Research Insights 2

Exploring regulatory clusters in dementia care

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The Australian Government (2014) describes regulation as 'any rule endorsed by government where there is an expectation of compliance'(p.3), which 'includes legislation, regulations, quasi-regulations and any other aspect of regulator behaviour which can influence or compel specific behaviour by business, community organisations or individuals' (p. 62); and as a 'key tool for achieving the social, economic and environmental policy objectives of governments' (Australian National Audit Office 2014, p. 3).

Regulation is often presented as a uniform tool of governance, but an analysis of how regulation is distributed is rare. In fact, our research has shown that the regulation of aged and dementia care is often uneven, with some care activities attracting more regulatory attention than others. Understanding such regulatory processes and patterns allows us to target particular areas and explore the relationship between, for example, protection of vulnerable adults and service innovation. It could also contribute to the more effective allocation of resources.

Our research identified various activities and points in dementia care where regulations tended to collect. We have developed the term *regulatory cluster* to account for this observation.

> ***Regulatory clusters** can be defined as the collection of regulations around activities and processes, contributing to the explicit control of behaviour. They occur where multiple systems interact, at critical transitions in individual care pathways and at particular points of perceived risk. At these points regulations collect together and may be critical in shaping the experience of care.*

Regulatory clusters collect at transitions and at points where different systems interact. The transition to residential care is perhaps the best example of a cluster, involving multiple assessments, different professional groups, plus financial and legal agreements. Regulatory clusters also occur where more than one agency has jurisdiction, such as in the provision of food, prompting repetitive monitoring and recording. Some daily activities also attract clusters, which can in turn affect both the physical layout of facilities and the allocation of staff responsibilities. For example medication and food management attract different degrees of regulation, in different forms and in specific settings. Entry into a care setting is therefore shaped by multiple regulations in a way many people have not previously experienced in everyday life.

In this *Insight* we use our research findings to identify some of the different forms these clusters can take.

It appears that there are at least four different ways to understand how regulations are clustered:

- ***The historical evolution of aged and dementia care regulations*** reveals how particular events have attracted the attention of governments and regulators, prompting reactive, usually top-down, regulatory responses.
- ***Mapping of the current aged care regulatory framework*** shows areas of overlap and duplication between different systems, regulatory agencies and jurisdictions.
- ***Tracing some of the pathways through care*** reveals specific points where individuals are likely to encounter multiple regulations. These often occur at transition points.
- ***Examining the application of regulations in residential aged care facilities (RACFs)*** shows how regulations tend to cluster around specific activities, particularly those associated with high risk.

These four forms of clustering suggest different pressure points in the regulatory system, with implications for consumer experience, service provision and future policy. They also allow us to begin to understand what is particular about dementia care and its regulation.

Historical clustering

Since the 1950s the Australian Government has gradually increased its role in regulating aged care provision, and has achieved a high level of regulatory control through funding and administrative arrangements (Fine 2007). According

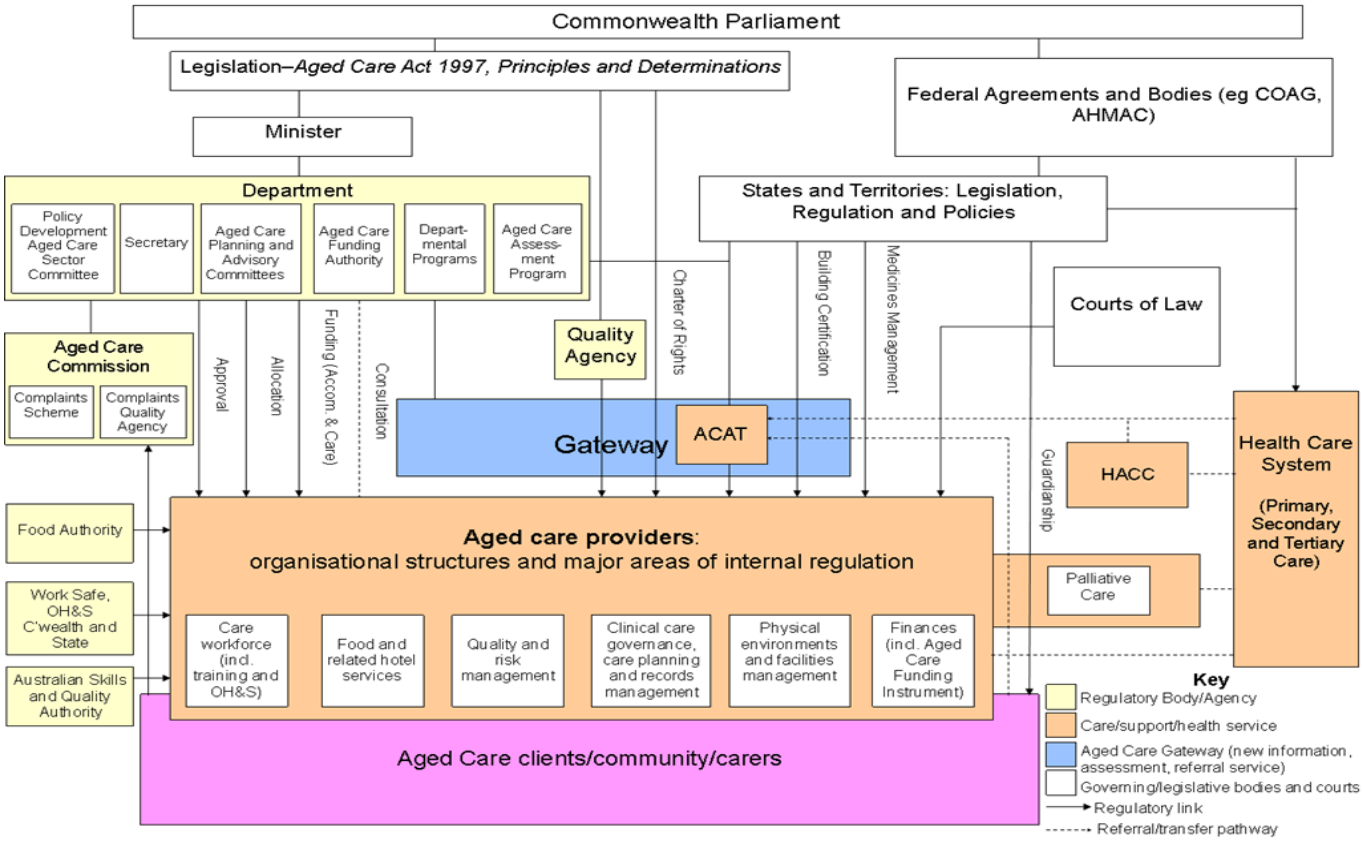
to one influential report (Hogan Review 2004, p. 2) aged care is 'more … constrained by regulation than many other industries', with the 'quality, quantity, location and price' of services heavily controlled at the national, and to a lesser extent, state government levels. While this has arisen through 'hard' forms of regulation, such as laws and acts of parliament, the increasing complexity and plurality of regulation has created a layer of 'soft' regulation, as providers and others have attempted to interpret their regulatory responsibilities in everyday practice. Softer forms of regulation, such as guidelines, manuals and communications, help translate legislation into everyday compliance (Haines 2011).

Regulations designed to protect individuals from harm are an important element of regulatory practice. Historically, incidences of exploitation, unsafe practice and other adverse events have provoked a number of scandals, which in turn provoked additional reactive legislation. According to Braithwaite (2012), 'Regulatory hot-spots' occur at points or events demanding urgent regulatory intervention to moderate emerging risks; in such cases central governments often intervene in a top-down fashion to prevent potential or further harm. Thus 'hot-spots' are generally followed by the introduction of new regulations to counter a specific problem. The additional regulation crystallises over time to become part of the regulatory landscape. Scandal has prompted increased regulation in areas such as care standards, fire and building safety, and the reporting requirements related to abuse and missing residents (see Braithwaite, Makkai & Braithwaite 2007). Over time regulations can cluster, in a haphazard manner, around particular areas of risk.

Mapping overlapping clusters

The Australian regulatory framework can be displayed as a map.

Figure 1 Aged care regulatory framework



This map portrays the regulatory landscape at one point in time, demonstrating its complexity and main players and suggesting regulatory points of overlap. The process of building the map led to the observation that clusters of regulations apply in residential care settings.

The *Aged Care Act 1997* currently includes 17 principles covering areas such as care standards, requirements for approval, allocation of care places, fees and payments, sanctions, record-keeping, prudential requirements and care recipient rights. The Act also stipulates the role and authority of the relevant Commonwealth department, minister

and their representatives as the principal regulators. State legislation deals with other areas related to care, such as building certification, medication management and aspects of food provision. There are more than six independent or semi-independent regulatory agencies, including the Aged Care Commission, the Australian Aged Care Quality Agency, the Aged Care Funding Authority, as well as national and state authorities covering food, building and training/skills. Courts of law, both state and federal, provide another source of regulatory influence. This creates a dense regulatory environment. Indeed the aged care system involves different levels of government, various sectors and multiple regulatory agencies; and there is considerable overlap between jurisdictions. Some aspects, such as care standards, fire safety, food safety and building design are the subject of multiple, overlapping rules and standards, multiple inspections and other monitoring activities. Provider organisations have also developed their own internal monitoring and auditing procedures.

Pathfinding and transitional clustering

Governments and international organisations have identified a number of ways to find a path through the planning and delivery of dementia care and some of these can help us to see where regulatory clusters occur. Pathways are important because they structure institutional authority over time, shape organisational and professional responses to individual care needs and reflect particular forms of experience. Here we identify, in order of development, some influential pathway approaches.

A diagnostic pathway

This first approach follows how symptoms of dementia develop over time, characterised as deterioration.

Global deterioration scale (Reisberg et al. 1982)						
No cognitive decline	Very mild cognitive decline (Age-associated memory impairment)	Mild cognitive decline	Moderate cognitive decline (Mild dementia)	Moderately severe cognitive decline (Moderate dementia)	Severe cognitive decline (Moderately severe dementia)	Very severe cognitive decline (Severe dementia)

An experiential pathway

During the 1980s and 1990s attempts were made to understand the subjective experience of dementia. Cohen and Eisdorfer (1986) describe six phases of how individuals react to cognitive losses before, during and after diagnosis.

Six stages of individual responses to cognitive loss (Cohen and Eisdorfer 1986)					
Pre-diagnosis	**During diagnosis**	**Post-diagnosis**			
Recognition and concern	Denial	Anger/guilt/sadness	Coping	Maturation	Separation from self

Kitwood (1997) and Bender (2002) challenged the notion of sequential disease stages, arguing instead for a greater focus on personal experience and individual variation, particularly during major care transitions. Aspects of this work have since been incorporated into service pathway models.

A clinical service pathway

One of the most influential pathfinding approaches has been developed by Alzheimer's Disease International (2009) and promoted by the World Health Organization. It attempts to harmonise clinical, service and experiential factors.

Seven-stage model for planning dementia services (ADI 2009)						
Pre-diagnosis	Diagnosis	Post-diagnosis and support	Coordination and care management	Community services	Continuing care	End of life palliative care

A service management pathway

Others have attempted to add a resource dimension. The KPMG (2011) service management pathway combines the economics of care, clinical stages and care needs, and service provision to describe 'the services required (including timing and sequencing) to meet the needs of people living with dementia and their carers' while emphasising 'efficient and effective service delivery and coordination'.

Four- stage pathway model (developed as part of the Australian Dementia Initiative) (KPMG 2011)			
Risk reduction, awareness and recognition	Assessment, diagnosis and post-diagnostic support	Management, care, support and review	End of life

A hybrid pathway

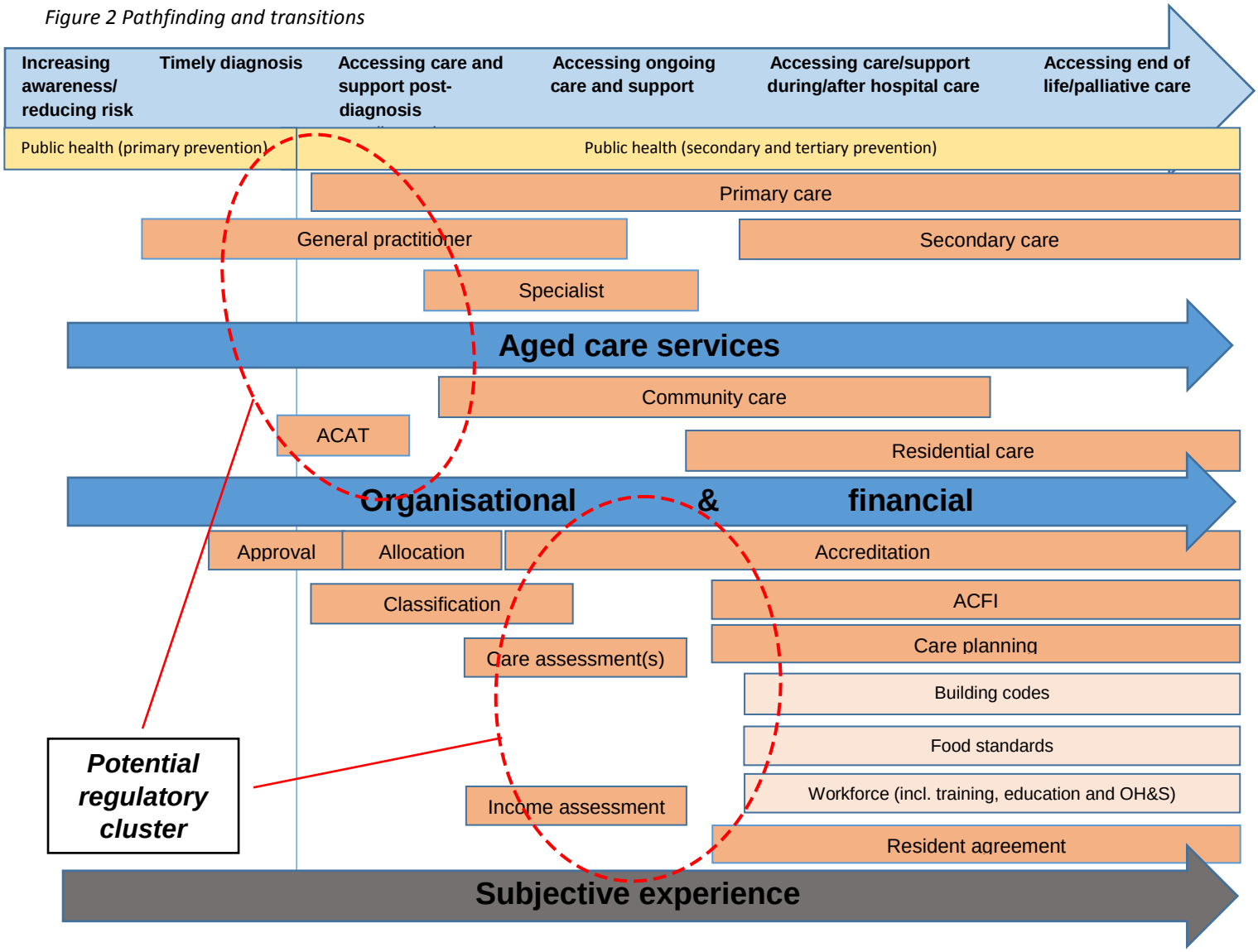
The Australian National Framework (2015) reflects a hybrid approach in which multiple pathways converge in an attempt to make sense of a whole system.

National Framework for Action on Dementia 2015-2019 (Priority Areas)					
Increasing awareness and reducing risk	**Timely diagnosis**	**Accessing care and support post-diagnosis**	**Accessing ongoing care and support**	**Accessing care and support during and after hospital care**	**Accessing end of life and palliative care**
Dementia-friendly communities Collaborative awareness and risk reduction strategies	Access to high quality early detection services Access to information and supports	Accessible, flexible and quality dementia care (for PLWD and their carers) Planning for the future	PLWD and their carers have access to quality dementia care and support BPSD Diverse needs groups	Acute care health professionals are able to recognise and respond to PLWD Standards for quality care of PLWD in an acute care setting	Advance care planning Adoption of a palliative approach High quality end of life care
Promoting and supporting research: Causes, diagnosis, care, treatment, carers, risk factors and risk reduction strategies, end of life care, cure					

While these pathways identify professional perspectives on the progress of cognitive decline, there is less emphasis on how the dementia care system is experienced by end users, such as people living with dementia (PLWD) and their carers. Within a complicated system, end users are likely to experience the complexity directly and can become experts in the coordination and quality of care itself.

By combining pathfinding with the system map we can identify critical points where PLWD and their carers might encounter regulations, and suggest where regulations might cluster around individuals.

Figure 2 Pathfinding and transitions



As individuals move through the system and across recognised care service stages, they encounter different rules and requirements for accessing services. At particular points different systems and agencies interact. At these points individuals are likely to encounter clusters of regulations.

On Figure 2 there are two areas that represent potential cluster points, showing where regulations are likely to collect around individuals. The first of these occurs upon diagnosis of dementia: the need to access health and aged care services sees the individual encounter multiple regulatory requirements and rules, often for the first time. The second regulatory cluster occurs at the transition into residential care, which can involve multiple care assessments, legal and financial agreements, and various care professions.

I think their first experience of it is the extraordinary process of trying to get into an aged care facility or a community program. I think their experience would be the minefield of documentation and they get a very early introduction to the funding structures, the eligibility criteria, the assessment requirements for ACAT [Aged Care Assessment Teams] they have to go through before they can even purchase services
(Senior manager)

Practice clustering around activities and situations

Within residential care settings, certain situations and activities attract high levels of regulation. This is due to factors including the risks posed, the regulatory history and the level of oversight required by government mandate and legislation. These situations and activities are not isolated, but connect together in interesting ways, as is the case with food, medication and daily routines. Such interaction intensifies the clustering effect.

By examining daily life in various dementia aged care settings, we identified certain patterns of clustering. Also we noticed a continuum of regulations, denoting different levels of prescription.

A continuum of regulatory clusters

- **Medication management**: Regulating the management of medication is highly prescriptive, and there is considerable agreement among the providers we studied that this is desirable and is essential to ensuring safe care. Medication management is also related to the regulation of professional behaviour and responsibility. Only a select group of professionals with special training are therefore allowed to administer medication. The high risks associated with medication misuse also mean that its management occurs in specified locations with controlled access. Tensions can arise, for example, in dementia care settings between specialised medication, use of multiple drugs and the possibility of chemical restraint.
- **Fire safety:** Regulating for fire safety in RACFs relates to building design and other requirements, such as fire safety plans and evacuation procedures. These aspects of regulation are defined by the Building Code of Australia and various state regulations. Multiple regulators and fire safety experts are involved in implementing and monitoring compliance. Previous scandals and adverse events have stimulated increased regulation and standardisation. Over time the regulation of fire safety has developed through the interplay of multiple standards, agencies and inspections. How such regulation is handled is key to the creation of a safe workplace and a homelike environment.
- **Food:** While many aspects of food are closely regulated, others allow flexibility and interpretation. Most RACFs are required to develop food safety plans, detailing the purchase, storage, preparation and disposal of food. Certain foods classed as high risk are often avoided in residential care. Some activities such as food temperature testing are prescribed. On the other hand, RACFs can exercise significant flexibility within the limits set by regulation to provide residents a degree of choice in relation to what, when and how to eat, including set meals, grazing and snacking.
- **The daily/morning routine:** In contrast to traditional notions of institutionalisation, the daily and morning routine was least affected by regulation in the providers we studied. There are no regulations determining when residents should get up, although prescriptive procedures related to manual handling and two-person assists do affect morning routines. The routines appear to be more influenced by staff rostering and the culture of the facility than regulation per se, allowing considerable flexibility in daily practice.

Conclusion

Our analysis of regulatory clusters shows how the level of prescription is not uniform, but different degrees of freedom are allowed around particular events. It therefore helps us to specify key areas of regulation, situating them within historical processes, regulating institutions, pathfinding and the activities of care. It helps to identify key areas of risk and flexibility and in so doing locates areas for practical and policy-based innovation. Clustering indicates that there is room to streamline the historical accretion of regulations, reduce institutional overlap, provide supports at transitions that attract regulatory clustering and discriminate between elements of daily residential practice that require strict regulation and those where more discretion is appropriate.

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About the project

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Further details

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