

QUALITY OF RESIDENTIAL AGED CARE: THE CONSUMER PERSPECTIVE

A REPORT FOR ALZHEIMER'S AUSTRALIA
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**TALKING ABOUT ALZHEIMER'S
ACROSS AUSTRALIA**
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CONTENTS

Foreword	4
Executive Summary	5
Background	7
Quality Issues In Residential Aged Care	8
Restraints	9
Physical assaults within aged care	11
Staffing	12
End of life care	13
Accreditation	15
Aged Care Complaints Scheme (the Scheme)	18
Transparency and information	19
International Examples Of Consumer Involvement In Health And Aged Care Services	22
Consumer involvement in accreditation	22
Measuring consumer satisfaction	24
Consumer involvement in complaints	27
Appendix 1: The current landscape of aged care in Australia	28
Appendix 2: Gold Standards Framework	32
References	35

FOREWORD

The aged care reforms aim to give consumers greater choice and more options to receive care at home. Importantly, the number of home care packages will be doubled on current plans over the next 10 years.

But home care packages alone can not provide the level of care required by people with complex care needs, such as those in the later stages of dementia or without an informal carer. Many people will still require residential aged care services and we need to ensure these services are able to provide the highest quality of care.

Nearly a quarter of a million people received residential aged care services in Australia last year. These people are among the most vulnerable in our community, with many of them having cognitive impairment, physical disability and limited connection to the outside community.

The majority of residents receive good quality care. There are thousands of dedicated nurses and care staff, who take great pride in their work, and go above and beyond the minimum care required. Many residents benefit from being in residential care and find the opportunities for interaction with other residents and staff to be beneficial.

Unfortunately, there are still too many cases where the basic human rights of people have been violated within residential care. Since becoming President of Alzheimer's Australia many consumers have shared disturbing stories with me of physical, psychological and sexual abuse, inappropriate use of restraint, unreported assaults and people in extreme pain at end of life not having access to palliative care.

This paper is written for the courageous people who have told their stories. It provides strategies as to how we can begin to address the systemic issues in the aged care system that are leading to breakdowns in care. The objective is to bring providers, staff and consumers together to determine the way ahead.

It also draws on international examples of initiatives where consumers play a key role in monitoring quality and determining accreditation of services.

We have a common commitment to make the aged care system in Australia as good as we can. We must have a zero tolerance policy for poor quality care.

I want to thank our CEO, Glenn Rees, and Ellen Skladzien, Samantha Blake and Kristen Holdsworth for their work on this publication.



**Ita Buttrose AO, OBE
National President
Alzheimer's Australia**

November 2013

EXECUTIVE SUMMARY

Over 222,000 people received permanent residential aged care services in 2012 with over 2,700 residential aged care facilities in operation nationally. The ageing of Australia's population will result in a significant rise in these numbers in the coming years.

Older people in residential aged care are among the most vulnerable in our society, which places them at considerable risk of serious abuse (Barnett & Hayes, 2010). This risk is due to a host of factors including cognitive impairment and dementia, depression, immobility, limited support and contact with the outside world and difficulties in accessing the appropriate channels through which to raise complaints as well as fear of victimisation for doing so (Barnett & Hayes, 2010).

We acknowledge that the majority of providers are providing good quality care even if they may be constrained by current levels of funding. But there must be zero tolerance for violations of human rights.

Over the past several years, consumers have shared their experiences with us of poor quality care and the frustrations they have experienced in attempting to navigate a highly complex system that at times affords little transparency. These stories have included the mismanagement of the behavioural and psychological symptoms of dementia (BPSD), chemical and physical restraint, care recipients treated with a lack of dignity and respect, and psychological, physical and sexual abuse. The stories shared by consumers paint a disturbing picture of an aged care system under strain which is in some cases failing to meet the basic human rights of our most vulnerable citizens.

Through the Aged Care Complaints Scheme (the Scheme) and the Aged Care Standards and Accreditation Agency (ACSAA), there are significant protections in place to assist in ensuring a minimum quality of care is provided to residents in aged care services. This report looks at the action that might be taken in the short term to ensure there is zero tolerance of poor care and in the longer term to develop a more consumer oriented care system.

The rights of residents and respect for their dignity is not going to be achieved unless there is a coming together of consumers, providers and staff on the action needed. The aged care reforms represent a shift towards increased consumer empowerment, with the implementation of consumer directed care, expansion of home care services, and greater access to information through the development of quality indicators. It is timely to consider how we can provide consumers with a greater role in monitoring quality and standards within the aged care system.

The strategies put forward in this paper, whether short or long term, are for discussion. Many of the strategies proposed have been the subject of consideration before but the opportunity to make significant changes to the system has not presented itself as it does now with the current aged care reforms. There is now some urgency for action in the view of Alzheimer's Australia and our consumer stakeholders.

To ensure minimum protections are in place and being upheld for all residents, the urgent and short-term strategies that might be considered include:

1. Expand the mandatory reporting of alleged physical or sexual assaults to the Aged Care Complaints Scheme within 24 hours to include assaults which are perpetrated by a person with a cognitive impairment. Families of both the resident who was assaulted and of the resident who is alleged to have perpetrated the assault should be notified immediately after the incident.
2. The Residential Aged Care Standards should require aged care providers to encourage residents to complete advance care plans as soon as appropriate.
3. Residential Aged care providers should ensure access to appropriate end of life care for all residents including through:
 - Working with residents and their families to develop a Palliative Care Plan that includes information for consumers about what palliative care services and supports are available in the facility or can be brought in and how they can be accessed.
 - Supporting staff to receive additional training on palliative care supports and also the legal rights of people at end of life.
4. Increase the reach of the Community Visitors Scheme and the role volunteers can have in quality monitoring, possibly as part of the accreditation process.
5. Ensure that the Aged Care Complaints Scheme escalates complaints which relate to serious incidents in the use of medications, use of restraint or assault, to a manager, within set timeframes to ensure the safety of residents.
6. Further work should be done to increase awareness amongst consumers about the role of the Aged Care Complaints Scheme and the National Aged Care Advocacy Program and to address consumer concerns about retribution.

In developing a more consumer oriented system Alzheimer's Australia believes longer term improvements could be achieved by a greater involvement of consumers in the monitoring, assessment and complaints processes. These longer term strategies to further improve the quality of care could include:

1. Review the Charter of Residents' Rights and Responsibilities in the context of the commitment in the aged care reforms to consumer directed care, including a focus on rights in relation to end of life wishes and consent to the use of physical and chemical restraints.
2. Funding arrangements which support appropriate care for people with behavioural and psychological symptoms of dementia (BPSD) including through:
 - Supporting staff members to receive additional training on BPSD.
 - Ensuring that staff have access to appropriate specialists, including the Dementia Behaviour Management Advisory Service (DBMAS) to assist with the care of people with BPSD.
 - Encouraging all residential aged care facilities to participate in benchmarking and self-audits of the use of restraints and antipsychotic medications to ensure that these are used appropriately, with consent and only when all other options have been exhausted.

BACKGROUND

3. The Government to commission an independent cost of care study into residential care to ensure that providers are receiving appropriate funding to employ sufficient staff and an appropriate skills mix to provide quality of care during the day and at night.
4. Reforming the accreditation process to reduce unnecessary administrative burden, increase focus on quality outcomes and provide opportunities for consumer involvement in the monitoring and assessment process.
5. Shifting the primary approach of accreditation to unannounced visits rather than planned visits.
6. The new quality indicators published on the 'My Aged Care' website should include information about use of restraint and psychotropic medications. The site should also have information about staffing and skills mix and about the outcomes of consumer satisfaction surveys.
7. The Younger Onset Dementia Key Worker Program should be expanded to provide support to all people with dementia of all ages, with an initial focus on supporting people from disadvantaged groups including people who are Culturally and Linguistically Diverse, Aboriginal and Torres Strait Islanders, homeless and those living alone.

Over the last three decades, the Australian aged care system has undergone significant changes in an attempt to develop a high quality, equitable system that can respond to the needs of an increasing number of older Australians (Hughes, 2011). These changes have resulted in an increase in the range and quality of care and support services available to older people (Hughes, 2011; Productivity Commission, 2011). An overview of the current aged care system can be found in Appendix 1.

The introduction of the Living Longer. Living Better. aged care reform package in 2012 marked the most significant shift in aged care policy for decades and aims to give older Australians more choice and greater control over the services they receive. The reforms have an increased focus on care and services provided to individuals in their home and community, but there will also be significant changes to the residential aged care landscape. Following the introduction of consumer directed care into all new home care packages, a trial of consumer directed care for residential aged care will be undertaken as part of the reforms.

The quality of care being provided in residential aged care homes will be the focus of the new Australian Aged Care Quality Agency which will begin operating from 1 January 2014. This new body will be the sole agency responsible for quality of both residential aged care and home care. A key component of the reforms will be the gradual introduction of national quality indicators for residential aged care from 1 July 2014 and in community care from 1 July 2016. Properly developed and tested quality indicators will provide much needed transparency and give consumers, their families and carers greater access to information about the quality of aged care services and greater control about the type of aged care services they use.

QUALITY ISSUES IN RESIDENTIAL AGED CARE

The Australian aged care system is generally considered by stakeholders and international peers as providing high quality services (Productivity Commission, 2011). Recently, however, there have been a number of examples in the media of the aged care system providing poor care and failing to respond to the needs of consumers.

Older people in residential aged care are among the most vulnerable in our society which places them at considerable risk of serious abuse (Barnett & Hayes, 2010). This risk is due to a host of factors including cognitive impairment and dementia, depression, immobility, limited support and contact with the outside world and difficulties in accessing the appropriate channels through which to raise complaints as well as fear of victimisation for doing so (Barnett & Hayes, 2010). The provision of quality aged care and support in a suitable environment is a central human right (Australian Human Rights Commission, 2012; International Covenant on Economic, Social & Cultural Rights, 1976; United Nations, 2000; United Nations). The United Nations Principles of Older persons (1991) states:

14. Older persons should be able to enjoy human rights and fundamental freedoms when residing in any shelter, care or treatment facility, including full respect for their dignity, beliefs, needs and privacy and for the right to make decisions about their care and the quality of their lives.

Consumers are often unaware of what their legal rights are with regard to complex issues such as the use of restraint and antipsychotic medications, assaults perpetrated by other residents and access to appropriate end of life care. This is so even though there is a Charter of Residents' Rights and Responsibilities which outlines the rights and responsibilities of both residents and aged care homes. The Charter is legislated under the Aged Care Act 1997 and should be displayed in residential aged care homes or a copy can be requested from the residential aged care home

when a care recipient is offered a Resident Agreement (Australian Government, 2013).

Consumers have identified a number of key areas for improvement of the aged care system, through consultations on aged care reforms conducted in 2011, feedback through Alzheimer's Australia's consumer advisory committees and more recently in stories provided to Alzheimer's Australia.

Consumer Stories – Violation of Human Rights

'My father entered a nursing home after sustaining a stroke. It became obvious within 3-4 days that the staff at the nursing home did not know or care about Dad's treatment - there were issues with medication, food and Dad had a fall within the first few days of entering the home. Dad stated that on a number of occasions he had difficulty in reaching staff for assistance with food and toileting, he was subjected to rough treatment at the hands of staff, was given the wrong medication, and had two fingers broken. He also had difficulty in accessing an appropriate health professional on one occasion when he was experiencing chest pain which resulted in a trip to the hospital where he was diagnosed with a lung infection'

Strategy

Review the Charter of Residents' Rights and Responsibilities in the context of the commitment in the aged care reforms to consumer directed care, including a focus on rights in relation to end of life wishes and consent to the use of physical and chemical restraints.

Restraints

The use of chemical and physical restraints in residential aged care has attracted significant attention in recent times. The majority of residents within residential facilities have a diagnosis of dementia, and many of these people will experience BPSD at some point in their illness. Some residential aged care services do not have sufficient staff or skills to provide appropriate care to these residents.

In some cases antipsychotic medications and restraint may be useful tools to respond to behaviours that are causing immediate danger or where an individual has not responded to other interventions. It is important to note that some carers have found these tools to be critical in the care of the person with dementia. This concern is whether the medications are being used appropriately and whether alternative treatments have been tried. As stipulated in the Charter of Residents' Rights and Responsibilities, residents have the right to live in a safe, secure and homelike environment, and to move freely both within and outside the residential care service without undue restriction.

The National Prescribing Service has issued guidelines for the use of antipsychotic medications which indicate that non-pharmacological approaches should be the first line approach for the behavioural symptoms of dementia and that antipsychotics should be used "only if aggression, agitation or psychotic symptoms of dementia cause severe distress or immediate risk of harm". These guidelines also indicate that if symptoms are stable, a gradual dose reduction and withdrawal of medication should be trialled. The guidelines warn that antipsychotic use in people with dementia is associated with an increased risk of death (NPS Practice Review, 2011). There is also the concern that staff may be unfamiliar with and not identify the extrapyramidal side effects of antipsychotics that can cause increased agitation and restlessness and further exacerbate their level of discomfort which may in turn increase behaviours of concern.

Despite these guidelines, the evidence suggests that some aged care facilities use psychotropic medications as the first response to behavioural symptoms. A recent study of psychotropic use in Sydney nursing homes in 2009 found that 47.5 per cent of residents were taking psychotropic medications (Snowdon et al., 2011).

Many jurisdictions require that a prescription of antipsychotics is approved by a proxy decision maker (i.e. family member or carer) when the person with dementia is unable to give informed consent, yet this requirement is rarely met (only 6.5 per cent of cases according to a study in New South Wales) (Rendina, Brodaty, Draper et al., 2009).

Concerns have also been raised that staff are not receiving adequate training in the management of BPSD and that staff are not taking the time with residents with dementia to address the causes of behaviour which in some instances arise due to inappropriate care. The Dementia Behaviour Management Advisory Service (DBMAS) can provide support to aged care facilities in appropriate care and management of BPSD but are often not approached in these cases.

There are a number of Government funded research projects currently underway looking at strategies to reduce the prescription of antipsychotic medications within residential aged care facilities. These include interventions which combine education, self-audit, and schedules for a trial of de-prescribing. Although the evidence is still being collected, strategies which provide better access to specialists, encourage self-audits and increased education for staff on alternative treatments may lead to more appropriate prescribing of these medications.

Consumer Stories - Restraint

'My husband was tied to a chair in the nursing home most of the day. I complained and I was told he wanders into other peoples rooms. He got aggressive when four people changed his pad so he was subdued with a tranquiliser. He was treated like a dog. I couldn't get anyone to listen to me, finally I found a broker and I found a nursing home'

'My husband was turned into a zombie within a couple of weeks. He wandered into ladies rooms and was put on an antipsychotic. They increased the dose against my wishes. He has been put on four antipsychotics that should not have been given together. He started falling. This is a serious concern because it has ended with my husband losing his mobility'

'I was shocked that my father had been put on a sedative without his or my knowledge despite our request for this to not be done'

'There is a willingness to sedate people with Alzheimer's. There is a link to antipsychotic drugs leading to other illnesses. The nursing home wanted her to be manageable, and therefore sedated her. I believe the longer the resident is in their own home the better. The bullying – there is no other word I can use. The bullying we have come across in nursing homes, from hospitals and doctors'

'My girlfriend was concerned that her mother's appetite had waned and was losing her strength. The antipsychotic had turned her mother into a zombie. The situation culminated in my girlfriend's mother collapsing and being unable to be roused'

'In the nursing home, residents with dementia were administered drugs and sat like zombies in a circle around the t.v. from nine o'clock in the morning where they were supervised by one staff member'

Strategies

Funding arrangements which support appropriate care for people with behavioural and psychological symptoms of dementia (BPSD) including through:

- Supporting staff members to receive additional training on BPSD .
- Ensuring that staff have access to appropriate specialists, including Dementia Behaviour Management Advisory Service (DBMAS) to assist with the care of people with BPSD.
- Encouraging all residential aged care facilities to participate in benchmarking and self-audits of the use of restraints and antipsychotic medications to ensure that these are used appropriately, with consent and only when all other options have been exhausted.

Physical assaults within aged care

Residential aged care providers are currently required to report any allegation of assaults to both the police and the Scheme within 24 hours of the allegation. In 2011-2012 the Department of Health and Ageing (now the Department of Social Services) received 1,971 notifications of reportable assaults. The role of the Scheme after they receive notification of the assault is to ensure that the victim of the alleged assault has received appropriate care and support, that residents of the home are safe, and that compulsory reporting requirements are complied with.

The legislation allows discretion not to report if the alleged assault was perpetrated by a resident with an assessed cognitive impairment. There is significant concern from consumers about the lack of requirement to report assaults perpetrated by a person with cognitive impairment and the impact this may have on the safety of other residents within an aged care home and the care and treatment the person with cognitive impairment is receiving. In particular, there is concern that there are no safeguards to ensure that the person who has been assaulted receives appropriate care, counselling and support or that the person who has perpetrated the assault has an appropriate behavioural management plan put in place.

This relates to broader issues around appropriate care and support for people with dementia who have very severe BPSD. In some cases, to ensure the safety of other residents there is a need to provide a short-term placement in a specialised psychogeriatric facility. But this option is not always available.

Consumer Stories – Physical assaults

'My mother was punched in the chest and had a pillow held over her face. The resident who assaulted her had done it before. That the attack and the seriousness of the attack on my mother is being regarded as (1) in the past now, (2) not serious because she did not die as a result, (3) to be expected in a dementia unit, (4) not going to be a problem because she has dementia and so won't remember (which completely disregards the nature of threat reactions and delayed shock reactions) is totally unacceptable to me'

Strategy

Expand the mandatory reporting of alleged physical or sexual assaults to the Aged Care Complaints Scheme within 24 hours to include assaults which are perpetrated by a person with a cognitive impairment. Families of both the resident who was assaulted and of the resident who is alleged to have perpetrated the assault should be notified immediately after the incident.

STAFFING

The impact of workforce issues upon the quality of care has also been discussed in consumer consultations with concerns being expressed about both the staffing level and skills mix of staff. Aged care homes are not required to have a specific staffing profile, but instead as part of the Accreditation process are expected to have “appropriately skilled and qualified staff sufficient to ensure that services are delivered in accordance with the standards and the residential care service’s philosophy and objectives”. There is no agreed benchmark for staffing levels or skills mix within residential aged care. Consumers are concerned that low staffing levels in some facilities or inappropriate skills mix exacerbates issues of low quality care as staff do not have adequate time to tend to the needs of all residents, particularly those with BPSD.

Consumers have also voiced their concerns over equitable pay for care staff and the impact this has on attracting the best workforce for aged care. Staff in aged care are consistently paid less than the equivalent workforce in the hospital sector. In the Aged Care Workforce 2012 report, workers overall indicated satisfaction with what they do, however, total pay was an area which workers were least satisfied. In 2012, nearly 60 per cent of Personal Care Attendants (PCA) indicated their dissatisfaction with their total pay along with nearly 57 per cent of allied health workers. Nurses were also dissatisfied with their total pay (48 per cent) (King et al., 2012).

Consumer Stories – Staffing

‘Staff to patient ratio needs to be raised greatly’

‘Without pay parity, we will not be able to keep experienced people in the aged care work place. We want people to have good care and feel that their families are being looked after. DoHA set a whole lot of standards but we are battling getting adequate staff’

‘There is a lack of training for dementia specific staff. From carers to nurses to people who run these places. I have had to sit there and explain to staff. The lack of training includes all staff’

Strategy

The Government to commission an independent cost of care study into residential care to ensure that providers are receiving appropriate funding to employ sufficient staff and an appropriate skills mix to provide quality of care during the day and at night.

End of life care

The quality of care received at the end of life has been a considerable concern to a number of consumers. Recent figures released from Australian Institute of Health and Welfare show that only 22 per cent of permanent aged care residents who died in 2010-2011 received palliative care services (AIHW, 2012). This is despite the latest evidence which suggests that around 70 per cent of people who die each year would benefit from access to palliative care.

In 2011, consumer consultations conducted by Alzheimer's Australia on behalf of DoHA revealed a number of instances where care staff did not respect the wishes of the person with dementia at the end of life and the substantial grief this caused loved ones. Accessing palliative care also proved problematic with family members being told that the person with dementia was not dying 'quickly enough' to be eligible for the service (Alzheimer's Australia, 2011).

Barriers to the provision of palliative care in Australia may be due to a number of factors including limited access to specialist palliative care consultancy services, limited funding for the delivery of palliative care, limited access to latest equipment and appropriate medications and little or no funding for bereavement services (NACA, 2011). The lack of understanding of dementia as a terminal illness and the additional complexities of issues around capacity and decision making contribute to people with dementia having limited access to palliative care services.

In some cases the barriers to good end of life care are related to practical issues. Consumers may not be aware of what services are available to them at end of life or how to access them. Some staff may not be aware of what the legal options are for people at end of life and are concerned about issues such as withdrawal of treatment or refusal of nutrition and hydration. Most people who die with dementia have not documented their wishes around end of life care (eg. through an advance care plan), which can make it difficult for both family and health professionals to make decisions about care at end of life.

An obvious strategy to improve care would be to encourage and support people who enter the aged care system to complete an advance care plan. This would ensure that there is an early discussion about preferences for end of life care. There is also a need for better training for staff and communication with consumers about the services that are available.

Consumer Stories – End of Life Care

'I've been told that if my mother does not die fast enough in a palliative care setting, she will be sent away. I am fighting for my mother to die in a palliative facility because I am told she is not worthy'

'There is a need for advanced care health directives to be completed at the time of diagnosis so the person can still be involved in how they die. I cared for my aunt and you wonder would she have wanted to die like this. If she had a directive would it be like this?'

'In the care plan they were meant to call me when my mother was distressed but they didn't. I was not able to be with her when she passed away'

'At no time did the service provider, doctor or the specialist tell us about palliative care in the home'

Strategies

- The Residential Aged Care Standards should require aged care providers to encourage residents to complete advance care plans as soon as appropriate.
- Residential aged care providers should ensure access to appropriate end of life care including through:
 - o Working with residents and their families to develop a Palliative Care Plan that includes information for consumers about what palliative care services and supports are available in the facility or can be brought in and how they can be accessed.
 - o Supporting staff to receive additional training on palliative care supports and also the legal rights of people at end of life.

ACCREDITATION

From the consumer perspective, the accreditation process has served to reassure consumers that over time, those providers offering unacceptable levels of care will be dealt with. But this has been at a cost and many consumers believe the accreditation process creates excessive red tape which limits staff time for care of residents and at the same time is not effective in focusing on outcomes for residents (Productivity Commission, 2011). Consumers have expressed concerns about the notification of visits and have indicated a preference for unannounced visits, rather than announced visits, to check the quality of care being provided.

Numerous submissions made to the Productivity Commission as a part of the 2011 report underscored the burdensome nature of administrative processes in the current system with the Council on the Ageing (Australia) (COTA) contending:

'... the accreditation process should not require substantially more paperwork than is required for normal business, clinical and care management needs. We have some sympathy with the view that quality accreditation processes in the health and aged care sectors have placed too much emphasis on excessive paper trails rather than on actual outcomes being achieved'. (Productivity Commission, 2011).

It has also been noted by consumers that the accreditation process is a blunt instrument as the vast majority of residential aged care providers (nearly 95 per cent as of 30 June 2012) pass the accreditation process with no changes required. The Agency reports whether the facility met each of the expected outcomes but this does not help consumers to ascertain whether the provider is delivering high quality care or just passing the minimum standards for accreditation.

The development of national quality indicators through the aged care reforms may result in greater transparency in relation to quality for consumers and assist service providers in continuous improvement. From the consumer perspective these indicators should include information about consumer satisfaction which could be monitored through surveys administered by the Aged Care Quality Agency.

According to Silvia Holcroft, Director of QPS Benchmarking, consumer and community empowerment can only be made possible if information is provided that is easy to access, easy to understand and transparent.

'The development of quality indicators is currently being discussed within the industry, however it should be acknowledged and well recognised that approximately a fifth of the aged care sector has been voluntarily measuring and benchmarking their performance through the QPS Benchmarking Program for the last 13 years. A wealth of information already exists that is used by the QPS Benchmarking members to drive improvements to the care and services delivered to their residents. The increased resident care needs are evident in the ACFI assessment domain results and service providers closely monitor and increase their care staff work hours to ensure they can continue to provide a high standard of care and service. Clinical practices are reviewed and prevention strategies are implemented to improve care outcomes for residents in areas such as facility acquired pressure injuries, falls with injury, infections and the use of restraint.'

Silvia Holcroft.

In addition to greater transparency, consumers would like to have a more central role in the accreditation and assessment process of residential aged care facilities. Involving carers or former carers as part of the assessment team would utilise their expertise as well as give consumers more confidence in the system. There are of course questions to be explored around developing appropriate training and whether consumers would be an equal member of the assessment team or play an advisory role.

Consumers have also identified the potential role of the Community Visitors Scheme in monitoring quality and standards within residential aged care homes. The Community Visitors Scheme is a national program that provides companionship to socially isolated people living in aged care facilities. As part of the aged care reforms, the Australian Government has committed \$19 million from 2013-2016 to expand the program. The accreditation teams currently interview some volunteers as part of the assessment process, but consideration could be given to involving the community visitors volunteers more directly in the accreditation process.

At present, assessment teams involve consumers through interviews and are expected to meet with at least 10 per cent of residents or their representatives at a residential aged care home to discuss the care and services they are receiving (Aged Care Standards and Accreditation Agency, 2011). There may be some hesitation on the part of residents and their family members to provide honest feedback about the services they are receiving as they do not want to be a burden or fear potential negative outcomes for doing so.

The Aged Care Standards and Accreditation Agency Assessor Handbook (2011) discusses the importance of incorporating people with cognitive impairment or dementia in the interview process. The Handbook suggests reviewing the resident's records or interviewing their representative, observing the resident if they are unable to sustain a conversation to ensure they are dressed appropriately for the weather and personal grooming, and details other strategies for interacting with the resident (Aged Care Standards and Accreditation Agency, 2011). The success of such strategies in gathering information, however, may be dependent upon the assessor's level of knowledge and experience with cognitive impairment or dementia. No assessment tools are suggested in the Handbook for use with this group of residents.

In 2011, ACSAA began examining the role of consumers in the accreditation process and consulted with a number of national consumer groups on how consumer involvement could be improved in the future. Based on these consultations and examination of international experience, ACSAA is currently exploring a number of options for involving consumers in accreditation assessments and reporting processes. Further work should be done to involve consumers in monitoring the standards and being involved in the Scheme, beyond the current interview process. Further information about international experience in consumer involvement in quality improvement is discussed later in this paper.

Consumer Stories – Accreditation

'In another life, I inspected nursing homes, that is why I chose to keep my father at home. There are many that make the minimum standards. I have seen people time and again drugged up and tied up'

'So many facilities are working so hard to meet the accreditation and they forget the human element. There should be more emphasis placed on the feedback from the residents in the facility. That way the feedback is coming from the residents, not the staff'

'I would like to see a link between the accreditation of the facilities and the quality of education of the training of the staff that are providing the care. There is no emphasis on this; staff are rotating through the facilities. The care given depends on the knowledge of the staff that they receive that day'

'I realise the importance of "paperwork". I realise paperwork is part of the care process. But it should not be considered to be more important than interaction with the human beings who are being cared for'

'The involvement of family or representatives in my parents care was problematic. Although the Accreditation Standards states that the physical and mental health of residents should be promoted and achieved at an optimum level in partnership between the resident (or his or her representative) and the health care team, this never really happened. There was a lack of discussion regarding issues including appropriate pain management, a lack of care plans (at least available for me to view), lack of notification regarding residents' meetings, and no notice from the facility that accreditation audits were being conducted'

Strategies

- Reforming the accreditation process to reduce unnecessary administrative burden, increase focus on quality outcomes and provide opportunities for consumer involvement in the monitoring and assessment process.
- Shifting the primary approach of accreditation to unannounced visits rather than planned visits
- Increase the reach of the Community Visitors Scheme and the role volunteers can have in quality monitoring, possibly as part of the accreditation process.

AGED CARE COMPLAINTS SCHEME (THE SCHEME)

In recent times, consumers and advocacy groups have voiced their concerns regarding the effectiveness of the Aged Care Complaints Scheme. These have included the Aged Care Complaints Scheme's focus on dispute resolution rather than consumer rights (Barnett & Hayes, 2010). Consumers are often unsure about the division of responsibilities between the Aged Care Complaints Scheme, the Agency and the role of the Compliance section of the Department.

Consumers have also raised the potential conflict of interest inherent in the current system; at present, the Federal Government funds, creates policy and regulates the sector. The Government has endeavoured to separate these responsibilities in a way that minimises any potential conflict of interest. Some consumers continue to have concerns and have called for an independent watchdog to increase transparency and accountability.

Although consumers have the option to lodge a complaint confidentially, some consumers are hesitant to contact the Aged Care Complaints Scheme due to a fear of reprisal or retribution for complaining about a residential aged care provider. This concern has been reiterated by consumers and advocacy groups on multiple occasions and is one of the main barriers for consumers in lodging a complaint.

In addition, many consumers may not be aware of the Aged Care Complaints Scheme and its role. A benchmark survey conducted into awareness of the Aged Care Complaints Scheme and associated reforms was conducted from August to October 2011 (Australian National Audit Office, 2012). The results revealed a high level of awareness of the Aged Care Complaints Scheme amongst care managers and to a lesser extent care staff, however, only one in three care recipients and one in four friends or family members were aware of the Aged Care Complaints Scheme (Australian National

Audit, 2012). The Department of Health and Ageing conducted a series of consultations with consumer advocacy groups to develop better communication tools with the goal of raising awareness of the Aged Care Complaints Scheme, which has resulted in a modest increase in awareness amongst consumers.

There are also concerns from consumers about adequate access to the Aged Care Complaints Scheme for residents. In 2011-12 care recipients accounted for 10.7 per cent of complaints to the Aged Care Complaints Scheme with the majority coming from care provider staff, care recipients' representatives and family members (Australian National Audit Office, 2012). The majority of complaints made to the Aged Care Complaints Scheme are done via telephone and private access to a telephone may be an issue for some residents at a residential aged care facility. For those consumers experiencing isolation, lodging a complaint anonymously or through a willing staff member or volunteer visiting the facility may be their only option. The aged care reforms provide for an expansion to consumer advocacy services under the National Aged Care Advocacy Program which provides assistance to individuals advocating on their own behalf, or advocates acting on behalf of people who are unable to do so themselves. Consumers should be provided with information about the role of this service in assisting them to exercise their rights.

The responsiveness of the current system has also been called into question. The timeframes for resolution of complaints are variable and dependent upon the nature of the complaint. The Aged Care Complaints Scheme undertakes a risk assessment during the intake phase to ensure that complaints that pose the greatest risks are escalated and responded to promptly. Consumers, however, remain concerned that some complaints which they view as critical and relating to the physical or mental wellbeing of the resident, such as the use of chemical or physical restraint or situations of assault, are not resolved promptly.

Consumer Stories – Aged Care Complaints Scheme

“During my complaints process, my father and I have been continuously subjected to lies and unprofessional behaviours by the aged-care facility including verbal excuses for their behaviour that contradict the documented evidence (including emails) supplied to the Complaints Scheme. The Scheme has not commented on these lies and untruths. While I appreciate that the Scheme is constrained by legislation, it’s important that people in the community continue their battle to improve what I perceive to be a system that has failed our elderly and is in desperate need of change. Within about one month of lodging each of my complaints with the Aged Care Complaints Scheme my father has been forced to lie in his own faeces: three complaints and three times this has occurred.’ I have been shocked by the Aged Care Complaints Scheme’s failure to recognise breaches to the Residents’ Charter of Rights and Responsibilities’

Strategies

- Ensure that the Aged Care Complaints Scheme escalates complaints which relate to serious incidents in the use of medications, use of restraint or assault to a manager, within set timeframes, to ensure the safety of residents.
- Further work should be done to increase awareness amongst consumers about the role of the Aged Care Complaints Scheme and the National Aged Care Advocacy Program and to address consumer concerns about retribution.

TRANSPARENCY AND INFORMATION

The lack of transparency in the current system has also been consistently raised by consumers and advocacy groups. In submissions made to the Productivity Commission, consumers detailed their difficulty in accessing comprehensive and timely information regarding the aged care system as well as information relating to their rights and responsibilities in accessing services and the level of co-contributions they are required to make (Productivity Commission, 2011). Consumers stated that the volume of information such as forms, pamphlets and brochures was often overwhelming which had resulted in some consumers resorting to hiring a broker at a cost of \$500-800 to assist in finding suitable residential care (Alzheimer’s Australia, 2011). Concerns regarding the fact that residential aged care providers are not required to make information relating to service fees publically available were also raised.

As part of the aged care reforms, the Government has established the Aged Care Gateway which aims to create an identifiable entry point to the aged care system and enable timely and reliable information to be accessed by older people, their families, and carers. Currently it comprises the My Aged Care website and a National Call Centre to provide consumers with up-to-date information about aged care and assist consumers to navigate the aged care system as well as provide referrals for assessment and service provision. Provisions have also been made in legislation to require providers to make service fees publically available on the My Aged Care website. This along with the residential fee calculator will afford consumers greater transparency in relation to residential aged care service provider charges.

The development of national quality indicators for residential care facilities which are to be published on the My Aged Care website from 1 July of 2014 may also increase transparency in relation to the quality of residential aged care services provided. The development of indicators is a complex task and likely to be one that will continue past 1 July 2014. From a consumer perspective, some of the issues that should be subject to monitoring include the use of restraint, psychotropic medications, and staffing levels and skills mix.

The My Aged Care website currently provides important information to consumers about what aged care services are available and how to access these services. There is also useful information about respite, counselling and support for carers and end of life care. There is, however, a need to develop more consumer friendly information on sanctions and notices of non-compliance on the My Aged Care website. The information currently available on the website is of a technical nature and is not consumer friendly. In addition, the latest accreditation report from the ACSAA for all residential aged care homes should be made available on the My Aged Care website

The Aged Care Gateway is in the early stage of development. There have been significant concerns raised by consumers about difficulties accessing information through a national call centre or website and the effectiveness of the telephone based assessment process that will commence in 2014. Whilst a Linking Service is proposed to assist those most vulnerable in the community, there will still be many people who may find accessing services through the Aged Care Gateway difficult.

For people with dementia, especially those who are from diverse groups including Culturally and Linguistically Diverse, Aboriginal and Torres Strait Islanders, those living alone and the homeless, access to one-on-one support through a key worker or Dementia Advisor will be essential. An expansion of the Younger Onset Dementia Key Worker program to encompass people with dementia of all ages could address some of the accessibility issues for these groups. Further consideration should also be given to the development of a networked Gateway that links with existing community networks and supports to ensure specialised services and expertise are easily available to the consumer.

Consumer Stories – Transparency and Information

'I concur about everything that has been said about complexity of the system. I ended up paying \$800 to someone to find me somewhere for my husband'

'Information when you need it. Which is often on the weekend when a crisis occurs. Over assessed and not enough services at the end of it. How many times do we have to say this?'

'Yes, information in a timely manner as you go through the stages – we were flooded with brochures on a few occasions but it's too much at once, carers need to be given the information again in a timely manner'

'We have nothing that can give us step by step of where we might go. No list of possibilities that can be given to us. We would like a person we can talk to individually, about what is troubling us'

'I would like [the government] to consider a case manager that works with the family. So you have one holistic management process. I could then go to the person who knows me, and when I get depressed I would know what to do. I need someone to develop a relationship who knows me, the family and circumstances.'

Strategies

- The new quality indicators published on the 'My Aged Care' website should include information about use of restraint and psychotropic medications. The site should also have information about staffing and skills mix and about the outcomes of consumer satisfaction surveys.
- The Younger Onset Dementia Key Worker Program should be expanded to provide support to all people with dementia of all ages, with an initial focus on supporting people from disadvantaged groups including people who are Culturally and Linguistically Diverse, Aboriginal and Torres Strait Islanders, homeless and those living alone.

INTERNATIONAL EXAMPLES OF CONSUMER INVOLVEMENT IN HEALTH AND AGED CARE SERVICES

Overseas, projects are being undertaken to further involve consumers in the evaluation of health and aged care services. These have included consumer participation in auditing processes, audit tools designed to capture the consumer experience for those unable to verbalise their experiences, consumer input into staff training and education, the grading of services, utilising consumer groups to improve services, and consumer driven ombudsmen programs. Brief overviews of some of these initiatives are outlined below and options for how these processes could be incorporated here in Australia are discussed.

CONSUMER INVOLVEMENT IN ACCREDITATION

Acting Together Program – (Experts by Experience) England: August 2011

The Acting Together program enables the Care Quality Commission (CQC) to involve people who have experience of using health, social care and mental health services and their family carers in their organisational activities. This can include a range of things such as helping to develop CQCs ways of working, co-producing public information, taking part in events and consultations, and CQC staff training.

Within Acting Together, CQC also have people who have been trained to take part in CQC inspection activities and Mental Health Act visits (conducted in hospitals, care homes, dentists, home care and General Practitioner (GP) services). These people, called 'Experts by Experience' accompany CQC inspectors and Mental Health Act Commissioners on visits where they talk to people who use services and their family carers and observe the environment around them. Their findings are used to support the inspector's judgement on the service (in conjunction with national standards for the particular service) and can also be included in the inspection report which is uploaded to the CQC website.

CQC works with a number of support organisations that recruit, train and support people to work on the Experts by Experience program including Age UK which supports older people and people with dementia and their carers. Information regarding the selection process, role requirements and necessary training is not currently available and further information will be sought via contact information provided on the CQC website.

The Experts by Experience program offers consumer involvement in the auditing process – due to their first-hand experience with services, consumers are better placed to identify what the key questions and issues are and capture invaluable information that may otherwise go undetected during standard auditing processes.

CQC: <http://www.cqc.org.uk/public/sharing-your-experience/involving-people-who-use-services>

Age UK: <http://www.ageuk.org.uk/professional-resources-home/services-and-practice/care-and-support/experts-by-experience/>

Aligning Forces for Quality (AF4Q) – United States: 2006

AF4Q aims to lift the overall quality of health care in 16 geographically, demographically, and economically diverse communities that together cover about 12.5 per cent of the US population. Each of the Aligning Forces communities has built its initiative around a core, multi-stakeholder leadership alliance working to advance the goals and activities of AF4Q at the local level. These alliances include participation from physicians, nurses, patients, consumers and consumer groups, purchasers, hospitals, health plans, and safety-net providers.

Each Alliance is charged with making sense of the quality problem in their area and meeting it with local solutions. The consumer engagement component of this project is looking at moving consumers away from 'passive recipients' to active, engaged agents in the health care system. A key area of this is ensuring that consumer friendly health and comparative performance information is readily accessible to consumers. These consumer reports inform key health decisions including choosing a provider, such

as a physician, a hospital or a health plan; choosing a particular treatment or procedure; or choosing to educate oneself about a particular health condition and appropriate, evidence-based standards of care.

Alliances are also working with consumers to ensure they are reporting measures and information in a meaningful and useful way. As alliances are releasing updated versions of their public reports, many are conducting research with consumers to determine which measures would be most valuable to them in making informed decisions about their care.

AF4Q: <http://forces4quality.org/>

National Gold Standards Framework (GSF) – United Kingdom: 2000

GSF was originally developed in 2000 as a grass roots initiative to improve primary palliative care from within Primary Care. The views and ideas of patients and carers were utilised in the development of the Framework to ensure its efficacy. The main aims of GSF are to provide security and support for patients through good communication and the provision of information, and support carers by keeping them informed and involved in patient care and encouraging communication, social and education support. The aims of GSF are met by ensuring that seven key aspects are developed within the care home, also known as the “seven Cs” (please see Appendix 2).

The GSF Training Programs focus on organisational and systems change within the home, and leads to quality assurance and recognition through an accreditation process. Resources are produced which include patient experiences and are incorporated into training sessions undertaken by staff. The GSF has had considerable success in the UK with over 2000 homes receiving training since 2004 and nearly 200 care homes a year accredited. A research project piloting

the framework is currently being undertaken at five residential aged care facilities in Tasmania.

GSF: <http://www.goldstandardsframework.org.uk/>

Consumer Technical Experts (CTE) – Australia: 2008

The National Disability Advocacy Program (NDAP) affords people with disability, access to effective disability advocacy that promotes, protects and ensures their full and equal enjoyment of all human rights thus enabling full community participation. Disability advocacy agencies are funded by the Commonwealth. As a part of NDAP, a Quality Assurance system was introduced which provide mechanisms, independent of government, to assess the compliance of disability advocacy services against the Disability Advocacy Standards (DAS). Implementation of the Quality Assurance system commenced from the 1st of July 2012, with every NDAP funded agency required to achieve a certificate of compliance against the DAS on or before 31st December 2013.

The NDAP Quality Assurance system is underpinned by an auditing procedure tailored to the needs of the program and is developed and overseen by the Joint Accreditation System for Australia and New Zealand (JAS-ANZ). Independent audit personnel, including people with disability who perform the role of Consumer Technical Expert (CTE), are employed by Certification Bodies accredited by JAS ANZ. These independent audit personnel perform on site audits in accordance with auditing procedures and guidelines to determine NDAP agencies’ compliance against the DAS.

A CTE is a person with disability, engaged for his/her specialist knowledge and abilities; for example empathy with the life experience of people with

disability, and ability to plan and facilitate the effective input of people with disability in an audit process. A CTE provides evidence to the Certification Body of having been a service recipient of a State or Commonwealth funded disability organisation in Australia. CTEs have successfully completed training required by the former Department of Families, Housing Community Service and Indigenous Affairs, which includes the nature of advocacy and advocacy models, and an understanding of the DAS, Key Performance Indicators and Evidence Guidelines, before auditing in the system.

CTEs actively participate in audit activities including but not limited to:

- a) Planning and preparing the methods of consumer participation in the audit and evaluating the need for independent support for consumers.
- b) Participating in the audit, including the opening meeting, audit team review meeting(s) and closing meeting.
- c) Engaging consumers during the audit to collect, examine and analyse evidence with respect to the DAS.
- d) Reviewing consumer files or follow up issues with consumers.
- e) Reviewing audit findings, determining audit ratings and preparing the written audit report.

NDAP: http://www.jas-anz.org/index.php?option=com_content&task=view&id=119&Itemid=1

MEASURING CONSUMER SATISFACTION

Quality Framework for Responsible Care (QFRC) – Netherlands: 2005

The QFRC program was developed in 2005 with the program falling under the Ministry for Health, Welfare and Sports which contracted several research organisations to develop an array of databases and tools for different sectors of health care (Frijters, 2010). The Ministry mandated the development of a national standard for measurement and comparison of consumer experiences, named the Consumer Quality Index (CQ-Index) (Organisation for Economic Cooperation and Development, 2013). All long-term care facilities are required to carry out surveys of users experience using the CQ-Index Long-Term Care once every two years (Organisation for Economic Cooperation and Development, 2013). The tool is used to measure and compare consumer experience across ten quality domains with each domain associated with a set of indicators:

1. Care/life plan to assure long term care recipients' involvement in care and life planning.
2. Communication and information to ensure that providers keep communication open and make efforts to listen to recipients' wishes.
3. Physical wellbeing for recipients to receive adequate support and to feel satisfied with the care provided.
4. Safety of care to prevent avoidable harms and restriction of freedom of movement.
5. Domestic and living conditions to respect recipients' privacy and their living atmosphere.
6. Participation and autonomy to ensure sufficient opportunities to participate in various activities.

7. Mental well-being to provide mental support (loneliness or depression) and pay attention to their choices and sense of purpose.
8. Safety of living environment.
9. Sufficient and competent personnel to ensure availability of qualified staff and sufficient care time.
10. Care co-ordination across health and adult social care.

The results from the QFRC are publicly reported for each organisation on www.KiesBeter.nl to ensure greater transparency of data and motivate organisations to improve their performance (Organisation for Economic Cooperation and Development, 2013). Research has indicated that the CQ Index Long-Term Care provides a good basis to investigate the quality of nursing homes, residential care homes and homecare from the clients' perspective. The CQ Index Long-Term Care enables a nationwide comparison of the quality of long-term care for the purpose of transparency and quality assurance.

Short Observational Framework for Inspection (SOFI) – England: 2006

SOFI was developed by the Commission for Social Care Inspection (CSCI) and the University of Bradford to try and capture, in a systematic way, the experience of care for people who use services who would otherwise be unable to communicate this to an inspector.

SOFI builds upon Dementia Care Mapping (DCM), an internationally recognised way of evaluating the quality of care from the perspective of the person with dementia, with the tool developed to evaluate the mood and engagement of the person using the service. The tool is administered alongside observations of staff communications and interactions

that either enhance or undermine the person's sense of wellbeing. SOFI is less intensive than DCM and focuses on three elements of observation:

- The general state of observable well-being: positive, passive, negative, withdrawn, asleep.
- The level of engagement that the participants show: with people, with animals, in a task/activity, with an object.
- The style of staff interaction: positive, neutral or negative.

SOFI is a methodology in development and is not intended to be the only source of evidence that inspectors base their judgements; instead, SOFI findings provide a snapshot of care, as experienced by the person using the service, and is used alongside other information collected during the course of the inspection. This may include speaking with staff and reviewing care plans, policies and procedures. The information obtained from inspections is provided to the person observed, care staff and managers with the findings from SOFI often utilised to help services improve their care.

SOFI: <http://www.cqc.org.uk/organisations-we-regulate/registered-services/how-we-inspect/short-observational-framework-inspectio>

Euro Health Consumer Index (EHCI) – Sweden: 2004

The EHCI has been published by the Health Consumer Powerhouse (HCP) since 2004 with the aim of promoting consumer-related healthcare across Europe. The EHCI serves as a tool to inform consumers regarding health policies, consumer services and quality outcomes to instigate reform in areas where services and care are lacking.

Thirty-five countries are monitored and compared on a 1000-point scale on 42 indicators, covering 5 key evaluation areas relating to the health of consumers: 1) patients' rights and information, 2) accessibility of treatment (waiting times), 3) medical outcomes, 4) range and reach of services provided, and 5) pharmaceuticals. The EHCI is compiled from a combination of public statistics, patient polls and independent research conducted by HCP.

The user-friendly index measurement methodology employed by the HCP allows consumers to take on healthcare performance and illness management. There are HCP comparisons of areas such as heart disease, diabetes, HIV-AIDS, Chronic Obstructive Pulmonary Disease, breast cancer, renal care, vaccines, smoking cessation and patient information.

The 42 indicators across the 5 key evaluation areas include access to own medical records; direct access to specialist; long term care for elderly; drug subsidies and access to new drugs; right to second opinion; and patient organisation involvement to name just a few.

HCP: <http://www.healthpowerhouse.com/index.php?Itemid=55>

Health Quality (Sundhedskvalitet.dk) – Denmark: 2007

In 2006, the National Board of Health and the former Ministry of the Interior and Health launched the website www.sundhedskvalitet.dk. The aim of the website is to communicate information on the quality and service at the different hospitals across the country. The information is easy to comprehend and allows consumers to select the best hospital care.

The website has information on both the clinical quality, for example information on the number

of complications, on the quality experienced by patients expressed through national survey of patient experiences (see below), and on the organisational quality, which among other things expresses the standard of hygiene and the hospitals' observance of agreements. Hospitals are graded on the website from one star to five stars.

On the website, patients can compare information on different hospitals. For a number of treatments, it is possible to see how the different hospitals are placed in relation to each other and compared to the national average, by choosing information on length of stay in hospitals, number of rehospitalisations, waiting time for treatments, hygiene etc.

Every second year, the Danish regions and the Ministry of Health and Prevention conduct a survey of the patients' experiences in hospitals. The objective of the survey is to compare patient experiences at the hospital level and at medical specialities and to compare patient experiences over time. The survey includes questions on clinical services, patient safety, patient and staff member continuity, co-involvement and communication, information, course of treatment, discharge, inter-sectoral cooperation, physical surroundings, waiting time and free hospital choice. The survey reveals patients' overall impressions of the hospitalisation process and areas for improvement.

Nursing Home Compare – United States: 2009

The Centers for Medicare & Medicaid Services have created the Five-Star Quality Rating system to help consumers, their families, and caregivers compare nursing homes more easily and to help identify areas about which the consumer may wish to ask more questions.

The website features a quality rating system that gives each nursing home a rating of between 1 and 5 stars. Nursing homes with 5 stars are considered to have much above average quality and nursing homes with 1 star are considered to have quality much below average. There is one Overall 5-star rating for each nursing home, and a separate rating for each of the following three sources of information:

- Health inspections – this rating contains information from the last three years of onsite inspections including both standard surveys and any complaint surveys. Information is gathered by individuals who go onsite to the nursing home and follow a specific process to determine the extent to which the nursing home has met Medicare’s minimum quality requirements. More than 200,000 onsite reviews are used in the health inspection scoring nationally.
- Staffing – this rating has information about the number of hours of care on average are provided to each resident each day by nursing staff. This rating considers differences in the level of need of care of residents in different nursing homes.
- Quality Measures (QMs) – this rating has information on nine different physical and clinical measures for nursing home residents, for example prevalence of pressure sores. Information is collected by nursing homes for all residents. The QMs offer information about how well nursing homes are caring for their residents’ physical and clinical needs. More information about these measures can be found at: <http://www.medicare.gov/NursingHomeCompare/Data/Risk-Adjustment.html>.

CONSUMER INVOLVEMENT IN COMPLAINTS

Long-term Care Ombudsman Program – United States

Long-term care ombudsmen act as advocates for residents of nursing homes, board and care homes, assisted living facilities and similar adult care facilities. The Ombudsmen work to resolve problems experienced by individual residents and instigate change at a local, state and national level to improve the lives of residents. The Ombudsmen do not regulate the aged care industry but advocate on behalf of residents, work to resolve complaints between residents and long-term care providers, provide staff training in long-term care facilities, and investigate complaints. The program employs 1,167 full-time staff and has 8,813 volunteers certified to handle complaints.

The National Long-Term Care Ombudsman Resource Center (NORC) provides support, technical assistance and training to the 53 state ombudsmen programs with the aim of enhancing skills, knowledge, and management capacity of the state programs to better enable them to handle resident’s complaints and represent resident interests. The resource center is largely operated by the Consumer Voice, a national body representing consumer interests and empowering consumers to advocate for themselves. The Consumer Voice also provides information and leadership on federal and state regulatory and legislative policy development and strategies to improve the quality of care and life of residents.

APPENDIX I:

The current landscape of aged care in Australia

In 2011-2012, 222,316 Australians received permanent residential care in aged care facilities. Nationally, 2,725 aged care homes across Australia delivered residential aged care with around 73 per cent of all operational residential care places being used for high level care. On average, around 92 per cent of all residential care places were occupied during the 2011-2012 period (Department of Health and Ageing, 2012).

FUNDING AND ACCREDITATION

Residential aged care in Australia is predominantly funded by the Commonwealth Government through tax revenue with some finance coming from other levels of government and user co-contributions (National Seniors Australia, 2010). Residential aged care provides the consumer with accommodation, living services (e.g. meals, laundry and cleaning) and assistance with personal tasks such as bathing, eating and dressing (National Seniors Australia, 2010). Allied health and nursing care are typically available to residents as required (National Seniors Australia, 2010).

Funding for each individual resident's care needs is determined by the Aged Care Funding Instrument (ACFI) with residents receiving a subsidy paid directly to the residential aged care provider (National Seniors Australia, 2010). The sum paid to the residential aged care provider is dependent upon the extent of the resident's care needs with the ACFI used to determine the total amount of the subsidy in three areas:

1. Activities of daily living – ratings on nutrition, mobility, personal hygiene, toileting and continence questions utilised to determine level of the basic subsidy.
2. Behavioural supplement – ratings on cognitive skills, wandering, verbal behaviour, physical behaviour and depression questions utilised to determine the behaviour supplement.
3. Complex health care supplement – ratings on medication and complex health care procedure questions utilised to determine the complex health care supplement (Department of Health & Ageing, 2012).

The subsidy paid to residential aged care providers by the Commonwealth Government forms a

part of an accreditation arrangement initiated by the Commonwealth Government to ensure that residential aged care providers are delivering quality care and services to residents (Organisation for Economic Cooperation and Development, 2013). In order for the residential aged care provider to receive Commonwealth Government subsidies, they must be accredited by ACSAA as an approved provider (Organisation for Economic Cooperation and Development, 2013). ACSAA is responsible for managing the accreditation process and monitoring residential care services as well as delivering education and training to residential aged care providers.

Accreditation involves the residential aged care provider being assessed against a set of legislated standards which comprises a total of 44 expected outcomes as outlined in the Quality of Care Principles 1997. The four accreditation standards comprise:

- 1) Management systems, staffing and organisational development - management systems are responsive to the needs of residents, their representatives, staff and stakeholders, and the changing environment in which the service operates.
- 2) Health and personal care - residents' physical and mental health will be promoted and achieved at the optimum level, in partnership between each resident (or his or her representative) and the health care team.
- 3) Resident lifestyle - residents retain their personal, civic, legal and consumer rights, and are assisted to achieve active control of their own lives within the residential care service and in the community.
- 4) Physical environment and safe systems - residents live in a safe and comfortable environment that ensures the quality of life and welfare of residents, staff and visitors (Aged Care Standards

& Accreditation Agency website, n.d.; Organisation for Economic Cooperation and Development, 2013).

The key elements of the accreditation process include:

- a) Self-assessment by the home against the Accreditation Standards.
- b) Submission of an application for re-accreditation (with or without the self-assessment).
- c) Assessment by a team of registered aged care quality assessors at a site audit – conducted over two to three days which includes interviews with residents, their family members and staff and management.
- d) A decision about the home's accreditation by a decision-maker (not part of the assessment team).
- e) Issue of an accreditation certificate.
- f) Publication of the decision on Accreditation Standards website.
- g) Unannounced visits to monitor homes' on-going performance.

Accreditation utilises a two-tiered score of 'compliant' or 'non-compliant' for each of the 44 expected outcomes. If ACSAA decides to accredit a residential aged care service, it must decide the period for which the service is to be accredited, whether there are any matters which must be improved to comply with the Accreditation Standards and the form and frequency of support contacts for that service. Residential aged care providers are generally awarded accreditation for a period of up to three years dependent upon past and present performance on accreditation assessments. As of the 30th of June 2012, 2,587 of the 2,731 accredited homes (94.7 per cent) were accredited for three years. New residential aged care homes are initially awarded a maximum of one year's accreditation (Commonwealth of Australia, 2005).

If a residential aged care provider is found to not comply with the Accreditation Standards or the provider's other responsibilities under the Act, ACSAA may request a review audit. The outcome of the review may result in a decision to revoke accreditation or to vary the period of accreditation (for instance, accreditation will only be granted for a period of 12 months) or to make no changes at all.

If ACSAA finds the residential aged care provider non-compliant with one or more of the 44 expected outcomes which may place or has placed the safety, health and well-being of residents at risk, this is reported to the Department of Social Services (formerly overseen by the Department of Health and Ageing (DoHA)) along with recommendations on whether sanctions or a notice of non-compliance should be imposed (Commonwealth of Australia, 2005).

A sanction will result in all residents of the residential aged care facility receiving a letter outlining the issues that resulted in a sanction being issued and what the residential aged care provider must do to rectify these issues. The residential aged care provider is also expected to meet with residents, discuss the identified problems and clarify what the provider will be doing to fix them. The Department of Social Services (DSS) closely observes the residential aged care provider to ensure that problems are corrected in a timely manner (Department of Health & Ageing, 2012).

Notices of non-compliance may also be issued when a residential aged care provider has not complied with its responsibilities in providing adequate care and services but where there is no immediate risk to the wellbeing of residents. The Notice details what issues must be attended to and a timeframe for rectification. Once again, the residential aged care provider is expected to meet with residents to discuss problems and repairs (Department of Health & Ageing, 2013).

Changes to the accreditation process have been detailed in the Living Longer. Living Better. package

released in 2012. This included the replacement of ACSAA with the Australian Aged Care Quality Agency from the 1st of January 2014. This new body will be the sole agency responsible for approved providers under the Aged Care Act 1997 whether services are delivered in a residential care home or in the person's own home. The new agency will maintain the same functions and objectives as ACSAA but with the additional responsibility of standards monitoring in home care. A set of national quality indicators for residential care facilities are to be established for residential aged care facilities which will be published on the My Aged Care website from the 1st of July 2014.

COMPLAINTS

Aged Care Complaints Scheme

The Aged Care Complaints Scheme (the Scheme) commenced operation on the 1st of May 2007 as the Complaints Investigation Scheme (CIS) and was established to investigate complaints lodged under the Aged Care Act 1997. In 2009, Associate Professor Merrilyn Walton undertook an independent review of the CIS to identify areas of improvement.

As a result, the Australian Government pledged \$50.6 million over four years to improve the CIS's capacity to deal with complaints. The CIS was renamed the Aged Care Complaints Scheme in 2011 to reflect greater flexibility in resolving concerns and also saw the replacement of the Investigation Principles 2007 with the Complaints Principles 2011 (Auditor General's Report, 2012). In February and March 2011, DoHA provided consumers with an opportunity to comment on how aged care complaints were managed through the www.yourHealth.gov.au website. Some 42 submissions were received from a variety of stakeholders including consumer representatives and advocacy groups. Furthermore, DoHA held a number of meetings with consumer groups and stakeholders

to discuss the Living Longer. Living Better. reforms and the production of new consumer information materials (Halton, 2011).

As a result of the 2011 changes and the introduction of the Complaints Principles 2011, additional complaint resolution options were established with a greater focus on resolution of complaints which also served to strengthen examination and reconsideration rights (Department of Health & Ageing (Scheme Guidelines), 2013). The Scheme is managed by the Office of Aged Care Quality and Compliance (OACQC) within DSS.

The current role of the Scheme is to:

- Examine information provided to the Scheme.
- Resolve complaints regarding the care and services provided to recipients of aged care services.
- Take action, where necessary, to protect the safety, health and wellbeing of care recipients.
- Refer information, where necessary, to internal and external organisations to assist them in performing their regulatory functions (Department of Health & Ageing (Scheme Guidelines), 2013).

The Scheme is free for consumers to raise their concerns about quality of care or services being delivered to individuals receiving aged care services subsidised by the Australian Government. Complaints can be submitted to the Scheme in writing, online or via telephone with the complainant able to submit their complaint openly, confidentially or anonymously. Confidential complaints ensure that all or part of the information provided by the complainant is not disclosed to the service provider or anonymous complaints where complainants do not disclose their details to the Scheme or if they do so, request their details to not be recorded (Department of Health & Ageing, 2013).

In the event a complaint is lodged and the Scheme finds the residential aged care provider is not meeting their responsibilities under the Act, a Direction can be issued. A Direction requires the residential aged care provider to demonstrate how they have or will meet their responsibilities under the Act or under their Commonwealth funding agreement. A Direction is issued in writing and outlines what the service provider must do within a set timeframe to address the issues of the complainant and meet their responsibilities. This process is monitored and enforced by DSS to ensure the residential aged care provider implements the required actions.

The Scheme can also refer a matter to the DSS compliance area for compliance action if there is concern that an residential aged care approved provider has not complied with or is not complying with its responsibilities under Parts 4.1 to 4.3 of the Aged Care Act. The Compliance Area is responsible for using notices of non-compliance, notices to remedy and sanctions.

The Scheme received a total of 11,517 contacts for the 2011-2012 period with 6,955 considered in-scope representing 60.4 per cent of all contacts. Of the 6,955 contacts received by the Scheme, 4,031 related to Australian Government subsidised residential and community aged care. The CIS and the Scheme finalised 4,246 complaints in 2011-2012, an average of 354 complaints finalised per month nationally. This figure includes some complaints which were received in 2010–11 (Department of Health & Ageing, 2012).

Aged Care Commissioner

The Aged Care Commissioner (ACC) is an independent body which can examine complaints by consumers regarding decisions, processes or conduct of either the Scheme or ACSAA. The ACC cannot directly examine complaints about care or services that consumers receive.

As a result of the Living Longer. Living Better reforms, the ACC's powers were strengthened from 1 August 2013. The changes aim to improve consumer and service provider confidence in the management of complaints and improve complaint outcomes.

The new functions of the Commissioner include:

- Independently examine decisions of the Scheme upon request from either complainants or approved providers and direct the Scheme to undertake a new resolution process where deemed appropriate
- Consider complaints about the processes of the Scheme upon request from either complainants or approved providers and make recommendations to the Scheme
- Examine complaints about the conduct of ACSAA or its assessors and provide recommendations to ACSAA
- Examine complaints processes or ACSAA conduct issues on the Commissioner's own initiative.

Additionally, under the Living Longer. Living Better reforms:

- The Scheme is required to provide draft finding to the Commissioner following a new resolution process and take into account any further comments before finalising the matter
- The Commissioner can take no further action where it is appropriate to do so
- The Scheme is required to provide information as requested by Commissioner relevant to the matter being examined
- The Commissioner is able to provide a report to the Minister on any matters relating to her functions (Australian Government, 2013).

APPENDIX 2:

Gold Standards Framework

PANEL:

THE SEVEN CS OF THE GOLD STANDARDS FRAMEWORK

1. Communication

- A supportive care register is compiled to record, plan and monitor patient care. This is used as a tool for discussion at health care team meetings.
- Regular primary health care team meetings are held to improve the flow of information.

2. Co-ordination

- A nominated co-ordinator (eg, a district nurse, practice manager or GP) is appointed to maintain a register of concerns and problems. The co-ordinator also organises team meetings for discussion, planning, case analysis and education.

3. Control of symptoms

- Patient symptoms are assessed, discussed and treated.
- Anticipatory prescribing is practised.

4. Continuity

- Palliative care patient details are passed on to local care specialists with transfer of information to the local out-of-hours service.
- Patients and carers are given information about the contacts for out-of-hours advice.

5. Continued learning

- Meetings are organised to discuss patients' care and to share ideas and problems
- Significant event analysis takes place to consider good examples of care and possible improvements for future work.

6. Carer support

- Carers are supported, listened to, encouraged and educated to play as full a role in the patient's care as they wish.
- A link with social services will be made to ensure that practical support is available.
- Health care professionals plan support for the carer when bereavement occurs.

7. Care in the dying phase

- The period when the patient is approaching the terminal phase (death is likely in the next two weeks) is recognised and this information is communicated to family and carers.
- Medicines for symptom control of all terminal symptoms is made available in the home.

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