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

Contact:

Julia Hall
Executive Director
National Association of Community Legal Centres

W. www.naclc.org.au

Vivienne Campion
Convenor
Network of Older Persons' Legal Services
National Association of Community Legal Centres

TABLE OF CONTENTS

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&issue=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&issue=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

[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.[4] 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.

[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/6E29D85E65EF32FACA25770300036CB1/$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

[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.

[11] [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