Mr Finn Pratt PSM
Secretary
Department of Social Services
PO Box 7576
Canberra Business Centre ACT 2610
agedcaresectorcommittee@dss.gov.au

Re: Adoption of international standards and risk assessments in the aged care sector

Dear Mr Pratt,

Alzheimer's Australia welcomes the opportunity to provide feedback to the Department of Social Services Deregulation Unit regarding the deregulation across the aged care sector and adoption of international standards and risk assessments when assessing aged care.

Alzheimer's Australia is the peak body providing support and advocacy for people with dementia and their families and carers in Australia. Dementia is the third leading cause of death in Australia, and will likely have an increasing impact on the health and aged care system due to the current demographic shift in the Australian population. The population aged 65 years and over is projected to increase from over 3 million currently to almost 5.8 million in 2031[1]. As a result of population ageing, we are also facing a rapid increase in the number of people who have dementia. Currently there are more than 342,000 Australians with dementia and this figure is expected to increase to almost 900,000 by 2050[2].

The ever increasing number of people with dementia has resulted in a rise in the numbers living in residential aged care. As of 30 June 2012, 52% of permanent residents (or 86,640) with an Aged Care Funding Instrument appraisal were living with dementia[3]. People with dementia were also more likely to be assessed as having high care needs than residents who did not have dementia (90% compared with 70% respectively).

Although a large number of people with dementia reside in residential care, the majority living with dementia (70%) remain in the community receiving both informal and formal care[4].

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[1] ABS (2013). 3222.0 Population Projections, Australia (2012) to 2101
[2] AIHW (2012). Dementia in Australia
[3] AIHW (2012) Dementia in Australia
[4] Alzheimer's Australia (2014) Living with Dementia in the Community: challenges & opportunities

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The accreditation and quality monitoring processes currently used in the aged care sector in Australia have been criticised by both consumers and aged care organisations due to their focus on administrative processes rather than resident and client outcomes.

The accreditation process invariably creates red tape limiting staff time with residents and places a greater emphasis on regulation rather than continuous improvement[5] and therefore the opportunity for systems reform is welcome.

At present there is no one internationally accepted standard or risk assessment process for aged care. Most countries have an individual approach to accreditation and standards review. Although it is probably not possible to adopt an international standard for aged care accreditation, it is important to examine the various models that exist internationally and identify what has and has not worked effectively and how these processes can be adapted to the Australian aged care sector with an increased focus on (a) measuring quality of care, (b) increased consumer involvement in accreditation and (c) complaints handling.

Measuring quality of care

Measurement of the quality in aged care is subject to considerable variation. At present, there is no one universal standard for monitoring quality; instead, the most common policy approach to monitoring quality in OECD countries focuses on controlling inputs (e.g. labour, infrastructure) by setting minimum acceptable standards and then enforcing compliance[6]. Although regulation, compliance and enforcement are typically utilised in the aged care sector both nationally and internationally, questions remain regarding how effective fines, warnings and threat of closures are in relation to quality and may in fact stifle innovation or discourage service providers from going beyond minimum standards[7].

In recent years, efforts have been made to develop and utilise quality measurements encompassing clinical quality, user-experience and quality of life in aged care, however, at the present time only a handful of OECD and European countries systematically collect information regarding quality[8]. International case studies are emerging revealing that quality assurance is now focused in three key areas: 1) the standards for provider participation; 2) the monitoring and enforcement of compliance; 3) and public reporting and other market based approaches to improve quality.

These international examples afford Australia the unique opportunity to learn from success and failures in implementing different systems and approaches in monitoring quality of care.

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[5] NACA (2012) Aged Care Reform Series – Quality of Care
[6] OECD (2013) A Good Life in Old Age – Monitoring and Improving Quality in Long-Term Care
[7] OECD (2013) A Good Life in Old Age – Monitoring and Improving Quality in Long-Term Care
[8] OECD (2013) A Good Life in Old Age – Monitoring and Improving Quality in Long-Term Care

International examples of measuring quality of care

Netherlands

Measuring Quality of Life (QoL) has been problematic due to varying definitions of what constitutes quality care, however, recently a number of countries have attempted to capture this information through the development of standardised assessment tools. In the Netherlands, the Institute for

Research in Healthcare (NIVEL) and several other organisations have developed the Consumer Quality Index (CQ Index) as a standardised system for measuring, analysing and reporting user experience in health care. The CQ Index provides insight into what clients find important and how they rate their experience with care. Surveys are carried out by accredited external agencies in accordance with the standards and guidelines. By law, each healthcare and long-term care organisation has to arrange a survey once every two years. Results can be used by clients to choose a health insurer or health services, by client organisations representing the interests of their members, by insurers to assess the quality of services purchased, by managers and professionals who want to improve their performance, and by public authorities and monitoring agencies.

The CQ Index is a substantial part of the Quality Framework for Responsible Care (QFRC) as it provides a range of measurable indicators that show whether health and long-term care organisations provide responsible care. The results of the QFRC are publicly reported for each organisation online in order to facilitate transparency, stimulate continuous improvement and allows for a nationwide comparison of the quality of care. Research has indicated that the CQ Index provides a good basis to investigate the quality of nursing homes, residential care and home care from the clients' perspective[9].

England

The Adult Social Care Outcomes Toolkit (ASCOT) was developed in England to capture information regarding social care outcomes which is expressed as a scale of an individual's long-term care across a range of care settings and users. The ASCOT tool focuses on items such as cleanliness and comfort, good nutrition, safety, control over daily life, social interaction, occupation, accommodation and dignity from the perspective of the care recipient. Data is collected via surveys involving interviews with the care recipient or their legal representative. The ASCOT tool was utilised as a part of a broader National Adult Social Care Survey to obtain information from all long- term care users nationally.

[9] OECD (2013) A Good Life in Old Age – Monitoring and Improving Quality in Long-Term Care

The tool provides an opportunity for a comparative analysis of aspects of social care, however, this is dependent upon the ability to collect data at a national level which may not be feasible. Research indicates some construct validity for the ASCOT lending support for the ASCOTs use in economic evaluation as well as providing evidence supporting its use amongst older people[10].

United States

In the United States, the Long-Term Care Minimum Data Set (MDS) forms the foundation of a federally mandated comprehensive clinical assessment for all residents in a Medicare or Medicaid-certified long-term care facility. This standardised primary screening and assessment of health status tool was born as a result of a number of scandals in long term care in the 80s. The MDS contains items that measure physical, psychological and psychosocial functioning and provides a multidimensional view of an individual's functional capacities. An updated version of the tool was recently launched following a national project to improve clinical relevance and accuracy of MDS assessments to increase the voice of residents in assessments, improve user satisfaction and increase the efficiency of reports[11].

A range of information is captured by the tool including the use of psychotropic medications. Information collected via the MDS is transmitted electronically by long-term care facilities to MDS databases in their respective states. State-based information is then captured utilising a national database at the Centres for Medicare and Medicaid (CMS) with the information utilised for a range of functions including feeding into the facility's quality indicator and quality measure reports and evaluations which can then be made publically available where applicable[12].

Consumer Involvement

From the consumer perspective, more involvement in the accreditation process and a greater focus on quality of life of residents would increase transparency in the aged care sector. Consumers would like to have a more central role in the accreditation and quality monitoring process and involving care recipients, carers or former carers as part of the assessment team would utilise their expertise as well as give consumers more confidence in the system.

The implementation of national quality indicators in the near future in the residential care setting will also be a positive step towards increasing transparency for consumers in the aged care sector.

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[10] Malley et al (2012) An assessment of the construct validity of the ASCOT measures of social care-related to quality of life with older people
[11] OECD (2013) A Good Life in Old Age – Monitoring and Improving Quality in Long-Term Care
[12] Kennedy et al (2006) Long Term Care in T Brown (ed). Handbook of Institutional Pharmacy Practice

International examples of consumer involvement in accreditation

England

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.

Age UK is delivering a part of the Experts by Experience program through the provision of recruitment, training and support of older people who are service users, family carers and people with dementia to act as Experts. A similar program to Experts by Experience was trialled by the Aged Care Standards & Accreditation Agency with further information regarding an evaluation of the project to be made available.

United States

Aligning Forces 4 Quality (AF4Q) was established in the US in 2006 with the aim of increasing the overall quality of health care in targeted communities to reduce racial and ethnic disparities and provide models for national reform. Consumers participating in the project are either receiving care, providing care or paying for care who work together to ensure a better quality of care in their community. At present, 16 geographically, demographically and economically diverse communities are participating in the project. Each participating community 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 being '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. An example of this was the launch of a website for one of the communities aimed at providing

personalised information so patients can better engage with doctors and hospital staff as well as obtain facts and statistics regarding care results for health practices in the region. 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.

Consumer involvement in complaints

Consumers in Australia have also raised concerns regarding the lack consumer involvement in the Aged Care Complaints Scheme.

Models to manage consumer complaints again vary internationally with mechanisms including guardianship systems and complaint handling bodies and ombudsman.

International examples of consumer involvement in complaints

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.

In summary, there is considerable global variation in the standards and assessments utilised to assess quality in aged care. No one universal standard for aged care currently exists and many OECD countries utilise accreditation systems to ensure the quality of care delivered to the community. The emphasis on administrative processes inherent in the current accreditation process adopted in Australia, however, often comes at the expense of the amount of time and care staff can provide residents. A shift from measuring processes towards measuring outcomes has begun but is still in relative infancy both in Australia and internationally. Despite this, a range of international examples are available and it will be necessary to ensure that these examples are assessed and reflected upon to facilitate successful implementation where applicable here in Australia.

Thank you for the opportunity to provide additional information.

Sincerely,

Carol Bennett
CEO, Alzheimer's Australia

20 January 2015