Why regulation?

Government regulation structures the various roles associated with aged and dementia care. It can restrict or facilitate conduct within provider organisations and is intended to moderate the multiple forms of risk that people living with dementia might be exposed to. It helps to create the space in which care takes place. Regulating care is a complex yet crucial undertaking, affecting the quality of the environment that residents, care workers and managers live and work in. Our research project is designed to map the current state of play in terms of existing regulatory frameworks and ways of pathfinding through them, examine state of the art opinion, and explore the strategies adopted at different levels of organisations to best implement regulation and improve care (see Table 1).

Key points

- Regulation is the main mechanism available to governments to influence the quality of care in a market economy. It sits at the crossroads of the state, provider organisations and the experience of care itself.
- It is a complex area involving different levels of government, multiple stakeholders and different layers of organisations.
- Developments in dementia care policy and practice reflect a shift from medical intervention towards creating positive environments for people living with dementia.
- There is concern about the growing numbers of both older adults and people living with dementia (PLWD) and how this will affect access to care, its quality and its cost.

Currently
15%
of the Australian population
are aged 65+ (ABS 2015)

By 2061 it is predicted that this age group will make up over
22%
of the population (ABS 2013)

900,000
is the estimated number of people who will be living with dementia by 2050 (AIHW 2012)

About 1 in 10 people in this age group are living with dementia (AHIW 2012)

- While people living with dementia rely on a range of care and support services, many of the policy and service developments have taken place in residential care.
- It is estimated that about half of all older adults in residential care and about 17% of those receiving a community care package are living with dementia (AIHW 2012).
- According to the Aged Care Financing Authority (2015) in the 2013–14 period residential aged care cost the Commonwealth almost $10 billion per year, with private individuals contributing another $4 billion over the same period.

170,000+
Number of people in residential care (Aust. Gov. 2015)

This equates to more than
85,000+
people living with dementia in residential care

90%
of whom are assessed as needing a high level of care (AIHW 2016)

Just over 1 in 2 of these individuals are living with dementia (AIHW 2012)

Our questions and activities

Table 1 outlines the project's research questions and the corresponding research activities that were developed over four phases.

Table 1

Research questions	Research activities				
	Phase 1		Phase 2	Phase 3	Phase 4
	Mapping aged and dementia care regulations	Literature and policy reviews	Stakeholder interviews	Organisational slice	Developing policy recommendations
1. What are the regulations affecting residential and community dementia care?	✓	✓			
2. To what degree is the aged care regulatory framework perceived to be positive, ambiguous or negative?			✓	✓	
3. How can the pathways taken through the care system best be described?	✓		✓		
4. How do key areas of regulation impact on day-to-day organisational culture?			✓	✓	
5. How do users, carers and workers navigate and interact within these areas?	✓		✓	✓	
6. What recommendations should be made to improve regulation?	✓	✓	✓	✓	✓

Phase 1

Reviewing
Making connections to key themes in previous research

Mapping
Understanding the regulatory environments and pathways

Designing
Using learning to plan and guide data collection

Identifying the parts of a complex system

Mapping regulatory regimes outlines the structures and agencies that influence the environment of care. While many of the structures are enduring, a map is still a snapshot taken at one point in time. It does, however, provide an opportunity to examine the arrangements that shape contemporary aged care systems.

A number of attempts have been made to find a pathway through the care environment. Each emphasises a specific element of progression, particular stakeholder priorities and a variety of professional, service or economic perspectives. The pathways largely reflect change over time for individuals and for organisations as they negotiate regulatory systems.

Here we try to combine such pathfinding with the map of contemporary regulation to examine interconnections between the two and see whether regulations cluster around particular events or transitions. Such clusters would suggest pressure points within the regulatory system that may have implications for the experience and provision of care and for future policy directions.

Understanding the state of regulatory play

- Regulations do not exist in a vacuum. They have become an important policy area because they exist where politics, governance, provider and end user interests, plus theoretical and research inquiry, all intersect.
- Together the various stakeholder groups contribute to a climate of opinion that helps to define the perceived purposes and the understanding of regulation by wider society.
- Because the groups have different stances toward regulation, the role, purpose and effects of regulation may often be contested, but paradoxically may also provide a common basis for action.
- As regulation has developed, it has been accompanied by the formation of new areas of expertise and growing specialisation.

Expertise is an essential part of governance arrangements for health and care (Rose 1993) and networks of care rely on the input of experts and expert knowledge (Burris et al. 2005). There are now nominated experts in quality assurance, clinical governance, risk management and compliance both external to and within provider organisations. End-users and their carers are a source of particular expertise, especially in the negotiation, coordination and experience of services.

In Phase 2 we employed an Oracle approach to identify and interview key stakeholders concerned with regulation. This was in order to understand the current state of play in regulating residential aged and dementia care and identify key themes for further investigation. We identified 27 experts across five groups—care consumers, policy-makers and public servants, peak bodies, specialist academics and aged care providers.

Phase 2
Interviewing
Gaining perspectives from stakeholder knowledge
Analysing
Identifying recurring issues and cross-group differences
Refining
Using findings to shape focus and move research forward

Examining practice in action

- Provider organisations operate in the middle ground between regulators and the consumers of care.
- Employees have different levels of engagement with systems of regulation depending on their role within an organisation.
- When negotiating complex governance arrangements, organisations and employees adopt particular strategies, which are shaped as well by their own culture and histories.

As regulation 'moves closer to the action' (see for example Huising and Silbey 2011), responding becomes less concerned with whole system issues and more concerned with the direct conduct of care. Each level has a different level of engagement with regulation. Strategies adopted at each level reflect this. There are often multiple regulations requiring complex reporting and assessment systems.

Our research identified three levels, which loosely correspond with management hierarchies. Members of each level were interviewed in three provider organisations from different parts of Australia, to explore their understanding of regulation, its prohibitive and facilitative effects and the strategies used to negotiate such complex systems. The levels and interview focus are detailed in Table 2.

Phase 3
Visiting
Examining practice with providers on site
Surveying
Developing a vertical slice perspective on key issues
Interpreting
Using findings to frame patterns, discourses and needs

Table 2

Level	Respondent	Principal focus
Organisation	Senior Manager	Strategic capture
Facility	Facility Manager	Operational capture
Direct care	Personal Care Workers	Interactional capture

Care consumers contributed to the research design via the project advisory group, and were also interviewed independently as part of this phase of research. This enabled the user voice to be incorporated into our research and its role in the system to be better understood.

In sum, examining the processes and procedures that translate regulation into action, the degree of flexibility available at each level, and the different ways in which regulation either restricts or facilitates interaction provides a deeper understanding of the role of aged care regulations on dementia care. It lets us know more about how the specific nature of care is reflected in contemporary regulatory practice, and what improvement might be required.

Phase 4

Advising
Providing recommendations to policy-makers and partners

Networking
Circulating research findings and influencing future agendas

Concluding
Completing the project, summarising and looking ahead

Recommending effective systems change

Our research was informed by an advisory group consisting of members of the Consumer Dementia Research Network and representatives of three leading Australian provider organisations. They participated throughout, giving input on research design, participant recruitment and, during the later stages, dissemination of the findings.

Over the course of the project, evidence was actively collected on any issues that might inform recommendations and priorities for change. In the final stages, these recommendations and priorities will be communicated to different levels of government and other stakeholders. They will help to develop policy, practice and system changes to improve care.

References

Australian Bureau of Statistics (ABS) 2015, *Australian demographic statistics, June quarter 2015*, cat. no. 3101.0, ABS, Canberra.

ABS 2013, *Population projections Australia, 2012 to 2101*, cat. no. 3222.0. ABS, Canberra.

Australian Government Department of Health (DoH) 2015, *2014-15 Report on the operation of the Aged Care Act 1997*, DoH, Canberra.

Australian Institute of Health and Welfare (AIHW) 2012, *Dementia in Australia*, cat. no. AGE 70, AIHW, Canberra.

AIHW 2016, *Dementia in residential aged care*, viewed 23 February 2016, http://www.aihw.gov.au/aged-care/residential-and-community-2011-12/dementia/.

Burris, S, Drahos, P & Shearing, C 2005, 'Nodal governance', *Australian Journal of Legal Philosophy,* vol. 30, pp. 30–58.

Huising, R & Silbey, S, 2011, 'Governing the gap: forging safe science through relational regulation', *Regulation & Governance,* vol. 5, pp. 14–42.

Rose, N 1993, 'Government, authority and expertise in advanced liberalism', *Economy and Society,* vol. 22, no. 3, pp. 283–299.

About the project

This project is Activity 7 of the Cognitive Decline Partnership Centre (CDPC), a national initiative funded jointly by the National Health and Medical Research Council (NHMRC), Alzheimer's Australia, which supports the Consumer Dementia Research Network (CDRN), and three aged care industry partners—Brightwater Care Group, Hammond Care and Helping Hand Aged Care.

Simon Biggs is Professor of Gerontology and Social Policy in the School of Social and Political Sciences, University of Melbourne, and in the Brotherhood of St Laurence (BSL) Research and Policy Centre.

Ashley Carr is a Research Fellow in the School of Social and Political Sciences, University of Melbourne and a Research Officer at the BSL Research and Policy Centre.

COGNITIVE DECLINE PARTNERSHIP CENTRE

Further details

Research Insights are published by the Brotherhood of St Laurence as a contribution to the CDPC.

For more information:
Simon Biggs SBiggs@bsl.org.au
Ashley Carr acarr@bsl.org.au

Or visit:

www.bsl.org.au

http://sydney.edu.au/medicine/cdpc/