PARLIAMENT OF AUSTRALIA

HOUSE OF REPRESENTATIVES STANDING COMMITTEE ON HEALTH, AGED CARE AND SPORT

INQUIRY INTO THE QUALITY OF CARE IN RESIDENTIAL AGED CARE FACILITIES IN AUSTRALIA

SUBMISSION BY TOWNSVILLE COMMUNITY LEGAL SERVICE INC

13 February 2018

Background to Submission

1 Townsville Community Legal Service Inc. (TCLS) is a community-based, non-profit legal centre. TCLS was established in 1991 as a voluntary service and funded by the Commonwealth in 1992. TCLS currently receives funding from Queensland and Commonwealth Governments. The Queensland Government funds TCLS to provide a specialist Seniors Legal and Support Service (SLASS). The SLASS focuses on older persons at risk of or suffering elder abuse. TCLS has over a decade of dealing with older persons experiencing and affected by elder abuse.

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3 TCLS notes the terms of reference of this Committee as follows:

> "The Standing Committee on Health, Aged Care and Sport will inquire into and report on:
>
> The incidence of all mistreatment of residents in residential aged care facilities and associated reporting and response mechanisms, including the treatment of whistle blowers;
>
> The effectiveness of the Australian Aged Care Quality Agency, the Aged Care Complaints Commission, and the Charter of Care Recipients' Rights and Responsibilities in ensuring adequate consumer protection in residential aged care; and
>
> The adequacy of consumer protection arrangements for aged care residents who do not have family, friends or other representatives to help them exercise choice and their rights in care." (House of Representatives, 2018)

4 This submission highlights some key issues to be considered in the context of the terms of reference.

Term of Reference 1

The incidence of all mistreatment of residents in residential aged care facilities and associated reporting and response mechanisms, including the treatment of whistle blowers

5 A number of important contextual points need to be made about the first term of reference:

- There is significant work to be done on key definitional issues;
- We have a very limited understanding of prevalence and incidence; and
- There are substantial problems with absent or misaligned reporting structures.

Key Definitional Issues

6 Definitions are vitally important to this reference. Some work has already been done to conceptualise elder mistreatment/abuse within a contemporary Australian context. We refer particularly to the recent work of the Australian Law Reform Commission (ALRC), inquiries into family violence and elder abuse in Queensland, New South Wales and Victoria and the ongoing work of the Australian Institute of Family Studies (AIFS).

7 'Elder Mistreatment' is not a term of art. It is used interchangeably with 'elder abuse'.

8 'Elder abuse' is the preferred term in all areas of relevance including research and public policy and legislative interventions. The United Nations and the World Health Organization use the term 'elder abuse'.

9 Institutional abuse of older persons or 'institutional elder abuse' is an accepted subset or type of elder abuse. (McDonald et al, 2012) Despite this, there is no accepted, authoritative definition of institutional abuse of older persons. (McDonald et al, 2011) Institutional abuse is often described as mistreatment or maltreatment or abuse of a person by or from a system of power. (Powers, 1990) Put simply, it is abuse within an institutional setting.

10 In our submission, abuse within residential aged care services (RACS) is institutional elder abuse. The WHO fact sheet on 'elder abuse' suggests:

> "Abusive acts in institutions include physically restraining patients, depriving them of dignity (for instance, by leaving them in soiled clothes) and choice over daily affairs; intentionally providing insufficient care (such as allowing them to develop pressure sores); over- and under-medicating and withholding medication from patients; and emotional neglect and abuse." (WHO, 2018)

11 Subsets of institutional abuse are said to include 'overt abuse', 'program abuse' and

'systems abuse'. (Powers, 1990)

12 RACS involvement in elder abuse is twofold. RACS sometimes commit abusive acts – they are 'the circumstance'. RACS are also the setting for various forms of abuse and violence, such as that perpetrated by family members, co-residents and staff. In some cases the institution may be both circumstance and setting, such as where the institution is complicit in, or party to the abuse.

13 In 'overt abuse' cases, the abuse might include overt financial, physical, sexual, or emotional abuse by an institutional actor or agent such as a staff member or contractor. As noted, the potential actors in cases of overt abuse are wide- ranging.

14 In cases of 'program abuse', the institution itself may cause harm by its acts or omissions, such as operating below acceptable conditions or improper use of its power to modify the behaviour of person. Complaints to the Aged Care Commission system generally reflect a range of overt and program issues, including breaches of the *Aged Care Act* 1997 and related instruments such as the Charter of Care Recipients' Rights and Responsibilities – Residential Care.

15 'Systems abuse' involves an entire care system that is stretched beyond capacity, and causes maltreatment through inadequate resources.

16 In reality, many types of institutional elder abuse appear to be hybrids of overt and program abuse.

17 There is no accepted Australian definition of elder mistreatment, elder abuse or institutional elder abuse. Recent inquiries such as the Royal Commission into Institutional Responses to Child Sexual Abuse have grappled with defining and contextualizing abuse within institutional settings.

18 Importantly, the AIFS is in the process of developing a rigorous Australian definition of the term 'elder abuse' or 'abuse of older people'. AIFS and partners seek to develop an evidence-based, nationally acceptable and usable definition of elder abuse. The breadth of the definition is very much a dynamic issue at present. This Committee's deliberations and findings are directly relevant to that process.

19 In the context of abuse within RACS, limited research has been done in Australia. This is notwithstanding a history of publicly aired examples of institutional elder abuse from Riverside through to Oakden.

20 It isn't clear how AIFS will incorporate institutional elder abuse as part of their ongoing work, though it has been suggested as an area of targeted research.

21 It is worth briefly mentioning the current work of the international community. The United Nations Open-ended Working Group on Ageing (OEWGA) is the UN's principal body considering the human rights of older persons. OEWGA is poised to look at older persons' human rights in long-term care in July 2018.

22 At its last session (2017) OEWGA received inputs from member states, national human rights institutions and civil society on the issue of violence, abuse and neglect in 2017. The Australian Government's submissions on violence, abuse and neglect noted:

> "b) Service providers, researchers and advocates consider that older persons who are socially isolated, have reduced cognitive capacity, are in poor health or who have a disability, who have a history of family violence and who are 'old-old' may be at higher risk of abuse." (Australian Government, 2017)

23 In 2018 OEWGA will formulate normative content on the right to freedom from violence, abuse and neglect. It will use the inputs of member states, National Human Rights Institutions (NHRIs) like our Australian Human Rights Commission and members of civil society. The inclusion of long-term care as a setting for violence, abuse and neglect is not controversial. The interrelationship between these two areas of interest for older persons' human rights is obvious. It is likely that the right to Freedom from Violence, Abuse and Neglect will mention long-term care. Conversely, the Right to Long-Term Care will likely articulate that such care must be free from violence, abuse and neglect.

24 In overseas jurisdictions, the elder abuse within aged care system has been subject of significant research. Townsend's Landmark Study '*The Last Refuge*' published in 1962 is often credited as an earlier pioneering work. The complexities uncovered by researchers cannot be understated. For example a Study on the sexual victimization of older women living in nursing homes in the United States revealed multiple types of abuse and perpetrators within that setting. (Teaster et al, 2015)

25 Similarly in Australia, studies like Norma's Project are just beginning to reveal the true nature of what can occur within institutional care.

26 Research across institutional abuse suggests the predominance of perpetrators and abusers are systemic actors such as employees. (McDonald et al, 2012) However, this clearly depends on how we define the circumstances and setting of institutional elder abuse. Actually, the potential perpetrators within an institutional setting are wide-ranging. They can include family members (including co-residents such as spouses), co-residents and visitors. See Diagram at Annexure 1.

27 There are many complexities about how types of violence, abuse and neglect overlap within RACS. For example, an older woman experiencing violence from her co-resident husband is very different from an older man suffering financial abuse from visiting relatives or family members which is different to an older women sexually abused by a staffer.

28 We need to understand that RACS are a place where domestic or intimate partner violence, family violence, interpersonal violence and elder abuse all coalesce within an institutional setting.

29 It is important to note that those living in care institutions (such as RACS) are more vulnerable to abuse and are more likely to have some degree of cognitive impairment and a disabling condition. (McDonald, 2012) Residents of RACS are often frailer and more dependent on others for care and support.

30 Government and Parliamentary Inquiries have regularly uncovered examples of institutional elder abuse, but their findings have rarely named the phenomenon as such. For example, the recent New South Wales Parliamentary Inquiry into Elder Abuse recounted the shock at the example of a man demeaned and treated roughly by nursing home staff. Yet, the same Inquiry dedicated minimal time to the issue because, "[I]t considers, however, that abuse of older people in aged care is an area of Commonwealth Government responsibility and thus outside the scope of this inquiry." (NSW Parliament, 2016)

31 The NSW Government Committee's comments highlight that the mythology of Commonwealth responsibility has been a barrier to proper regulation of all aspects of institutional elder abuse.

Prevalence and Incidence

32 Prevalence studies are essential to identify how many older adults are mistreated in institutions at a given point in time or during a given time frame. (McDonald et al, 2012) A significant limitation of most elder abuse prevalence studies is that they do not include older persons in institutional care. (Kaspiew et al, 2015) Similarly, considering prevalence rates, the WHO noted:

> "Crucially, these rates exclude both older adults with cognitive impairments and those living in nursing homes or long-term care facilities." (WHO, 2015)

33 The WHO noted the possible impact of this exclusion:

> "For example, one review found that psychological abuse of older adults with dementia ranged from 28% to 62%, and physical abuse affected 3.5% to 23% of older adults with dementia (203)." (WHO, 2015)

34 Accordingly, prevalence studies into elder abuse have rarely captured cases of institutional elder abuse. Therefore, most prevalence studies can only reflect a partial view of the extent of elder abuse. (Kaspiew et al, 2015) Prevalence studies have principally focused on private households:

> "Studies of the prevalence of elder abuse have been conducted in several countries, including Canada, the UK, Portugal, Ireland, Spain, Israel and the USA. ... In each of the listed prevalence studies, the focus was on older people in private households who were deemed to have the cognitive capacity to participate in the study. Older people living in residential aged care facilities and those who lived in private dwellings but did not have sufficient cognitive capacity to discuss their circumstances and experiences in an interview were excluded from the estimation of the prevalence of elder abuse in these studies." (Kaspiew et al, 2015)

35 This situation is concerning given that older people living in RACS, and those living in private dwellings who lacked the capacity to be interviewed may be at greater risk of abuse than the rest of the population of older persons. Their inclusion might give us a very different picture of elder abuse and pending national research should address this gap.

36 There are recent studies of great interest including the work of Ibrahim and his colleagues that catalogued a range of preventable deaths in RACS. His work shows what is possible where we have reporting systems that align with definitions of abuse.

In that case the research was limited to the sorts of deaths currently reported to Coroners.

Reporting and Response

37 As noted to the ALRC elder abuse Inquiry, several reporting systems need reform. These include restrictive practices, serious incident reporting, and assessment of staff suitability and coronial reportability.

Restrictive Practices Reporting

38 Concerns with the use of restrictive practices (also called restrictive interventions) within RACS are long-standing. The Public Advocate of Queensland has reported that "[I] t is concerning that the inappropriate use of restraints in RACS in Australia has been a factor in the deaths of some people upon whom the restraints were applied..." (Burgess, 2017)

39 The Administrative Appeals Tribunal (the AAT) equated restrictive practices to breaches of the *Aged Care Act* 1997 standards owed to residents under that legislative scheme. In *Saitta Pty Ltd v Secretary, Department of Health and Ageing*, the AAT found:

> "[122] A resident was observed an hour after breakfast had concluded sitting in the dining room (not at the table) with a lap belt restraining her. It was Dr Lett's oral evidence that, as well as restraining the resident from undertaking normal activity, this is also a dangerous practice as the resident may try to wiggle out causing skin to tear or bruise or the resident to fall and injure him/herself. This is an example of an incident where even it was a once off occurrence the fact of it happening is strongly indicative of serious non compliance, as the restraint could easily be removed when the resident had finished her meal. The Tribunal is satisfied that there is non-compliance with Standard Pt 3 Item 3.5 (residents to be assisted to achieve maximum independence), Item 3.6 (right to dignity) and Standard Part Item 4.4 (management actively working to provide a safe and comfortable environment consistent with residents' needs)."

40 The decision in *Saitta v Secretary, DHA* shows how procedures such as restrictive practices might amount to institutional elder abuse. The Aged Care Complaints Commissioner would no doubt deal with many examples of this in that system.

41 The absence of regulatory frameworks for the use of restrictive practice and interventions in RACS is concerning and subject of numerous recommendations for reform. (Mitchell 2015, ALRC 2017, Burgess 2017) The key legislation governing the

activities of federally funded aged care services in Australia — the *Aged Care Act 1997* (Cth) — does not prohibit, legislate for, or regulate the use of restrictive practices to manage the challenging behaviours of some aged care residents. (Burgess, 2017)

42 There have been many calls for regulation including from the author, the ALRC and the Public Advocate of Queensland.

43 The differential treatment of older persons in untenable. Is the treatment of young people in nursing homes (YPINH) monitored under NDIS and state disability services standards and principles or are they treated differentially, though clearly not ideally given their placement in nursing care. It isn't a statement in support of YPINH, rather an example of how older persons are treated differently in this important area of public policy. Restrictive practices are restrictive practices wherever they are used.

Serious Incident Reporting

44 The ALRC and many others have called for reform in this area. At present the system contains far too much discretion around when and what to report. The regime has some serious limitations. What is reportable is weakened in two keys areas:

- Assaults between staff and residents; and
- Assaults between residents and residents.

45 Between staff and residents, any unreasonable use of force is only notified where a staff member determines that an action constitutes unreasonable use of force. Between residents, the legislation allows discretion to not report if a resident with an assessed cognitive impairment perpetrated the alleged assault and certain steps are taken. This includes an unlawful sexual contact. (Department of Social Services)

46 There has been significant criticism of the reporting regime. Barnett and Hayes suggest that reports made "may underestimate significantly the level of abuse, neglect, and breaches of standards by aged care facilities." (Barnett et al, 2010) Principal concerns about the reporting system are:

- The exemptions make the system discretionary and
- The nature of the discretion means that there may not be an appropriate response to an assault.

47 Consequently, assaults occur for which:

- The victim loses any right to redress or remedy;
- The situation reinforces a substandard response to violence;
- The family of the victim may not be aware of the assault;
- The perpetrator potentially faces no sanctions, whether civil or criminal;
- The service provider potentially faces no sanctions.

48 In reality, without knowing exactly how many assaults (including all defined at 63-1AA(9)) are not reported, it is difficult to determine the utility of the system. It might be very few, or notifications may represent the tip of an iceberg.

49 The authors of Norma's Project noted that: "…compulsory and proposed mandatory reporting policies, while enacted with the best intentions of protecting older women, place them in a different situation to other victims / survivors of sexual assault who have the right to choose whether to report to police or not." (Mann et al, 2014)

50 In our view there should be discussion around the utility of the system as it stands and recommendations for reform. The exemptions are an in fact antithetical to the objects of a protective system. We are not advocating a system that persecutes those with cognitive impairments for behaviour beyond their control, rather a dynamic system that protects all from abuse.

Staff Suitability Screening

51 The system at present is essentially a self-regulating model. While not a reporting model, it is a safeguard for older persons that needs urgent reform.

52 Background checks are assessed under Guidelines which be should be carried out in a proportional and appropriate manner, taking into account rights arising under *Human Rights and Equal Opportunity Commission Act 1986* (Cth) (HREOC Act) and associated regulations and International Labour Organisation Convention 111 (ILO 111).

53 However, there are views that the assessment would be better handled by a specialist body such as is the case with screening for blue and yellow cards in Queensland. The aged care industry employs a workforce of 352,145. A system needs to have initial and ongoing checks of suitability to be robust. Whether all court outcomes, arrests and charges should be included is a question for discussion.

54 Obviously resourcing an agency to conduct suitability checks must be part of the

compliance system and contributions should come from service providers through the licensing system. An alternative would be providing referred powers to state and territory suitability assessors based on a consistent set of suitability values.

Coronial Reportability

55 The reportability of deaths in aged care needs urgent consideration.

56 Coronial systems infrequently look into deaths of older persons or deaths that occur in RACS. Recent Australian epidemiological research on premature deaths of nursing home residents highlighted that coronial systems fail to identify factors to prevent deaths. (Ibrahim et al, 2017) Ibrahim and his colleagues found:

> "...that premature and preventable deaths occur in nursing homes, and it follows that coroners have an important role in identifying factors that may prevent death and injury. However, formal coroners' inquests examined fewer than 3% of the external cause deaths, and in 98.4% of all cases coroners made no recommendations about injury prevention. There were substantial variations between jurisdictions in the number of cases for which recommendations were delivered (0- 21%)." (Ibrahim et al, 2017)

57 The research assumed that all deaths directly or indirectly resulting from injury or non- natural causes must be reported to coroners. This assumption is logical but actually reinforced the need to improve triggers that lead to reporting and investigation of deaths. The study's cohort of 21,672 deaths revealed only 95 resulted in inquests. (Ibrahim et al, 2017) Of the cases that resulted in inquests, only 53 cases lead to recommendations by Coroners that sought to identify preventative or remedial actions. (Ibrahim et al, 2017) Across Australian jurisdictions, the rate of inquest ranged from 0-8% of reported deaths and the rate of recommendations ranged from 0-21%. (Ibrahim et al, 2017)

58 Crucially, and in line with previous comments, the cohort studied only included cases from the National Coronial Information System (NCIS), which means they were limited to deaths that had been reported to a coroner. The study therefore missed cases that had not triggered a report for coronial attention. How many of the 21,672 deaths subject of the study were cases of institutional elder abuse is unknown.

59 How then is it that deaths in RACS are not reported? All Australian jurisdictions use

statutory 'triggers' that require reporting of certain deaths to coroners. These deaths are known as 'reportable deaths'. They are reportable by virtue of circumstance (examples include violent or unnatural, sudden, unknown cause, suspicious or unusual) or setting (examples include custody, care, recent health procedure). We might call this aspect 'reportability'.

60 A death in RACS is not a prescribed circumstance or setting in any Australian jurisdiction. The term 'death in care' is a common class of reportable death but this class does not explicitly include deaths that occur in RACS. Arguably the definition of 'death in care' actively excludes deaths in RACS.

61 Likewise there is a 'health care death' or similar in most jurisdictions. Mostly this also doesn't assist in reporting deaths form institutional elder abuse.

62 Operational policies recognises the consequences of limited reportability. For example, the *Queensland Coroner's Guidelines* provide specific procedures for making referrals to the Office of Aged Care Quality and Compliance. (Queensland Courts)

63 This clearly represents a different approach to any other death in care.

64 Ibrahim and others have provided a comprehensive analysis of preventable deaths in RACS with recommendations looking at causes including choking, medication, physical restraints, respite, resident-to-resident aggression, suicide, and unexplained absences. (Ibrahim et al, 2017)

65 This information should be used to identify preventable abuses.

Death Reviews

66 Family Violence Death Reviews also do not effectively target elder abuse or institutional elder abuse.

67 Some Australian jurisdictions use these specialised processes in cases of family or domestic violence or homicide. Family violence death review processes have the potential to be aligned around informal care arrangements, including those that occurred in home care where death was as a result of neglect.

Term of Reference 2:

The effectiveness of the Australian Aged Care Quality Agency, the Aged Care Complaints Commission, and the Charter of Care Recipients' Rights and Responsibilities in ensuring adequate consumer protection in residential aged care

68 The real question to be asked here is adequate consumer protection from what? Is it presumed that the ACCC is there to protect older persons in RACS from all or only specific abuses?

69 In her submission to the ALRC the Aged care Complaints Commissioner noted that

> "It must be acknowledged that defining an action as abusive is somewhat subjective. What some complainants see as abuse others may see as poor care and vice versa. Complaint issues may be recorded by us under a keyword other than 'abuse' depending on the circumstances and how the complainant raises their concern." (Aged care Complaints Commissioner, 2016)

70 There is an obvious gap between the sorts of abuse that might occur in a RACS and the powers of the ACCC to deal with a complaint. Like all other areas, so much depends on how we define the experiences of older persons in RACS.

71 Whether RACS are defined in or out of the definition will determine the future role of the ACCC is dealing with institutional elder abuse. At present the jurisdiction relies on the functions set out in the *Aged Care Act 1997*. The Quality Agency is also similarly constrained.

72 Any proper consideration of how the ACCC and ACQC might be better empowered to deal with institutional elder abuse depends on the results from other processes such as the formulation of a national definition.

73 In any event that role of the ACCC and the ACQC will only ever provide part of the system of complaint and remediation of institutional elder abuse. That the system is centred around a model of private dispute resolution clearly limits the possible outcomes for older persons.

Term of Reference 3:

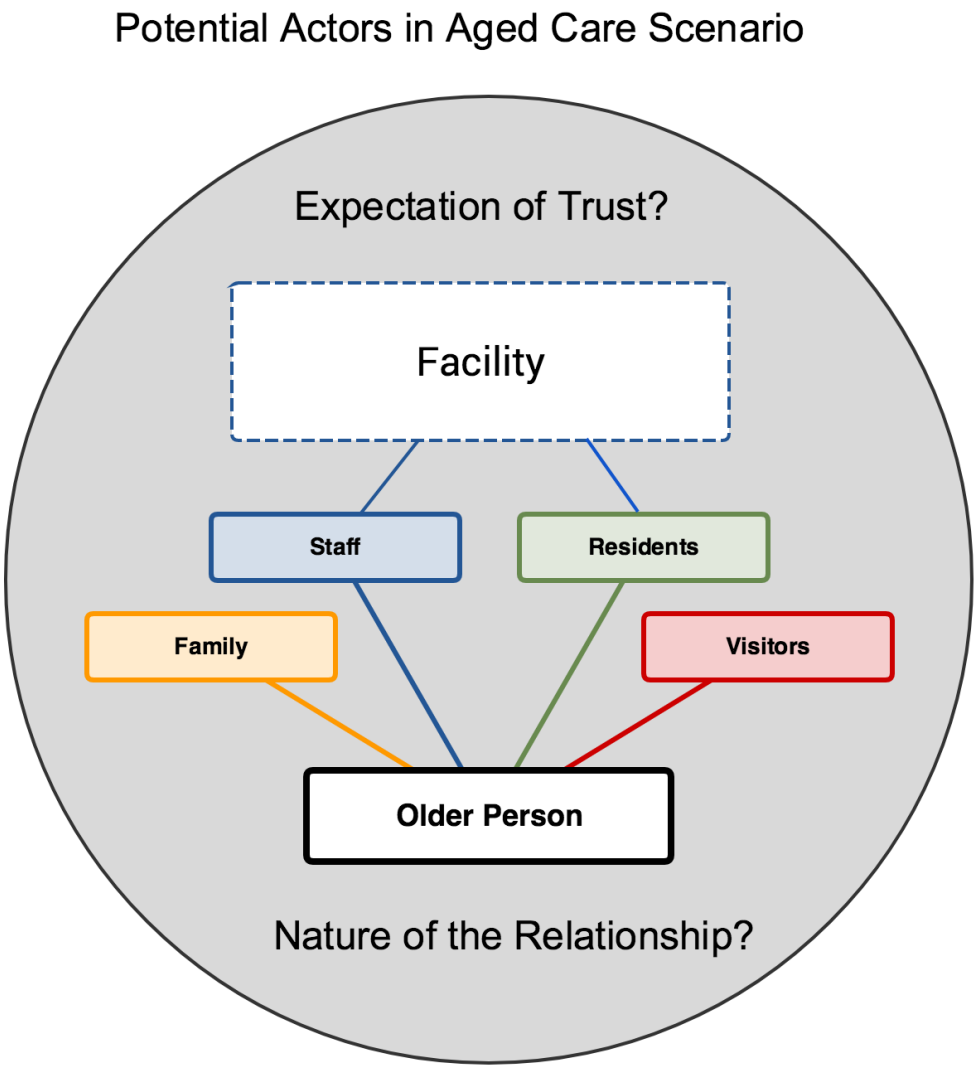
The adequacy of consumer protection arrangements for aged care residents who do not have family, friends or other representatives to help them exercise choice and their rights in care.

74 Autonomy is both an underlying principle that governs every human right and a right in and of itself. The principle of autonomy presumes that individuals are able to make choices according to their own will and preferences. In order to make autonomous decisions, and for these decisions to be legally effective, the law requires that the individual has the legal capacity to do so. To enjoy their right to autonomy therefore, older persons must enjoy legal capacity and equal recognition before the law on an equal basis with others.

75 The ALRC's work on Equality, Capacity and Disability in Commonwealth Laws is directly relevant to this TOR. In particular the recommendations 6-2 and 8-2 should be fully implemented.

*** SUBMISSION ENDS ***

Diagram


Potential Actors in Aged Care Scenario
Expectation of Trust?
Facility
Staff
Residents
Family
Visitors
Older Person
Nature of the Relationship?
(c) TCLS 2016

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