National Association of Community Legal Centres

Submission to the Senate Community Affairs Legislation Committee

Inquiry into the

Aged Care (Living Longer Living Better) Bill 2013;
Australian Aged Care Quality Agency Bill 2013;
Australian Aged Care Quality Agency (Transitional Provisions) Bill 2013;
Aged Care (Bond Security) Amendment Bill 2013;
Aged Care (Bond Security) Levy Amendment Bill 2013

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1. Introduction

1.1 About this submission

On 14 March 2013, the Senate jointly referred the Aged Care (Bond Security) Amendment Bill 2013 and the Aged Care (Bond Security) Levy Amendment Bill 2013 and the Aged Care (Living Longer Living Better) Bill 2013 and the Australian Aged Care Quality Agency (Transitional Provisions) Bill 2013 and the Australian Aged Care Quality Agency Bill 2013 for inquiry and report.

The National Association of Community Legal Centres Inc. (NACLC) submits to this Inquiry with its network of Older Persons Legal Services (OPLS). We are grateful for the opportunity to submit and the extension of time granted to allow us to complete this submission and contribute to the Inquiry. We would welcome the opportunity to comment further on this submission.

The centres that have contributed to this submission have specialist expertise in seniors' rights issues and elder law. This submission draws on many years of practical experience assisting clients to navigate the Commonwealth aged care system. CLCs bring particular expertise and understanding of what the barriers are to accessing justice for older people and understand the myriad of complexities older persons face within the aged care system.

1.2 About the National Association of Community Legal Centres

NACLC is the peak national organisation representing over 200 community legal centres (CLCs) in Australia. Its members are the state and territory associations of CLCs that represent over 200 centres in various metropolitan, regional, rural and remote locations across Australia.

CLCs are not-for-profit, community-based organisations that provide legal advice, casework, advocacy, information and a range of community development services to their local or special interest communities. The work of CLCs is targeted at disadvantaged members of society and those with special needs, and in undertaking matters in the public interest. NACLC has accredited NGO status with the United Nations (UN).

1.3 About the Older Persons Legal Services Network

OPLS is a network of NACLC, with its members consisting of CLCs across Australia. OPLS undertakes social justice campaigns and advocates for the human rights of older persons in Australia and internationally.

2. Recommendations

- **1.** The Bills be drafted so as to ensure that the human rights of older persons are recognised and protected within the aged care system. Protections must be at a structural level and an individual level.
- 2. The Bills must include mechanisms to combat ageism where it occurs in the aged care system. Positive models of ageing and aged care must be promoted to complement the passage of the Bills, as part of a National Strategy or National Positive Ageing Campaign.
- 3. The measures in the Bills that seek to put quality at the forefront of the system must be made obvious to the community in order to give them the opportunity to provide feedback on their and their family's experience of the system in action. A culture of feedback can only enrich and strengthen the aged care system and ultimately benefit those who live within it.
- 4. The Bills must provide a contemporary, complementary system of merits review and dispute resolution including standards of dispute resolution required at internal and external levels. It should build on the existing schemes including the ACCS, the ACC and the Complaints Principles 2011.
- **5.** The Quality of Care Principles must be reviewed to ensure compatibility with current human rights norms especially those that are relevant to the rights of older persons.
- **6.** Relevant Quality of Care Principles are a mandatory consideration within any complaints scheme looking at whether service providers have met their responsibilities in providing care.
- 7. Further paragraphs should be added to clause 4(2) of the Aged Care (Living Longer Living Better) Bill 2013 that require periodic review of the effectiveness of arrangements for individual complaint and review, whether the protection of human rights is achieved through Quality of

Care Principles and other mechanisms.

- **8.** Any consideration of veterans at clause 11(3) of the legislation should also include veterans' families, especially widows and other dependents.
- **9.** Home care standards and plans must allow for individual needs and must also include access to dispute resolution in cases where the balancing of services and allocation of services is at issue.
- 10. Education in human rights must be provided to community care and aged care workers, as well as managers and administrative staff in aged care facilities. Accreditors and Community Visitors should also be aware of the human rights of older people to inform their work.
- 11. The Aged Care Pricing Commissioner must have the power to make determinations about fee reductions or future fee credits where there are circumstances that warrant such action. There needs to be a simple mechanism where residents can apply for such a decision. Additionally, Quality of Care Principles need to clearly articulate the rights of residents in situations where their quiet enjoyment and privacy are compromised.
- 12. Breaches of the Quality of Care Principles must have a clear dispute resolution process that complies with recognised dispute resolution standards such as ASIC-approved schemes. The outcome of the process must be an enforceable decision.
- **13.** There needs to be a mechanism for resolution of collective complaints especially in the area of quality of care and fees.
- 14. Accreditation must include consideration of the diversity of opportunities available to residents and how care plans reflect the individual needs and interests of residents. It should also include consideration of facilities for residents to gather with community groups to remain socially included.

- 15. The Scheme and Commissioner should have the power to investigate deaths of residents on behalf of the Commonwealth or other interested parties such as personal representatives, family or next of kin, providing this does not duplicate or impede upon the Coroner's jurisdiction. Any findings could be used by the Commissioner in the process of quality or accreditation review.
- **16.** Aboriginal and Torres Strait Islander peoples, people from CALD background, LGBTI peoples and others must be consulted with in order to ensure the amendments are appropriate and ensure the care provided is culturally safe, respectful and informed.

3. Background and context

Australia's population is aging. Population forecasts by the Australian Bureau of Statistics predict that one quarter of Australians will be 65 years or older, over the next 50 years.¹

In 2007 Australia's population was 21 million people, with 13% being 65 years or older. By 2056 Australia's population is projected to increase to between 31 and 43 million people, with around 23% to 25% being 65 years or older. The number of people aged 85 years or over is also likely to increase rapidly over the next 50 years, from 344,000 people in 2007 to between 1.7 million and 3.1 million people in 2056. By then, people aged 85 years or over will make up 5% to 7% of Australia's population, compared to only 1.6% in 2007.²

This demographic shift will continue to have an increasingly significant impact on the provision of health and aged care services for older Australians. Intergenerational reports note that aged care costs are among the key factors impacting on Australia's future economic state.

¹ Australian Bureau of Statistics, *Population Projections, Australia, 2006–2101* (cat. no. 3222.0). At http://www.abs.gov.au/AUSSTATS/abs@.nsf/Latestproducts/3222.0Media% 20Release12006%20to%202101?opendocument&tabname=Summary&prodno=3222.0&issu e=2006%20to%202101&num=&view=

² Australian Bureau of Statistics, *Population Projections, Australia, 2006–2101* (cat. no. 3222.0). At http://www.abs.gov.au/AUSSTATS/abs@.nsf/Latestproducts/3222.0Media %20Release12006%20to%202101?opendocument&tabname=Summary&prodno=3222.0&iss ue=2006%20to%202101&num=&view=

It is not surprising that there might be a parallel tension on related human rights of older people where Federal government expenditure is stretched so heavily. For this reason, OPLS considers that the Federal government must ensure that the Bills adequately promote and protect the human rights of older persons.

In response to the perception that current funding models were inadequate to meet a sharp increase in demand for aged care services, the Federal government released an aged care reform program in April 2012, known as "Living Longer Living Better", which followed on from the Productivity Commission's report on current aged care services in Australia.³

NACLC and OPLS understands that the Living Longer Living Better suite of Bills provides the legislative framework for the implementation of the reform agenda for which the Federal government is providing \$3.7 billion over 5 years. The reforms will be introduced over a 10 year period with provision for review at 5 years.

NACLC and OPLS are not in a position to comment on the structural detail of the Bills themselves. However, we can provide clear guidance to the Senate on the higher level concerns that older persons have about aged care and how such concerns might be addressed in the Australian system.

In our view, many of the problems in the aged care system might be addressed or at least improved by some key approaches:

- Adopting a human rights approach to the rights of older persons, including moving towards a UN Convention on the Rights of Older Persons;
- Adopting a human rights approach to aged care as was suggested by the Australian Human Rights Commission, thus promoting and protecting human rights of older persons both at a structural level and an individual level;
- Talking steps to eradicate ageism within the aged care system; and

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³ Australian Productivity Commission, *Caring for older Australians*, 2011. At http://www.pc.gov.au/projects/inquiry/aged-care.

 Ensuring that the aged care system has a modern system of complaint, review and appeal that facilitates the enforcement of human rights.

Recommendation 1:

The Bills be drafted so as to ensure that the human rights of older persons are recognised and protected within the aged care system. Protections must be at a structural level and an individual level.

4. Ageism in the community

"Ageism, is insidious and 'menacing,' a conspiracy to sap confidence and deny competence", except from Agewise: Fighting the New Ageism in America (2011) by Margaret Morganroth Gullete

Ageism is a poison that requires an antidote in our community. It infects community and stains our approach to older persons. Despite its sole function of providing "care" to the "aged", the aged care system is festooned with examples of ageism, where the rights and interests of older persons are overlooked or at worst sacrificed for the sake of efficiencies, policies or exigencies.

That many in our community (including older persons) view aged care as a "dumping ground" reflects the attitude that has been allowed to fester and grow.

In NACLC and OPLS view any system of "care" necessarily implies that recipients are respected, treated with dignity and not left without affection, love and humanity, are not socially isolated or left at risk of abuse or exploitation. To do so is the antithesis of caring. These issues reflect concerns that are held for some in the aged care system at present.

It is well documented that ageist attitudes encourage financial and physical abuse and fail to allow older people to exercise their self-determination in key areas of life such as their health and aged care arrangements.

Ageist attitudes are further inflamed by the media encouraging intergenerational conflict particularly in such matters as the "burden of care" and "drain on health resources" represented by older generations.

The public perception of the numbers of older persons in residential care appears to be consistently conflated by the media. In fact, 94% of Australians aged 65 and over live in their own homes or supported accommodation, and 77% of those aged over 85 live at home. In addition, myths and perceptions which highlight the "burden of older people" operate as barriers to older people exercising their human rights and act as yet another form of discrimination against this sector of the population.

There is also the challenge of reaching a socially or geographically isolated population and the need to educate family and friends who provide care in an older person's home about their responsibility to provide treatment which is not degrading and respects the older person's right to a private life. Aged care providers must address the complexity of balancing institutional requirements with the right to a private life in aged care settings.

Recommendation 2:

The Bills must include mechanisms to combat ageism where it occurs in the aged care system. Positive models of ageing and aged care must be promoted to complement the passage of the Bills, as part of a National Strategy or National Positive Ageing Campaign.

Recommendation 3:

The measures in the Bills that seek to put quality at the forefront of the system must be made obvious to the community in order to give them the opportunity to provide feedback on their and their family's experience of the system in action. A culture of feedback can only enrich and strengthen the aged care system and ultimately benefit those who live within it.

⁴ Australian Institute of Health and Welfare, *Australia's welfare: ageing and aged care* (cat. no. AUS 142). At http://www.aihw.gov.au/WorkArea/DownloadAsset.aspx?id=10737420624

5. The suite of Bills

We have no specific comments about the Aged Care (Bond Security) Levy Amendment Bill 2013, the Australian Aged Care Quality Agency (Transitional Provisions) Bill 2013 and the Aged Care (Bond Security) Amendment Bill 2013.

In respect of the Aged Care Quality Agency Bill 2013, NACLC and OPLS notes that while the Bill seeks to ensure quality through a regulatory approach, it does nothing to improve the individual rights of older persons within the system, nor does it improve the system of dispute resolution to deal with individual complaints or enforcement of individual rights about access to or quality of care.

One complexity is that the aged care scheme is outsourced and as such it has struggled to find an appropriate balance between industry regulation and imposed legal and administrative oversights. The outcome has been that aged care complaints tend to be about "principles" and findings are generally non-binding or that much of what might be complained about is outside scope. The limitations of the scheme were summarised by the Productivity Commission.⁵

NACLC and OPLS takes the view that the time has come to ensure an appropriate, independent system is put in place that does not adversely impact the older person. This includes a system of internal and independent external dispute resolution incorporating complaint handling, case management, mediation/conciliation and where needed determination by an independent Tribunal.

There are examples, such as Financial Ombudsman Service (FOS) where consumer complaints against private industry are handled by a recognised dispute resolution scheme, capable of significant outcomes including awards of compensation where appropriate. FOS is required to apply the law and good industry standards and policy, and achieves outcomes that meet government and regulatory standards and industry-wide policy.

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⁵ Productivity Commission, *Caring for Older Australians*, Chapter 15. At http://www.pc.gov.au/projects/inquiry/aged-care/report

In the case of aged care, it is essential that the dispute resolution scheme matches the level of quality at least achieved pursuant to ASIC-approved dispute resolution schemes.⁶ Similar recommendations were also made by the Walton Review.⁷

NACLC and OPLS note that some progress was made with the introduction of the Complaints Principles in 2011, the new Aged Care Complaints Scheme (ACCS) and the Aged Care Commissioner (ACC). It is, however, the ability to deal with a blend of complaints about private providers *and* government merits decisions that elude the scheme as a whole. What is needed is a contemporary, system of complaint/dispute resolution which has an independent, external body and where needed access to existing merits review tribunals.

Recommendation 4:

The Bills must provide a contemporary, complementary and independent system of merits review and dispute resolution including standards of dispute resolution required at internal and external levels. It should build on the existing schemes including the ACCS, the ACC and the Complaints Principles 2011.

Much debate exists around the complexity of the financial administration of aged care facilities, however, many of our clients complaints relate to the quality of their care and basic human rights rather than fees, except in the instances of financial hardship.

In responding to the submission, OPLS believes that the voices of older people themselves need to be heard in this debate. Accordingly, NACLC and OPLS have included information garnered from older people about their fears of ageing, of losing their independence and entry into residential aged care.

This information is provided to assist the Senate to understand older people's concerns about their quality of care in the community and in residential care.

⁶ ASIC, Complaints resolution scheme, 2013. At http://www.asic.gov.au/asic/ASIC.NSF/byHeadline/Complaints%20resolution%20schemes

⁷ M. Walton, Review of the Aged Care Complaints Scheme, 2009. At http://www.health.gov.au/internet/main/publishing.nsf/Content/6E29D85E65EF32FACA25770 300036CB1/\$File/ReviewCIS21009.pdf

The information was taken from the "Townsville Seniors Speak Out" report (see Annexure A), produced by Townsville Community Legal Service.

Additionally, NACLC and OPLS have used actual client cases to highlight some of the current issues faced by those in the aged care system.

6. Townsville Seniors Speak Out Forums

6.1 About the forums

In 2010, the Townsville Community Legal Service, undertook forums with 120 older people. The forums were held to empower older people to speak out about their needs and to harness their knowledge of how risk factors for elder abuse can be addressed in the community. Loss of independence and transition to residential aged care were specifically identified as concerns.

6.2 Loss of independence

Many older people were concerned that they will become dependent on others in future. There was consensus that older people do not want to be a burden, a bother or nuisance to others and that it is difficult for older people to ask others for help because of how they may be perceived. The fears of dependence related to loss of health, physical function, mobility, capacity (not being able to make decisions for themselves), drivers licence, grooming ability, personal care and a general sense of loss of control over their life.

"Once you become dependent, you feel like you have lost the lot", Participant, Townsville Seniors Speak Out Forum

Many of these issues are heightened at the time a person is making a transition to aged care and in fact one or more of the issues may have been a "lightning rod" in the decision-making process about whether to enter the aged care system or not. Loss of independence often quickens the decision to enter the aged care system, whether that decision is made by the older person themselves or those around them – either in consultation with the older person or in isolation from the older person.

Not all older people who enter aged care have lost their independence, but many have lost markers of it. It is this context through which aged care must be seen and why human rights must be at the forefront of the system.

6.3 Transition to residential aged care

Older people are fearful about the transition into residential aged care and have a negative perception of the aged care system and facilities. Their concerns related to the following:

- Losing their dignity;
- The lack of privacy;
- Losing their freedom;
- Not being listened to;
- Living in a "depressing" environment;
- Entering "God's Waiting Room" and accepting the finality of life;
- Leaving behind their home, possessions and other symbols of independence;
- Living with the restrictions, rules and regulations present in residential facilities; and
- The lack of companionship and concerns that, once placed in a home, they will become forgotten.

"If you take me out of my home, I will die", Participant, Townsville Seniors Speak Out Forum

Older people attributed their concerns to observing past experiences of a family member in residential care, observing the quality of life of residents, rumour, and media reports about abuse or mistreatment of residents by staff.

Particular mention was made about the building works and redevelopment of residential care facilities. It was perceived that there was a lack of respect or concern for the comfort of residents during a redevelopment process. Residents are not compensated nor are their fees reduced in recognition of the upheaval and discomfort associated with the process.

There was also a concern about the lack of choices for people entering residential care. The size of waiting lists was seen as being very problematic as people have to take whatever place becomes available. Older people considered application for entry very complex.

There was a perception that all levels of government have not fully considered

the needs of older people and the lack of facilities available, the location of facilities, the type of facilities built and the complexity of entry criteria reflect this. Older people felt that residential care facilities could be improved by:

- Improving the choice of activities available;
- Care plans are individualised and include diversional therapy;
- Staff training that focuses specifically on respect for residents;
- Promoting residential care facilities as a place to live rather than a place to die;
- Allowing residents to choose which social activities they wish to be involved in rather than forcing participation in activities that a person may find demeaning;
- Inspectors being able to attend without notice and have right of entry to all areas of a facility; and
- Improving staff to resident ratios so that more than the basic needs of residents can be met.

"So, what do you think? If I give up my apartment, I'm finished, it's all over. No more kitchen, no more curtains, no more linen, no more cutlery. All your life you accumulate, in the end they tell you to get rid of everything", except from Dance Like a Butterfly by Aviva Ravel

6.4 Conclusion from the forums

Older people are well aware of the issues that they will face as they age and have significant ideas about changes that could occur to enhance dignity, respect and care for older people in the community. Although unspoken, older people inherently understood that human rights are about dignity and respect.

There were concerns amongst the older people that as they age, changes in health could leave them dependent, isolated, alone and requiring care. These concerns or fears appear to be related to their observations of how the community treats older people. Add to this their view that there are insufficient services, supports, age-friendly environments, transport and information to allow them to remain living independently for as long as possible.

Older people perceived that their needs are overlooked, their voices are unheard and they are treated as invisible. It was evident that older people feel disempowered and discriminated against, because of their age. Older people provided practical and achievable solutions that would combat the ageist

attitudes they describe, as well as enhance their ability to live and participate independently.

"Design for the young and you exclude the old; design for the old and you include the young", the late Bernard Isaacs, Founding Director of the Birmingham Centre for Applied Gerontology

7. Human rights of older people receiving aged care

In the explanatory memorandum for the Australian Aged Quality of Care Agency Bill 2013, The Hon. Mark Butler MP, Minister for Mental Health and Ageing states:

This Bill is compatible with human rights because it promotes the human right to the enjoyment of the highest attainable standard of physical and mental health and, to the extent that it limits the human right to protection against arbitrary interference with privacy, those limitations are reasonable, necessary and proportionate.

Part of the specific function of the CEO of the Quality of Care Agency is to accredit residential aged care services and review home care services to the standards outlined in the Quality of Care Principles 1997.

NACLC and OPLS remain concerned that the Quality of Care Principles that the Quality Agency is to be responsible for have not been updated to reflect the outlined changes to levels of care and are not consistent with the spirit of "living better" in the Aged Care (Living Longer Living Better) Bill 2013.

NACLC and OPLS believe that the Quality of Care Principles must be updated to reflect the human rights protections for older Australians, particularly around the areas of dignity, safety, financial, social and decision-making independence and health and wellbeing. Additionally, that the complaints mechanism must be strengthened and modernised to enhance the protections for older Australians receiving any level of aged care service.

The Australian Human Rights Commission (AHRC) and other groups have also commented on the need to improve and update the principles

themselves, to ensure they are reflected properly in accreditation reviews and to ensure mechanisms of review, complaint and appeal are available to older persons, including family and substituted decision-makers.⁸

Further, NACLC and OPLS have indicated its support for a Convention on the Rights of Older persons and recently made submissions to the Office of the High Commissioner for Human Rights in respect of its Public Consultation on the Human Rights of Older Persons (See Annexure B).

Recommendation 5:

The Quality of Care Principles must be reviewed to ensure compatibility with current human rights norms especially those that are relevant to the rights of older persons.

Recommendation 6:

Relevant Quality of Care Principles are a mandatory consideration within any complaints scheme looking at whether service providers have met their responsibilities in providing care.

Recommendation 7:

Further paragraphs should be added to clause 4(2) of the Aged Care (Living Longer Living Better) Bill 2013 that require periodic review of the effectiveness of arrangements for individual complaint and review, whether the protection of human rights is achieved through Quality of Care Principles and other mechanisms.

Recommendation 8:

Any consideration of veterans at clause 11(3) of the legislation should also include veterans' families, especially widows and other dependents.

8. Community care standards

NACLC and OPLS notes that community care will become home care under

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⁸ Australian Human Rights Commission, *Respect and choice: a human rights approach to ageing and health*, 2012. At http://www.humanrights.gov.au/human-rights-approach-ageing-and-health-respect-and-choice-home-based-and-residential-care-older

the new system. While all types of care must be measured against accreditation and quality principles, home care is quite different to residential care. While both forms of care seek to achieve similar aims, they differ greatly in their context. The Federal government must carefully consider where these differences in context lie so it can properly identify quality care in each respective context. The likely breaches of quality care principles in home care will differ to those in residential care. The vulnerabilities of care recipients are different in the home to the residential facility. Social isolation, for example, may be more prevalent for those receiving home care. One-on-one nursing assistance may be more difficult in a residential setting. These are just examples and seek to identify the fine balance that must be achieved to ensure that care in all forms achieves the objects of the aged care system.

On 1 March 2011, there was a significant shift for Community Care Standards. Schedule 5 replaced schedule 4.

Schedule 4 Standards included:

- a) information and consultation;
- b) identifying care needs;
- c) coordinated, planned and reliable service delivery;
- d) social independence;
- e) privacy, dignity, confidentiality and access to personal information;
- f) complaints and disputes; and
- g) advocacy.

Schedule 5 standards include:

- a) effective management
- b) appropriate access and service delivery; and
- c) service user rights and responsibilities.

We have been concerned that this shift may have diminished the human rights objectives of the Principles in relation to community care and in particular, the removal of social independence. Independence is still encouraged in Schedule 5, Part 3.5, but it is not defined as in Schedule 4.

Case study 1 typifies the tensions between the standards and user rights and the reality of community care provision. Often, older persons' community care is used principally for activities such as medical, allied health and pharmacy appointments, thereby impinging on activities that might reduce social

isolation. Home care plans must not only identify care needs but likely contextual care quality gaps.

Case study 1

Mr. P, an 83-year-old man from a culturally and linguistically diverse (CALD) background, who had a visual impairment and no family or friendship supports, was in receipt of a Community Aged Care Package (CACP). The man was incredibly isolated. He had been told by his GP that for health reasons he must undertake exercise of some form. Mr P desired the opportunity to undertake his old recreational pursuits of walking or fishing. He was no longer able to undertake these activities independently as a result of his visual impairment. Mr P's CACP provider would not consent to reducing his hours for cleaning, shopping, cooking and transport to allow him the opportunity to undertake the activities of his choice. Rather the provider offered him group social activities, which he found unsuitable. The man remains isolated and entrapped in his home. This could be considered a contravention of Mr P's, human and economic, social and cultural rights.

It is therefore important that structural (accreditation) and individual dispute resolution mechanisms at internal and external levels are able to address and resolve disputes about allocation of care including the balance of services. Appropriate access and service delivery must be flexible enough to meet the broad range of needs, rights and interests of users.

Recommendation 9:

Home care standards and plans must allow for individual needs and must also include access to dispute resolution in cases where the balancing of services and allocation of services is at issue.

9. Residential aged care standards

9.1 Viewing the standards through a human rights lens

Older people living in residential aged care are one of the most vulnerable groups in our community, thus protection of their human rights is paramount. NACLC and OPLS has been concerned for some time that despite the requirement for residential aged care services to meet the Accreditation Standards, the reality remains that the care that residents receive does not

necessarily meet these standards.

In order to ensure the human rights of older people are protected, those who are in positions of power to enforce these rights and ensure they are not breached need to be educated about their responsibilities. Without this investment it is unlikely that conditions for many residents will significantly improve.

Recommendation 10:

Education in human rights must be provided to community care and aged care workers, as well as managers and administrative staff in aged care facilities. Accreditors and Community Visitors should also be aware of the human rights of older people to inform their work.

NACLC and OPLS has noted with concern the omission of the "Resident Lifestyle" principle in the Quality of Care Principles. The superseded "Resident Lifestyle" principles reflected a number of human rights – the right to dignity and privacy, the right to a cultural and spiritual life, and the right to participate in decision-making.

The case studies below are real situations that OPLS members have encountered. They involve the services that must be provided in Schedule 1 in a way that meets the Accreditation Standards outlined in Schedule 2 of the Quality of Care Principles 1997 and are compared against the UN Universal Declaration of Human Rights.

9.2 The requirement to adequately maintain buildings and grounds

Case study 2

Mrs. J entered a residential aged care facility in 2010. At the time of her entry she was advised that because of building works she would be required to share a room for 3 weeks, after this time she would be provided with her own room. Over 18 months later, Mrs J was still sharing a small one-bedroom room with another resident who had significant behavioural difficulties. Mrs. .J thought that she should be entitled to reduced aged care fees as compensation in the way that she would have been if she were a tenant in a rental property in the general community. Mrs. J was very distressed that there is no entitlement for seniors in care and felt that this was discriminatory.

Case study 3

A client, Mr. B, received a complaint in a residential aged care facility about the level of noise immediately outside the facility's walls caused by excavators and heavy machinery, which were being used to create roadway access to a new block of independent living units within the complex. He was advised by the facility administration "not to bother complaining" and told that no reduction in fees was possible. Mr. B reported feeling constantly stressed by the noise and the impact it was having on the other residents.

There is a requirement in Schedule 1, Item 1.2 to adequately maintain buildings and grounds. The principles of Schedule 2 Parts 1, 2, 3 and 4 would indicate that this should be done in a way that is responsive to the needs of the residents, promotes their physical and mental health, retains their consumer rights and provides a safe and comfortable environment.

The reality of renovation or building works is that there is constant construction noise and residents may be shifted and required to share a room designed for one with another resident. These changes create months of prolonged noise stress and reduced privacy and could not be considered comfortable for the resident. While "adequately maintaining buildings and grounds" is discussed there is no mention of building and construction, which has a far greater impact on the wellbeing of residents.

OPLS notes that the Aged Care (Living Longer Living Better) Bill 2013 provides for a Pricing Commissioner who will assess fees based on the quality of accommodation provided. It is unclear in the Bill if during periods of construction whether residents will be entitled to a reduction in fees to compensate them for the stress and disturbance they endure.

Articles 2, 7,12, 24 and 25 of the UN Universal Declaration of Human Rights do not appear to be considered in relation to this matter. Residents of residential aged care do not have equal tenancy rights to those in the community. Nor do they have any protection during periods of construction against arbitrary attacks against their privacy. Residents do not receive sufficient rest and respite from noise. Noise stress is well-documented to have a significant impact on a person's health and wellbeing and can cause hearing impairment, hypertension, ischemic heart disease, annoyance, sleep

disturbance and changes in the immune system.9

Recommendation 11:

The Aged Care Pricing Commissioner must have the power to make determinations about fee reductions or future fee credits where there are circumstances that warrant such action. There needs to be a simple mechanism where residents can apply for such a decision. Additionally, Quality of Care Principles need to clearly articulate the rights of residents in situations where their quiet enjoyment and privacy are compromised.

9.3 The requirement to provide meals of quality, variety and regularity

Case study 4

Residents of a particular aged care facility complained about the quality of their meals. They stated that they had noted that the meat was tough and that the food was tasteless. In a residents' meeting they were advised that there was nothing the kitchen staff could do about this because the care provider had made a decision that all of their residential facilities across the State would move from a cook-fresh method (food cooked fresh in an on-site kitchen) to a cook-chill method (food cooked in bulk off-site and sent around the State for reheating at on-site kitchens). The care provider stated that their reason for this was to enhance variety due to consumer demand. Yet residents themselves did not want this as they felt that the food had become inedible. Despite complaints the cook-chill system continues.

Case study 5

Mrs. K was the carer for her aged mother Mrs. M. Both Mrs. K and Mrs. M were from a CALD background. When Mrs. M's dementia became very severe, Mrs. K had no option but to admit her mother to a residential care facility. Mrs. K noticed that after the first month of Mrs. M's entry into residential care that she had lost a significant amount of weight. Mrs. M's doctor admitted her to hospital as she was suffering malnutrition. Mrs. K could not understand why her mother was malnourished as she had talked with staff on several occasions about her mother's weight loss. Eventually Mrs. K discovered that her mother would not eat at meal times. Due to her dementia,

⁹ W Passchier-Vermeer & WF Passchier, 'Noise exposure and public health, environmental health perspectives', *Environmental Health Perspectives*, vol. 108, suppl. 1, 123-131. At http://www.ncbi.nlm.nih.gov/pmc/articles/PMC1637786/

Mrs. M had reverted to only speaking her language of origin and would only eat food that was traditional to her culture. Mrs. K discussed this with staff and was advised that they could not provide the cultural foods that Mrs. M required. Mrs. K was told that she would have to prepare her mother's meals and bring them in. Mrs. K asked for a reduction in fees to help pay for her mother's food. The care provider refused. Mrs. K was left to pay for her mother's meals from her own pension creating financial hardship for her. Mrs K. had to take a bus three times a day to provide her mother with meals.

Schedule 1, Part 1.10 states that the care provider must provide meals of adequate variety, quality and quantity for each resident at times generally acceptable to both residents and management, and generally consisting of 3 meals per day plus morning tea, afternoon tea and supper. It also states that special dietary requirements must have regard to medical, religious or cultural observance. Schedule 2, Part 1, 2, 3 and 4 indicate that this should be done in a way that is responsive to the needs of the residents and their representatives, promotes their physical and mental health, retains their personal, civic, legal and consumer rights and provides a safe and comfortable environment.

While the Quality of Care Principles dictate strong guidance on the provision of meals, the reality can be quite different as indicated by the above case studies. Articles 2, 7 and 25 of the UN Universal Declaration of Human rights indicate that all persons are entitled to equal treatment, protection from discrimination and to a standard of living adequate for their health and well-being. Complaints that are upheld regarding quality of food will only receive a recommendation for change from the Aged Care Complaints Scheme.

Food is a necessity of daily life yet there is no ability to enforce its appropriate provision. Article 10 of the UN Universal Declaration of Human Rights states that everyone is entitled in full equality to a fair and public hearing by an independent and impartial tribunal, in the determination of his rights and obligations.

Recommendation 12:

Breaches of the Quality of Care Principles must have a clear dispute resolution process. The outcome of the process must be an enforceable decision. Such issues must be picked up in quality or accreditation reviews as well.

In cases such as case study 4 there needs to be an opportunity to consider how facility-wide decisions can be reviewed, particularly where there appears to be widespread concern among residents. Fee disputes are another area where collective complaints might arise and there needs to be a mechanism for resolving issues for more than one resident. This needs to be a complimentary mechanism to the work of a Community Visitor; a scheme, which we are pleased to note, has been extended to home care services.

Recommendation 13:

There needs to be a mechanism for resolution of collective complaints especially in the area of quality of care and fees.

9.4 The requirement to provide appropriate social activities that respect and enhance resident life

Case study 6

Mrs. Q held tertiary qualifications and prior to entering residential care due to a stroke had academic interests. Mrs. Q retained capacity however was left with physical disabilities and an inability to communicate verbally. Mrs. Q's facility, despite Mrs. Q's non-verbal indication that she did not want to go, forced her to attend activities such as word bingo. Mrs. Q was severely distressed by this and felt that the activities that the facility chose for her to participate in were demeaning and lacked foresight in regard to her disabilities. Mrs. Q would have preferred for poetry audio books to have been arranged for her.

Schedule 1 of the Quality of Care Principles requires that programs encourage residents to take part in social activities that promote and protect their dignity, and to take part in community life outside the residential care service. Schedule 2 requires that residents are assisted to achieve maximum independence, maintain friendships and participate in the life of the

community within and outside the residential care service and that residents are encouraged and supported to participate in a wide range of interests and activities of interest to them.

Articles 26, 27 and 29 of the UN Universal Declaration of Human Rights refer to everyone's right to education to assist in the full development of personality, to be able to participate freely in cultural life.

It is evident that residential care facilities encourage participation in social activities, however NACLC and OPLS are concerned that residents may not be able to freely choose if they attend; that the activities provided do not necessarily increase participation in the community outside the facility; may not provide life-long learning opportunities; and may not be reflective of resident interests.

Residential care services could enhance their variety and level of activities simply by offering space to community groups. Residents would then have the ability to choose to be a part of the community groups that meet on the premises. A recent example of this method is 'Seniors Creating Change' (SCC). Seniors Creating Change are a grass roots group of older people who sing to raise awareness of older people's issues in Queensland.

Concerned about the lack of social inclusion for residents, SCC now meet once a month to practice at local residential care services. Residents are invited to participate. Numbers of residents attending each month at the SCC practice is increasing. Residents state that they are enjoying being part of a community group again.

Recommendation 14:

Accreditation must include consideration of the diversity of opportunities available to residents and how care plans reflect the individual needs and interests of residents. It should also include consideration of facilities for residents to gather with community groups to remain socially included.

9.5 The power to investigate resident deaths

Case study 7

A client, Mrs. J, complained that her father, Mr. S, who was suffering from Parkinson's disease, had fallen out of bed in his residential aged care facility, and been left lying on the floor for several hours. When he was eventually moved, it was found that he had fractured his hip and required hospitalisation. Mrs. J also stated that she had been dissatisfied with the care her father had been receiving prior to this incident and had made several complaints about the standard of nursing care Mr. S was receiving. It was Mrs. J's belief that the neglect of her father was retribution for the previous complaints. Over an 18 month period there were four similar complaints by clients about this residential care service. None were successfully resolved in favour of the clients.

Case study 8

Mrs. F's family contacted a CLC, after their mother had been dropped from a hoist during a transfer. Mrs. F sustained injuries, which resulted in the rapid deterioration of her health. Mrs. F died a few weeks later. Medical evidence was available to prove Mrs. F's family's concerns however their complaint was not successfully resolved. The residential care service had stated during the investigation that the drop had not occurred, thus the Commissioner had ruled in the facility's favour.

Both case studies raise serious concerns about the ability of family to agitate for review of matters after the death of a resident where there are genuine concerns about whether the death was related to abuse or neglect. While matters may be referred to a Coroner as a death in care, inquests are not commonly held in these sorts of cases. Inquests into aged care deaths have looked at issues including storage of equipment (hoist), staffing levels, patient supervision, notification of infectious diseases and health management.

There needs to be some mechanism whereby deaths in facilities can be the subject of individual and systemic review in a way that does not encroach on the Coroner's jurisdiction. Where a Coroner is satisfied that an inquest does not need to be held there is no reason why an investigation into the same circumstances could not be held by the Commonwealth or its agencies. The findings would be of great relevance to any quality or accreditation review.

Recommendation 15:

The Scheme and Commissioner should have the power to investigate deaths of residents on behalf of the Commonwealth or other interested parties such as personal representatives, family or next of kin, providing this does not duplicate or impede upon the Coroner's jurisdiction. Any findings could be used by the Commissioner in the process of quality or accreditation review of the facility.

9.6 The need to involve residents in decision-making

Case study 9

Mrs. H was an Australian of European origin who suffered urinary tract infections. These caused her to become episodically unwell and required antibiotic treatment for which she was hospitalised on a number of occasions. As a result of her hospitalisations and an 8 year diagnosis of Alzheimers' Disease, which was listed on her medical chart (despite a full assessment never having been made), she was placed in a dementia ward – an active role in the process being taken by her attorney. Despite this, Mrs. H had been working as a tea lady up until a few weeks beforehand, and was proficient with a computer, printer and mobile phone, all of which accompanied her into the dementia ward. Mrs H was able to Google the seniors' legal service which had helped her on a previous occasion and the process was started to obtain a declaration of capacity for her, revoke her power of attorney, and obtain a release from the dementia ward. Residential care staff commented to the legal service that "Mrs. H did not belong there" but also advised that they did not feel they could speak out to the senior administrative staff. Although Mrs. H found many of her household items missing when she returned home, this case had a relatively positive ending – Mrs H was released from the dementia ward after 10 months, and resumed her part-time job and fitness classes.

Consistent with the cases reported to OPLS members and the findings of the Townsville Seniors Speak Out Forums, the loss of independence, and significantly that of decision-making, remain of greatest concern.

Currently, when the Enduring Power of Attorney for an older person for financial and/or personal and health care is active, the regime applied is "substituted decision-making" on the part of the attorney, often regardless of whether the older adult still has capacity to be consulted on any of these

matters. For example, while the general principles contained in the *Power of Attorney Act 1998* (Qld) and the *Guardianship and Administration Act 2000* (Qld) invoke the human rights of the older person, it has been the experience of OPLS that these are honoured in the breach rather than in the observance.

When older people are receiving aged care services, it has been our experience that service providers or aged care facilities will deal only with the substitute decision-maker regardless of the level of capacity of the older person. Where the older person has retained capacity, they may then have little or no input into the issues that affect them directly, thus perpetuating a regime of disempowerment and ageism in the sector. In this light, the loss of the "Resident Lifestyle" component details from the current Quality of Care Principles 1997 in Schedules 1 and 5 is significant.

Elder abuse, and in particular, financial abuse, is facilitated by a regime that disregards the ability or capacity of the older person to be consulted directly about matters that affect them, and this applies in aged care facilities as much as it does in the community.

The stakes are very high when the issue is one affecting the decision-making independence of the older person. Mrs. H stated that she felt "wrongfully imprisoned" and as if she had "no rights at all." The experience in the dementia ward cost her \$20,000 at a time of life when it was impossible to replace that sum, and was a great blow to her personal confidence.

Article 12 of the UN Convention on the Rights of Persons with Disabilities states that a person should not be deprived of the right to make decisions simply because of their disability. To this end the concept of "supported decision-making" is appropriate in recognising the trusted relationships the older person has within their network, and in identifying those individuals from whom the older person wishes to receive support.

The concept of "assisted decision-making" is similar, but provides for practical assistance to be given to the older person (collection of information, discussion of options), so that autonomy is preserved for the older person, subject only to the provision of practical assistance.¹⁰

¹⁰ Australian Human Rights Commission, 2012, *Respect and choice: a human rights approach to ageing and health.* At http://www.humanrights.gov.au/human-rights-approach-ageing-and-health-respect-and-choice-home-based-and-residential-care-older

It is the view of NACLC and OPLS that substituted decision-making should be reserved for only those cases where impairment is so severe that decision making is severely compromised or non-existent.

9. The diversity of the ageing experience

The intersectional needs of older people receiving community care and/or residential care who are Aboriginal and Torres Strait Islander, from a culturally linguistically diverse background (CALD) and/or identify as gay, lesbian, bisexual, transgender or intersex (LGBTI) need to be responded to by government and service providers. As part of the reforms, national strategies have been developed for both CALD and LGBTI older people, recognising the need for appropriate, respectful and discriminatory-free services.¹¹

We note that amendments within the Aged Care (Living Longer Living Better) Bill 2013 ensure that these groups are considered "people with special needs" under the legislation. We commend the expanded lists, which sees the inclusion of LGBTI people, people from CALD backgrounds and people who are homeless or at risk of becoming homeless as groups with special needs.

Older people in these groups need to be consulted with, along with representative bodies, in order to ensure that services are culturally appropriate. We note the Aged Care (Living Longer Living Better) Bill 2013 at clause 4 states that an independent review must be undertaken of the operation of the amendments made under the Bills, and that this review must make provision for public consultation with these groups.

Recommendation 16:

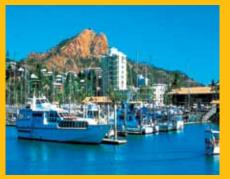
Aboriginal and Torres Strait Islander peoples, people from CALD background, LGBTI peoples and other groups must be consulted with in order to ensure the amendments are appropriate and that the care provided is culturally safe, respectful and informed.

1

¹¹ Department of Health and Ageing, *Lesbian, Gay, Bisexual, Transgender and Intersex (LGBTI) Ageing and Aged Care Strategy*, 2012. At http://www.health.gov.au/internet/main/publishing.nsf/Content/lgbti-ageing-and-aged-care-strategy and *National Ageing and Aged Care Strategy for People from Culturally and Linguistically Diverse (CALD) Backgrounds*. At http://www.health.gov.au/internet/main/publishing.nsf/Content/ageing-cald-national-aged-care-strategy

Townsville Seniors Speak Out















The Townsville Community Legal Service Inc. acknowledges the 122 Townsville seniors who bravely and honestly spoke out about the issues they face. Their voices are the outcome of this report.

TCLS thanks actor **Una Way** and director **Paul Wilson** who brought to life the play **Dance Like a Butterfly** to life. Their talent and commitment to the forums was integral to the success.

TCLS thanks the **Townsville Returned Services Leagues Club** for their care and attention to the requirements to the Forum and the seniors who attended.

TCLS also thanks the facilitators of the discussions who generously gave their time to make the Townsville Seniors Speak Out Forums a success:

Neville Abbey Seniors Legal and Support Service Reference group

Ginni Hall Seniors Legal and Support Service Reference group

Sandy McIntyre Carers Queensland

Errol Neale Townsville Regional Committee of the Ageing

Arthur Schultz *Townsville City Council.*

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Townsville Community **LEGAL SERVICE INC**







Executive Summary

This report reflects the views of the seniors involved in the Townsville Seniors Speak Out Forums. The Forums were held to empower seniors to speak out about their needs and to harness their knowledge of how the risk factors for elder abuse can be addressed in the community.

The Forums also sought to identify barriers that prevent seniors from planning ahead and to assess seniors' understanding of legal documents that assist to prevent elder abuse.

This is not a scientific report. Rather, it is an amalgam of the views expressed by seniors, research that supports their opinions and the conclusions that can be drawn from these two sources.

Part 1 - Background

Part 1 provides a background introduction to the initiators of this report, the Townsville Community Legal Service Inc., its specialist Seniors Legal and Support Service along with demographic and statistical information about the Townsville community.

Part 2 - Elder Abuse

Part 2 introduces elder abuse by defining the term, identifying the risk factors and explaining the consequential impact for seniors who experience this type of harm.

It also explores the costs to the individual and community as well as the cost-saving benefits available if preventative measures are employed.

Part 3 - The Townsville Seniors Speak Out Forum

Part 3 provides information about the development of the Forums. It explains the genesis of the concept, the recruitment of participants, the choice of venue and room layout. There is a description of the program format, the method of gathering information during the facilitated discussions, the subsequent analysis and evaluation method.

Part 4 - Dance Like a Butterfly

Part 4 provides information about the play "Dance Like a Butterfly" which was the central platform for the Forums' facilitated discussions.

Part 5 - Themes and Findings

Part 5 presents the three main themes that were evident from the facilitated discussions — loss of independence, social Isolation and transition to aged care.

It also provides information about other areas of concern that seniors raised such as the perceived lack of support for independent retirees and Centrelink recipients.

The seniors' solutions to issues arising out of these themes can also be found within this part.

Part 6 - Barriers to planning for the later years

Part 6 presents the seniors' views about the barriers that may inhibit them from planning for future years.

It explores seniors' knowledge of legal documents such as Wills, Enduring Powers of Attorney, Advanced Health Directives, Family Agreements and Loan Agreements.

It also provides information about solutions that seniors thought would assist them to consider future arrangements.

Part 7 - Conclusion

Part 7 draws together the findings of the Forums and seeks to establish a way forward that would allow the implementation of the seniors' solutions as sustainable actions.

It presents a framework that would assist seniors in the local community and more broadly at a national level.









Background

Townsville Community Legal Service

Townsville Community Legal Service is a non-profit, community based legal centre. It was established as a volunteer service in 1991 and funded in 1992.

Since then the Service has grown and offers general legal advice, casework and representation and provides a range of specialist services including:

- Welfare Rights advice, casework and representation
- Immigration advice and assistance
- Financial Counselling
- Seniors Legal and Support Service
- Cyclone Legal Help
- Family Law advice

The Seniors Legal and Support Service

The Seniors Legal and Support Service (SLASS) began as a pilot project funded by the Queensland Government's Department of Communities in 2007.

SLASS was established to provide legal assistance and support to people over the age of 60 at risk of or experiencing elder abuse or financial exploitation.

The pilot was funded in five sites throughout Queensland including, Brisbane, Toowoomba, Hervey Bay, Townsville and Cairns.

In 2010 SLASS became triennially funded.

The SLASS is staffed by three EFT positions – administrative officer, solicitor and social worker.

In its first three years the Seniors **Legal and Support service provided:**

- 325 seniors with casework assistance
- 150 seniors with legal advice
- 1224 seniors with legal information

The majority of clients accessing SLASS were within the 70-80 year age range.



Townsville

Townsville is situated in coastal North Queensland. It lies approximately 1,300 kilometres north of Brisbane, and 350 kilometres south of Cairns.

As at 30 June 2009, Townsville had a population of 181,743. Of this population 9.3% were aged 65 years and over. 1

The national population of people over the age of 65, as at May 2010 was 13.5%.2





Elder Abuse

Australian research estimates that between 3-7% of seniors will experience abuse each year. ³ With the proportion of the population aged 65+ set to increase from 13% of the population to 23-25% by 2056, elder abuse is a significant social issue. ⁴

Definition

Elder abuse is defined as "Any act occurring within a relationship where there is an implication of trust, which results in harm to an older person. Abuse can include physical, sexual, financial, psychological and social abuse and/or neglect." 5

The Risk Factors

The main risk factors of elder abuse are:

- Isolation
- Dementia
- Family conflict
- Physical illness
- Lack of services
- Dependency of the victim due to physical or mental incapacity
- Psychopathology of the perpetrator (including substance abuse).

A number of other factors have been cited as contributing to elder abuse including community attitudes towards the ageing population, carer stress, financial dependency on seniors, shared living arrangements, a lack of community awareness about elder abuse and lack of support for carers. ⁷

The Impact on the Individual

Elder abuse has significant consequences for seniors. Seniors who are abused:

- O Have an increased risk of developing depression⁸
- Have an increased risk of developing dementia 9
- Are more than three times more likely to die within three years than those who have not been abused ¹⁰
- Are more likely to enter residential care prematurely. 11









The Cost of Elder Abuse

The cost of elder abuse is largely unknown. There are direct costs to the individual and indirect costs to the broader community – the cost to the taxpayer and government.

The Elder Abuse Prevention Unit in Oueensland (EAPU) has estimated that almost \$100 million is taken from Queensland seniors each year as a result of financial exploitation.

The EAPU has also estimated a total cost to the Queensland community of up to \$5.8 billion each year.

This included the cost to seniors and government services. 12

Saving Costs through Prevention and Intervention

To reduce the cost to the community and impact on the individual we need to move away from treating elder abuse with a narrow person-centred approach and a move toward developing a holistic community response.

Elder abuse needs a response that addresses inequalities, develops community intolerance of abuse, provides community education, creates support services and as a last resort, provides legal intervention. 13

Preventing elder abuse saves costs across the board. The Institute for Sustainable Futures investigated the economic value of prevention and intervention activities of community legal centres (CLCs).

The Institute found that in cases where CLCs assisted victims of financial exploitation, elder abuse and domestic violence, the broader outcomes included cost savings across all levels of Government and to the community.

They also found preventative activities such as theatre style community education were a proactive approach that filled an important service gap.

These activities provided a medium to assist a social group that face significant legal challenges and isolation from society. 14 The activities also helped prevent potential legal disputes. 15

Elder abuse is estimated to cost the Queensland community up to \$5.8 billion each year.





Townsville Seniors Speak Out Forum

Each year around World Elder Abuse Awareness Day (marked on 15 June), TCLS conducts a "Step Out Speak Out" campaign to raise awareness of elder abuse and to promote protective strategies to combat it.

As part of the 2010 campaign, two Forums for seniors were held at Townsville RSL to give seniors the opportunity to speak out about the issues affecting them.

The Concept

In 2002 the World Health Organisation and the International Network for the Prevention of Elder Abuse (INPEA) released "Missing Voices: Views Of Older Persons On Elder Abuse".

The report collated and analysed information received from focus groups held with seniors and health professionals in eight countries. It identified ageist attitudes and disempowerment as a major cause of elder abuse and a contributor to its hidden nature.

A significant recommendation from this report was that seniors should be empowered to exercise their own rights and advocate their own interests. ¹⁶ This recommendation was the genesis of the Forums.

The Forums were designed to provide an avenue for Townsville seniors to come together and speak about their concerns and interests and to have their voices heard.

Participants

SLASS invited seniors to attend one of two Forums held at the Townsville RSL. The first Forum was held in the morning and the second Forum was held in afternoon.

The SLASS drew seniors from local seniors' groups through community networks and advertising.

Venue/Entry/Seating

The Townsville RSL Club was chosen as a senior friendly venue. Each Forum was ticketed to ensure that catering was adequate, although entrance was complimentary. Seating was planned to ensure that the seniors could view the performance and interact easily with each other during facilitated discussions.

Accordingly, seniors were seated in a horseshoe shape in groups of nine at round tables facing the stage. An empty chair was placed at the top of the horseshoe to allow the facilitator to join the discussion during the breaks. If the seniors knew each other they were seated together.









Format

The format of each Forum was based around excerpts from the play "Dance Like a Butterfly" by Aviva Ravel. The SLASS chose to use theatrical performance to create a platform for discussion and gathering information.

Discussion Sessions

Two 30 minute facilitated discussion sessions were held during the course of each Forum. These sessions were arranged at points in the play that highlighted hot topics for seniors.

Discussion was initiated by open questions that reflected the issues highlighted by the play. The facilitators (staff and volunteers from TCLS) were instructed to focus on collecting the views, comments and opinions of the seniors, without leading the conversation.

Discussion questions focused on the issues raised by "Dance Like a Butterfly" and centred on three of the major risk factors associated with elder abuse:

- 1. Social Isolation
- 2. Loss of Independence
- 3. Transition to Aged Care

Discussion also traversed the barriers that prevent seniors from planning ahead for their later years. Additionally, discussion sought to assess seniors' knowledge of measures that may assist to prevent abuse or exploitation. Specific questions were asked of the seniors about these issues.

Morning or Afternoon tea was served to the seniors at their tables to allow the conversations to continue during a break.

Data Analysis

Hand written notes of the discussions from each table were transcribed. Themes evident from discussion notes were collated.

The themes are the basis for the recommendations in this report.

Evaluation

Feedback forms were used to capture any further comments, identify the best way to provide information to seniors in the community and to gauge the success of the Forum.





Dance Like a Butterfly

The play "Dance Like a Butterfly" by Canadian playwright Aviva Ravel¹⁷ was performed at the Forums by an accomplished local actor Una Way, and directed by Paul Wilson.

The play was chosen because it explores a number of issues and fears associated with ageing that place a vulnerable senior at risk of abuse.

"Dance Like a Butterfly" is a cleverly crafted script, which highlights the sudden decisions that a person may need to make as they age. This poignant yet humorous monologue tells the story of Tillie Rheinblatt, an 85 year old migrant woman, who finds herself in a rehabilitation ward following a series of falls.

The issues raised include social isolation, the role of family and friends in deciding aged care or financial matters, the fears of leaving one's home to enter nursing home care and the grief associated with adjusting to what is often considered the final step in life.

Tillie's niece has informed her that she now requires 24 hour a day care and must make a decision about her future residential care placement. Tillie takes the audience through the emotional decision making process associated with the transition to residential care.

Tillie openly chats about the grief of letting go of her home, her possessions, her freedom and her independence.

"Not so long ago I was just like you. I could walk and run and dance like a butterfly.

Now, I sit like a stone. Did I ask for it? No.

It just happened, like an earthquake happens. You have no control.

It's like when you play poker, you have no control over the cards you get – unless you cheat."









Themes and Findings

Analysis of the seniors' facilitated discussion indicated there were concerns that as they age they will be faced with challenges that they feel ill-prepared for, such as:

- becoming dependent
- becoming socially isolated
- entering residential aged care facilities.

Seniors identified significant fears about these challenges.







Loss of Independence: issues

"Once you become dependent you feel like you have lost the lot"

- Participant, Townsville Seniors Speak Out Forum

Many seniors were concerned that they will become dependent on others in the future.

There was consensus that seniors do not want to be a burden. a bother or nuisance to others and that it is difficult for them to ask others for help because of how they may be perceived.

The fears of dependence related to loss of health, physical function, mobility, capacity (not being able to make decisions for themselves), drivers licence, grooming ability, personal care and a general sense of loss of control over their life.

While some of the fears discussed were common to all, others appeared more gender specific e.g. more men discussed concerns about losing their licence while more women discussed concerns regarding the loss of ability to groom and dress themselves. One female participant stated that she did not want to be dressed in "funny clothes and shoes".

The fear of becoming dependent on others is a fear that is often expressed by seniors along with the fear of developing dementia or losing one's memory. A survey undertaken by Bupa Care Services found that four out of five Australians have this fear.

The Alzheimers Association predicts that the numbers of people living with dementia will more than triple from 212,000 currently to 730,000 by 2050.

Developing an illness such as Dementia or Alzheimer's is not the sole cause of loss of independence in later years. Other factors such as ill health, lack of transport and changing technology contribute to lost independence.

Research into the financial management of assets by seniors, indicated that:

- 72% of older Australians received help with their paperwork
- 55% received help with paying bills
- 42% received help with accessing their money and banking
- 37% received help with their pensions and superannuation
- 31% received help with their property management
- 16% received help with accessing financial advice
- 11% received help with their investments. 20

These findings did not include other forms of assistance such as transport, home/yard maintenance and personal care. Dependence on others for assistance with some or all tasks is a reality for the majority of seniors in their later life. Seniors were aware that dependence on others, especially for financial management of assets could place them at risk of abuse.









Loss of independence: solutions

Seniors identified that these fears may be alleviated by:

- Running home-support seminars to provide information about the availability of in home care and how to access it
- Increasing the availability of in-home services and appropriate transport
- Individuals creating care plans with family through family meetings or discussions
- O Having self-determination "maintaining a sense of independence to the end."

- Retirement
- Losing a licence
- The death of a partner
- A sudden change in health
- Moving to a different community. 23

Seniors were specifically asked why they thought people became socially isolated and what could be done to assist them to participate more fully in social and community activities.

Seniors' responses supported the findings of research. Seniors themselves attributed the causes of isolation to the following:

Social Isolation: issues

"Isolation is very real"

- participant, Townsville Seniors Speak Out Forum

"Social isolation can be described as having two components; a low level of interaction with others combined with the experience of loneliness." 21

The impact of social isolation is significant and can be associated with an increase in depression, poor health and wellbeing, morbidity and mortality. People experiencing social isolation are less likely to access health and support services. Approximately 8% of seniors experience social isolation. ²²

Age itself does not cause isolation; rather it tends to be triggered by key life events that generally occur in the later vears such as:

- Fear of crime
- Neighbourhoods
- Lack of transport
- The death of a partner
- The cost of participating
- Lack of public amenities
- Changing structures of family
- Changes in community attitudes
- Layout and entry of shopping centres





Ageist attitude

Seniors identified that they are often marginalised and treated differently. They said:

- "You feel like people are pushing you. They think because you are old they have to make the decisions for you, as they think they know what is right for you"
- "People think you are hard of hearing"
- "Young ones don't understand what it is like. They need to adapt to the needs of older people"
- "There is a lack of recognition for older peoples skills and knowledge"
- "They claim that older people don't really know"
- "The media forget elderly people. If you are not young and beautiful you are not on TV or in magazines"
- "People don't listen to you"
- "Young people don't respect older people"
- "Young people think that they can bully older people and discriminate against them."

Ageist attitudes towards seniors arise out of the myths that surround ageing, the ageing process and being old.²⁴

Ageist attitudes have a negative consequence on the wellbeing of seniors.

The Australian Human Rights Commission recommended action to address the current negative stereotypes of seniors in the community if their wellbeing, participation and contribution to the economy are to be improved. ²⁵

Lack of Public Amenities

Seniors raised concerns about the inability to easily access public amenities, including toilets. They suggested that this would prevent a person from participating due to likely embarrassment if they were unable to control their bladder or bowels.

Seniors identified that lack of access to toilets is an issue in many places they frequented including government agencies, public malls, business districts and shopping centres.

It is estimated that around 37% of seniors over the age of 60 experience symptoms of incontinence. ²⁶

The Department of Health and Ageing suggests that people who experience incontinence or other toileting issues can place major life restrictions on themselves to avoid embarrassment.

These restrictions can include limiting fluid intake, limiting social outings only to places where they know the location of toilets, avoiding places (such as theatres) where it is difficult to get to a toilet, restricting social and intimate interactions or ceasing going out all together and becoming isolated. ²⁷

A review of the National Public Toilet Map for Townsville revealed the Map is incomplete and incorrect. For example, major shopping centres did not even have their toilets listed.

"Lack of toilets can stop an older person from going out because they are too scared that they won't be able to control themselves"







Costs of participation

Many seniors discussed the expense of social participation and made statements such as:

- "I love the theatre, particularly the Civic, but I can't afford the \$40 (pensioner price) ticket"
- "As a former serviceman it costs me double to join the RSL as a social member."

The costs of a social life and being entertained were noted as the lowest budget priority and were often relinquished for life's necessities.

Disability Access

Accessibility of public places including shopping centres was cited as a reason for not being able to participate and attend to daily living activities. The seniors identified a number of issues:

- Disability car parks are difficult to access
- The centres are often too large leading to a sense of disorientation
- That shopping centre entries are not designed for people with disabilities
- There is insufficient seating within shopping centres to be able to have a rest
- Parking in general is quite a distance to the entrance, especially for those who are required to carry medical equipment such as an oxygen tank.

"Shopping centres are a wilderness"

- participant, Townsville Seniors Speak Out Forum

Other Obstacles

Seniors also named footpaths, street lighting and roaming dogs as factors that inhibit participation and activity.

Fear of Crime

Seniors identified the fear of being a victim of crime prevented some seniors from participating in the community.

Seniors made numerous comments that related to the level of fear, its causes and the isolating impact that it can have on seniors.

Fear of Crime

- "I'm too scared to go out after dark"
- "I'm too scared to even go for a walk"
- "I don't feel safe in large shopping centres or the mall"
- "You go through a routine of locking yourself in at night"
- "I don't even go down the backyard because it is too difficult to lock up"

Police and the Justice System

- "The Police don't come when you need them"
- "The Police have said that they are unable to physically handle people"
- "Police don't act when they should"
- "The justice system is too soft. A fish is worth more in fines (\$10,000) then a human being drink diving"

Community

- "A lot of people are suspicious of others"
- "It's too hard to go out at night-time frightened, poor eye sight"
- "Feel vulnerable with the way some of the young ones act"

Media

- "We only hear about older people being bashed"
- "All the focus is on crime"





Seniors are less likely to be the victim of crime than those of a younger age group, yet they are more likely to report fear of being a victim of crime. ²⁸ Seniors appear to fear crime at a higher rate than their younger counterparts. A number of factors create a sense of vulnerability, including:

- Isolation living alone and having no-one to assist during a crime, provide support while reporting an event or not knowing the neighbours well enough to ask for help
- Decline in physical health, strength, agility, sight, hearing and the subsequent perception of diminished ability to protect oneself
- The likely consequences of being a victim can be seen as more serious for older people due to an increased risk of serious injury and the reduced economic, physical and social resources to recover
- Perception of incivilities disorderly environments (abandoned vehicles, broken glass, graffiti, untidy yards) or signs of social unrest (disruptive neighbours, rowdy youths or homeless people) can lead to a belief that a neighbourhood is out of control
- Media sensationalism headlines such as "Thugs assault elderly walker", "Elderly man slain in own home", "Youth crime haunts region" can reinforce a notion that older people are not safe in the community
- Political law and order campaigns can lead to an unintended effect of increasing anxiety
- Lack of confidence in the police and a perception that offenders are not being adequately punished. 29

Whether seniors fear crime more than other groups within the community is unresolved. Seniors at the Forums indicated that there is fear of crime amongst seniors and that this is affecting participation within the community. ³⁰

Justified or not, fear of crime leads to social isolation.

Changing Lifestyle and Family Structures

Seniors identified that changes to the family unit can lead to isolation. The changes identified included:

- The competing interests within blended families
- The mobility of families
- The loss of extended family
- Social breakdown in the family itself.

There was a view that younger people felt they knew everything but in fact had very little understanding of seniors' lives.

There was a general feeling amongst the seniors that seniors feel very alone when family or friends do not visit them. While these generational issues are "old chestnuts", they continue to contribute to social isolation.

"There is no family unity, so there is no longer dignity and respect"

- participant, Townsville Seniors Speak Out Forum







Lack of Transport

Lack of transport was considered a major reason that seniors become isolated. Seniors listed a number of difficulties with current transport options:

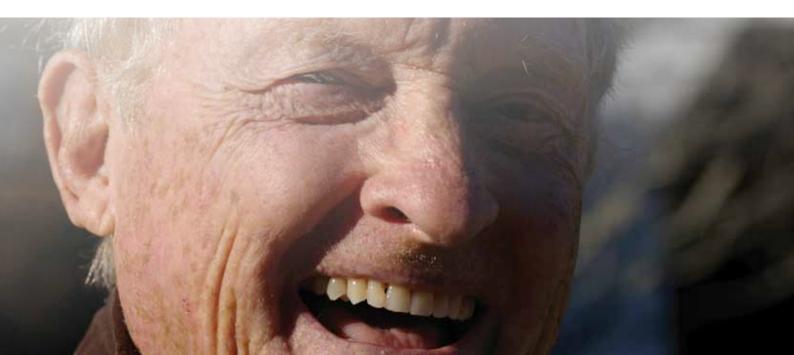
- O Living too far away from bus routes
- O Limited or no weekend service after 6pm
- O Physically being unable to get onto the bus
- Limited information available about public transport
- O Community venues being inaccessible because of lack of transport.

Some seniors were aware of community transport schemes and others had not heard of them.

Seniors identified that while community based transport options provided an excellent service, for many it was unaffordable.

"Public transport is not OK – you can't even get to the bus stop"

- participant, Townsville Seniors Speak Out Forum







Health

A number of health reasons were cited as causing isolation, including being hearing and vision impaired, feeling unwell, breathing difficulties, pain and losing mobility.

Poor health has been found to be the most significant predictor of social isolation in seniors. ³¹ There is also evidence that social isolation itself is linked with negative health outcomes and lower quality of life. ³²

A recent comparison between poor social relationships and known risk factors for mortality found that social isolation has a similar influence upon health to smoking 15 cigarettes a day, consuming six alcoholic drinks a day and that the risk exceeds factors such as obesity and physical inactivity.

DETERIORATING HEALTH

ability to cope alone impact on daily living reluctant to ask for help

illness progression

weak

It concluded that people with adequate social relationships are 50% more likely to live longer than those with poor or inadequate social relationships. ³³

There is a spiralling relationship between social isolation, ill health and difficulty negotiating the health care system, which causes fear and powerlessness for seniors. ³⁴

Figure 1 A Spiral of Deterioration: Socially isolated, Old and Getting Sicker, below illustrates this relationship.

POWERLESSNESS

- inability to argue with doctors
- only choice to accept what is offered
- passive acceptance of services
- further loss of autonomy
- vulnerability

BECOMING INVISIBLE

- only the young matter
- no longer valued
- past used by date
- ignored

WAITING

surgery proceedures

DEPENDENCE/SENSE OF LOSS

- falls
- loss of autonomy
- loss of mobility
- unable to cope
- being along

TRANSPORT

- further loss of independence
- inability to use public transport
- increased driving restrictions
- decreased ability to use own car

Figure 1.

referrals merry-go-round

extended delay for specialist services

Greaves and Rogers-Clark (2009)







Emotional/psychological barriers

Seniors' comments indicated that there are numerous emotional and psychological barriers that prevent participation. These included:

- Depression
- Living alone
- Fear of rejection
- No-one to go out with
- O Grief after the death of a partner
- Not wanting to "put other people out"
- Feeling lonely after the entry of a partner into nursing home.

"It's hard at any age to be rejected"

- participant, Townsville Seniors Speak Out Forum

Neighbourhood

Seniors observed that neighbourhoods and communities had changed significantly over time and that there was "no sense of community anymore" adding to the isolation felt by older people. They attributed the reduced interaction in the neighbourhood to:

- Neighbours no longer socialise together
- Most neighbours work and spend long hours at work
- O Young neighbours have a lack of understanding of the elderly
- New people moving into the area are not interested in getting to know their neighbours
- O Neighbours no longer care about each other.

Social Activities/Groups

Seniors identified that there is inadequate information available in the community about social activities and groups. They also noted that the multiplicity of rules and regulations for committees running social groups. This "red tape" created concern amongst committee members regarding personal liability.

Seniors identified that elitism within social groups can impact upon participation or prevent new members from joining.

Many of the seniors indicated that they wanted to be involved in mixed age group activities. Seniors highlighted that younger people are reluctant to join in if a club was associated with seniors or had the word "senior" in it.

Technology

The seniors observed that information that would assist with participation in the community is often promoted through the internet now.

The seniors stated that some "elderly do not want to keep up with modern technology."

Particular mention was made about automated telephone services used by government departments. The service was described as "Robots on phones" that "push you from one place to another". There was concern that communication in this manner is impersonal and confusing.





Retirement Villages

Seniors raised concerns about retirement villages. There was a view that retirement villages are promoted as social living environments but the reality was quite different.

The lack of intergenerational contact and the size and location of retirement villages were seen as factors that hinder residents from being able to participate in the wider community.

Social Isolation: Solutions

The fears surrounding social isolation and the solutions clearly identify that seniors want to remain connected and that many barriers related to ageing, neighbourhoods, finances, transport and current ageist attitudes prevent participation.

Seniors clearly identified wanting to interact with all age groups and not wanting to be herded to "seniors activities."

Seniors made many suggestions about preventing social isolation. Seniors suggested preventing isolation early through educating people in their fifties and sixties about the importance of staying socially active.

Seniors suggested enhancing inter-generational interaction and improving understanding and respect for seniors through:

- Mixing groups so that younger people and seniors socially interact
- School-based education programs on respectful relationships, including respect for seniors
- Increasing participation of residents in the community through attendance at events or activities
- Developing a community program such as "adopt a senior" to encourage children to connect with older people

- Encouraging schools to increase intergenerational opportunities through: organising excursions to residential care facilities where students can talk with or read to the residents; inviting seniors to attend generational chats or be involved in classroom activities
- Improving the provision of information to seniors about activities through advertising in the free paper and on radio.

Seniors suggested reducing the cost of participating through:

- Increasing the rate of age pension
- Funding social groups for seniors
- Reducing the cost of registering a car for seniors
- Reducing the price of public transport for seniors
- Reducing the price of seniors tickets for theatre events
- Increase funding for community-based transport services
- Providing seniors card holders with free entry and transport to public events.









Seniors suggested improving transport and pathways through:

- Providing bus services after 6pm
- Maintaining footpaths to disability standards
- Improving disability parking by colour coding parking spaces to match disability stickers
- O Providing specific bus services into Retirement Villages and Aged Care Facilities
- Linking pathways and roads to ensure accessibility for people in wheelchairs, motor scooters or mobility aids
- Providing buses for seniors to take them to community events such as the Fireworks on the Strand.

Seniors suggested preventing crime and increasing safety through:

- Improving street lighting
- Enhancing community policing
- Reducing media sensationalism in the reporting of events
- Improving police understanding of how to respond to seniors.

Seniors themselves taking responsibility to reduce isolation of their peers through:

- Volunteering
- Encouraging friends to attend groups with them
- O Being part of a volunteer group that telephones people who live alone
- O Being part of a volunteering group which visits isolated people, develops rapport and trust with the person and eventually assists the senior to become involved in mainstream activities.





Transition to Residential Aged Care: Issues

Seniors are fearful about the transition into residential aged care and have a negative perception of the aged care system and facilities. Their concerns related to the following:

- Losing their dignity
- The lack of privacy
- Losing their freedom
- Not being listened to
- Living in a "depressing" environment
- Entering "God's Waiting Room" and accepting the finality of life
- Leaving behind their home, possessions and other symbols of independence
- Living with the restrictions, rules and regulations present in residential facilities
- The lack of companionship and concerns that, once placed in a home, they will become forgotten.

Seniors attributed their concerns to observing past experiences of a family member in residential care, observing the quality of life of residents and media reports about abuse or mistreatment of residents by staff members and rumours.

Particular mention was made about the building works and redevelopment of residential care facilities. It was perceived that there was a lack of respect or concern for the comfort of residents during a redevelopment process. Residents are not compensated nor are their fees reduced in recognition of the upheaval and discomfort associated with the process.

There was also a concern about the lack of choices for people entering residential care.

The size of waiting lists was seen as being very problematic as people have to take whatever place becomes available. Application for entry was very complex.

There was a perception that all forms of government have not fully considered the needs of seniors and that this is reflected by the lack of facilities available, the type of facilities built and the complexity of entry criteria.

"If you take me out of my home I will die"







Transition to Residential Aged Care: Solutions

Seniors felt that residential care facilities could be improved by:

- Improving the choice of activities available
- Individual Care Plans that include diversional therapy
- O Staff training that focuses specifically on respect for residents
- Promoting residential care facilities as a place to live rather than a place to die
- Allowing residents to choose which social activities they wish to be involved in rather than forcing participation in activities that a person may find demeaning
- Inspectors being able to attend without notice and have right of entry to all areas of a facility
- Improving staff to resident ratios so that more than the basic needs of residents can be met.

Centrelink

Seniors stated accessing Centrelink to make enquiries was difficult. Lengthy waiting times to speak to a customer service officer when making a telephone or face-to-face enquiry and the locality of the Seniors Office in Townsville were raised as contributors to this.

Seniors raised concern that the sale of their home could impact upon their pension rates.

Many seniors were concerned about their ability to meet the rising cost of daily living.

Other Issues

Independent Retirees

There was a view amongst seniors who were independent retirees that they tend to be forgotten. They observed that they do not receive concessions to assist them with rates, electricity or other expenses.

They stated that they feel "penalised for being careful with their money and saving for retirement." They considered that the lack of assistance for independent retirees creates a lack of incentive for people to save.

"So what do you think? If I give up my apartment, I'm finished, it's all over.

No more kitchen, no more curtains, no more linen, no more cutlery.

All your life you accumulate, in the end they tell you to get rid of everything."

An excerpt from "Dance Like a Butterfly" by Aviva Ravel





Barriers to planning for the later years

The **Seniors Legal and Support Service** (SLASS) has observed that some seniors presenting at the service were resistant to consider plans for their future years that may assist to prevent elder abuse.

The SLASS was interested in hearing the views of participants as to why this attitude might exist and how it may be overcome.











Planning for the later years

Seniors were specifically asked why they put off planning for their later years when most people plan for other developmental areas of life such as purchasing their first car or home, marriage, children and retirement. The responses indicated that:

- There are significant emotional/psychological barriers to planning including denial of ageing, lack of confidence in oneself, fear of legal documents, fear of change and fear of loss.
- Seniors thought that the aged care system was too complex and they would not be able to negotiate it without assistance. They felt that there is a lack of information available about options for community assistance and residential care, the costs involved, funeral planning and the legal documents one requires.
- Housing was raised as an issue that seniors would like to know more about including where to find low level accessible accommodation to purchase at a reasonable price, how to make a choice between renovating one's home or moving, when is the best time to make this choice.

Legal Documents

Information was gathered about seniors' knowledge of legal documents that might assist to prevent elder abuse and exploitation. Seniors were specifically asked about Wills, Enduring Powers of Attorney, Advanced Health Directives, Family Agreements and Loan Agreements. Analysis of the discussion suggests that seniors were all well aware of the function of a Will.

There appeared to be mixed levels of understanding about the function of Powers of Attorney (General and Enduring), Advanced Health Directives and how these documents can be created, varied and revoked. There was concern that Powers of Attorney can easily be misused. There appeared to be limited knowledge about Family Agreements and Loan Agreements and their ability to protect a person from elder abuse. Seniors also viewed legal documents as expensive to create and that the actual (or perceived) cost was a deterrent from having these types of documents drawn up.

Solutions suggested by seniors to increase knowledge amongst seniors about the importance of planning for later life included:

- Encourage media to run stories on the importance of these types of documents
- O Develop an easy to read guide that contains all the information required to plan ahead
- Encourage Health Professionals to provide this type of information to clients or patients
- Develop a "whole of community" campaign to promote the benefits of these documents and move the public perception from seeing this as a seniors issue
- O Create a workbook for seniors to help with decision making and recording of any arrangements or decisions made
- Harmonise these types of documents across all states so that they are consistent nationally
- O Continuous advertising through workshops, newspaper articles, Centrelink's seniors magazine articles and radio interviews.

"They are the **final decisions** I will ever make"





Conclusions

Seniors are well aware of the issues that they will face as they age and have significant ideas about changes that could occur to enhance dignity, respect and care for older people in the community. Although unspoken, the seniors seemed to inherently understand that human rights are about dignity and respect.

There were concerns amongst the seniors that as they age, changes in health could leave them dependent, isolated, alone and requiring care. These concerns or fears appear to be related to their observations of how the community treats seniors.

Add to this their view that there are insufficient services, support, age-friendly environment, transport and information to allow them to remain living independently for as long as possible.

The combination of theatre and discussion appeared to create a safe avenue whereby seniors were able to normalise their emotive reactions to ageing and identify that their peers also had similar concerns.

Seniors perceived that their needs are overlooked, their voices are unheard and they are treated as invisible. It was evident that seniors feel disempowered and discriminated against, because of their age.

Seniors provided practical and achievable solutions that would combat the ageist attitudes they describe, as well as enhance their ability to live and participate independently. Yet, it is impossible for the seniors' solutions to become sustainable actions without considerable reorientation of societal views, policy, legislation and resources.

It also requires a collaborative commitment between all tiers of government, non-government agencies, and the wider community.

For example, the seniors recommend intergenerational chats in schools as a way to improve respect and understanding between the older and younger generations.

Local Government has the ability through their library curriculum to coordinate this. The Federal Government have developed a National Framework for Values Education in Australian Schools that includes enhancing respect.

Yet, if the State Government chose not to implement this into their Education Queensland curriculum this recommendation would be unachievable.

Progress is already underway with each layer of Government planning for the changing age demographic.

The Townsville City Council have consulted widely with seniors in the community and are developing a Seniors Action Plan.

The Queensland Government have consulted with seniors throughout the State and have developed a Positively Ageless Seniors Strategy to take the Queensland Community through to 2020.

The Federal Government have initiated a number of reviews such as the Older Persons and the Law report to explore the needs of seniors into the future.









A national framework would be useful to draw together the work already accomplished by the different tiers of government. This would ensure cooperation and commitment to change. The framework would need to:

- O Collaboratively involve all levels of government and community
- Address inequality
- Seek to change public attitudes through promoting and protecting the rights of seniors
- Develop urban environments that enhance participation
- O Provide services that increase independence and choice
- O Intervene early where there is mistreatment toward seniors
- O Deal with and redress the most significant form of mistreatment of seniors, elder abuse
- Restore dignity and care following harm
- Be underpinned by the values of the United Nations principles for older people - Independence, Participation, Self-fulfillment, Dignity and Care

A national framework thereby would increase the wellbeing of all seniors and address the risk factors associated with elder abuse and could prevent its incidence.

"Design for the young and you exclude the old; design for the old and you include the young"

- The late Bernard Isaacs, founding Director of the Birmingham Centre for Applied Gerontology'





An example framework, heavily influenced by the Population Health model and seniors' feedback has been developed and is displayed in figure 2 below.

Seniors themselves have the wisdom and knowledge to contribute to this change and need to be given opportunities, such as the Forums, to participate in creating inclusive, age friendly places.

Solutions in this report stand on their own merits. Those with the power to create change must now do their part.

Figure 2: A model for creating dignity, safety and care for all senior Australiians

Whole population Individual

PrimarySocietal/Structural change

Some examples:

- reorientation of Federal, State and Local Government policy and regulation
- major law reform
- create age friendly environments especially in local communities and residential care facilities
- improve intergenerational and community connectedness
- human rights/healthy relationships based education in schools.

Secondary

Capacity Build/Early Intervention

Some examples:

- community awareness campaigns - create abhorrence of elder abuse
- community/legal health education
- screening for elder abuse risk factors
- skill building professionals
- fund an elder abuse clearing house to gather research and evidence to inform practice.

Tertiary

Treatment/Regulation

Some expamples:

- fund services to respond to and support victims of elder abuse
- ensure access to legal services for seniors
- provide adequate safe housing to care for seniors in crisis
- prosecute perpetrators of abuse
- provide age-friendly residential facilities.

Quarternary

Harm reduction/ Rehabilitation

Some examples:

- enhance and support seniors decision making capacity in conjunction with guardians/trustees (if required)
- education to prevent reoccurrence of abuse
- support programs
- perpetrator education programs

UN Principles for Older People

Independence Participation

Self-fulfillment

Dignity

Care







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National Association of Community Legal Centres submission to the

Office of the High Commissioner for Human Rights

Public Consultation on the Human Rights of Older Persons

2013



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1. ABOUT THE NATIONAL ASSOCIATION OF COMMUNITY LEGAL CENTRES

The National Association of Community Legal Centres is the peak national organisation representing over 200 community legal centres (CLCs) in Australia. CLCs are not-for-profit, community-based organisations that provide legal advice, casework, advocacy, information and a range of community development services to their local or special interest communities. The work of CLCs is targeted at disadvantaged members of society and those with special needs, and in undertaking matters in the public interest.

The submission has been coordinated by the Older Persons Legal Services (OPLS) which is a network of the National Association of Community Legal Centres. OPLS undertakes social justice campaigns and advocates for the human rights of Older Persons both in Australia and internationally.

The CLCs that have contributed to this submission have specialist expertise in seniors' rights issues and elder law. This submission draws on CLCs' many years of practical experience assisting clients to navigate both the Commonwealth and state or territory systems. CLCs bring particular expertise and understanding of what the barriers are to accessing justice for older people.

The National Association of Community Legal Centres has accredited NGO status with the United Nations.

2. BACKGROUND

Similar to many countries worldwide, ¹ Australia's population is aging at an unprecedented rate. Population forecasts by the Australian Bureau of Statistics predict that one quarter of Australians will be 65 years or older by 2056. ² In 2007 Australia's population was 21 million people, with 13% being 65 years or older. By 2056 Australia's population is projected to increase to between 31 and 43 million people, with 23% to 25% being 65 years or older. The number of people aged 85 years or over is also likely to increase rapidly over the next 50 years, from 344,000 people in 2007 to between 1.7 million and 3.1 million people in 2056. By then, people aged 85 years or over will make up 5% to 7% of Australia's population, compared to only 1.6% in 2007. ³

The diversity of this ageing population is likewise unprecedented. There will be huge disparities in wealth within the ageing population, with some older people being wholly in receipt of social security payments, while others will be non-pensioners, some of whom will have access to superannuation savings. For the first time, large numbers of people from diverse groups, such as people from culturally and linguistically diverse backgrounds, will comprise the older population.⁴

Rather than regarding this demographic shift as the trigger for an ageing "crisis", it can arguably be referred to as a manageable "transition" phase.⁵ For Australia, it is important that the challenges associated with an ageing population do not overshadow the unique opportunities that will arise as a result of such a shift. The "Australia to 2050: Future Challenges" report by the Commonwealth Government claims that as the population ages in Australia, the rate of economic growth will slow and that the ageing population will also significantly increase spending pressure in the areas of health, age-related pensions and aged care⁶.

However, it is also important to recognise the economic contribution of older people, who, for example, contribute a substantial amount of unpaid work to the economy through structured volunteering and informal caring.⁷ While older people need to be valued, irrespective of their ability to be part of the economy, ageist attitudes and some current laws do hinder the ability of older people to participate within employment and the broader civil society. By inhibiting employment opportunities, this reduces the tax contributions made my older people. Tax breaks available to non-pensioners are also more significant than those for pensioners.

Over the past decade, there have been a significant number of reports and inquiries into older people and the law in Australia. Most notably, the House of Representatives, Standing Committee on Legal and Constitutional Affairs in 2007 conducted an inquiry into Older People and the Law. The final report identified a number of key areas of concern including fraud and financial abuse, substitute decision making, family agreements, barriers to older Australian's accessing legal services, discrimination and retirement villages. Many of the recommendations have not been implemented. There has also been a systemic failure to implement recommendations from a number of state and territory level inquiries.

3. STRUCTURE OF THIS SUBMISSION

This submission looks at the legal and policy protections available to older people in Australia against the three areas identified by the Office of the High Commissioner of Human Rights (OHCHR):

- Information on the main challenges related to promotion and protection of the human rights of older persons in Australia.
- Information on constitutions or legislation explicitly forbidding discrimination on the basis of old age, and on the existence of specific bodies which protect against age discrimination or are mandated to protect and promote the rights of older persons.
- Information on specific national legislation, national policies, strategies and plans of action adopted to ensure the equal enjoyment of rights by older persons.

4. LIST OF SUPPPORTING ORGANISATIONS

Australian Pensioners & Superannuants League

Cairns Community Legal Centre

Caxton Legal Centre

COTA Australia

COTA New South Wales

COTA Queensland

COTA South Australia

COTA Victoria

COTA Western Australia

Darwin Community Legal Service

Eastern Community Legal Centre

Goldfields Community Legal Centre

Human Rights Network of the National Association of Community Legal Centres

Kingsford Legal Centre

Life Activities Clubs Victoria

Mid North Coast Community Legal Centre

National Association of Community Legal Centres Network of Older Persons Legal

Services

Northern Suburbs Community Legal Centre Inc.

Older People's Rights Service (WA)

Public Interest Law Clearing House (Vic)

Redfern Legal Centre

Seniors Legal and Support Service Cairns
Seniors Legal and Support Service Hervey Bay
Seniors Rights Victoria at COTA Victoria
Taylor St Community Legal Centre
The Aged-Care Rights Service
Townsville Community Legal Service
UnitingCare Elder Abuse Prevention Unit
Women's Legal Services (NSW)
Women's Law Centre of WA

5. INFORMATION ON THE MAIN CHALLENGES RELATED TO PROMOTION AND PROTECTION OF THE HUMAN RIGHTS OF OLDER PERSONS IN AUSTRALIA

5.1 Promotion

Principal challenges for promotion of the human rights of older persons arise in a number of contexts:

In Australia, the **prevalence of ageism** and ageist attitudes at the individual, community, corporate and institutional level constrict opportunities in employment and participation in private and public life – opportunities that are more readily afforded to younger people. Ageist assumptions deny older people their individuality and ability to live active, social lives; situates cognitive and physical decline as an inevitable, 'natural' outcome of the ageing process; infantalises older people; and by assuming older people cannot understand or operate new technologies, diminishes their employability and potential for digital connectedness.

Such attitudes impact on how people interact and communicate with older people, and moreover, can shape how older people perceive themselves. Ageist attitudes can influence how the medical and legal professions, in particular, treat older people. As stated, physical decline is assumed to be a *fait accompli*, of ageing. While Balmain Hospital's The STRONG Clinic challenges this assumption by focusing on the importance of appropriate exercises such as strength training for older people, ¹¹ it is the only one of its type in Australia. ¹² Within the hospital system, older people are often regarded as "bed-blockers", when a bed is occupied by an older person awaiting appropriate care arrangements to allow them to return to their home or when necessary, be placed in a suitable residential aged care facility. ¹³ Rather than encouraging older people to make full use of the health system, older people are positioned as increasing the shortage of hospital beds by "overstaying". As this does not occur for younger people, this gives the impression that people are conferred with rights and opportunities when they are young, but these very same rights and opportunities are systematically stripped away as they age.

In terms of the legal system, **ageist attitudes both give rise to legal problems and manifest within the law itself**. For example, ageism is commonly regarded as one of the main contributing factors to the financial and physical abuse of some older people. Conversely, attitudes about older people, particularly those that regard chronological age as *the* determinant of mental capacity, inform laws. In Victoria, the law confers on VicRoads a blanket discretion to issue shorter term licences for drivers over 75 years, rather than the 10 year standard period. Older drivers have reported that they are automatically receiving licences of limited length, despite good driving histories. VicRoads may also require a person to be re-tested to determine their fitness to drive. In other jurisdictions similar restrictions and the requirement for re-testing after a certain age apply, despite research clearly indicating that the driving demographic who are overrepresented in traffic accidents are young, male drivers. Such licence limitations negatively impact on the ability of older people to be independent and employed, as well as travel, care for relatives and socialise. Once again, the rights afforded to people as they age are constricted.

Media coverage also promotes ageist attitudes with alarmist headlines. The framing of such discussions, particularly stories focusing on the perceived 'drain' on resources represented by older generations and the increasing 'burden of care', encourage intergenerational division.

A **National Strategy or National Campaign** to promote and educate the community about the ageing process and the rights of older people is long overdue. Such a strategy must not just focus on rights, but also challenge ageist attitudes and provide examples of **positive ageing** that disrupt the automatic association of physical and mental decline with getting older. The peak representative body for older Australians, COTA Australia, has repeatedly recommended that the Commonwealth government implement a five-year National Positive Ageing Campaign, targeted at the broader community, rather than solely older people. As COTA Australia notes, "The design of such a strategy should be undertaken in close consultation with older people on the basis of 'nothing about us, without us', following similar approaches in Wales, the Republic of Ireland and across the European Union". Such a campaign can complement existing laws, as both are necessary to enable older people to live fulfilling lives. After all:

Anti discrimination legislation is only one part of the solution. Although it may reduce the incidence of overt age discrimination it can never on its own eliminate ageism. Ageism is deeply embedded in Australian society and there will need to be positive action to change community attitudes. Such action needs to include community campaigns through the media and community organisations addressing the issues of discrimination and actively promoting more positive images of older people.²¹

There remains inconsistent treatment across local, state and federal jurisdictions of key issues to promote self-reliance and participation in public and community life. This includes age-friendly environments, affordable housing, transport, access to technology, access to justice and sociopolitical participation. Further there is a lack of co-ordination between federal, state and local laws protecting older persons from violence and abuse. This results in a fragmented and complex legal landscape adverse to the promotion and protections of the human rights of older persons.

There is also the challenge of reaching especially vulnerable older persons such as those who are **socially isolated**, **which can be exacerbated** by living a regional, rural or remote location or identifying with a marginalised or disadvantaged demographic. There exists a need to educate family and friends who provide care in an older person's home about their responsibility to provide treatment, which is not degrading and respects the older person's right to a private life. Aged Care providers must also address the complexity of balancing institutional requirements with the right to a private life in aged care settings.

5.2 Protection

The principal challenges for the protection are also multi-faceted:

The **prevalence of ageism** and ageist attitudes at the individual, corporate and institutional levels facilitates the abuse of older people, inhibits support for reform and limits the opportunities available to older people.

Attitudes and underrepresentation can lead to the **inability of older people** to participate and achieve outcomes in the public policy arena, especially given the primacy of their interests in the population demographic.

The lack of a comprehensive constitutional and national human rights framework have resulted in the ad hoc development of policy and laws for the protection of the rights of older persons.

The **complexity of existing laws** in many key areas of law including but not limited to Social Security, Veterans Affairs, Aged Care, Guardianship and Administration, Succession, Powers of Attorney and Health Directives, Residential Tenancy and Retirement village laws inhibit access to protections for older people.

The **interplay between federal and state laws** and inconsistent treatment of key issues across jurisdictions such as succession, guardianship, powers of attorney and health directives, and discrimination laws further limit access to existing protections.

The lack of accessible, specialist, and competent practitioners in private and public legal practice deny access to justice for older persons.

The **absence of specific laws**, including but not limited to elder abuse and financial exploitation deny civil redress and policing assistance for older victims of abuse and exploitation.

Ultimately, the Australian human rights framework is fragmented and complex; a patchwork of legislative, policy and institutional frameworks arising from historic approaches which are inadequate to address the human rights challenges that face people as they age.

There is a need for leadership at the United Nations and domestic level to ensure the development of policy and laws that promote and protect older person's human rights, challenge ageist attitudes and encourage positive ageing across the lifespan.

6. INFORMATION ON CONSTITUTIONS OR LEGISLATION EXPLICITLY FORBIDDING DISCRIMINATION ON THE BASIS OF OLD AGE, AND ON THE EXISTENCE OF SPECIFIC BODIES WHICH PROTECT AGAINST AGE DISCRIMINATION OR ARE MANDATED TO PROTECT AND PROMOTE THE RIGHTS OF OLDER PERSONS

6.1 Constitutional Protections

There are no constitutional protections against age discrimination.

6.2 Federal Legislation

Age discrimination is prohibited by several federal laws. ²² The *Age Discrimination Act 2004* (Cth) protects individuals across Australia from discrimination on the basis of age in many parts of public life, including employment, education, accommodation and the provision of goods and services. The *Fair Work Act 2009* (Cth) provides specific protections in relation to employment.

However there are a multitude of exceptions in federal law, where an older person is not protected from discrimination. These include situations where the discrimination is carried out by a voluntary, charitable or religious body, for example where a charitable organisation offers benefits, facilities and services to members. Nor do the laws protect older persons when the discrimination is done in direct compliance with other laws, for instance those to do with taxation, Commonwealth employment programs, health, migration, citizenship, pensions, allowances and benefits.²³

The Senate Inquiry into the (then) *Age Discrimination Bill 2003* (Cth) incorporated a dissenting report that highlighted a range of concerns, including the use of a "dominant reason" test, exemptions that were too wide and unjustifiable and the absence of age specific harassment provisions.²⁴ It is widely considered that "[C]ompared to other federal anti-discrimination legislation the Age Discrimination Act contains the broadest permanent exemptions to the protections offered by the Act."²⁵ The *Age Discrimination Act 2004* (Cth) is the weakest of its cohort of federal laws.

The impact of this on older persons is that they are not adequately protected from age discrimination, harassment and vilification in many areas of public and private life. In turn this perpetuates prevailing ageist attitudes at many levels of community and society. Where the overriding federal law allows ageism, it provides a poor role model for our community's actions.

6.3 State and Territory Legislation

Age is included as a prohibited basis for discrimination in all of Australia's state and territory jurisdictions.²⁶ As is the case in federal law each jurisdiction has age-specific exceptions.²⁷ These include instances of discrimination involving genuine occupational requirements, benefits and concessions, recreational tours and accommodation, clubs, sport, superannuation, provision of insurance and credit applications.

Like their federal counterparts, state and territory laws provide sub-optimal protections for older people who are subjected to ageism, age-based harassment, age-based vilification and discrimination. The low numbers of complaints (outside the work area) illustrate the limited reliance older persons place on these laws to combat ageism.

Victoria, however, does provide additional protections to older people through the *Charter of Human Rights and Responsibilities Act 2006* (Vic). The Charter outlines the basic human rights of all people in Victoria, however there is no explicit reference to the rights of older people. In a recent report, older people reported a general lack of awareness about the Charter and suggested that a campaign was required to raise awareness about its existence and usage.²⁸

6.4 Anti-discrimination Bodies

At federal and state and territory level, age discrimination legislation is overseen by specialist Boards or Commissions²⁹ and subject to final resolution by Tribunals or Courts.³⁰ However the use of these bodies by those who have experienced age discrimination is relatively infrequent. Federal age discrimination laws are under-utilised, with age discrimination enquiries to the Australian Human Rights Commission totalling less than 5 per cent (786 of 17,047) of complaints received.³¹ The number of formal complaints of age discrimination lodged with the Commission was similarly low, totalling only 7.5 per cent (196 of 2,610) of complaints.³² The majority of these complaints were about age discrimination in employment.³³ In state and territory jurisdictions the number of age discrimination complaints made is slowly increasing over time, but the number of complaints received also remains relatively small.³⁴

Bodies that oversee age discrimination laws at all levels of government acknowledge that more work needs to be done to educate, promote and inform the community about age discrimination laws.³⁵ The challenge is twofold: ensuring that the laws are strengthened to achieve equality with others areas of discrimination law; and promoting the use of the laws to resolve individual and systemic concerns.

7. INFORMATION ON SPECIFIC NATIONAL LEGISLATION, NATIONAL POLICIES, STRATEGIES AND PLANS OF ACTION ADOPTED TO ENSURE THE EQUAL ENJOYMENT OF RIGHTS BY OLDER PERSONS

7.1 Violence and Abuse

There are no federal laws particularly aimed at protecting older people from **violence and abuse**. State and territory family and domestic violence laws provide limited responses and remedies in respect of elder abuse and financial exploitation.³⁶ These laws lack any properly adapted provisions. In some instances, crimes including assaults become "aggravated" at law where they are committed against older or infirmed people.³⁷ These laws, however, remain patchwork and fail to protect older people from elder abuse in a consistent manner. The Australian Institute of Criminology undertook research in this area in the early 90s, however it is yet to return to the issues of elder abuse and exploitation. ³⁸ Much of this research remains contemporaneous, especially studies seeking to identify the sources of elder abuse.³⁹

In addition to the absence of legislative protections at the federal level, a national strategy to address elder abuse is yet to be developed. States and territories have taken a lead approach, however the extent of the resources given to support these strategies differs across jurisdictions. While Queensland does not have a dedicated strategy, elder abuse has been a long-standing identified issue, resulting in the establishment of the Elder Abuse Prevention Unit in 1997, which remains tasked with educating the community and services about elder abuse, undertaking policy work, and ensuring coordinated responses exist across government agencies.⁴⁰

Other jurisdictions that have taken a lead approach include the Australian Capital Territory (ACT), New South Wales (NSW), Victoria and Tasmania. In 2007, the NSW Government introduced interagency protocols to strengthen and streamline how government agencies recognise and respond to elder abuse. Two years later, the ACT, Victoria and Tasmania each released a prevention policy, similarly focussed on government responses. In 2012, Victorian released a complementary, follow-up document outlining the government's priorities and action plans to address elder abuse, particularly within a health, rather than a legalistic, framework. Again, the patchwork nature of these approaches and the fact that a strategy or guideline has not been implemented across all jurisdictions, demonstrates that there is a role for the Federal Government to take in ensuring a dedicated, national strategy is implemented.

While a national, dedicated elder abuse prevention hotline does not exist; some states and territories have established a central contact number. Queensland⁴⁴ and Victoria⁴⁵ were two of the first states to establish a dedicated telephone hotline providing information, support and referrals for any individual experiencing elder abuse. Tasmania subsequently launched a hotline in 2012,⁴⁶ while a hotline and resource unit was announced for New South Wales in 2012.⁴⁷

7.2 Social protection

The federal Government argues that **social protection** for older Australians is based around a three-pillar system: social security age pension, compulsory superannuation and voluntary superannuation. Relevant laws include the *Social Security Act 1991* and the *Veterans' Entitlements Act 1986*. The adequacy of the Age Pension has been a key political controversy for some time, culminating in the 'Harmer Pension Review Report' in 2009. The rate of the Age Pension was raised in September 2012 as part of the Government's 'Secure and Sustainable Pensions Package' in the 2009-2010 Federal Budget. While the age pension is currently indexed twice per year in accordance with increases in the cost of living, up to 34.9% of older people aged over 64 years remain at risk of poverty in Australia. Some peak bodies have called for the age pension to be further increased. It is also notable that the age at which an older person qualifies for an Age Pension is climbing. Age Pension age for men is currently 65 years and for women 64.5 years (rising to 65 years on 1 July 2013). The general qualifying age for the Age Pension will increase from 65 in 2017 to 67 by 2023.

Given the scarcity of employment opportunities for people aged 60 years plus and the documented barriers to employment such as workers compensation age limit cut-offs,⁵⁴ older people who cannot find employment *and* do not yet quality for the Age Pension, are further mired in poverty due to inadequacy of the unemployment benefit, the Newstart Allowance. At the time of writing, a recipient of the Age Pension who is single receives \$712 fortnightly,⁵⁵ while a Newstart recipient is paid considerably less at \$492.60 fortnightly.⁵⁶

Further, the Age Pension is indexed at a higher rate than the Newstart Allowance, and recipients receive a Pensioner Concession Card, which entitles them to pay less for prescription medicines under the Pharmaceutical Benefits Scheme as well as render them eligible for reduced property and water rates, energy and telephone bills, public transport fares and vehicle registration. An older person who is receiving the Newstart Allowance might be granted a Pensioner Concession Card, but only after they have been on the payment for nine months.⁵⁷ Adding further complexity to this, there is no consistent system of concessions for older persons. Each state and territory has its own scheme.

Unless the Newstart Allowance is increased, it will be decrease further relative to other social security payments. The Organisation for Economic Co-operation and Development (OECD) estimates that by 2040, the Newstart Allowance will be less than half the amount of the Age Pension. Pressure by peak welfare groups has been placed on the Government to increase the Newstart Allowance, following the OECD report and recommendations contained in the 'Australia's Future Tax System' report (known as the 'Henry Tax Review'). As part of the 2012-2013 Federal Budget, an Income Support Bonus was announced for Newstart Allowance recipients of \$210 for single people per year, to be paid after 20 March 2013. With this amount equating to a \$4 on average increase per week, peak welfare groups continue to lobby for the rate of the Newstart Allowance to be raised to at least \$50 per week to meet the cost of living.

7.3 Housing

Accommodation is generally regulated by generally state and territory laws. These laws cover residential tenancies, ⁶³ retirement villages, ⁶⁴ residential parks⁶⁵ and public housing. ⁶⁶ Public housing is the subject of a Commonwealth/State agreement. ⁶⁷ Many older people are experiencing housing stress due to the lack of affordable housing stock, particularly women due to a complex range of factors from increased child-rearing responsibilities through to low incomes, forced early retirement, divorce and less superannuation. ⁶⁸ In 2006, 7,400 people aged 64-years-old and above were reported as homeless, an increase of 23% since 2001. ⁶⁹ Both the availability and suitability of public housing stock is a critical issue for older people who are frail and/or disabled and require accessible premises. ⁷⁰

7.4 Legal Capacity

There are no federal laws relating to legal capacity or mental health. In respect of legal capacity, each state and territory has its own distinct laws relating to systems of substituted decision making.⁷¹ Each state and territory also has its own mental health laws.⁷² This nationally inconsistent regime for dealing with legal capacity, mental health and substituted decision-making is a critical area for law reform.

7.5 Aged Care

Federal laws such as the *Aged Care Act 1997* (Cth) provide the regulatory and continuous quality improvement framework through which aged care services are funded. Services must meet accreditation standards focussed on optimising resident health and personal care, promotion of personal and civil rights and the proving a safe physical environment.

The Australian Productivity Commission's 2011 report, 'Caring for Older Australians'⁷³ noted, "[o]ver one million older Australians receive aged care services. The range and quality of these services have improved over past decades, but more needs to be done."⁷⁴ Future challenges include the increasing numbers and expectations of older people, a relative fall in the number of informal carers, and the need for more workers. By 2050, over 3.5 million Australians are

expected to use aged care services each year.⁷⁵ Key weaknesses of the system are that it is difficult to navigate. Services are limited, as is consumer choice. Quality is variable. Coverage of needs, pricing, subsidies and user co-contributions are inconsistent or inequitable. Workforce shortages are exacerbated by low wages and some workers have insufficient skills.⁷⁶

In 2012, the AHRC published 'Respect and Choice - A human rights approach for ageing and health', which addresses many important issues in this area. The Commission noted "[t]he aged care reform package can be strengthened by incorporating a human rights approach to the delivery of services for older Australians. The aim would be to promote people-centred decision-making and real change in organisational culture."

To an extent, this is occurring, but needs to be strengthened further. The 'Living Longer, Living Better' aged care reform package, introduced in 2012, is a decade-long plan that seeks to support older people to 'age in place' at home, in part by giving older people greater choice and control over home care packages.⁷⁹ Consumer-directed care, which allows the consumer to choose the type of care and service provider, will be trialled in residential aged care settings.⁸⁰

7.6 Disability

Consumer-directed care is also a central component of the Australian Government's proposed National Disability Insurance Scheme (NDIS), which will provide long-term support to people with a permanent disability. However, older people 65-years-old and above will be ineligible to access to the scheme due to their age. As COTA Australia noted in their submission on the scheme's draft legislation, the NDIS makes a distinction between disability acquired as part of the aging process and disability acquired at any other time during an individual's life.⁸¹ This arbitrary distinction will mean older people cannot access much needed services and funding. It typifies the widespread disconnect between the health, disability and aged care systems.

7.7 Access to justice

Access to justice issues for older people in Australia are multiple and were well summarised by the AHRC in their submission to a 2006 Federal Parliament Inquiry, they include:

- Technological barriers, particularly for telephone and web based services
- A lack of awareness regarding where to obtain legal information and assistance
- A lack of appropriately-communicated legal information
- The high cost of legal services
- · A lack of interest by some legal practitioners in older clients
- Potential conflicts of interest when legal practitioners for older people are arranged by family members
- Difficulties in accessing legal aid, including restrictive eligibility tests
- · Lack of availability of legal aid for civil disputes
- Lack of specialised legal services for older people, particularly in rural, regional and remote areas
- Lack of resources in community legal centres to tailor their services to the needs of older people.⁸²

While specialist legal services for older people exist across the states and territories, ⁸³ these are insufficient for an ageing population. The above barriers render the legal system inequitable and mean older people cannot adequately understand or enforce their rights. The outcomes achieved by OPLS members validates the need for increased funds for community legal services for older people. The Senate Report recommended "the Australian Government increase funding to the Community Legal Services Program specifically for the expansion of services, including outreach services, to older people by Community Legal Centres."

7.8 National Human Rights Action Plan

In the absence of a constitutionally entrenched Bill of Rights or a federally legislated Bill of Rights, the Commonwealth government developed a National Human Rights Action Plan in 2012. While older people are mentioned in the Action Plan, the focus is primarily on aged care under the

Living Longer Living Better reforms, with actions also relating to elder abuse, financial security and freedom from age discrimination under existing laws. The Action Plan does state the Commonwealth government will continue to participate in the Open-Ended Working Group, and will explore the feasibility and necessity of further instruments and measures.⁸⁵

7.9 Health Care and Palliative Care

Health care for older people is one of the major challenges faced by Australia. This includes home care, community care and hospital care. The real challenge to health care for older people is summarised by the Intergenerational Report:

As the population ages, more people will fall into the older age groups that are the most frequent users of the public health system. Combined with population growth, this will play an important role in increasing future health costs. From 2009–10 to 2049–50, real health spending on those aged over 65 years is expected to increase around seven-fold. Over the same period, real health spending on those over 85 years is expected to increase around twelve-fold. 86

A key health care concern for older people is ensuring appropriate end of life care is available, and having the option to die in the familiar surroundings of home. Despite the majority of people expressing a desire to die at home, only 16% do – the remainder die in hospitals and aged care facilities. Annually, there are up to 72,000 people with palliative care requirements in Australia.

The Australian Government funds palliative care, but service delivery is the responsibility of the states and territories. While 'The National Palliative Care Strategy' is meant to guide service delivery, ⁸⁹ the quality and availability of care differs across jurisdictions. ⁹⁰ As Palliative Care Australia, stated in their submission to the 2012 Senate inquiry, "Palliative care in Australia is nothing short of a lottery, predominately determined by your location, but also affected by your diagnosis, the education of your health professional, cultural background, and your age". ⁹¹ Recommendations addressing these concerns were made in the Senate's final report. ⁹²

Similarly, Allen and Kahn recently indicated that:

There are many barriers which limit the effective provision of palliative care to those in need. Four salient themes were identified overall: communication between organisations and professionals; inadequate education of health care professionals; lack of knowledge surrounding palliative care; and insufficient pain management. Significant knowledge deficits were highlighted amongst GPs and aged care facility carers regarding palliative care. Future health promotion projects could focus on education within aged care facilities and general practice. Addressing these barriers is an integral step in furthering the effective provision of palliative care in Australia. 93

As a result of potential reductions in to the level of funding made available to the states and territories through the National Health Reform Agreement and the conclusion of a partnership between the Australian Government and the various jurisdictions, people with palliative care needs will be negatively impacted. Palliative Care Australia reports that beds will be reduced, services such as palliative care outpatient clients will close or downsize and trained primary and allied health staff will be lost. It is anticipated this will result in more people dying in hospital, rather than being supported in their homes. Hence, the options available to older people during the final stage of life will be limited, much like their ability to exercise self-determination.

7.10 Differences in the ageing experience

The intersectional needs of older people who are Aboriginal and/or Torres Strait Islander, from a culturally linguistically diverse background (CALD) and/or identify as gay, lesbian, bisexual, transgender or intersex (LGBTI) need to be recognised and responded to by government and service providers. As part of the 'Living Longer, Living Better' aged care reform package, national strategies have been developed for both CALD and LGBTI older people, recognising the need for appropriate, respectful and discriminatory-free services. 94 A national ageing strategy does not

exist for older Aboriginal and Torres Strait Islander peoples, but 'people from Aboriginal and Torres Strait Islander communities' are recognised in the *Aged Care Act 1997* (Cth) as a "special needs group", as are CALD older people. ⁹⁵ LGBTI people are listed as a "special needs group" in the Allocation Principles 1997 (Cth) made under the Act. ⁹⁶

For older Aboriginal and/or Torres Strait Islander peoples, the differences in the ageing experience need to be framed against lived experiences marked by prejudice, discrimination and successive government policies from dispossession through to assimilation. It is important that the definition of 'older' is broad enough to include Aboriginal and/or Torres Strait Islander peoples. Due to the 17-year life experience gap, 50 years is often considered 'older' for Aboriginal and/or Torres Strait Islander peoples, particularly in the context of government-provided services, such as Home and Community Care. 97 Currently, the life expectancy for men is 59 years, while for women it is 65 years. In comparison, the life expectancy for non-Aboriginal and Torres Strait Islander peoples is 78 years for men and 83 years for females. 98

While the experiences of older Aboriginal and/or Torres Strait Islander people cannot be homogenised, and it needs to be recognised that older people live in metropolitan, regional, rural and remote areas, a number of issues and needs have been identified in the literature. Such barriers to care experienced by older Aboriginal and/or Torres Strait Islander peoples are a fear of institutionalisation within aged care facilities arising from the Stolen Generations, when children were forcibly removed from their families and communities; and the need for service providers to be aware of these social, economic and historical factors that contribute to ill-health and shortened life expectancy. Identified needs include the need to build the capacity for Aboriginal-identified aged care providers to deliver services, and the need for aged care providers to assess whether services are delivered in a culturally safe manner, for example, by recognising the importance of retaining involvement with culture and kinship relationships.

In the report "The Ageing Experience of Australians from Migrant Backgrounds", National Seniors Australia identified a number of ageing issues for the CALD community. ¹⁰⁰ In 2006, those born in non-English speaking or CALD countries were 19% of the over 50 population. ¹⁰¹ The report found that ethnicity, cultural factors and migration experiences may have some influence on well being and ageing experience. ¹⁰² In addition to aged and health care systems, family and ethnic community supports were identified as important factors for health, economic and social well being of CALD older people. ¹⁰³ Overall, it was found that more research was needed in this area. They said: "[B]ehind the well-worn phrase of 'an ageing Australia' lies a wealth of complexity. Just as ageing is a unique journey for all of us as individuals, so too is the ageing experience of people from immigrant backgrounds. So far, research into these differences has been fairly limited." ¹⁰⁴

Older people who identify as LGBTI have experienced prejudice, discrimination, interventions and sanctions from government, legal, medical and religious institutions throughout their lives. Much research has been undertaken on how elder abuse is sometimes a continuation of these histories. For example, nursing staff refusing to provide care on account of a person's sex, sexuality or gender diversity, avoiding physical contact and making assumptions about HIV status. For some LGBTI older people, this can give rise to self-neglect, meaning the individual is reluctant to engage services and reveal their identity for fear of discrimination.

The dedicated, LGBTI national strategy seeks to ensure LGBTI-identifying people experience ageing in an inclusive manner. For example, the first goal is ensuring LGBTI older people experience equitable access to appropriate ageing and aged care services. The realisation of this goal remains threatened by the fact that religious organisations that receive government funding to provide aged care services are exempt from discrimination laws. Such organisations, as a consequence, can discriminate against accepting someone who identifies as LGBTI as a resident. Considering religious organisations run a significant number of aged care facilities, this means older people who are LGBTI continue to face discrimination as they age. While the exemption remained in the *Exposure Draft of the Human Rights Anti-Discrimination Bill*

2012 (Cth),¹⁰⁸ which seeks to consolidate the five existing pieces of discrimination legislation, the recent Senate Inquiry recommended that the exemption be removed.¹⁰⁹ Lobby groups during the Senate Inquiry into the consolidation have advocated removing the exemption, in the lead up to the Bill being debated in the Australian Parliament.¹¹⁰

7.11 Policy Frameworks

States and territories have targeted policy frameworks. ¹¹¹These policy frameworks suffer from a lack of national leadership and coordination.

8. CONCLUSION

With the number of people over 60 in the rise both in Australia and overseas, it is imperative that the rights of older people are explicitly recognised in international law. Although the core international human rights treaties cover all people, including older persons, it is apparent that some rights that are well-respected when people are young are not well protected in their older age. It is also acknowledged that while laws can protect human rights, challenging ageist attitudes needs to remain in focus, as ageist attitudes can and do give rise to legal problems, such as elder abuse and workers compensation laws that disadvantage older people from participating in employment and volunteering opportunities.

Both domestically and internationally there has been a groundswell of support among NGOs and NHRIs for a Convention on the Rights of Older Persons. Susan Ryan AO, the Australian Age Discrimination Commissioner recently said:

A new convention would strengthen the position of civil society and policy makers to achieve reforms in those many countries where older people have no protection of their basic rights. In these places, the basics of food, housing, income, and health care are not available to older people and the consequent suffering is terrible. My view of Australia as a good international citizen, able to offer leadership in improving the lives of older people, has led me to propose Australia's support for the convention. 113

While Australia's support for a Convention would be demonstrative of being a "good international citizen", such an instrument would also protect the human rights of older citizens in this country. As discussed throughout this submission, there are significant gaps in Australian laws and policies regarding older people's rights, particularly in respect of violence and abuse, social security, housing, legal capacity, aged care, access to justice and health care. These gaps are often particularly pronounced for diverse groups like Aboriginal and Torres Strait Islander peoples, people from culturally and linguistically diverse backgrounds, people with disabilities and LGBTI people, not withstanding socioeconomic differences within the ageing population.

NACLC supports the drafting of a Convention on the Rights of Older Persons to ensure that all people are able to lead dignified, secure and participatory lives, regardless of their age.

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