do not assist residents or their representatives to access aged care advocates. This can be contrasted with the small number of RACFs that ensure all staff - including managers, reception staff, kitchen, garden and maintenance staff - attend sessions run by aged care advocates as they are aware of the possibility of staff observing something in the older person or their situation which requires addressing.

The provision of independent information on aged care rights, on the role of advocates and on the availability of formal advocates (including legal advocates), should be

compulsory for providers of aged care - and particularly for RACFs. Staff, including managers in RACFs, should also be required to complete compulsory training on these topics. SRS suggests that non-government agencies should deliver rights and advocacy information and education to older people, as many older people do not trust that government will “be on their side”. This is particularly true for older people who have experienced life in countries that had corrupt or repressive governments, or those who may have been removed from their families based on government policies in the past. Moreover, as aged care service providers are now operating in a ‘market’ (essentially as businesses), auspices would preferably be independent from the market-based delivery of aged care services.

Therefore SRS recommends:

- **Rights and Advocacy training should be compulsory for aged care providers, and should be conducted annually. Also, managers as well as front line staff should be required to attend sessions.**
- **That the quality review process more explicitly and extensively require service providers to provide evidence of access to advocacy and advocates by residents/consumers.**
- **That the quality review process more explicitly and extensively require service providers to provide evidence of compulsory annual training on rights, advocacy and person-centred care to all staff.**
- **That Guidelines be developed for interpreting and applying the Charter of Aged Care Rights from a person-centred and culturally appropriate perspective.**
- **That information to older persons be delivered by non-government agencies, preferably that are independent of market-based aged care service delivery.**

4.3 Links to Community Visitors Scheme

The Community Visitors Scheme (CVS) is an extremely important option for older people who are socially isolated or are at risk of social isolation and loneliness. Through the scheme, dedicated volunteers provide companionship and friendship to older people who are recipients of Australian Government-subsidised aged care services. The CVS is particularly important to people of culturally and linguistically diverse (CALD) backgrounds living in residential care.¹⁰

Whilst the primary purpose of the CVS is meeting the social needs of isolated older people. However, the CVS could be supported to provide another pathway to accessing advocacy supports. As the ALRC (2017) has already reported, the CVS currently “lacks detailed national guidelines” and apart from the internally developed policies of CVS auspice agencies, “there is limited guidance on what these should contain, including limited guidance about how to respond to concerns about abuse and neglect.”¹¹ A Review of the Community Visitors Scheme (2017) also noted a lack of effective connection between the CVS and the broader rights-protecting components of the aged care sector. The Review noted that where the visitor has concerns about any aspect of the older person’s wellbeing it is reported to the auspice coordinator, who follows up with the aged care service provider.¹² The possible overlooking the explicit voice of the older person in representing these concerns is a notable divergence from the view that they are at the centre of all aged care systems. It is also pertinent to note (as the CVS Review did) that CVS auspice coordinators “rarely ... seek advice from advocacy services through the NACAP if they have particular concerns about consumers’ rights”.¹³

SRS believes there is an opportunity to strengthen and standardise the orientation provided to CVS volunteers

¹⁰ Review of Aged Care Advocacy Services 2015, Australian Healthcare Associates (2015), Department of Social Services Review of Commonwealth Aged Care Advocacy Services Final Report, accessed from https://agedcare.health.gov.au/sites/default/files/documents/03_2016/advocacy_review_final_report_accessible_published_version_changed_0.pdf on 16/8/19

¹¹ Australian Law Reform Commission, Elder Abuse—A National Legal Response (ALRC Report 131), accessed from <https://www.alrc.gov.au/publications/elder-abuse-report> on 22/8/19.

¹² Australian Healthcare Associates, (2017), Department of Health Review of the community Visitors Scheme Final Report, pg.20 accessed from REF https://agedcare.health.gov.au/sites/default/files/documents/05_2017/cvs_review_final_report_pdf on 22/8/19.

¹³ Ibid, pg.20.

and CVS auspices, to enable the Scheme to be a more reliable conduit to sources of rights information, education and individual advocacy to older people. Whilst it is not reasonable to expect or compel a volunteer to make a referral to an advocacy service, it may be reasonable to strengthen and formalise connections between CVS auspice agencies and NACAP providers. After all, the target group for the CVS are likely to be amongst the most vulnerable to the power imbalances referred to earlier in this chapter. In this context of power imbalance, it would be concerning if it is still the case that CVS auspice coordinators are referring concerns or issues back to the providers only.

Therefore, SRS recommends that:

- **The CVS Guidelines be reviewed to require standardised policies and procedures linking CVS and NACAP when a CVS client raises issues about their choice and control not being respected. These Guidelines should be consistent with the requirements of the various Aged Care Diversity Frameworks and related Action Plans.**
- **CVS volunteers, auspices and auspice coordinators receive annual information and/or training on Rights, the role of aged care Advocates and how to access advocates.**
- **CVS volunteers receive a standard range of orientation materials that includes information on Rights, the role of aged care Advocates and how to access advocates.**

4.4 Aged Care Agreements and Power Imbalances

4.4.1 Residential Care

When most of us enter consumer arrangements, particularly when purchasing services, we can be reasonably assured that our consumer rights will be respected. If they are not, we have recourse to various means to remedy the situation. This does not appear to be the case for older residents of NSW who have entered into contracts (service arrangements) relating to the delivery of aged care services. Instead, SRS encounters older people who seem resigned to the reality that many

of the legal rights they once enjoyed as an adult living in NSW are effectively no longer extended to them once they enter care – particularly residential aged care. For example SRS has seen many aged care agreements that are, in their opinion, confusing or misleading and sometimes include additional information about the provider's right to evict a resident using clauses such as "and for any other reason at our discretion". Many times a year SRS assists elderly residents and their families to make formal complaints to the Aged Care Quality and Safety Commission to complain about breaches of the Aged Care Act and User Rights and Security of Tenure in relation to "discharging" an older person from the RACF to hospital, usually because staff cannot manage behaviours and other symptoms of dementia that staff find challenging. In some cases, there seems to be no means of seeking a reversal of these decisions, nor access to any legal remedy to challenge them. Moreover, SRS aged care advocates are often not satisfied such evictions are justified, particularly where aged care staff have not engaged appropriate professional behaviour support and dementia services which can assist in managing distress and aggressive behaviours of people with cognitive impairment or mental ill-health.

Eva's Experience

Eva was being evicted from the aged care home she had lived in for 2 years. The family was informed that she had refused to take a shower so was uncooperative and needed more care than they could provide. Eva had full capacity and when her family asked why she was not choosing to wash, Eva explained there was nowhere to put her soap during her shower. The SRS Advocate assisted Eva and her family to meet with the care staff and discuss Eva's rights. Strategies were suggested including replacing the soap holder or using a soap-on-a-rope. A week later maintenance staff attended to repairs. As a result, Eva was not evicted.

4.4.2 Home Care Packages

Protections of consumer law are also not extended to aged care contracts, or care agreements relating to Home Care Packages. In fact, Home Care Package Agreements are emerging as a significant source of power imbalance for older residents of NSW, and are a

significant driver of demand for information and support from SRS. Although the Australian Government's reforms seeking to implement an "end-to-end, market-based system ... (in which) ... the consumer drives quality"¹⁴ are yet to be fully implemented, early indications are that many providers are engaging in unconscionable conduct. SRS hears many instances of Home Care Package providers applying exorbitant charges, giving no monthly accounts, "pressuring" older people to enter new agreements where further charges are added, and charging consumers for services they do not require or want. Home Care Package providers' administration and case management fees can exceed 55% of the total package budget, leaving little for actual care or services to address the older persons needs and provide quality of life. Some charge large exit fees if a person wishes to change providers. An exit fee has in some instances prevented older persons from raising issues because they fear the package may be cancelled.

Currently, providers are required to deliver Quality of Care under the Aged Care Act. However, compliance with Aged Care Quality Standards is not required to be included in a resident agreement under the Aged Care Act. What is required is "the level of care and services that the approved provider has the capacity to provide be stated" (s59-1 (1)(b) Aged Care Act). This does not commit the service provider to provide to the resident in the resident agreement a defined, or any, standard of service. Further, if there is a failure of the provider to meet its responsibilities under Ch 4 of the Aged Care Act, the failure is not an offence under the Aged Care Act itself, it has no consequences under any other law s53-2.¹⁵

Finally, even where an older person initiates legal or consumer protection remedies, if the person is of very advanced age (e.g. over 90), any delays in implementing these remedies are, for all intents and purposes, a means of denying the rights of older people to the possibility of enforcing their rights. Perhaps for these reasons, older

people do not seek consumer protection from agencies such as Australian Competition & Consumer Commission or NSW Fair Trading.

Therefore to restore the consumer rights of older people in receipt of aged care services, and the rights to fair tenancy arrangements in RACF, SRS recommends that:

- **Residential Aged Care Agreements be mandated to include defined standards of service, and that failure to meet that standard be a civil offence for which compensation is to be paid.**
- **Security of tenure be established with a limited number of explicit reasons why a resident's contract can be terminated and that the service provider must obtain the approval of a Tribunal before this can take place.**
- **There be standard clauses in aged care service contracts, and further that Statutory warranties be promulgated establishing that a standard of care must be met.**
- **The full protection of consumer law be applied in real terms to older people receiving aged care services under a residential aged care or Home Care Package contract.**
- **The Council of Australian Governments (COAG) negotiate with states and territories to extend Civil and Administrative Tribunals' powers to enable aged care recipients to have consumer rights restored in real terms. Tribunals should be mobile, and able to have 'bedside hearings.' Also, older people should have access to representation at the Tribunal (in the form of support persons or legal representatives) for this type of matter.**
- **Any interested person may make an application to enforce the standards for an individual.**

¹⁴ See Department of Health, 'Single quality framework: focus on consumers' website accessed from <https://agedcare.health.gov.au/quality/single-quality-framework-focus-on-consumers> on 22/8/19.

¹⁵ Lewis, R. (2011), *Elder Law in Australia*, 2nd Ed. Butterworths, Australia. p.307.

5. Demand Outstripping Supply

The limited supply of Home Care Packages (HCPs) has led to long wait-lists and significant unmet need in the community. Services funded under the Commonwealth Home Support Program (CHSP) have been required to “take up the slack” where there is capacity to do so. There simply is no capacity in services delivering personal care or domestic assistance. This means that in reality, thousands are doing without these vital services which may be very pertinent to their needs and quality of life.

Where CHSP does have capacity and are accepting referrals for people awaiting HCPs, concerns are growing about compounding risks where for example, social support groups have growing proportions of people assessed as eligible for level 3 or 4 packages. CHSP services are designed, and their staff trained and geared towards supporting people with entry-level needs. Worse is the many stories SRS has heard of carers struggling to support their loved one at home (many are co-caring older couples); of older people who have no option but to enter residential aged care; and some have died before receiving aged care supports.

Older Australians have been informed that they have the right to access government subsidised aged care services to support their assessed needs. This right is not being upheld for a growing number of Australians.

Hence, SRS supports the recommendations of the Legislated Review of Aged Care¹⁶ in addressing:

- **Insufficient Home Care Packages, particularly the need for more packages (Levels 3 & 4).**
- **Cost disparities between CHSP & HCP Lv1, & disproportionate fees for HCP Levels 1 and 2.**



¹⁶ Tune, D. (2017), Legislated Review of Aged Care, accessed from (REF DOH Single quality framework: focus on consumers <https://agedcare.health.gov.au/quality/single-quality-framework-focus-on-consumers> on 22/8/19.

6. Insufficient Acknowledgement of the Needs of Carers

SRS is regularly contacted by distressed family members who are frustrated and alarmed by RACFs failing to involve them in the care planning for their loved one. Family members describe how RACFs simply do not acknowledge the extensive information the family has about their loved-one's usual care routines and how the older person prefers care to be delivered. This compounds the already significant and often unpleasant transition for the older person going from care provided in the home, to care provided in a RACF. This could be alleviated if, with the consent of the older person and if the former primary carer wishes to, the former primary carer could be involved in the development of care plans and staff instructions for the older person.

Even though a person is in residential care, there is still an important role for persons who had been the primary carer in the community setting to work with the facility to ensure the most appropriate care for the older person. Apart from the older person themselves, it is the previous carer who knows the most about the preferences and needs of the older person. Where the older person's

decision making is affected and/or they are unable to communicate their wishes, the previous carer is the person in the best situation to advocate for their loved one. In our experience, some RACFs do not acknowledge previous carers and family who wish to remain involved in the planning and care of their loved one. Occasionally, even the legal Guardian of the older person is not involved or recognised in the care planning process.

Thus SRS recommends that:

- **Pilot programs be developed to explore an evidence base on how transitions from home to a RACF can be better managed and how the older person and their former carer (where this is wanted by both parties) can be involved in planning the transition.**
- **ACQSC compliance systems require providers to give evidence for how Guardians are universally involved in the care planning process and, with the consent of the older person, how former carers can assist to develop care plans.**



7. Abuse of Older People

SRS is of the view that the mistreatment of residents in RACFs is significantly under-reported. The startling place to start (again, particularly in RACF settings) is the seeming inability of the aged care sector and others to acknowledge and indeed insist, that ALL laws protecting the rights of adult citizens should and must be extended to people living in residential aged care.

And yet as Russell Westacott, CEO of SRS states,

“...recognition that the Crimes Act and tort law actually does extend to aged care seems to be an almost universally held blind spot. Too often, internal procedures and aged care complaints handling processes are used when it would have been more appropriate for the police to be called and for the older person to be offered the full protection of the law.”

To illustrate this point, SRS offers the following examples of poor-quality care and neglect of older residents where police were never called, and where legal remedies were not considered as an option. These include:

- An older person (aged care resident) was left on the cold floor for hours following a fall as no one came to see them.
- Poor continence care, with insufficient continence aids being supplied, and where older persons are left in wet or soiled pads because no one was available to attend to them.
- Family members feeling they have to visit their every day at meal-times, otherwise staff would not reliably take the time to assist their loved one to eat their meal.
- Older persons not being assisted to change their position in bed or seating, or not being washed for several hours when they are incontinent.
- Some family members called an ambulance as their parent was very unwell and staff did not think it necessary, or “decided Mum was too old and wished to die”, even when their parent’s Advance Care Directive explained their wishes clearly.
- Serious assaults on aged care residents have taken place and not reported. No incident report, internal investigation or police report is made. Many residents choose not to report mistreatment because they fear retribution.

- In extreme cases older people have suffered horrific deaths alone following a fall or an assault as they are not checked on often, and families and the community are traumatised by this experience.

It is particularly concerning, moreover, that the reporting of serious incidents can only be made by providers. This is concerning because there are too many instances where SRS hears reports of concerns about possible elder abuse being dismissed by providers, as evidenced by the following story:

Fouzia and Aisha’s Experience

Fouzia lives in an aged care home. Her daughter Aisha, alerted staff to the bruising she observed on her Mother’s arms. Aisha reported that the bruising looked like “fingers pressed into the skin”. Aisha said the manager became “quite defensive” and “demanded” to know when she had noticed this. The manager also gave the immediate explanation that Fouzia “probably fell”.

SRS has extensive experience working with communities across NSW raising awareness about rights, as well as of suspected elder abuse and how to address it. We continue to seek innovative ways to reach out and work with community to address the issue. For example, in the last year SRS collaborated with the Hon Dr Kay Patterson AO, Aged Discrimination Commissioner to deliver “Infotainment” sessions in regional NSW. At the events, SRS discussed ageism, elder abuse, power of attorney documents and other issues while having some fun with games of bingo and other entertainment on stage.

Russell Westacott, CEO of SRS reported after the event that:

“... the most poignant feedback I received at one of the events was from an older lady who told me she had a neighbour who experiences abuse from her son. She would never have come to an event to discuss elder abuse, but by entwining the topic into a game of bingo, she learned a lot and now has the names of organisations who can assist her neighbour.”¹⁷

This extensive contact with seniors across NSW tells us that mistreatment or abuse is occurring in the community and is significantly under-reported. In 2017/18, SRS responded to 750 issues involving suspected or

actual elder abuse.¹⁸ Of all legal issues raised with SRS, Guardianship was the most frequently raised, Wills and Estates the second, Consumer Law the third, and Power of Attorney the fourth, closely followed by Elder Abuse (financial).¹⁹ Reports of financial abuse are steadily increasing. This increase may relate to increased awareness of the issue, but it may also indicate that financial tensions around the transfer of wealth (or not) from one generation of Australians to the next²⁰ is generating both the need for older Australians to seek accurate and independent legal information to prevent potential elder abuse (Wills, POA, Financial arrangements etc.) and the need to access should financial abuse eventuate. Given the increased focus on the wealth held by the generations born between 1939 and 1964 needed to co-fund the aged care system,²¹ it can be anticipated that potential or actual financial abuse related to wealth transfer will increase in the coming years.

Angie's and her Mother's Experience

Angie rang seeking information about what help her mother could obtain. Her mother had authorised her other daughter, Jessica, to be a signatory on her bank account. Unfortunately, Jessica had a drug addiction and withdrew large sums from her mother's account in \$2,000 and \$3,000 lots and spent the funds on drugs. Angie said her mother did not recollect signing the authority. Seniors Rights Service said that when a person with capacity has voluntarily signed an authority without duress or undue influence, there is no remedy against the bank, since they had acted within the terms of the authority. The only remedy would be if the mother had made it clear to Jessica (preferably in writing) that access to the account was given solely so she could spend funds in her mother's best interests. Then the mother could pursue a debt recovery action against Jessica for misappropriation of funds. We also noted the possible*

futility of taking action against people, such as Jessica, who have little or no money or assets.

In relation to preventing and responding to elder abuse, SRS offers the following recommendations, that:

- **Awareness campaigns relating to elder abuse include explicit statements that the laws and protections of federal, state and common law are equally applicable to older people living in RACF or home-based settings. People should be informed of the right and, in some circumstances their obligation, to call the police if they have witnessed or been subjected to a crime.**
- **Legal penalties be applied to those found to have perpetrated elder abuse.**
- **The recommendations of the following be implemented:**
 - **Australian Law Reform Commission (2017), Elder Abuse - A National Legal Response (Report 131)**²²
 - **'Abuse of Older People: A Community Response, Final Report' (2018),²³ by the Community Led Strategies for Change group, to Commonwealth Attorney-General's Department) and**
 - **Carnell and Paterson (2017)²⁴ recommendations to establish a new Serious Incidents Response Scheme.**
- **Aggression and abuse between consumers in residential aged care settings be included in definitions of serious incidents.**
- **Unexplained serious injury in residential aged care settings be included in definitions of serious incidents.**

¹⁷ Seniors Rights Service (2019), Annual Report, CEO Report, currently Unpublished.

¹⁸ Ibid.

¹⁹ Ibid.

²⁰ Laurence, J. and Goodnow, J., (2011), 'Perspectives on intergenerational bequests: Inheritance arrangements and family resources', Family Matters, Issue 88, August 2011, accessed from <https://aifs.gov.au/publications/family-matters/issue-88/perspectives-intergenerational-bequests> on 22/8/19.

²¹ Productivity Commission, (2011), Caring for Older Australians, pp.57-63, accessed from <https://www.pc.gov.au/inquiries/completed/aged-care/report/>

aged-care-volume1.pdf on 22/8/19.

²² ALRC (2017), Report 131.

²³ Senior's Rights Service (lead) and National Work Group of concerned community advocates throughout Australia (2018), Abuse of Older People: A Community Response, Final Report, accessed from https://seniorsrightsservice.org.au/wp-content/uploads/2019/07/COMMUNITY-RESPONSE_Web-min.pdf on 22/8/19.

²⁴ Carnell, K. & Prof Paterson, R. (2017), Review of Aged Care Quality Regulatory Processes accessed from <https://agedcare.health.gov.au/quality/review-of-national-aged-care-quality-regulatory-processes-report> on 1/8/19

8. Growing Demand on Advocacy Services

The demographic shifts occurring in Australia are reflected in the growing demand on aged care advocacy services. Over the last several years SRS has increased delivery to older residents of NSW significantly. This has been achieved partly by a funding increase from the Australian Government, associated with the 2017 retendering of the NACAP, which SRS delivers in NSW for OPAN. As an indication of the volume of information and support provided in by SRS, in 2018/19:²⁵

- 34,336 people attended education forums and related events. This represents an increase of around 21% on the number attending the previous 12 months. Of those attending education and events, 45% were from regional/rural or remote locations, and 6,300 were people from culturally and linguistically diverse (CALD) backgrounds.
- Advocacy services delivered to 4,451 older persons living in a RACF. This represents an increase of around 27% from 2017/18. Over half our advocacy clients were from regional, rural or remote locations.
- Legal services were delivered to 3,422 older persons. This represents a 24% increase from 2017/18.
- Our Strata Legal Service team assists more than 100 individuals per quarter. The number of people accessing this service has tripled from 2017/18 to 2018/19.
- Our Advocates attended 21 meetings at aged care homes where the Department of Health has notified residents and their families of sanctions being imposed on their facility.
- Advocates delivered 21 education sessions to Aboriginal and Torres Strait Islander aged care facilities or services, 64 CALD aged care services, six veteran aged care services, and four LGBTIQ+ aged care services.

These figures represent a 20-25% increase on the previous year and our client satisfaction rate (92%) remains high.²⁶ However, demand and the increasing proportion of SRS clients experiencing complex circumstances²⁷ will shortly impact the capacity of SRS to respond. Wait-lists and/or other demand-management strategies will need to be considered. Such strategies have already been implemented in other Service Delivery Organisations of OPAN. SRS is currently engaged in a strategic planning process to identify further capacity building strategies within current funding and current service system context, however given capacity has grown by up to 67% since 2017²⁸, it is highly likely the capacity building activities will start showing diminishing returns. Demand management and capacity building will be implemented, but simply put, more resources are needed to employ more advocates. Similarly, access to free or affordable legal services that specialise in 'elder law' will be required. Preferably, these services should be formally linked to NACAP delivery agencies, to enable access to qualified legal information and where needed, timely legal representation.

Therefore SRS recommends that:

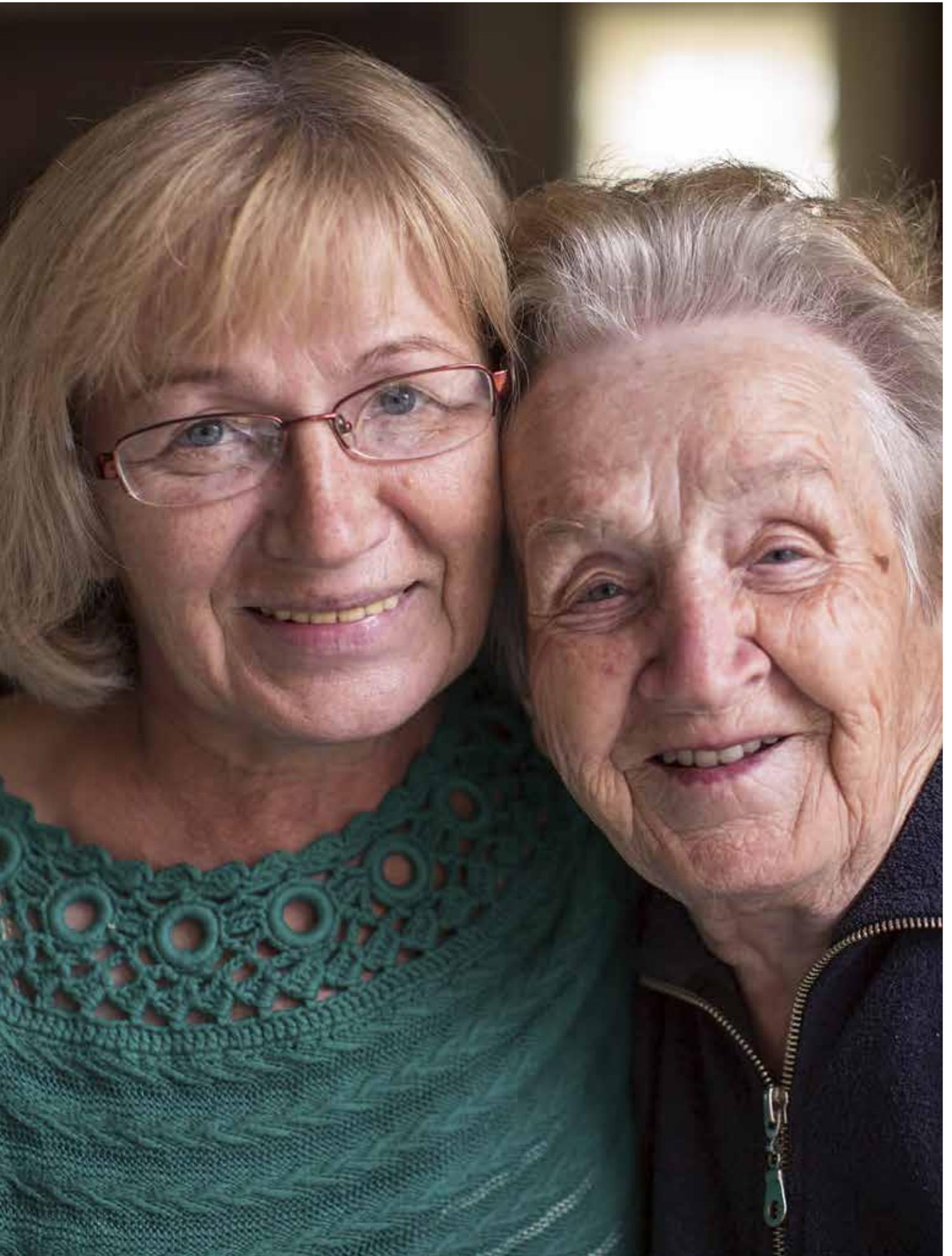
- **The Older Persons Advocacy Network (OPAN) across Australia be strengthened so older people can be made aware of their rights and choices.**
- **NACAP be increased to enable greater provision of information and advocacy services, to keep pace with the expected increase in the number of older Australians who are eligible for aged care.**
- **Increased funding for specialist legal advocates be made available and that formal guidelines and referral protocols be developed between the NACAP providers and these legal specialist services.**

²⁵ Senior's Rights Service (2019), Annual Report 2018-2019, currently Unpublished.

²⁶ SRS (2019), Annual Report 2018-2019, currently Unpublished.

²⁷ Ibid.

²⁸ OPAN (2019), NACAP Progress Report, Full Year Report, 2018/19, pg. 2. Unpublished.



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