



THE ORGANISATION OF RISK:

How do dementia care providers adapt to regulation?

Ashley Carr & Simon Biggs 2018



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Acknowledgments

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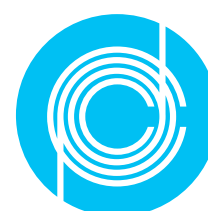
We would also like to thank the many research participants—facility managers, senior managers, personal care workers and people living with dementia—whose involvement was critical in understanding the role and effects of regulation on aged and dementia care. While they came from different backgrounds and represented different constituencies they were all committed to making the experience of care better for people living with dementia.

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SUMMARY

The relationship between regulation, care provision and risk has been an area of continuing policy debate, with regulation becoming a key focus for issues relating to the quality of dementia care plus the monitoring and enforcement of care standards.

This report reflects findings from a three-year research project detailing the effects of regulation on residential care services for people with dementia. We have worked with three leading provider organisations and Dementia Australia's National Consumer Network. Interviews took place with care-users (10), senior managers (17), facility managers (13) and personal care workers (30) across eight aged care facilities, in addition to a scoping exercise with experts from a variety of backgrounds. We also made observational site visits to the organisations involved. In this study we looked at the ways organisations adapt to regulatory demands. First we mapped the agencies, regulatory bodies and pathways involved. Second we looked at organisational strategies at different levels. Third we identified two coping approaches used in everyday care interaction. Regulation emerges not as a matter of more or less or good and bad, but as a practice of adaptation that can both reduce risk and enhance innovation.

Findings

First, regulation is not uniform: it clusters around particular events or transitions, such as when people move into care, or activities such as around food. Sometimes this reflects risk, but clustering also occurs for administrative reasons or through an overlap of multiple authorities on the same issue. None of the stakeholders or practitioners interviewed thought regulation was unnecessary, but many considered it too complex and confused. Identifying clustering may help to target services and identify areas requiring review of their efficiency and effectiveness. It may also be used to identify areas where innovation and co-creation between providers and care users can be achieved more easily.

Second, provider organisations respond to the demands of regulation through a process of interpretation, cultural preference and specialisation by level. These processes of differentiation allow an organisation to adapt by identifying specific activities that both protect against risk and provoke a series of processes that enhance the everyday practice of care. Statutory requirements emerge as requiring interpretation to inform effective practice, including the translation of formal regulation into guidance, training, monitoring and environmental design. Considerable care and subtlety were found in the ways that organisations 'engineered' risk out of their everyday systems. Recognising the specialisation involved in organisational responding has implications for training and the quality of a whole-organisation approach.

Third, an analysis of everyday practice identified two distinctive consequences of regulation: misattention and a puzzle approach. Pressure and anxiety around regulation can lead to 'misattention'. Here the intent behind regulation was eclipsed by a routinised approach to compliance. When the environment was more relaxed, a problem-solving or 'puzzle' approach occurred. Here, emotional connection and professional distance were balanced in encounters between staff and residents. Using a puzzle approach to encounters in dementia care could become an important part of future training for care staff.

Altogether the picture of the interaction between regulation and care provision is one of a complex system that is nevertheless open to adaptation and interpretation. We found that not only did organisations strategise their general orientation to regulation, but also responding was attuned to different functions within provision and the clustering

of regulation around particular activities. Care users provide a distinctive voice wishing to balance protection, rights and autonomy. Viewing regulation as an interpretive process reveals significant areas of flexibility, particularly at the organisational and practice levels. Here, practice can be adapted to address the specific care needs of people living with dementia without compromising regulatory compliance.

Recommendations

Based on our research, which looked at processes rather than particular statutory instruments, we recommend change in four key areas:

Systems overlap, duplication and intent

We recommend a national review of the aged care regulatory framework to identify the intent of regulations and simplify areas of operational overlap or legislative duplication. Examples might include identifying areas where the work of Quality Agency assessors overlaps with or duplicates the work of other regulatory bodies, such as in building design and fire safety, food safety and workplace health and safety. In such instances, we recommend that specific technical assessments are collated by an overview agency in what could be called a 'specialism and overview' model. The review should re-state the intent of regulation, and propose measures connecting regulation to care quality, seeking to improve feedback between provider organisations and the accreditation system.

Regulatory clusters, innovation and consumer engagement

We recommend an increased focus on participation by people living with dementia and carers, recognising consumer expertness. Regulatory clusters should be identified in order to target specific areas of support to consumers when navigating the care system. Regulatory clusters can also be used to identify areas where providers can engage in service innovation and in identifying opportunities for decision sharing with users, regulators and policy makers.

Organisational differentiation and risk management

We recommend that guidance and training should better reflect the multiple functions and responsibilities of staff at specific levels within care provider organisations. This should take into account the different ways that regulation is interpreted by workers at those levels and their interactions with regulators. Risk management systems should be used to anticipate patterns of risk and engineer them out of care environments. We recommend that provider organisations more effectively balance risk, regulation and the specific care needs of people with dementia plus the demanding nature of care work.

Welfare markets and the role of regulation

We recommend that regulation should be seen as providing opportunities to balance innovation and risk management. Choice should be recognised beyond the point of taking up a service to include participation within caring environments themselves. Where regulation and associated bureaucracy cluster around transitions, this complexity inhibits end user choice and so should be simplified significantly.

Details of each recommendation can be found in the final section of the report.

THE RESEARCH

This report reflects findings from a three-year research project detailing the effects of regulation on residential care services for people with dementia.

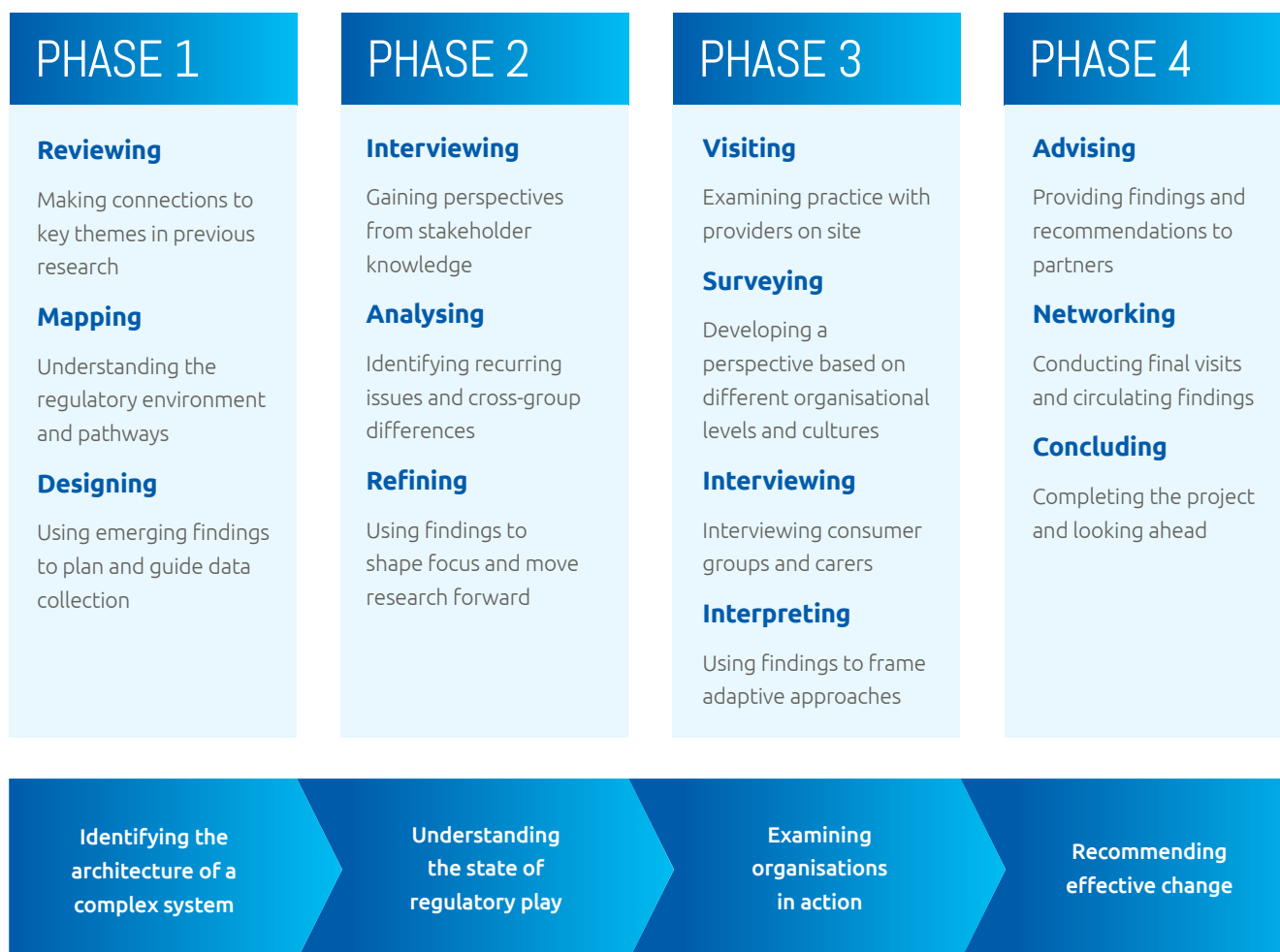


The relationship between regulation, care provision and risk has been an area of continuing policy debate, with regulation becoming a key focus for issues relating to the quality of dementia care plus the monitoring and enforcement of care standards. There is, however, limited research on the ways organisations respond to regulation and how it can affect daily practice.

In the public domain, the role of regulation is contested. Some argue for a lessening of regulation. Others suggest that more is needed. On the one hand concerns have been raised that regulation constrains organisations in their caring goals, inhibits innovation and conceals qualities of 'good' dementia care; on the other, promoting a level playing field, protecting vulnerable citizens and guaranteeing their rights and entitlements are seen as benefits. Public debate tends to present regulation in simplistic and partial terms, inhibiting a deeper understanding of how regulation influences the daily organisation of care and how innovation in care can be achieved. Addressing such issues requires a critical and nuanced understanding of how regulating dementia care plays out as a system, in provider organisations and in day-to-day care.

To find out how provider organisations adapt to regulation, our research sought to examine the complex regulatory framework under which care providers operate; understand multiple perspectives on regulation, its function and practice; and critically assess the role of regulation as it affects practice in action. The focus has been on the systems and conduct of regulation, rather than the impact of specific regulations.

Four phases of research, each with a specific aim and tied to particular research activities, were designed as follows:



Research activities, carried out across the four phases of research, included:

- 1 Literature and policy reviews
- 2 Site visits and discussions with staff in three aged care provider organisations
- 3 Scoping interviews with members of key stakeholder groups—policy-makers, senior personnel in aged care provider organisations, industry peak bodies, academics and consumers (30 interviews in total).
- 4 Research interviews with three levels of aged care provider organisations—17 senior managers (SM), 13 facility managers (FM), and 30 direct care workers (CW)—from three aged care provider organisations and covering eight residential aged care facilities
- 5 Research interviews with 10 care users (C)
- 6 Feedback workshops with aged care staff to present and discuss research findings and develop policy and practice recommendations
- 7 Research dissemination, including conference presentations and various publications.

The research team worked closely in each phase with an Advisory Group comprising six representatives from three provider organisations—Brightwater Care Group (WA), HammondCare (National) and Helping Hand Aged Care (SA)—and two representatives from Dementia Australia's Consumer Network (people living with dementia and their carers).



DEMENTIA & DEMENTIA CARE

Dementia is defined as a major neurocognitive disorder (DSM-5, American Psychiatric Association 2013) and an umbrella term for a syndrome associated with more than 100 diseases of the brain, characterised by impairments in brain function, particularly in areas such as language, memory, perception, personality and cognitive skills (AIHW 2012; Alzheimer's Disease International 2009).

Dementia is usually gradual in onset, progressive and irreversible (AIHW 2012). However, the form and severity of symptoms, as well as its development, vary depending on the type and age of onset (AIHW 2012). While the risk of developing dementia increases with age, dementia also affects people in younger age groups (Alzheimer's Disease International 2009).

People living with dementia use care and support services across different sectors and systems, such as primary care, hospital, mental health and aged care services (AIHW 2012). They tend to access services more often than other groups, and have a particularly high rate of admission into residential aged care services (Karmel et al. 2012). Aged care services play a critical role in the care and support people living with dementia receive

in their homes, communities and residential care facilities (AIHW 2012; Department of Health 2016). One of the key challenges for aged care services and accompanying regulations is to ensure that the specific needs of people with dementia are accommodated within a generic system of compliance.

Since the 1990s Australian policy initiatives have been designed to incorporate dementia care within established service systems, mainly aged care services (Department of Health, Housing and Community Services 1992). This has been achieved through the identification of service gaps, and the development of dementia-specific services. At the same time dementia, as a leading cause of disability and death in later life, has been prioritised as an area for national action. In 2012 it was declared the ninth national health priority. The current national plan for dementia, introduced in 2015, targets seven priority areas:

- 1 increasing awareness and reducing risk
- 2 timely diagnosis
- 3 post-diagnostic care and support
- 4 ongoing care and support
- 5 care and support during and after hospital care
- 6 end-of-life and palliative care, and
- 7 research.

The plan also aims to better coordinate and integrate the range of care and support services people with dementia and their carers require (Australian Government 2015).

More details of this research can be found in the publication, 'Research Insights 1: The role of regulation in aged and dementia care', available at: <https://www.bsl.org.au/research/research-themes/inclusive-ageing/> or the Cognitive Decline Partnership Centre website: <http://sydney.edu.au/medicine/cdpc/research/attitude-culture.php>

REGULATION: THE ARCHITECTURE OF A COMPLEX SYSTEM

The Australian Government (2014, p. 3) describes regulation as 'Any rule endorsed by government where there is an expectation of compliance' and 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).

Regulation is also understood as a 'key tool for achieving the social, economic and environmental policy objectives of governments' (Australian National Audit Office, 2014, p. 3), and as one of the 'key levers by which governments act to promote economic prosperity, enhance welfare and pursue the public interest' (Organisation for Economic Co-operation and Development (OECD) 2012, p. 3).

For governments, regulation is one of the main mechanisms to govern at a distance and to influence quality in a mixed economy of care. The regulation of care is important for protecting vulnerable citizens, guaranteeing rights and entitlements, managing risk and making public services like aged and dementia care accountable. However, regulation does not always work as intended or produce the desired results. It also requires significant resources and staff time. While very few argue for a regulation-free care system, there is significant debate around regulatory design, the scale and scope of current regulatory arrangements and the extent to which regulation crowds out or compromises care.

Not only has regulation increased in recent decades but has also become more diverse, now including multiple means for regulating behaviour, such as self-regulation, professional codes of conduct and economic inducements (Haines 2011). Central government is not the only source of regulation. In aged and dementia care, Commonwealth, state and local

governments continue to play central roles in setting and maintaining regulatory policy and control. They regulate chiefly through legislation, which sets out the parameters of formal care provision, and the various roles and responsibilities of care providers and regulatory agencies, which help make the governance of formal care both possible and accountable. While Australian governments are considered by some to maintain a high level of regulatory control (see Yeung 2004), this role may shift as 'lighter touch' approaches are piloted (Aged Care Sector Committee and the Australian Government 2015).

Regulations as they appear in the statute books need interpretation to be used effectively (Huisin & Silbey 2011). If laws and Acts of parliament can be considered sources of 'hard' regulation, the increasing complexity and plural forms of regulation have created a layer of 'soft' regulation, as care providers and others have attempted to interpret it in practice. Softer forms include guidelines, manuals and communications that translate legislation into everyday compliance. According to Freiberg (2010), this occupies a very large part of the regulatory terrain as experienced by most regulatees. It suggests a middle-ground in which a range of activities (such as the guidelines and protocols, and policies and procedures developed within provider organisations) translate regulation into something useable in daily practice. As Haines (2011) points out, regulation is interpreted not simply in terms of technical expertise but also in the context of cultural and political priorities.

Such priorities need to be balanced with the need for practice innovation and flexibility as recognised components of high quality care. Matching regulations with the everyday realities they are intended to govern is, however, a painstaking, time-consuming and often messy process (Heimer 2013). Seeing the implementation of regulation as an interpretative process, opens up the possibility of examining the different ways standard regulations are adapted to fit settings such as dementia care.

Mapping the aged care regulatory environment

The aged care system is a complex arrangement of multiple, overlapping and often competing stakeholders, public and private agencies and regulatory authorities. The system and regulatory framework are not static, however. Changes in policy priorities, periods of reform and new regulatory approaches have shaped the care and regulatory system we are familiar with today. Key elements in the evolution of this system include shifting Commonwealth-state relations, the changing balance between residential and community care, and a growing emphasis on markets and user choice.

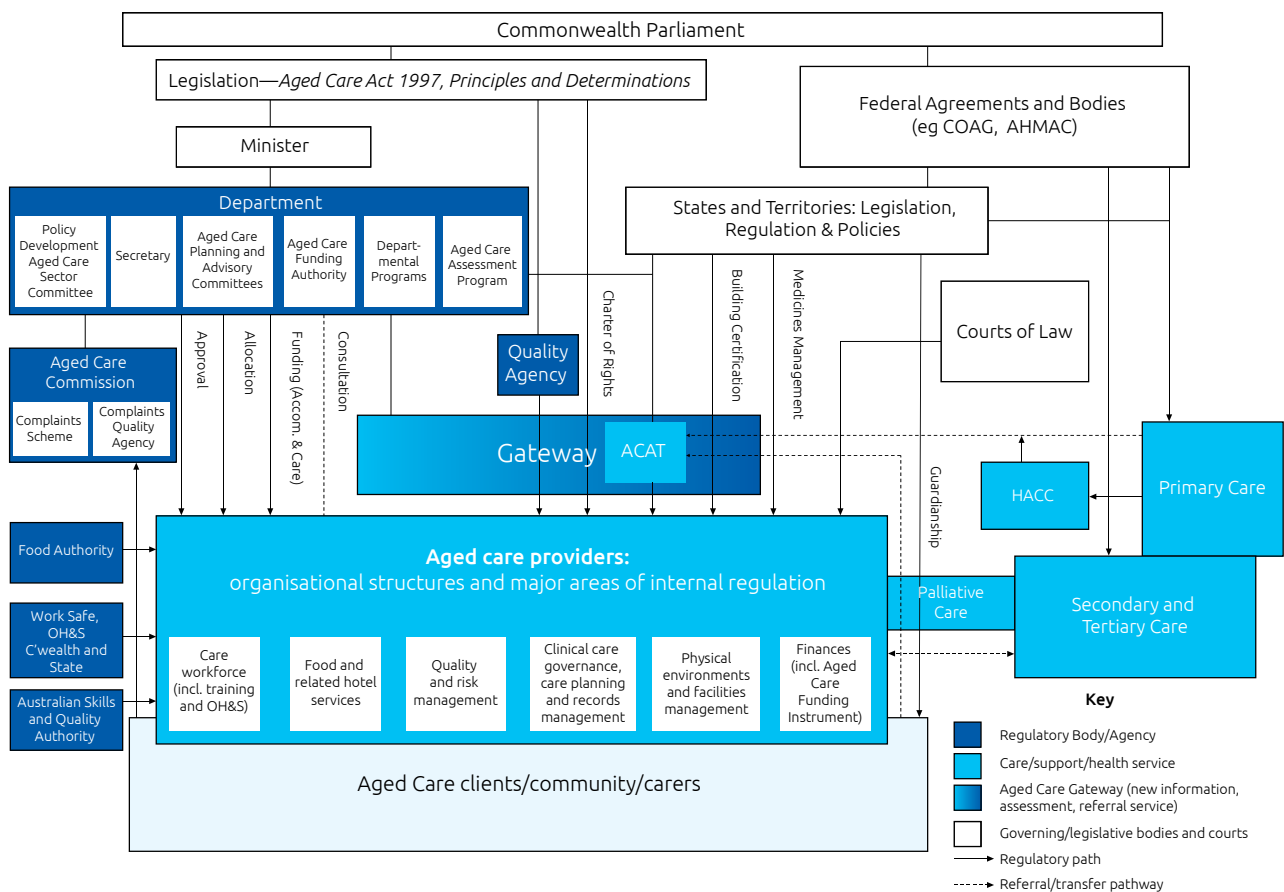
The chief source for regulating aged and dementia care is the *Aged Care Act 1997*. It currently includes 17 principles covering factors such as care standards, requirements for approval,

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 factors 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 and the Aged Care Funding Authority, as well as national and state authorities covering food, building, workplace safety and training/skills regulations. Courts of law, at both the state and federal levels, provide another source of regulatory activity. This creates a dense regulatory environment in need of interpretation and guidance.

Mapping the regulatory environment of the Australian aged care system outlines the structures and agencies under which care providers operate. While many of these structures are enduring, any such map is a snapshot taken at one point in time. It does, however, reveal the institutional arrangements that shape the contemporary aged care system. The map details the complexity of contemporary sources of regulation and some of the key regulatory players or agencies (see Figure 1).

Figure 1: Mapping the regulatory environment

Aged Care Regulatory Framework





Navigating pathways through care

For care-users, navigating the system of services and rules, including eligibility requirements, income and other assessments, is notoriously difficult. Finding a pathway through care introduces care users to range of services, professional groups and a complex array of rules and requirements. Governments and international organisations have identified a number of ways to find a path through the planning and delivery of dementia care. Care pathways are also present in the academic and practice literatures. Different pathways emphasise specific elements of progression, particular stakeholder priorities and a variety of professional, service or economic perspectives. They show as well the points at which regulation influences care provision.

The following types of pathways have been used to describe the different ways people living with dementia encounter care.

- 1 **Diagnostic pathways:** follow how symptoms develop over time, normally characterised as deterioration; capable of linking diagnostic stage with relevant care and support services (see, for example, Global deterioration scale, Reisberg et al. 1982).
- 2 **Experiential pathways:** detail the emotional response of people with dementia to key stages of dementia progression and cognitive loss (see, for example, Cohen & Eisdorfer 1986; see Kitwood (1997) and Bender (2002) for a greater emphasis on personal experience and individual variation, rather than sequential disease stages).

- 3 **Clinical service pathways:** follow the stages of clinical progression and decline, matched with service provision, and some attempt to harmonise clinical, service and experiential factors (see Alzheimer's Disease International (2009) and the 'Seven-stage model for planning dementia services'; see also Brodaty, Draper and Low (2003) for the 'seven-tiered model of service delivery', which links dementia severity and prevalence with appropriate care and support services).
- 4 **Service management pathways:** combine the economics of care, clinical stages and care needs, and service provision to manage care at the system level (see the KPMG (2011) 'Four-stage pathway model').
- 5 **Hybrid pathways:** bring together multiple paths in an attempt to make sense of a complex system, and the multiple factors and inputs that contribute to care (see, for example, the current National framework for action on dementia 2015–2019).

While these pathways identify professional perspectives or the experiential progress of cognitive decline, there is less emphasis on how the system itself is experienced by care users, such as people with dementia and their informal carers. In a complicated system, these care users are likely to become the experts in the coordination and quality of care itself.

THE VIEWS OF CARE USERS ON REGULATION

The views of care users, who included people living with dementia in the community, as well as their carers or advocates, highlighted specific dimensions of the relationship between regulation and provision.

Five people living with dementia currently accessing community care services and five carers or advocates were interviewed as part of this project.

At the time of writing, care users were an emerging voice in the co-creation of care environments that can influence regulation, monitoring and reporting on the practice of formal care. Care users' views on regulation include distinctive as well as common principles when compared with other stakeholder groups. The views of care users are summarised in Table 1. Most notably, regulation was seen as a guarantor of rights and protections against poor practice in a situation where people may feel disadvantaged in terms of information, voice or power relations.



Table 1: Care users' comments on regulation

THEME	COMMENT
Rights and entitlements	Care users saw regulation as supporting their rights and entitlements in a fair and accessible way, and as important for formally determining the level and type of care that care users are entitled to receive. Failure to ensure rights and entitlements, including the right to choose and self-determine within facilities, was seen to be caused by inadequate regulatory controls or non-compliance by care organisations and their workers.
Regulation and care quality	Care users linked regulation to high quality care. While they observed the various other inputs that contribute to care, such as staffing levels and staff training/education, these were often assumed to be controlled by formal regulatory requirements and the responsible regulatory agencies, such as the Quality Agency, rather than the care provider.
Advocacy	Care users saw the ability to advocate for oneself or others as an integral part of formal care, and one that could be enhanced through regulation, such as formal processes related to complaints, co-creation and substitute decision-making.
Managing transitions and navigating a complex system	Care users may be confused and frustrated by complex regulatory requirements when navigating the system and managing transition between service systems. Assistance with navigating the system appears to improve their experience of care.
Autonomy	In a best case scenario regulation would form a secure background that allowed people with dementia to simply get on with their lives.

“ Regulation is always good because otherwise it will be unfair for somebody who will not talk. Unfair for somebody who doesn't know ... (C5)

“ If their organisational management is not geared towards a person-centred approach, I just don't think that they fulfil their obligations ... if they do pursue a person-centred approach where people's needs are met, then that's how I interpret the regulations. (C1)

“ It's like you look at a mountain and you think 'I've got to climb there to get where I want to go' and it just looks all too hard. (C6)

Care users made a number of suggestions for improvement with respect to regulation. These included:

- more care staff, particularly in residential settings, and more time spent caring to enhance person-to-person interactions in formal care
- more stringent accreditation and care quality processes
- improved integration of care services at the system and organisational levels
- limits to the intrusiveness of regulatory processes
- more attention to care user rights and entitlements.



UNDERSTANDING HOW REGULATIONS CLUSTER

Regulation is often presented as a uniform tool of governance, but an analysis of how regulation is distributed is rare.

Combining the map of the aged care system and the pathways through care reveals, for example, the uneven distribution of regulation throughout the system and at particular points in the care continuum.

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

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, with regulations collecting over time.
- Mapping of the current aged care regulatory framework can reveal areas of overlap and duplication between different agencies and jurisdictions.
- Tracing some of the pathways through care suggests specific points where individuals are likely to encounter multiple regulations. These often occur at transition points, particularly the transition into residential care.
- Examining the application of regulations inside residential aged care facilities shows how regulations tend to cluster around specific activities, particularly those associated with high risk.

Such clustering suggests pressure points within the regulatory system, with implications for care user experience, service provision and for future policy. It indicates where efforts at innovation and change are best directed. Clustering at transition points suggests the need for additional supports and guidance to assist people living with dementia and their carers to negotiate multiple regulatory demands. In care environments, dense clustering around points of high risk reduces freedom of interpretation, whereas areas that are less regulated give providers more scope to experiment. The combination of historical accretion and multiple jurisdictions provokes the need for a systematic review of existing clusters and the re-establishment of a coordinated national approach. In addition, in a consumer-directed environment care users are expected to play an increasing role in managing their own care. The clustering of regulations around care home activities affects the way that organisations and staff adapt to the regulation of risk, which is explored in the next section.

More information on the state of regulatory play and the clustering of regulation can be found in the publication, 'Research Insights 2: Exploring regulatory clusters in dementia care' at: <https://www.bsl.org.au/research/research-themes/inclusive-ageing/> or via the Cognitive Decline Partnership Centre website: <http://sydney.edu.au/medicine/cdpc/research/attitude-culture.php>

EXAMINING ORGANISATIONS

Aged care organisations are complex entities, comprising 'distinct roles, distributed authority, and varied expertise' (Gray & Silbey 2014, p. 97). This implies that different levels within organisations may respond to regulation in specific ways and that distinctive cultures of dementia care exist in particular provider organisations.



Providers are involved in a continuous process of balancing competing demands, marked by a strategic orientation toward regulation. The strategies that organisations and their workers develop provide insight into dementia care practice and its regulation.

The journey from regulation to practice involves acts of translation adapted to particular organisational cultures: from hard to soft regulation, into interpretive guidelines, training and supervision, as well as the management of the boundary between the provider environment and the outside world. Different levels of an organisation facilitate translation by filtering regulation into work and care settings. Rather than thinking about governance as a universal function performed uniformly throughout an organisation, it should be seen as differentiated and specialised, therefore requiring processes of application and coordination.

An organisation's strategic orientation

One of the key challenges for dementia care organisations is to find the correct balance for best practice within their regulatory environment. Creating a homelike atmosphere, putting residents first, managing risk and promoting innovation were identified by our interviewees as key organisational and care practice principles. Regulatory compliance may, however, risk compromising key principles of care. For instance, requirements related to building design and fire safety can create an institutional environment that is not homelike, or rules around food provision may prevent resident choice. We found that organisations responded to regulation through a variety of strategic orientations, described in the table below.

Table 2: Strategic orientations towards regulation

STRATEGIC ORIENTATIONS	EXAMPLES
<p>Above and beyond: Using regulation as minimum standards or sets of requirements which the organisation seeks to exceed. Here the organisational response is aligned with the goals of regulation, particularly the principle of 'continuous improvement', (which is part of the Quality Care Principles of the <i>Aged Care Act 1997</i>).</p>	<p>Provision of training, including dementia-specific training, beyond the minimum or mandatory training topics.</p> <p>Clearly identified management regimes for specific medical or behavioural problems, aimed at all staff.</p> <ul style="list-style-type: none"> “ We not only set a minimum standard ... we try to set our benchmark above any minimum standard (SM 10) “ [So] even when you don't quite grab your own standards you're still well above what they're saying are the minimum (SM 13) “ [The organisation] believes that passing accreditation is the barest minimum (FM 11)
<p>Pushing back: Challenging regulations, regulatory decisions and regulators, in the perceived interests of the organisation, its workers and clients. Here the organisation is positioned in opposition to regulation, and a more adversarial relationship is adopted.</p>	<p>Rejection of specific regulatory decisions, such as a requirement to have both hot and cold taps coloured yellow, excessive food labelling requirements and advice on food cooking times that restricts resident choice.</p> <p>Challenging assessor expectations where these were perceived not to be in the interests of quality care.</p> <ul style="list-style-type: none"> “ I think if there's something that we don't necessarily agree with we challenge it (SM 15) “ If the rule's not going to work for the residents, then I'm not going to do that rule (FM 10) “ Legislation is a hard one because it is used probably very often to govern and to control choice, which is something that we are trying to push very hard against at the moment (SM 7)
<p>Predicting and avoiding risk: Developing systems that translate regulation into action by pulling multiple factors together. Systems were observed around the admission process, care planning, and in relation to particular activities such as food provision. Organisation-wide systems, such as those developed to manage risk, were also important. Such an approach aimed to 'engineer out' problems before they became critical.</p>	<p>Use of risk management platforms for monitoring, pattern seeking and reporting emerging risks.</p> <p>Food safety plans incorporating all food-related processes and linked to other areas of regulation, such as care standards and building design.</p> <ul style="list-style-type: none"> “ You have to have a system to manage the system (SM 9) “ I've put in systems that collate incidents, and we've got regulation registers so that we can see what legislation is changing (SM 8) “ You can very easily without realising start to not maintain certain requirements unless of course you've got your own internal monitoring systems (SM 5)

While the culture and history of a provider organisation influence its overall approach to regulation, each strategic orientation appeared in varying degrees across the organisations studied.

Organising space

In particular, the built environment can be used to enhance everyday and homelike environments and minimise the intrusiveness of risk prevention activities. This was observed in four approaches:

- 1 **Facility design:** Some facilities were purposefully designed for people living with dementia. According to senior managers this required collaboration with architects and regulators to balance good dementia design with regulatory compliance.
 - 2 **From front to back-stage:** Relegating regulatory processes to back-of-house and away from residents' living areas was one way to maintain homelike environments. Staff hand-washing basins and fire safety precautions such as evacuation signage and extinguishers could be moved to areas accessible only to staff. This helped to reduce the institutional feel of facilities. It could also prevent fire extinguishers and alarms being set off accidentally, and the confusion arising from signage that people living with dementia may misinterpret. Such approaches do, however, require additional work to ensure and demonstrate compliance, such as specific staff training and negotiation with regulators.
 - 3 **Dividing space into high and low risk areas:** High risk areas such as medicines management or large cooking areas were separated from living areas to reduce intrusiveness and the feeling of an institution. By placing these closely regulated spaces at a distance, the normality of everyday living spaces was maintained.
 - 4 **Environmental cues:** In some cases sensory prompts were used to guide behaviour. Visual cues, smells and sounds were used to attract residents to certain areas at certain times or reduce interest in thoroughfares and specialist equipment.
- “ We don't have fire extinguishers down the corridors ... our fire extinguishers are hidden behind doors, so they're not easily seen and they don't have a big red sign above them to say that they're behind that cupboard door, but the staff are trained on their location. (SM 13)
- “ We designed a central kitchen big enough to plate all the food there, but we designed it with the intent that food would be essentially prepared and then taken to the wings or the areas where clients live in smaller groupings ... One area is open to residents at any one time ... and then the secondary place can be secured. (SM 9)



Looking at organisational levels

Care providers also interpret regulation at different levels of their organisation. We explored three levels, as part of a 'vertical slice' approach, interviewing senior management, facility management and personal care workers (Table 3). Each was found to reflect distinctive understandings, knowledge and interaction with respect to regulation, revealing how regulatory responding is translated and distributed.

Table 3: Functions of three organisational levels

LEVEL	FUNCTIONS IN RELATION TO REGULATION
Senior management	<ul style="list-style-type: none"> • Executive functions, the co-creation of guidance and other interpretive strategies • Managing the boundary between the organisation itself and regulatory authorities • Forms of strategic response including training initiatives, role differentiation and monitoring • Developing specialist expertise and areas of knowledge in relation to regulation • Providing services to other levels to support responding to assessment and regulatory visits • Mostly downward translation to facility managers and personal care workers
Facility management	<ul style="list-style-type: none"> • Operational functions including the management of guidance and supervision systems • Managing transactions across the boundary between the facility, inspectors, families and the local community • Developing knowledge of care standards, coordination and guidance and appreciation for how regulation is operationalised locally • Forms of operational response including collating and collecting data, multi-tasking, responding to internal and external challenges • Upward and downward translations to senior and personal care staff
Personal care work	<ul style="list-style-type: none"> • Interpersonal functions including managing day-to-day interactions with service users • Managing boundaries between regulatory governance and residents' preferences • Knowledge about procedure and the limits to role responsibilities • Responding through interpersonal relations and record keeping, within the limits of time and space available • Mostly upward communication when difficulties arise

The three levels above perform complementary functions in the management of boundaries, while interactions between levels ensure mutual support around the regulatory task. The balancing of care principles with regulation, the development of organisational strategies to meet multiple demands and the distribution of regulation across three levels of the organisation show that staff respond to their regulatory requirements in ways that are specifically attuned to their position in an organisation.

- “ If we’re meeting our people’s needs then really everything else should fall into line behind that ... Where the legislation doesn’t allow for that, we actually ... go back to the regulators and have conversations with them ... We have no problem ringing them up and going, ‘This is the situation we have in front of us, what are your thoughts?’ (SM 13)
- “ [You] work your way around it and normally the governing authorities, they’re not too hardnosed about it ... If you work with them and they see that the intent is right ... there doesn’t ... need to be a problem. (SM 11)
-
- “ I suppose the two most important aspects of my job are keeping the staff working at their peak, and keeping them motivated and content ... [and] monitoring at all times, the wellbeing of all the residents. (FM 11)
- “ There will definitely be strategies from head office put in place about things that you have to follow. I think you distribute it on your site as your site needs it ... So we have a strong lead from head office, and then sit down here with the leaders, care managers, and the leadership team ... Then it will float over to the care managers and their staff on site. So there will be strategies and we talk about specific things, how to change things. (FM 5)
-
- “ We have to have regulations to make it work otherwise you’d have anarchy in the workplace, so there are certain rules that have to come into play ... But the flexibility for how you do the job or how you go about it ... You have to be flexible in it. (CW 21)
- “ There’s not one dementia case that’s the same [as another] ... And that needs to be taken into consideration that one rule or regulation that works for 20 may not work for another five. (CW 4)

Looking at levels reveals the distribution of responsibility for risk within an organisation. It allows us to examine forms of boundary management, communication and expertise. These address particular aspects of regulation as they interact with organisational function and different degrees of engagement with a variety of stakeholders. Surprisingly, the vertical distribution of risk management and responding to regulatory environments has not been a prominent aspect of the literature in this area. However it could play an important role not only in understanding how providers adapt to regulation but also in the targeting of specialised training and supports.

More information about organisational responses to regulation and dementia care can be found in the publication, ‘Research Insights 3: Organisational levels, strategies and design in the regulation of dementia care’ at: <https://www.bsl.org.au/research/research-themes/inclusive-ageing/> or via the Cognitive Decline Partnership Centre website: <http://sydney.edu.au/medicine/cdpc/research/attitude-culture.php>

REGULATION & EVERYDAY PRACTICE

Care workers also respond to regulation directly, in their everyday interaction with residents. We found that workers deployed various approaches in order to balance individual care needs, regulation and the emotional demands of care work.

These approaches revealed how regulatory requirements are incorporated within daily routines, indicating the different ways regulation can hinder or enhance dementia care.

While the conduct of care work is the focus of both hard and soft regulation, care workers do not follow such guidance without thinking. They need to know what should be followed to the letter, and what permits some flexibility. They are also required to make on-the-spot decisions, adapt work routines and provide emotional support to residents with dementia, their families and carers.

Dementia care can be unpredictable and most care workers saw value in regulation for the sense of order it could provide.

A continuum of risk and innovation

Daily care practice comprises many different responsibilities and tasks. It follows that there is an uneven distribution of regulation within the day-to-day practice of care. Some activities are closely constrained, whereas others are subject to much less regulatory control. Here we looked at medication management, fire safety, food and getting up in the morning as key routines of residential life, which presented radically different forms of risk, regulation and freedom for manoeuvre.

A continuum of risk and innovation

Medication management

Regulating the management of medication is highly prescriptive, and there was 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.

- “ There’s a lot of rules ... not just the Poisons Act but, you know, the Aged Care Act, and all of that sort of stuff that impacts on how we administer medications, that’s a thing, a big thing. (SM 3)
- “ They are regulated under the Substances Act ... I think it’s important to have legislation in place for medication management, especially when we’ve got that many nursing staff obviously administering ... dangerous drugs. (FM 7)

Fire safety

Regulating for fire safety in facilities relates to building design and other requirements such as fire safety plans and evacuation procedures. These aspects of regulation are controlled by the Building Code of Australia and various state regulations. 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.

- “ *The big one for us really is around fire safety and we acknowledge that the standards for things like fire sprinklers and smoke detection, things like that are important to help diminish the risk associated with fires in nursing homes ... So, we work with fire engineers and fire consultants to not only deliver the locations and baselines ... but also help environments to look domestic and familiar. (SM 15)*

Food

While many aspects of food are closely regulated, flexibility and interpretation are allowed in other food areas. Most facilities are required to develop food safety plans, detailing the purchase, storage, preparation and disposal of food. Some activities such as food temperature testing are prescribed. Certain foods classed as high risk are often avoided in residential care. On the other hand, significant flexibility exists in food culture, in the presentation and availability of food, providing residents with a degree of choice in relation to what, when and how to eat, such as set meals, grazing and snacking.

- “ *... we have to buy food ... our suppliers have to be accredited ... we've got rules around how we receive it, temperatures that we can accept it, they're all tested on and visually inspected and temperatures done on appropriate food storage ... There's all the rules about the preparation and temperatures that they can serve and how long they can leave the cold food before it has to be consumed. (SM 14)*
- “ *So, we are constantly doing a lot of work to make sure that people are happy with the food because it's so important from a wellbeing perspective ... we're trying to improve the whole dining experience, acknowledging that the enjoyment of food is not just about the food on the plate it's about how it's presented, it's about a whole range of things to do with the experience. (SM 6)*
- “ *Part of our model is residents helping in the kitchen and our kitchens are always open, so the residents could go to the fridge and help themselves. (FM 12)*

Morning routines

In contrast to traditional notions of institutionalisation, daily and morning routines were found to be least affected by regulation in the provider organisations that we studied. There are no regulations determining when residents should get up, although prescriptive procedures for manual handling and two-person assists do affect morning routines. The routines appear to be influenced more by staff rostering and the culture of the facility than by regulation per se, allowing considerable flexibility in daily practice.

- “ *Changing the routine happens all the time really. I mean sometimes you have to skip a shower because they're really not going to do it. (CW 1)*
- “ *Everyone up and dressed [at a certain time] ... that's not meeting the Aged Care Act ... that's an agenda set by the facility for their own management so that they can have staff working at that time. (FM 11)*
- “ *Sometimes those routines just have to be out of whack, because we're dealing with an individual, somebody who doesn't want to get up that morning ... and doesn't want to have a shower ... You can't force somebody to do something. (CW 15)*
- “ *We only have one person on at night ... due to the funding, and they can't go and get someone up because you've got to be around for the other residents in case there's an accident, so I think ... just staggering [start] times, it would be more beneficial for the residents than to have them walking around in their pyjamas. (CW 15)*

Different activities therefore fall along a continuum of risk and regulation, denoting different degrees of prescription for specific care activities. This suggests a particular form of clustering, around different types of daily activity. Care workers are able to exercise flexibility around certain care activities, but may be more constrained around others. Once these clusters of risk and control are understood, it is much easier to identify areas where innovation can be quickly achieved and where regulation may create a risk-averse response. Dealing with this unevenness requires clear guidance within provider organisations to balance the use of discretion, best practice in caring relationships and regulatory requirements.

Coping with regulation in care

Care practice involves a complex set of factors. These include the emotional impacts of engagement with people with advanced dementia, the monitoring and recording of daily practice, plus the pressures of regulatory assessment visits. We found that staff adopt a variety of ways of coping. These constitute attempts to balance care, regulation and degrees of emotional engagement. We identified two quite different styles adopted towards this balancing act. One we have called 'misattention' and the other the 'puzzle' approach.

Misattention

A combination of regular reporting schedules, emotional stress and frequent regulatory visits can lead to a form of distancing termed 'misattention'. Here, role performance is interpreted rigidly so that success in responding to specific regulatory items replaces understanding of the intention underlying the regulations. Emotional engagement is avoided by immersing oneself in bureaucratic tasks. Such an approach was referred to by care workers as 'box-ticking', 'rule-following', 'looking busy'. Misattention occurs when such rule-following behaviours are mistakenly identified as the core purpose of a caring role.

Organisational pressures can make misattention a preferred strategy for dealing with care demands. In a worst case scenario, regulatory surveillance can create an atmosphere suffused with fear of underperformance, regardless of the actual performance of a facility. Workers who feel that they are being negatively evaluated may then defend themselves against complexity and emotional connection to residents by relying on routinised work and reporting practices. This can also occur as an organisational form of avoidance, not allowing staff enough time to interact meaningfully with residents. While regular, accurate reporting is a necessary part of aged care work, the problem here is that workers 'misattend' to performance by associating best practice with successful reporting on individual tasks rather than with positive and appropriate interaction with residents. This gives a feeling of performing but misses the key element of interpersonal connection, resulting in:

- individual staff behaviour that is routinised
- timetabling that fails to allow opportunities for interaction
- detailed attention to monitoring regimes that intrude upon everyday behaviour
- an overly prescriptive approach towards 'soft' guidance
- introducing specifications that do not actually exist in the regulations.

“ You feel like you don't have any breathing space to be creative and be yourself ... I think it's one of the risks of services ending up being driven by the legislation rather than by the people they care for, because they're there so often that we feel like we've got to meet them. And it's easier to go, 'You know what, if I do this bit of

paper over here and I have everyone signing it then I meet the piece of legislation', but there's not necessarily that reflection on what does that mean for staff time and contact with our residents and our people and that engagement that they should be giving in that space (SM 13)

- “ Sometimes there can be a policy that you don't know about and you could be violating ... if there's too many or if they're too detailed, then it can make people feel less confident in their role (CW 1)
- “ I don't think there is a requirement that we need to document in a resident's progress notes every day. However, we still ask our staff to do that because we're scared that if we don't and something happens the governing bodies will come and look at the file and go, 'Well you're not providing any care because nothing's written there'. (FM 10)
- “ I always follow the rules because if we follow the rules it'll be alright ... Otherwise it's not good (CW 8)
- “ I have to follow them, because if something happens it's my fault. I have to follow by the book (CW 5)

We have called this response misattention because it loses contact with the intent of regulation, replacing caring interaction with mechanical compliance. It attends to the letter rather than the spirit of risk avoidance.

A puzzle approach

Some workers that we interviewed had developed a framework for understanding residents and for valuing their individual experience, by seeing their behaviour as a puzzle. In their view good care is about finding and implementing solutions to such puzzles, in a way that is both meaningful and rewarding. The puzzle motif suggests the complexity of individuals and the many factors that can contribute to their wellbeing or distress. This is consistent with feedback from facility managers and care workers who likened understanding people experiencing dementia to learning a different language, an approach that resonated with care workers from non-English speaking backgrounds.

Table 4: Care workers' techniques to reassure and relieve confusion

Prompting	“ You have to try and give verbal direction and prompts all the time just to make sure that these people get the individual care that they need and that everything is covered. Communication is vital. (CW 17)
Reassurance	“ Just talk to them like anyone else and give them the confidence that you know what you're doing, that they feel comfortable with you to do the procedures that you need to do for the day. (CW 15)
Relating	“ I talk with them and there are many little things which come out from their heart, like what their wants or their wishes [are] (CW 12)
Offering choices	“ I think you give them the choice, you offer the flannel, you also ask them if they do need assistance. (CW 16)
Relieving stress	“ A lot of our residents are in a stage where they know that they're not remembering, so they get anxious and that's when staff really need to reassure them, that okay this is just something that's happening. So, they do spend a lot of time reassuring. (FM 12)

When systems were working well, care workers used a range of techniques to engage with people living with dementia and their shared tasks. Many of these aimed to relieve a resident's distress or confusion, at the same time as achieving tasks in a timely and sensitive manner. Walking away and postponing care activities, slowing down communication, using conversation and humour, and matching staff members to residents' preferences were some of the ways care workers managed individual care. Learned formally, inductively and intuitively, these techniques were also informed by the need to keep staff and residents safe, to respect the rights of individuals and to comply with the regulations surrounding activities such as medication management and food safety. The most prominent are detailed in Table 4.

In crafting solutions to people and behaviour as puzzles, knowledge is gleaned from other care workers, health professionals, experts and relatives. The approach empowers care workers to make certain care decisions and gain satisfaction from the care they provide. It allows the care worker to achieve a healthy balance between intimacy, curiosity and distance. According to interviewees, the dimensions of people as puzzles might include:

- knowing the person's story, in order to know what they like/dislike, or what activities they find meaningful
- attending to verbal and non-verbal communication to determine what causes or makes people feel good or bad
- watching for signs, such as when a resident looks tired or unsteady on their feet, in order to be ready to act in a pre-emptive or preventative fashion
- identifying basic physical causes, such as infections and pain, to explain their distress or other responses
- modifying aspects of the physical environments that can foster wellbeing or reduce distress and confusion.

Getting the right balance between empathic understanding, professional distance and problem solving emerged as core elements of the puzzle approach as used by care staff.

Empathic understanding

The ability of care workers to empathise with residents is an important element of dementia care. The idea of seeing the world from a resident's perspective was expressed by care workers as the need to know the resident, leading many to cultivate a professional type of closeness. Knowing the person involves knowing individual biographies and social identities, awareness of likes and dislikes, and attention to moods and feelings. From these elements care workers were able to put themselves in the shoes of someone experiencing dementia and respond in more sensitive and effective ways.

- “ We go into their world, we don't expect them to come into our world. (FM 8)
- “ With dementia ... you have to kind of project a lot of how you would feel comfortable in the situation, because a lot of them can't communicate, so you have to sort of do the thinking for them. So, you have to be generally a very considerate person. (CW 1)
- “ It's not like office work, you're not dealing with pieces of paper, you're dealing with flesh and blood, you're dealing with people, you're dealing with their fears and emotions and their confusion and it's terrifying for some of these people to have that window of insight. (CW 17)

Professional distancing

At times, for effective care to take place, care workers were required to distance themselves from the feelings evoked by residents and avoid emotionally-charged situations. Using their professional and practical experience care workers could stand back and assess the events, triggers and/or patterns that prompted particular responses. Through such distancing, otherwise confusing situations could be recognised as an understandable response to factors such as the physical environment or individual fears and anxieties. Assuming a professional distance enabled care workers to logically and reasonably assess the cause of particular behaviours. From this standpoint they were able to engage with individual residents more effectively. Such professionalism also enabled residents to trust in the care they were receiving and those providing it.

“ Let’s take medication for example. People who don’t want to take medication for whatever reason ... Maybe they don’t like you, maybe they don’t like what you’re wearing. There’s a thousand things why they might say no ... so it’s all to do with encouragement and prompting. (CW 17)

“ ... if we’re trying to dress them and they don’t want any help, we’ll say that’s fine and back away and let them do it and we just monitor them. (CW 20)

“ You wouldn’t just drag them [to the shower], you’d be spending the time trying to build some sort of trust with that resident. You’d have an excellent set-up happening. You’d have everything possibly on hand that you may need. There would be a lot of soothing talk, emphasis on words like warm water, that sort of thing. And you’d be doing it as quickly as you could, the quicker the better. (CW 24)

Problem-solving

By combining empathic understanding and professional distancing, care workers were able to develop a problem-solving approach to the puzzle that dementia presents. Solutions to puzzles came from a range of sources, including clinical practice, modifying the physical environment, flexible work schedules, understanding personal biographies and social identities, plus information gleaned from families and friends. Care workers played a key role in contributing, trialling and refining solutions, and could experience the puzzle approach as rewarding. While most participants acknowledged the impossibility of arresting the progress of dementia, much could be done to engage with its effects, even though the solutions to particular puzzles could change from day to day and from individual to individual.

“ Pulling together all of the evidence and what the reasons for the behaviour could be. Having a look to see if the resident is unwell or if they’ve got an infection. (FM 6)

“ It’s problem-solving every day ... to make these people’s lives as best as they can [be]. (CW 21)

“ And what is frustrating for the staff I think is they develop a strategy that seems to work one day and then the next it doesn’t, so they’ve got to go back to the drawing board and start again. (FM 12)

Care workers demonstrated a range of approaches in managing the challenges of dementia care and regulation. As well as engaging with the emotions of individual residents, they must also manage their own feelings. Perhaps the most effective and creative approach is to see care interactions as puzzling. This enables a problem-based approach to be applied and balanced with the twin demands of empathy and professional distancing. Less helpful were regimes dominated by rigid rule following instead of interpersonal connection.

Where care staff at residential facilities were aided by supports from other levels in the organisation, such as regular contact and strategic discussion with quality agencies, plus specialist teamwork around managing the process of inspection itself, a protective space was created that appeared to make misattention less and problem solving approaches more likely to emerge. The ‘puzzle’ approach leading to problem solving that takes into account the feeling as well as the thinking elements of the care task holds considerable promise for future training.

More information about regulation and daily care practice in dementias care can be found in the publication, ‘Research Insights 4: ‘Misattention and problem solving in interactions between care workers and dementia care residents’, which is available at: <https://www.bsl.org.au/research/research-themes/inclusive-ageing/> or via the Cognitive Decline Partnership Centre website: <http://sydney.edu.au/medicine/cdpc/research/attitude-culture.php>



CONCLUSIONS

The practice of regulation emerged from this research as both complex and nuanced, and not a uniform phenomenon. We have examined the ways in which it influences practice by looking from systemic, organisational and everyday perspectives.

This has included: identifying the architecture for a complex system through mapping regulatory mechanisms and examining pathways through it, understanding the state of regulatory play through engaging stakeholder groups and examining practice by organisations and in interactions around direct care itself. Each influences the processing of risk and the creation of high quality care.

We found that:

First, regulation clusters around particular activities or transitions—for example, in activities involving food, or at the time when people move into care. Sometimes this reflects risk, but clustering also occurs for administrative reasons or through an overlap of multiple authorities on the same issue. None of the stakeholders or practitioners interviewed thought regulation was unnecessary, but many considered it overly complex and confused. An analysis of clustering may help to target services and identify areas requiring review of their efficiency and effectiveness. It may also be used to identify areas where innovation may be more easily or more difficult to achieve. Identifying clusters at different levels of an organisation would not only locate areas of innovative co-creation between providers and care users, it would provide an effective means for targeting training and support services.

Second, provider organisations respond to the demands of regulation through a process of interpretation, cultural preference and specialisation by organisational level. Organisations do not simply manage risk to residents; they also need to manage the risks associated with regulation itself. Practices are created to support the process of accreditation,

with specific roles emerging at different levels. These processes of differentiation allow an organisation to adapt by identifying specific activities that both protect against risk and provoke a series of processes that themselves enhance the everyday practice of care. Statutory requirements emerge as requiring interpretation to inform effective practice, including the translation of formal regulation into guidance, training, monitoring and environmental design. Considerable care and subtlety was found in the ways that organisations ‘engineered’ risk out of their everyday systems. Recognising the specialisation involved in organisational responding has implications for training and the quality of a whole organisation approach.

Third, an analysis of everyday practice identified two distinctive staff approaches toward dementia care: misattention and a puzzle approach. First, pressure and anxiety can lead to ‘misattention’. Here the intent behind regulation was eclipsed by a routinised approach to compliance. Second, when the environment was more relaxed, a problem-solving or ‘puzzle’ approach might occur. Here, emotional connection and professional distance were balanced in encounters between staff and residents. Care workers are not simply constrained by regulation, but use it as a means to cope with the uncertainty of dementia care and the emotional demands of care work. Clustering also appeared at an everyday level as a continuum, with compliance collecting around certain areas of practice, and not others. Indeed some areas of traditional institutionalisation were found to be relatively free of regulation, giving scope for practices that were both innovative and flexible.



Altogether the picture of interaction between regulation and provision is one of a complex system that is nevertheless open to adaptation and interpretation. We found that not only did organisations strategise their general orientation to regulation, but also responding was attuned to different functions within provision and the clustering of regulation around particular activities. Care workers also varied in their response to regulation depending on the degree of support in their environment. Care users provide a distinctive voice wishing to balance protection, rights and autonomy. Viewing regulation as an interpretative process reveals significant areas of flexibility, particularly at the organisational and practice levels. Here practice can be adapted to address the specific care needs of people living with dementia without compromising regulatory compliance.

It is important to recognise the supportive role that regulation can play, particularly for care workers and care users. Organisations had unexpected discretion in the process of implementing regulations. Claims that regulation restricts or inhibits care need to be balanced with the flexibility that interpreting and implementing regulation in local settings enables.

Many of the practices described in this report were grasped intuitively within organisations and in everyday engagement with dementia. Once made explicit their potential for an innovative understanding of living with regulation was recognised. Using clustering, organisational level, voice and individual problem solving would have implications for future understanding of the impacts of regulation.



RECOMMENDATIONS

As our research progressed, recommendations in four areas arose from an analysis of the clustering and overlap of regulation, information and feedback from workers at different levels within provider organisations and the views of care users.

Systems overlap, duplication and intent

We recommend a national review to identify regulatory intent and simplify areas of operational overlap or legislative duplication.

Mapping existing regulation reveals considerable duplication, which can both be costly to providers and present hurdles to innovative practice. We recommend two steps, one to clarify intent and two to simplify accreditation based on expertise.

A combination of the historical accretion of specific regulatory responses and multiple jurisdictions suggests the need for a systematic review of existing regulatory clusters and the re-establishment of a coordinated national approach. It is recommended that a collaborative overhaul should include the intent and structure of legislation. A re-statement of the intent and principles underlying legislation would be a positive step towards clarity and better linking of policy and regulatory principles with care guidance and practice.

Overlap between regulatory agencies, resulting in duplication of effort, should be streamlined. At the level of assessment and accreditation it is recommended that where duplication exists between Commonwealth, state or local government regulation (for example in food safety, building design and fire safety) the authority with the greatest specialist expertise should inspect, submitting their report for integration into a quality assurance overview. An overview agency would then collate specialist assessments and achieve an overall impression, checking that the system itself was working effectively. This 'specialism-overview'

model provides a way of stacking reports and assessments and would have the advantage of reducing the number of inspections in the same area, reducing provider stress and increasing both effective and efficient use of technical expertise.

Regulatory clusters, innovation and consumer engagement

We recommend a renewed focus on participation by people living with dementia and carers, recognising consumer expertise and using regulatory clusters to identify areas for support and participatory services.

Within a complicated system, end users are likely to become experts in the coordination and quality of care itself. In this study, care users were also the most likely to approve of regulation as a means of securing their rights, but wanted regulation and assessment to be an unobtrusive backdrop to everyday activities. While consumer views are often taken into account in terms of care quality, greater attention should be paid to how the regulatory system itself is experienced by end users, such as people living with dementia and their carers.

Clustering identifies a dense regulatory environment, requiring interpretation and guidance. For care users, care transitions, including eligibility and means testing, in addition to diagnostic assessments and care needs assessments, are notoriously difficult to navigate. Essentially, people wanted to be free to live their lives, with regulation providing a safe environment in which to do so. The current system often produces a significant

administrative burden, negatively affecting care users and service efficiency alike. Clustering at transition points suggests the need for additional supports and guidance to assist care users to navigate multiple regulatory demands at such pressure points. A 'plain-English' guide to the regulatory landscape, tailored for care-users, and translated into community languages is also recommended.

Innovation can occur in the context of regulation. The distribution of risk and accompanying regulation forms a continuum. In care environments, dense clustering around points of high risk such as medication reduces freedom to innovate, whereas areas that are relatively regulation-free such as morning routines give providers more scope to experiment. Once these clusters of risk and control are understood, it is much easier to identify areas where innovation can be quickly achieved and where regulation may form a constraint. Dealing with this unevenness requires clear guidance within provider organisations to balance best practice, caring relationships and regulatory requirements. We recommend that a care-user perspective be included in the process not only of assessments but in the creation of regulatory systems themselves. The voices of care-users and those of professionals should be clearly differentiated. Seeing regulation as a continuum would assist in identifying opportunities for innovation within a regulatory framework.

Organisational differentiation and risk management

We recommend that guidance and training on regulation should be tailored to different roles and responsibilities within provider organisations.

Organisations have created internal systems to manage the tensions arising from regulatory compliance and accreditation. While these can be interpreted as an extra cost of regulation, they enhance understanding of the care task and may also help to reduce stress associated with regulation. Guidance and other soft, interpretive forms of regulating conduct also translate generic aged care regulations into the context of dementia care. Rather than stipulate a particular approach, regulation should create a bounded space where the limits to acceptable behaviour are identified and within which innovation around special needs can take place. This may allow adaptation to take place without setting static principles of best practice at any one point in time.

An analysis at different levels within provider organisations uncovered a differentiated interpretation of regulation depending upon function. We recommend that future training and guidance be tailored to the performance of these distinctive roles and their interconnection.

Reducing stress associated with the regulation of dementia care should be a priority. The mechanisms for doing so include processes that 'engineer' risk out of everyday situations through effective internal monitoring of risk identification and risk prevention, the design of the built environment, plus

the fostering of a 'puzzle' or problem solving approach. The stress arising from inspections and assessor visits might be reduced by removing duplication as suggested above, but also by providing feedback, both positive and negative, plus multi-level organisational liaison with accrediting agencies. While such liaison needs to avoid the risk of collusion, it allows interpretive practices to adapt to changing regulations or innovation in care, and greater cooperation to emerge in pursuing the intent of regulation.

Welfare markets and the role of regulation

We recommend that regulation be seen as providing opportunities to balance innovation and risk management. Choice should be recognised as extending beyond the point of taking up a service to include interpretation within caring environments themselves. Where regulation and associated bureaucracy cluster around transitions, the complexity inhibits end user choice and so should be simplified significantly.

Regulation emerges from this research not just as a mechanism for government to exert control from a distance but as a means of protecting rights and of structuring organisations to achieve best practice and avoid risk. While the value of regulation is contested, none of the groups interviewed would want a world without regulation. Having said that, certain issues have implications for a market model of care. First, at the level of systems, regulation (and assessment) is currently both too complicated and subject to duplication. It might be made more efficient through review and simplification. Second, operational tensions exist between innovative practice and risk avoidance. Both are necessary in a care market to stimulate service improvement within safe and reliable boundaries. Third, regulation works best when regulators, providers and care users maintain regular channels for interpretation and feedback on the meaning of compliance. Fourth, choice does not simply exist at the point of taking up a service; indeed that point appears to be where bureaucratic clustering should be reduced. It also exists in the way that provider organisations adapt to regulatory requirements, how these are interpreted in local guidance, which then affects care worker conduct and the opportunities for resident engagement and decision making. In other words transition points have become clogged by clustering which should be reduced, while choice and engagement should be seen as a much wider enterprise that embraces the everyday experience of residential living.

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