Clustering and the Organisation of Risk: The role of regulation in Australian dementia care

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

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Further details
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Research design

Phase 1
Reviewing
Making connections to key themes in previous research
Mapping
Understanding the regulatory environments and pathways
Designing
Using learning to plan and guide data collection
Jan – Dec 2014

Phase 2
Interviewing
Gaining perspectives from stakeholder knowledge
Analysing
Identifying recurring issues and cross-group differences
Refining
Using findings to shape focus and move research forward
Jan – Mar 2015

Phase 3
Visiting
Examining practice with providers on site
Surveying
Developing a vertical slice perspective on key issues
Interpreting
Using findings to frame patterns, discourses and needs
Apr – Dec 2015

Phase 4
Advising
Providing recommendations to policy-makers and partners
Networking
Circulating research findings and influencing future agendas
Concluding
Completing the project, summarising and looking ahead
Jan – Dec 2016

Identifying architecture for a complex system
Understanding the state of regulatory play
Examining practice in action
Recommended effective systems change
Context
Contextual factors

• Economic, social and administrative factors
• Regulation and governance in a market economy
• Technical, political and cultural components
Multiple perspectives
Hotspots and Clusters
Hotspots

- **Hotspots** can be seen as points or events that demand urgent regulatory intervention. According to Braithwaite (2012), central governments commonly intervene in a top-down fashion at such hotspots to prevent harm to the public.

- Care standard failures
- Fire safety events
- Elder abuse
- Food poisoning
Clusters

• **Clusters** occur when multiple regulatory regimes, jurisdictions and agencies intersect at a single point or around a particular activity. The degree of clustering identifies areas of intensive or light touch regulation.

• Historical accretion
• Overlapping authorities
• Risky clusters
Regulations, maps and pathfinding
Regulations, Maps and Pathfinding

1. Mapping
2. Pathfinding
3. ‘Hot-spots’ and ‘regulatory clusters’
Entering aged (residential) care

‘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, they have to go through before they can even purchase services.’ (SM 9)

‘ACAPSs are the people who assess people in the community, their level of requirement, like whether they can access aged care services to some degree, whether it’s in home or whether it’s residential, so they’re the ones that do the initial assessment...That gets put into Medicare [and]...[v]arious bodies can see that information on Medicare. (SM 1)
(Ongoing) Organisational assessments

‘...on entry to the home we do assessments on residents’ wishes. So we do a sleep assessment, we ask what time clients would prefer to go to sleep in our residential care, what their normal routines would be, what times they get up, whether they prefer to have a shower before they have their breakfast, whether they want to come out and have their breakfast in the dining room or have it in their bedroom.... Some of our residents like to be checked on in the middle of the night, others prefer not to be disturbed. So our staff, through those initial assessments and ongoing care plans, have a clear guide as to what our clients’ requirements are.’ (SM 10).
Combining Maps, pathways and policy development

• Over time an accretion of regulation has taken place, often reactive to particular areas of public concern
• Pathfinding tends to follow established professional or institutional channels
• The complexity of regulation leads to clusters, the swarming of regulation around key activities and points in pathfinding
• Interviews of staff indicate everyday clustering of regulatory space around issues such as food, medications and fire safety
• an amalgam of economic, social and administrative vectors
Risky Clusters?

A continuum: Restrictive - Interpretive dimensions

• Medicines and Fire safety

• Food

• Getting up and Going to bed
‘Then there’s things about medication management...There’s a lot of rules around that, not just the Poison’s Act but, you know, the Aged Care Act and all of that sort of stuff that impacts on how we administer medications...there’s a lot of rules. It is quite hard and it’s okay for us because we’re a...large organisation with good infrastructure...’ (SM 3).
Fire safety

‘...fire is very important as you can well appreciate in this industry... [A]s part of the accreditation they look at the building, the fire safety and the building code... On top of that we have the local metropolitan fire service who also come through every three years. They look at it more of an operational type thing just to make sure that everything is being maintained, access is still okay, communication, staff training is still happening and then in date. Then on top of that we’ve now got the local council coming through....we have potentially three or four different bodies of groups coming through looking at...the same thing, the fire safety and compliance of that building. But...they’ve all got a different spin on it all.’ (SM 11).
Food

‘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...and the rotation of food.... [T]here’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).
The social setting of food

‘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 experience of the 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).
Getting up and going to bed

‘If somebody didn’t want to get up or is quite resistive to getting up at what was their normal time let’s say 7:30 am in the morning to have breakfast at 8:00 am. And they suddenly over a period of time don’t want to do that or become quite resistive. We can certainly change routine so that person can stay in bed. Maybe have a shower in the evening and have breakfast in bed rather than having to get up. So it all depends on very much the situation really.’ (Facility Manager 6)
Flexible morning routines

‘Well, getting up time is whenever the resident chooses to get up...some residents with high level dementia don’t ever want to get up, because they can’t initiate that themselves. So it varies depending on how well you know the resident and their routine during the day or how they are that day. Some may be up all night here, and might sleep during the day. Others might get up at six, some at seven. Some might be not getting up until nearer to lunch, it depends, based on what the resident would prefer.’ (Care Worker 24).

‘...we’ve really got to fit into residents because they’re not going to fit into a routine for us...’ (Facility Manager 13).

‘...if someone wants to sleep in they sleep in, if someone want to stay up til 2.00am, they stay up til 2.00am. If that’s in their best interest, if that’s what’s worked for them in the past...’ (Facility Manager 11).
Futures

Can regulatory spaces facilitate as well as restrict conduct?
Using Clusters for effective targeting

• It's not regulation ‘more or less’ or ‘good or bad’
• A more fine grained approach
• Support to PLWD and Informal Carers for regulation around transitions
• Space can be used creatively to balance ‘home-like’ and ‘risk averse’ clustering
• Some areas are (rightly) closely regulated
• The room for innovation may be around moderate or low areas of clustering
Regulatory Governance

- Smaller government does not necessarily entail less regulation.
- Complexity arises from multiple stakeholders, agencies and pathways.
- As risks accumulate, regulation becomes more dense and specific.
- Good regulation leaves space for interpretation within the intent of the regulation at hand.
Recommendations on the future of regulation

- A Commonwealth review to identify and simplify areas of operational overlap or legislative duplication
- Collaborative overhaul and re-statement of the intent and structure of umbrella legislation.
- A renewed focus on pathfinding as experienced by PLWD and carers, recognising consumer expertness.
- Identification of ‘clustering’ of regulation at certain points in care, and its implications for innovation.
- A ‘Plain-English’ guide to the regulatory landscape, one that might be of particular use to care-users, and translated into CALD-friendly formats.
- Toward a one-stop-shop for regulatory processes.