Applicability of Consumer Directed Care principles in residential aged care homes

Final report

July 2014
Department of Social Services
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The findings in this paper have been formed on the above basis.

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Executive summary

This report sets out the findings of initial research in the applicability of Consumer Directed Care (CDC) approaches in residential aged care settings in Australia. The project was conducted between May and July 2014 and sought to address the following broad research questions:

- To what extent is CDC currently being delivered in residential aged care or long-term residential care settings in Australia and overseas?
- Based on the identified evidence, what are the key enablers for CDC approaches in residential aged care?
- Based on the identified evidence and key enablers, what are the critical pre-conditions for moving towards CDC approaches in Australian residential aged care?

Approach

There were two methods of information gathering for this project: a literature review which explored the current theory and evidence base for CDC in residential aged care, and targeted consultation with 15 stakeholders.

Key findings

**Conceptualising CDC in residential aged care**

CDC is both a philosophy and an orientation to service delivery where consumers can choose and control the services they get, to the extent that they are capable and wish to do so. Person-centred practice is a key component of CDC. It emphasises the wellbeing and quality of life of the individual person, as defined by the person. Consultations for this project indicated a high level of support for person-centred practice in residential aged care, but suggested that the extent to which current practice is genuinely person-centred appears to vary considerably.

International literature indicates some key features of consumer-direction in aged care homes including returning control and decision-making to residents; empowering direct care staff; transforming the facility into a more home-like environment; and inverting the formal decision-making chain. Consultations conducted for this project indicated broad, qualified support for these features, but did not identify many examples of their application in Australia.

Australian literature suggests that current regulatory and funding environment is perceived as a barrier for aged care homes in providing more flexible care and support. The consultations confirmed that this is a widely held view. Overcoming this contention that regulations and funding are a barrier to CDC is a challenge that will need to be considered as the sector reorients to CDC.

**Applying CDC in residential care**

*Person-centred and goals-based approaches to assessment and planning*

It difficult to assess the scale of person-centred, goals-based assessment and planning in residential aged care. However, there is stakeholder agreement that embedding a consistent culture of person-driven, individualised goal setting would potentially be a good place to start reorientation to CDC within the sector.

*Choice and control for residents*

Under a CDC approach, residents should be offered opportunities to exercise choice and control over the care they receive. The emerging evidence is that higher levels of choice and control are
associated with positive health, wellbeing and social outcomes for residents and are cost effective. Consultations identified almost unanimous support for the concept of resident choice and control, but some differences of opinion in relation to the practical application of it.

**Participative person-centred practice care**

In residential aged care, person-centred care is often equated to relationship-centred or relationship-based care, in contrast to traditional task-based ways of working. Emphasis is placed on workers getting to know residents as individuals, and understanding their preferences and needs.

Consultations indicated strong support for participative person-centred care, and several stakeholders observed that person-centred approaches have underpinned better practice in residential aged care for some years. However, some stakeholders suggested that, whilst the concepts were indeed widely understood, the effectiveness of their application was variable.

**Individualised funding and transparency**

There is no consensus at this time about the role of an individual budget in a CDC approach for residential aged care, or how it would operate in practice.

**Supplementary or ‘extra’ services**

Under CDC, consumers should have opportunities to supplement their care and services with additional or ‘extra’ service from their own resources (where they have capacity to pay). The consultations indicated wide agreement that access to on-demand, price-controlled extra service was a key platform for moving towards a CDC approach in residential aged care.

**Evidence of benefit**

There is evidence that the quality of care is no different under a CDC or non-CDC approach, but the quality of life and wellbeing for residents is higher. There are some positive associations between CDC approaches with staff outcomes (satisfaction, capacity to provide individualised care, retention). However, there is generally a lack of evidence of provider and system benefits of CDC which may contribute to wariness or resistance to CDC in the residential care sector.

**Conclusion**

The available evidence suggests that a reorientation to CDC for residential to aged care would be consistent with contemporary international practice, and is generally supported by key aged care stakeholders. There is broad agreement on the key elements of CDC identified in this report.

However, there are currently a number of challenges and barriers to CDC reorientation. Primarily, there is a lack of a shared vision, definition and scope of CDC for residential aged care in Australia. This is compounded by a lack of knowledge and informed discussion about emerging CDC practice, considerable cultural barriers within the sector, and concerns about how to balance provider duty of care with enhanced consumer choice and control principles.

Currently, there is no single ‘CDC model’ for residential care that could be implemented. It is suggested that reorientation to a CDC approach be considered as a process to be developed over time, rather than a specific ‘model’ to be implemented.

The conclusion of this report is that a staged reorientation to CDC should be considered. This could involve the following stages:

- Firstly, developing a shared vision, definition and scope for CDC in residential aged care, which could inform a national development and implementation strategy;
• Secondly, addressing cultural barriers to CDC reorientation through a research and knowledge sharing agenda to identify, assess and promote emerging CDC practice in Australia, highlighting practical considerations as well as benefits for consumers, providers and staff;

• Thirdly, developing, assessing and comparing several provider-led trials of reorienting current services to incorporate elements of CDC. Initially, these need not be full ‘CDC models’ per se but should include various CDC elements such as implementation of goals-based planning, enhanced choice and control of care and services, and, possibly, some form of individual budget. This may also include some experiments with changes to the built environment to promote and enhance CDC.

• Finally, drawing on learnings from the development stages, a general CDC model of care could be developed and implemented across the sector.
1. Introduction

This report sets out the findings of initial research in the applicability of Consumer Directed Care (CDC) approaches in residential aged care settings in Australia.

Consumer-directed or “person-centred” approaches to the design and delivery of adult social care initially developed through the disability rights and self-determination movements in North America and the United Kingdom (UK) in the 1970s and 1980s, and were further developed by the disability self-advocacy and empowerment movement in the 1990s. In Australia, person-centred approaches have emerged over the past decade in the disability sector, and more recently in the community care sector, to empower people to make choices and decisions about their lives and the service they access, and to respond to increasing demands for flexibility and choice.

KPMG was engaged by the Department of Social Services (the Department) to undertake initial research into the applicability of CDC principles in residential aged care settings. This included a literature review supplemented by targeted consultation with 15 stakeholder groups to identify:

- key elements of CDC relevant to residential aged care settings in Australia and overseas, including consideration of how these elements relate to the CDC principles already established for Australian community aged care;
- any examples and evidence of whether, and how, CDC is currently being delivered in residential aged care or similar settings in Australia and overseas; and
- key considerations for exploring a potential trial of CDC in Australian residential aged care.

1.1 Aged care reform context

The Australian Government is currently implementing a significant aged care reform program. As part of those reforms, CDC is being implemented in the home care sector, with all home care packages expected to convert to consumer-direction by July 2015.

A range of reforms to residential aged care are also currently underway. This includes strengthened means testing for people entering residential aged care, more flexible arrangements for residents to pay for their residential accommodation payments (with a choice between a daily payment, a deposit or a combination of both), and the requirement for all aged care homes to publish their maximum accommodation prices on the MyAgedCare website.

Two other aspects of the reforms, which both commenced on 1 July 2014, are particularly relevant to considering CDC in residential aged care:

- changes to the schedule of specified care and services, including which residents may be charged additional fees for certain care and services; and
- changes to the ‘Extra Service’ principles which is expected to expand the availability and flexibility of Extra Service provision, and also introduces an oversight role in pricing of such services by the Aged Care Pricing Commissioner.

This considerable level of reform activity is indicative of the dynamic environment in which residential aged care is currently operating.
1.2 Definition and key features of a consumer directed care approach

For the purposes of this literature review, the definition of CDC was drawn from the Commonwealth Home Care Packages Programme Guidelines:

CDC is a way of delivering services that allows consumers to have greater control over their own lives by allowing them to make choices about the types of care and services they access and the delivery of those services, including who will deliver services and when. Under a CDC approach, consumers are encouraged to identify goals, which could include independence, wellness and re-ablement.

The consumer decides the level of involvement they wish to have in managing their (care).

Through the introduction of an individualised budget, CDC provides greater transparency to the consumer about what funding is available under the package and how those funds are spent.1

Applying this definition, the key aspects or indicators of a CDC approach are understood to be:

1. Person-centred and goals-based approaches to assessment and planning, where the person is at the centre of assessment and care planning, actively participates in the planning process, and where the planning process is goal-based (focusing on independence, wellness, re-ablement or other goals that are meaningful to the person and enhancing their self-defined quality of life)

2. Greater choice and control for consumers about the types of care and services they access, the design of their care and services, who delivers their care and services,

3. Person-centred care or individualised care, where care and services are tailored to a person’s needs, preferences and circumstances, with a focus on wellbeing and quality of life

4. Individualised funding or individualised budgets, and input into or control over the allocation of this budget, as well as transparency for consumers about the cost of care and services

5. Opportunities for people to supplement their care and services with additional or extra services from their own resources (where they have the capacity to pay).

These parameters were used to assess the extent to which models identified in the literature are ‘consumer-directed’.

1.3 Structure of this report

This report is structured as follows:

- the project approach, including methodology (Section 2);
- project findings (Sections 3, 4 and 5); and
- conclusions (Section 6).

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2. **Approach**

This section outlines the approach taken to conduct the project. The project sought to address the following broad research questions:

- **To what extent is CDC currently being delivered in residential aged care or long-term residential care settings in Australia and overseas?**
  - This included examination of how CDC is conceptualised in residential care settings, and identification of examples and evidence of CDC approaches in residential aged care and other long-term care settings.

- **Based on the identified evidence, what are the key enablers for CDC approaches in residential aged care?**
  - This included identification of structural and practice enablers for adopting and delivering a CDC approach in residential aged care.

- **Based on the identified evidence and key enablers, what are the critical pre-conditions for moving towards CDC approaches in Australian residential aged care?**

There were two methods of information gathering for this project. The first method was an initial literature review which explored the current theory and evidence base for CDC in residential aged care. The second method was a targeted consultation with 15 stakeholders, which sought to validate and expand on some of the key findings from the literature review. Each of these methods is discussed in more detail below.

### 2.1 Literature review

The review targeted literature published in English since 2004 relating primarily to practices in Australia and other Organisation for Economic Cooperation and Development (OECD) member countries. The databases searched for the review were:

- ProQuest Health and Medical complete;
- ProQuest Central;
- PubMed;
- Wiley Online Library;
- Medical Journal of Australia;
- British Medical Journal;
- Australasian Journal on Ageing.

A search using the Google search engine was also undertaken. The search term combinations that were applied are summarised in Table 1 overleaf.

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2 Member countries include: Australia, Austria, Belgium, Canada, Chile, Czech Republic, Denmark, Estonia, Finland, France, Germany, Greece, Hungary, Iceland, Ireland, Israel, Italy, Japan, Korea, Luxembourg, Mexico, Netherlands, New Zealand, Norway, Poland, Portugal, Slovak Republic, Slovenia, Spain, Sweden, Switzerland, Turkey, United Kingdom and the United States.
Table 1: Literature review search terms

<table>
<thead>
<tr>
<th>Search term 1:</th>
<th>Search term 2:</th>
<th>Search term 3:</th>
</tr>
</thead>
<tbody>
<tr>
<td>Consumer-directed</td>
<td>Residential care</td>
<td>Care</td>
</tr>
<tr>
<td>Self-directed</td>
<td>Aged care home</td>
<td>Care planning</td>
</tr>
<tr>
<td>Resident-directed</td>
<td>Aged care facility</td>
<td>Services</td>
</tr>
<tr>
<td>Choice and control</td>
<td>Long-term care</td>
<td>Service delivery</td>
</tr>
<tr>
<td>Person-centred</td>
<td>Assisted living facility</td>
<td>Support</td>
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<tr>
<td>Personalised</td>
<td>Supported living facility</td>
<td>Wellness</td>
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<tr>
<td>Individualised</td>
<td>Care home</td>
<td>Re-enablement</td>
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<tr>
<td></td>
<td>Rest home</td>
<td>Re-ablement</td>
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<td></td>
<td>Institutional care</td>
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Source: KPMG

**Scope and quality of the literature**

There is a wealth of literature relating to consumer directed approaches for social care, that is, support for older people (and people with a disability) living in the community, including in supported accommodation settings. Some consumer directed models have a relatively wide scope and give people significant choice and control over many aspects of their care and services.

These models allow people to choose or have input into where they live (including the setting and location) and who they live with, the supports they receive in the place that they live, and the supports that allow them to participate in social and economic aspects of life. Other consumer directed models have a more limited scope and may only provide for choice and decision-making within identified programs (e.g. social or community participation programs, and community care programs).

However, this review sought information on CDC models and approaches in place specifically in residential settings – from Australia, OECD countries and other European jurisdictions. While CDC concepts in residential aged care have been evolving over a period of some twenty years, there is limited literature available on CDC models and approaches within a residential aged care setting, and a lack of evidence relating to the efficacy or outcomes of CDC in residential aged care. What is available tends to come from the United States, and there are some studies of CDC models in residential aged care currently underway in the United Kingdom, but the early results of these will not be available until 2015.

In the literature, CDC in residential aged care is often limited to the lens of practice change within care homes, as opposed to structural or system level change. There is tendency within much of the literature to focus on relatively minor, day-to-day opportunities for residents of care homes to exercise some limited choice. For example, in choosing whether they would prefer coffee or tea, or...
serving themselves meal portions. These examples highlight the importance of offering choice and the value in supporting person-centred practice, however they do not offer evidence of a holistic consumer-directed model of care (of which choice and person-centred practice are key components, but not the only components).

This review also sought to examine CDC approaches in other residential settings. There are a number of examples in the disability and mental health sectors of models and approaches which provide people with choice and control over a range of supports including their accommodation support, however these approaches are not restricted to a single residential setting.

2.2 Consultations

The purpose of the targeted consultations was to gather additional information on applicability of CDC principles in residential aged care homes. The Department provided an introductory letter and invitation to 15 stakeholders. KPMG contacted stakeholders to confirm their willingness to participate. Thirteen of the 15 identified stakeholders agreed to participate in an interview (one other provided written comments). All stakeholders were provided with a list of interview questions in advance of their interview (refer to Appendix A). The following organisations participated in the consultations:

- Aged and Community Services;
- ACH Group;
- Alzheimer’s Australia;
- Benetas Aged Care;
- Bupa Australia;
- Council on the Ageing;
- First People’s Disability Alliance;
- JewishCare;
- Just Better Care;
- KinCare;
- Leading Aged Services Australia;
- Living Care Aged Care;
- National Rural Health Alliance; and
- Outrageous Ageing.

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3. Conceptualising CDC in residential care

This section explores the way in which CDC is conceptualised in the residential care setting. Drawing primarily on the findings of the literature review, this section begins with a discussion on the general concept of CDC and its interaction with (and distinction from) person-centred practice, and continues on to explore how CDC has been conceptualised internationally for specific residential care settings.

3.1 Conceptualising CDC

CDC is both a philosophy and an orientation to service delivery where consumers can choose and control the services they get, to the extent that they are capable and wish to do so.6 7 The main objective of CDC is to offer consumers more choice and control than they would have from traditional ‘provider-directed’ approaches.8 9 10 It is an approach to service delivery, rather than a model of service delivery per se.

The literature associates many broad benefits with CDC approaches, including increased consumer and carer satisfaction, improved health and wellbeing outcomes, and reduced unmet needs – although, historically, the extent to which these benefits have been experienced by older people using CDC, as opposed to younger people with a disability, has been variable.11 12 13 14 15

**CDC as a mechanism to promote autonomy and self-determination**

The concept of consumer-direction is fundamentally based upon an ethical understanding of the intrinsic value of individual autonomy and self-direction.16 Moving into an aged care home is often a disempowering experience for older people, which can induce feelings of helplessness and loss of control. Research shows that this can be exacerbated when people feel they are treated with disrespect or inconsideration, experience frequent changes of care workers, have changes made to

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their daily routine or care plan without being consulted, feel that care workers are neglecting tasks, or feel pressured or intimidated. Residents’ autonomy, and subsequently their quality of life, can often be eroded by practices within aged care facilities.

**CDC as a continuum**

Consumer-direction is often described in terms of a continuum. The Pioneer Network, a US-based group of long-term care professionals established in 1997 to advocate for consumer-directed care approaches, has developed a CDC continuum specific to residential aged care. At the provider-directed end of the spectrum, management makes most decisions with little consideration of the impact on staff or residents while residents are expected to accommodate staff preferences and follow set routines. At the consumer-directed end of the continuum, residents make every day decisions about their own daily routines and, when they are incapable of doing so, staff will honour previously observed preferences and habits. Figure 1 is an adaptation of this continuum.

Figure 1: Continuum of CDC in residential aged care

Source: Adapted from Misiorski and Rader (2005), Pioneer Network.

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The role of person-centred practice to CDC

The CDC continuum model at Figure 1 presented ‘person-centred care’ as a stage before consumer-direction. Person-centred practice is a key component – and, indeed, a fundamental enabler – of CDC. Person-centred practice places the person at the centre of their own care. It is a philosophy of care emphasising the wellbeing and quality of life of the person, as defined by the person.\(^{21}\)

The literature shows that elements of person-centred practice include personhood or respecting the individualism of the care recipient, workers knowing the person as an individual, maximising autonomy and independence for the person, quality care, nurturing relationships and a supportive physical and organisational environment that respects the independence and dignity of the individual.\(^{22}\) Person-centred interventions in aged care are typically multifactorial comprising elements of environmental enhancement, providing opportunities for social stimulation and interaction, changes to management and leadership to ensure a focus on ‘the person’ receiving care, and an individualised philosophy of care.\(^{23}\)

Consultations for this project indicated a high level of understanding and support for person-centred practice in the residential aged care sector. Although it was indicated that the extent to which current practice is in fact person-centred varies considerably across providers.

3.2 Development of CDC in residential aged care settings internationally

To date, the majority of CDC development, implementation and evaluation activity has focussed on people living independently in the community or living in semi-independent supported accommodation, receiving long-term home care and services. However, CDC concepts specific to long-term residential care settings (including residential aged care) are developing, particularly from the nursing home ‘culture change’ movement in the United States, and, to a lesser extent, the ongoing personalisation of care services in the United Kingdom. More recently, some early Australian discourse on CDC in aged care homes has also emerged.

The move towards consumer-direction in the US began with the Nursing Home Reform Law, passed on 1987, which promised residents the right to participation in their care, full disclosure and fundamental right to dignity.\(^{24}\) The ‘culture change’ movement emerged in the 1990s as a provider-initiated grassroots effort to expand on this and ‘radically transform nursing homes by delivering resident-directed care and empowering staff’.\(^{25}\) It has been defined as ‘a philosophy and a process that seeks to transform nursing homes from restrictive institutions to vibrant communities of older adults and the people who care for them’.\(^{26}\)

\(^{22}\) Ibid.
In practice, this essentially involves a journey of transformation from provider-direction to resident-direction, with a particular focus on empowering residents (including through enhanced choice and control) and direct care staff (allowing them to make decisions applying resident-directed principles), as well as creating a more ‘home-like’ setting for residents through environmental and practice changes.\textsuperscript{27} \textsuperscript{28} A more succinct description of the aims of culture change is to simply ‘make long-term care less about tasks and more about caring for people and the relationships between people’.\textsuperscript{29} 

There is a limited but growing body of evidence on the benefits of culture change: like community-based CDC approaches, it is associated with improved psychosocial outcomes and some health outcomes, but there is a need for more research on the impact of culture change programmes on clinical outcomes and quality of care.\textsuperscript{30}

In terms of conceptualising CDC in residential aged care, the culture change literature indicates the following key features of a move towards consumer-direction in aged care homes:

- returning control and decision-making to residents in all areas of their life, including daily routines such as waking, bathing and bedtime, eating, activities, and the design of their personal spaces – homes should institute flexible dining room times, offer a range of meal and self-service snack options, promote flexibility in bathing, and make provision for individualised activities;

- recognising that genuine self-determination includes residents being able to engage in the ‘dignity of risk’ – that is, some choices that self-determining, informed adults want to make will involve a level of risk or potential harm; aged care homes that seek to remove all risk will restrict residents’ freedom;

- empowering direct care staff by training them in person-centred approaches, enhancing their clinical skills, giving them time to build individual relationships with residents to know their needs and preferences, and giving them authority to make individualised care decisions for residents, applying a consumer-directed ethos (as opposed to working within a highly prescribed, one-size-fits-all, management-directed and task-driven approach to care delivery);

- transforming the facility itself into a more home-like environment so that all residents (including those with cognitive impairment) can freely exercise choices and participate – homes could include a mix of public and private spaces, kitchens and laundries that can be accessed by residents, a bistro/cafe style dining room or alternative menu;

- inverting the formal decision-making chain within aged care homes, away from a ‘top-down’ pyramid of management authority towards a flatter structure where direct care staff are empowered to make decisions and residents are at the top (or centre) of the chain; and

\textsuperscript{27} Mueller, C. (2008) Nurses’ involvement in culture change: Opportunity for improving residents’ quality of care and quality of life (funded by the Commonwealth Fund), Hartford Institute for Geriatric Nursing/New York University College of Nursing.

\textsuperscript{28} CNA HealthPro (2009) Culture change: Reaping the benefits of resident-directed care, CareFullySpeaking: A risk management resource for aging services, Issue 2.


• incorporating a regenerative care approach (similar to restorative or re-ablement concepts described in Australian and UK literature, but with a focus not only on restoring or maintaining functional abilities that affirms a person can still develop at any age or life stage).

The consultations conducted for this project indicated broad – albeit qualified – support for most of these features, although there were few examples identified that demonstrated their application in an Australian setting. Almost all of the providers and provider peak bodies interviewed referred to the importance of transforming aged care homes into more home-like facilities as a key enabler for CDC; this was one of the most consistent messages of the consultations. The need to empower and build the capacity of staff (and, more broadly, to address a risk-averse, task-focussed culture in the sector) was also discussed by most providers and other stakeholders.

Most stakeholders interviewed for this project supported the concepts of resident empowerment and ‘dignity of risk’ – but for providers, this support was heavily qualified by the need to balance resident freedom with their duty of care and their focus on compliance with quality and safety obligations. This perceived tension between consumer choice principles and compliance with legal responsibilities was commonly cited in theoretical terms (e.g. what if a resident wants to have a meal prepared in a manner that is not consistent with healthy and hygiene requirements; or does not want to take required medications at the required time; or does not want to shower for a week but this would compromise their hygiene as well as the comfort of other residents).

Despite this, numerous examples were also provided during the consultations where some providers had successfully implemented greater choice for residents in these very same areas. The conflicting information suggests that whether or not the regulatory environment is an actual barrier to consumer choice and control, the perception by providers that it is a barrier must be overcome as part of a move towards CDC.

Very few of the stakeholders interviewed for this project referred to inverting the power and decision-making chain in aged care homes, or to regenerative care approaches, as an aspect of CDC. This is perhaps indicative of the different conceptual stage that CDC is at in Australia.

The ‘personalisation’ agenda in the United Kingdom is a well-established transformation programme that has focussed on reorienting community care services to a more person-centred and consumer-directed approach. This has included provision for individual budgets and direct payments allowing consumers to control what supports they review, and which providers delivers them. Aspects of the personalisation agenda are now expanding into health services (with trials of individual budgets for primary health care services) and residential care settings for older people and people with a disability.

Enhancing choice and control for aged care residents is now a component of the overall personalisation agenda.\textsuperscript{31,32} The 2012 government white paper, \textit{Caring for our future: Reforming care and support}, enshrines individuals’ rights to person-centred planning practices and an entitlement to a person budget.\textsuperscript{33} It also introduces direct payments for people in residential care – an approach that is currently being trialled at 18 pilot sites.


\textsuperscript{32} SCIE (2010b). \textit{At a glance 20: Personalisation briefing – Implications for Nursing Homes}. Social Care Institute of Excellence.

\textsuperscript{33} HM Goverment (2012) \textit{Caring for our future: Reforming care and support}, Department of Health: London
Prior to these changes, personalisation had already had an impact on residential aged care facilities, improving choice within many facilities through person-centred methods of assessment, care planning and nursing practices.34

In terms of conceptualising CDC in residential aged care, the personalisation policy discourse indicates the following key features of a move towards consumer-direction in aged care homes:

- establishing a legal right for consumers to access person-centred assessment and care planning;
- holistic assessment of aged care residents focussing on individual needs and preferences;
- enhancing choice and control for residents through practice change (staff taking the time to get to know residents as people, not assuming that consumers can’t make decisions, and valuing time spent with people as much as time undertaking tasks);
- a move away from ‘task-driven’ service models to relationship-based delivery of care;
- ensuring staff have skills to communicate with and elicit preferences and, where possible, choices from people with cognitive impairments;
- encouraging residents to participate in the wider community; and
- exploring options for residents to exercise some level of control over care funds through direct payments or individual budgets.

The UK discourse about CDC in residential care largely reflects the conceptualisation of CDC in the community sector. However there are two key divergences from community-based approaches. Firstly, there is a recognition that CDC in residential aged care will need to cater for greater numbers of consumers with high-needs.35 36

Overall, many of the key features identified in the UK literature overlap with those from the US culture change literature. In both, CDC in residential aged care is conceptualised as enhanced choice and control by consumers (particularly over their own daily activities), underpinned by person-centred assessment and care approaches that are supported by active strategies to empower consumers and care staff. The main difference between US and UK bodies of literature is that the US concept extends the focus to the physical environment of the aged care home, positing that a more ‘home-like’ environment is essential for facilitating an effective CDC approach in residential aged care. Another difference is that the UK is exploring direct payments as a component of residential care, which has not been a feature of the US approach.

The discourse on CDC in residential aged care in Australia is relatively recent and has so far focussed on theoretically exploring how CDC might be applied in the residential aged care setting. The Australian literature tends to focus on the potential expansion of extra services as a key tenet of CDC in residential care.

Offering a set package of services for an additional fee would provide more options for more consumers, but there is also a need to ask consumers what type of services they want, and then bring

in the services they choose. This will require a ‘complete shift in culture’, with staff having to be more focussed on customer service than traditional care – providers will still have a duty of care, but they will not choose the care.\textsuperscript{37} As part of this shift, the following changes to the Australian approach to delivering residential aged care are envisaged:

- providers becoming more innovative and flexible in the type of services they offer;
- consumers being more involved in designing their care plans and services, and in making daily choices;
- access to fee-based extra services on demand;
- embracing the ‘dignity of risk’ concept – respecting consumers’ autonomy and self-determination by ‘allowing’ them to choose to take some risks to do things that they enjoy;
- more flexible staffing models to meet the demands of consumers;
- flexible meal times with kitchens open all hours;
- better information about aged care homes being available to consumers before they enter the home (including a website with comparative information);
- more transparency to consumers about quality indicators for their homes, and costs;
- consumers participating in the management of homes.

The literature suggests that current regulatory and funding environment is widely perceived as a barrier for aged care homes being able to provide more flexible care and support in Australia: ‘Most facilities can’t offer flexible care support due to regulations, accreditation and risk aversion’.\textsuperscript{38} A key concern for providers – as it has been with Australian community care providers reorienting to a CDC approach – is how to balance their legislated duty of care with consumer choice.\textsuperscript{39}

The consultations conducted for this project confirmed that many providers find the current regulatory and funding environment as a potential barrier to CDC. In terms of the regulatory environment, it appears that many providers are, understandably, focussed on compliance with their responsibilities under the aged care accreditation standards, particularly Standards Two (health and personal care) and Four (physical environment and safe systems). Ensuring compliance with these responsibilities can sometimes lead to rigid, inflexible processes, a task-based approach to care delivery, and a highly risk-averse service culture with little ability to rearrange defined practices and processes to accommodate individual preferences.

In other words, for some providers the focus on compliance and maintaining accreditation standards is interpreted as requiring standardised, highly-controlled processes and systems which leave little if any scope for consumer choice, and practically no scope for consumer control: indeed, consumer choice and control is seen as somewhat of a risk to the system. Interestingly, however, accreditation standard three, which relates to the consumers’ lifestyle and independence, appears to receive less attention in terms of this ‘compliance focus’.


In the most recent version of the standards released in July 2014, accreditation standard three includes an unambiguous statement relating to choice and decision-making that each resident or their representative ‘participates in decisions about the services the care recipient receives, and is enabled to exercise choice and control over his or her lifestyle while not infringing on the rights of other people’. Several stakeholders interviewed for this project observed that many providers have traditionally focussed on requirements to assure quality of care, but there has been less attention given to assuring quality of life. These stakeholders saw a move to CDC approaches as a way to rebalance that focus.

In terms of the funding environment, the consultations suggest that many providers perceive the current level of funding as a barrier to CDC. Other stakeholders suggested a number of ways that, with some innovation and creativity, choice and control principles could be successfully integrated into the current system within the current funding levels, albeit that it may require a redistribution of those funds so that residents could choose, for example, to purchase personal care from a visiting external provider and continue to receive accommodation from the home, rather than the current ‘one-stop-shop’ model which effectively prohibits this kind of choice.

This would mean a transfer of power from the provider to the consumer, which is a concept at the heart of CDC. The findings from these consultations demonstrates that the very strong perception across the sector that funding is a barrier to CDC, is in fact a barrier in itself. Similarly, the reluctance to consider changes to process that would involve a genuine shift in power from providers to consumers, and the fears that such a shift would present a risk to providers, is indicative of another ingrained cultural barrier to CDC in residential aged care which would need to be carefully considered in timing a reorientation of the sector towards CDC.

It should be noted of course that many providers do embrace choice and control principles, some examples of which were provided during the consultations. Some stakeholders suggested that for-profit providers are particularly focussed on enabling consumer choice, recognising it as differentiator in the marketplace. Others suggested that the size of the provider was relevant, although there was no agreement on what size worked best for CDC (some suggested larger providers had access to more resources to better facilitate choices; others suggested smaller providers were better at delivering personalised care with consistent care workers; still others suggested that medium sized providers were in the better position to reorient to CDC).

It is unclear from the literature whether an individual budget approach to CDC in residential aged care is supported in Australia. Some indicated that an individual budget would allow consumers to pick and choose services (i.e. they may choose to shower four times a week rather than seven, and use the cost difference to pay for extra lifestyle services). Others suggest that older people moving into residential care do not place priority on self-managing or coordinating their care, but they do value participation in choosing the type of service and delivery of their care. In other words, people entering aged care value choice and want to participate in facilitated decision-making about their care, but do not want to manage their own budget or co-ordinate services. It is also suggested that after accounting for facility operating costs and basic care needs, residents would only be left with

about two hours per month of discretionary spending.\textsuperscript{43} This analysis does not consider the potential separation of accommodation and basic care needs, so that consumers could use some of those funds to purchase non-discretionary care from providers other than the aged care home.

The consultations did not resolve this lack of clarity about individual budgets. Some stakeholders were adamant that a genuine CDC model was explicitly linked to having an individual budget; others considered that many elements of CDC could be implemented to facilitate greater choice and control for residents whether or not that included an individual budget.

Where stakeholders did agree was that, whatever the delivery model, the aim of CDC in residential care should be to improve a resident’s quality of life. Stakeholders almost unanimously stated that the current model developed with a strong focus on quality of care and safety at the expense of individualised care, and saw CDC as an opportunity to refocus on quality of life.

4. Applying CDC in residential care settings

This section draws on information identified from the literature review and the consultations to explore ways in which the various aspects of CDC are, or could, be applied in residential care settings. The discussion is organised around six areas:

- Person-centred and goals-based approaches to assessment and planning;
- Choice and control for residents;
- Participative person-centred practice care;
- Individualised funding and transparency;
- Supplementary or ‘extra’ services; and
- Considerations for consumers with special needs.

The section concludes with a discussion on the evidence of the benefits of applying CDC in residential care settings.

Person-centred and goals-based approaches to assessment and planning

There are many examples of applying person-centred assessment and planning in community care, health care and disability support settings; there are fewer examples in the literature of its application in residential aged care.

An important aspect of person-centred assessment and planning is that it takes a positive or strengths-based approach to assessment focusing on what a person can do and would like to do, in contrast to the traditional ‘deficit model’ of assessment which focuses on a person’s health, impairments or disability. A guide developed for Home and Community Care clients in Victoria provides the following description of person-centred assessment:

> Assessment is done ‘with’ not ‘to’ a person. Information is obtained, exchanged and jointly considered in a culture of collaborative problem solving and partnership. The assessor’s skills and knowledge are an expert resource which should help the person make informed choices to achieve their own goals. The assessment process is flexible and modified to respond to each individual person. Assessment is not ‘one size fits all.’

The literature suggests that assessment and planning should start with the taking of a detailed life history, getting to know the person and their passions and interests, and not by cataloguing their ailments and impairments. The assessor first should determine what is important to the person, and frame the planning of care and services around that. Key elements of person-centred assessment and planning are that:

- the person is at the centre of the process;

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• the person and their family are involved in the assessment and planning;
• the resulting care plan reflects what is important to the person, the strengths and their goals;
• the plan reflects what is possible, not just what is available;
• the plan results in actions, not just the delivery of services; and
• the plan is periodically reviewed.47

Goal setting is part of the assessment process and informs care planning. It involves identifying goals that are meaningful to the person, and implementing actions to realise those goals. Pascale (2013) provides a useful framework linking person-centred assessment, goal setting and planning.

Table 2: Framework for person-centred assessment, goal setting and planning

<table>
<thead>
<tr>
<th>Assessment</th>
<th>Involves:</th>
</tr>
</thead>
<tbody>
<tr>
<td>Conduct a comprehensive and holistic assessment of the client’s situation and needs, in the context of their life and what is important to them</td>
<td>• Gathering a rich life history</td>
</tr>
<tr>
<td></td>
<td>• Considering factors impacting on person’s function, attitude and goals</td>
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<tr>
<td></td>
<td>• Identifying existing supports</td>
</tr>
<tr>
<td></td>
<td>• Listening and observing</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Goal setting</th>
<th>Involves:</th>
</tr>
</thead>
<tbody>
<tr>
<td>Collaboratively identify and prioritise the person’s goals (those relating to the specific service, as well as broader life goals)</td>
<td>• Understanding the person’s needs, priorities and values</td>
</tr>
<tr>
<td></td>
<td>• Identifying the person’s strengths, passions and interests</td>
</tr>
<tr>
<td></td>
<td>• Developing (and if appropriate) documenting goals</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Planning</th>
<th>Involves:</th>
</tr>
</thead>
<tbody>
<tr>
<td>Working together to develop and document prioritised actions to support the person achieve their goals, focusing on what supports the person needs to achieve their goals – not on what services are provided by the assessing agency.</td>
<td>• Identifying links between actions and goals</td>
</tr>
<tr>
<td></td>
<td>• Encouraging the person to self-identify solutions and share responsibility for care</td>
</tr>
<tr>
<td></td>
<td>• Prioritising actions based on urgent and fundamental needs</td>
</tr>
<tr>
<td></td>
<td>• Developing and documenting a care plan</td>
</tr>
<tr>
<td></td>
<td>• Reviewing the care plan over time</td>
</tr>
</tbody>
</table>

Source: Pascale (2013)48

Consultations conducted for this project indicated that it is difficult to assess the scale of person-centred and goals-based approaches to assessment and planning in the current system. Provider stakeholders suggested that some did this very well, but that there was wide variation in these practices. Non-provider stakeholders suggested that there was little evidence of genuine person-centred and goals-based approaches to assessment and planning in the current system. Provider stakeholders suggested that some did this very well, but that there was wide variation in these practices. Non-provider stakeholders suggested that there was little evidence of genuine person-centred and goals-based approaches to assessment and planning in the current system.


48 Pascale, K. (2013) Goal directed planning toolkit: Practical strategies to support effective goal setting and care planning with HACC clients, EMR HACC Alliance.
centred assessment and planning, and little if any evidence of person-driven, individualised goal setting. These stakeholders suggested that embedding a consistent culture of person-driven, individualised goal setting when a person enters aged care would potentially be a good place to start reorientation to CDC in the sector.

**Choice and control for residents**

Choice and control is identified in the literature as the core tangible component of genuine ‘self-direction’. In a practical sense, on a day-to-day basis, this relates to the exercise of choice and control over:

- the types of care and services a person is able to access and use;
- who provides the care and services;
- how they are designed and delivered; and
- how resources are used.

Under a CDC approach, residents should be offered opportunities to exercise choice and control over the care they receive. To facilitate this, homes should put in place mechanisms by which the preferences of residents may be elicited and honoured in the delivery of daily care activities and social activities.49

Choice and control may occur in the delivery of daily care activities through the scheduling of activities based on residents’ preferences, as expressed during care planning. However, on a day-to-day basis, communication between staff and residents is the key mechanism by which choice may be exercised in care activities, such as waking and bed times, preferred clothing, preferred bathing times and frequency, preferences for food and meal times, and toileting.50 51

An observational protocol developed to assess the quality of staff-resident communication relevant to choice in their morning care routine highlights several ways in which staff may routinely offer choice to residents. Residents’ ability to exercise choice during morning care provision are reliant on staff ascertaining when the resident wants to get out of bed, when and where the resident prefers to bathe and dress, what the resident prefers to wear and where the resident would prefer to eat breakfast through conversation or responding to resident behaviours.52

There are risks associated with encouraging choice in the context of medical care provision. According to the literature, in circumstances where residents make a non-compliant choice, the associated risks should be managed through appropriate notification of resident’s basic rights and freedoms and through fully informing residents and their families/carers of potential risks of exercising choice in their medical care. Mechanisms to manage these risks may include use of ‘informed choice documentation’ and resident record keeping, risk sharing agreements or

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consultation processes with independent associations of family and friends of residents called ‘family councils’.\(^{53}\)

Choice should also be available in social and recreation activities – ideally, these should be designed and delivered on an individualised basis.\(^{54}\) In many cases, the types of social activities available to residents of care homes are generic and predictable. In order to offer genuine choice and control, care homes should enhance the variety of opportunities to partake in social activities through engaging with community organisations and volunteers, creating a social activity planning committee, scheduling regular one-off events or day trips and offering a variety of in-house activities scheduled throughout the week and weekends. Social activities targeted to cognitively impaired residents should be included. Importantly, residents should be made aware of opportunities but should not be pressured to participate in social activities.\(^{55}\)

In practice, the mechanisms for encouraging residents to exercise choice and control in daily care and social activities should be incorporated into initial care planning and goal setting, and reviewed on a regular basis to acknowledge that residents' condition and preferences may change over time.\(^{56}\) Some residents may require support to make informed decisions.

Decision supports may range from access to information, assistance to communicate and advocacy through varying levels of assistance to make decisions, to substituted decision making. For residents with cognitive impairment, service providers should work from the basis that all challenging behaviours represent meaningful communication of the care-recipients needs and preferences. Staff providing direct care to residents play the key role in providing choice and control in practice, meaning that education and training are pivotal to implementing cultural change.\(^{57}\)

Service providers looking to implement greater choice and control for residents face the challenge of measuring progress against their objectives in such a way that can be translated into actionable service improvements. In the US, a new toolkit has been developed to assist service providers in evaluating their person centered approaches. The ‘Advancing Excellence PCC Toolkit’ allows service providers to monitor monthly resident satisfaction data in order to assess whether preferences are being met. A pilot evaluation found that the toolkit was useful to service providers in identifying opportunities for improvement of their person centered care approach, such as strengthening staff training, enhancing care planning and quality of programming.\(^{58}\)

The emerging evidence is that higher levels of choice and control are associated with positive health, wellbeing and social outcomes for residents and are cost effective.\(^{59}\)

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\(^{53}\) CNA HealthPro (2009) Culture change: Reaping the benefits of resident-directed care, CareFullySpeaking: A risk management resource for aging services, Issue 2.

\(^{54}\) Hoban, V. (2011) Bingo sessions are not enough, *Nursing Times*, August 2011.

\(^{55}\) CNA HealthPro (2009) Culture change: Reaping the benefits of resident-directed care, CareFullySpeaking: A risk management resource for aging services, Issue 2.

\(^{56}\) CNA HealthPro (2009) Culture change: Reaping the benefits of resident-directed care, CareFullySpeaking: A risk management resource for aging services, Issue 2.


The diagram below illustrates how a choice and control pathway might look for an aged care resident, under an ‘ideal’ approach.

*Figure 2: Choice and control pathway*

**Example: Choice and control in residential aged care, Seattle, United States**

The Providence Mount St Vincent (the Mount) is a large aged care home in Seattle, Washington with over 400 residents and nearly 500 staff. In 1990 it commenced a journey to move away from a traditional ‘medical’ model of care in an institutional setting to a more ‘resident-directed’ service orientation.

Prior to starting its ‘cultural shift’, staff were focussed on efficiency and residents tended to be categorised by their medical conditions. Professional care meant ‘protecting residents to the point that they had no freedom, dignity or basic rights’. The physical environment was sterile. Residents felt well cared for, but also bored, lonely and frustrated at the lack of control they had over their own lives.

A change of management led to a new, long-term vision: to build from scratch an aged care facility that felt like a home. Nine million dollars was spent on renovations to change the physical environment, including the transformation of corridors into ‘neighbourhoods’ to promote social engagement and ‘homeliness’. Each neighbourhood houses about 20 residents and has its own kitchen and dining room, and its own dedicated care staff. Residents furnish their rooms as they wish. As part of a strategy to engage more with the wider community, an onsite child care centre was constructed within the home – providing inter-generational stimulation for residents. One of the most controversial changes was removing secure units and integrating residents with dementia into neighbourhoods. This proved challenging, but ultimately reduced dementia stigma and removed the fear that residents once had of one day being moved to the former secure unit.

The physical changes were complemented by a fundamental reorientation of service-delivery to ‘resident-directed care’. This requires both residents and direct care staff to be empowered to make...
decisions (rather than management). Residents make all decisions about their daily routines. They choose what and when they eat, when they get up and go to bed, what they do with their time and how their own space is furnished. Staff schedules are organised around residents’ preferences. Staff assignments do not rotate, ensuring continuity of carers and emphasising the importance of relationships over specific tasks. Staff are expected to take time to get to know residents as individuals.

Nearly twenty years on, the Mount has become a model for the ‘culture change’ movement. Resident and staff satisfaction is high. Staff retention is very high – although there were many changes of roles and functions, including a significant reduction in middle managers. The home is also an active part of its community, through the child care centre and events such as regular garden concerts for 200+ people.

**Indicators of CDC in this example:**

- Person-centred, goals-based assessment
- Choice and control for residents
- Person-centred care


**Person-centred care**

Following on from person-centred assessment and planning (determining what care and services will be provided to meet the person’s needs), and the provision of choice and control (which deal with issues such as when and by whom care and services are delivered), the question then arises about how care and services are delivered under a CDC approach. Person-centred care or individualised care is where the delivery of care and services are tailored to a person’s needs, preferences and circumstances.

Person-centred approaches are increasingly the philosophical and practical premise for contemporary disability policy, long-term social care and support, and other forms of health and community support. These approaches are also practised in some forms of residential care (most notably, to date, in the disability sector). Person centred care seeks to reframe the delivery of care and services around an individual’s needs and goals.

In the aged care setting, person-centred care is often equated to relationship-centred or relationship-based care, in contrast to traditional task-based ways of working. Emphasis is placed on workers getting to know residents as individuals, and understanding their preferences and needs (which is particularly important for non-verbal residents and/or those with cognitive impairments). Residents and their families should have a voice which is listened to, understood and acted upon. This can be challenging for some care homes, because it requires that staff are able to take the time to understand each person’s life story and preferences, and traditionally, time spent ‘getting to know
residents’ has not always been valued in an efficiency-driven operating environment such as an aged care home.61 62

Person-centred care is just as relevant for people with special needs, such as residents with behavioural and psychological symptoms of dementia. A person-centred approach to care sees the person first as an individual, rather than as a ‘person with dementia’. Using a person-centred approach focused on getting to know about the person’s preferences and activities that they have enjoyed over their lifetime (through a combination of information gained from families and observation) can assist in managing dementia behaviours, sometimes reducing the need for medications, as well as providing a level of choice and control for the person who may not be able to easily communicate their feelings and preferences.63

Person-centred care takes a holistic perspective on residents’ health and wellbeing. In addition to getting to know residents as individuals, a person-centred approach to care delivery also frames the provision of care around the individual’s needs and preferences – giving regard to all of their needs and preferences, not only those relating to the provision of essential or basic care and services. In other words, the person is seen as a whole person, not just a ‘care recipient’.

Positive indicators of this could be incorporating the person’s spiritual and cultural preferences into their daily life, allowing residents to have their guests stay for meals or overnight visits, offering a range of activities and stimulation opportunities that residents can enjoy individually or as a group, and respecting the privacy and dignity of residents (including respect for their personal cultural, spiritual and sexual needs).64

This ‘whole person’ focus is important because, when asked about what is important to them for a ‘good life’ or a good quality of life, older people tend to rate factors such as ‘being active’, ‘feeling valued and belonging’, and the importance of relationships above the quality of services and care they receive.65

Despite the prevalence of literature on person-centred care, there is very little available which explores its application in residential aged care.66 One international example of a residential aged care service that reoriented to a person-centred care model involved a chain of for-profit aged care homes in the US in 2008. The model involved organisational and practice change to embed person-centred care across the homes. The process was evaluated using a number of tools, including cultural change scales and resident quality of life measures. It was associated with increased quality of life for residents, compared to a comparison group of homes in the same chain, and a better work environment for staff. Importantly for a for-profit provider, the reorientation was also found not to

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64 Bupa Care Services and Alzheimer’s Australia (n.d.) Choosing a care home: Seven signposts of person-centred care, Bupa Care Services.
have led to significant increased operating costs. The box below describes an Australian example of implementing person-centred care in a residential aged care setting.

**Example: Trialling person-centred CDC in residential aged care, NSW, Australia**

Living Well, an Australian not-for-profit residential aged care provider with nine homes across NSW established a CDC model to provide residents with greater control of the design over their care and services. The model targeted residents who were dissatisfied with the existing model of care. There is an opt in/opt out choice for staff.

The CDC model was introduced on a trial basis across several facilities in 2013. In the planning phase, operational processes were changed and tools were developed to track qualitative and quantitative measures. Changes were also made to the physical environment: each room having its own address recognising that it was someone’s home.

Residents recruited for the CDC trial were those who did not feel comfortable with the existing residential environment or communal lifestyle. Staff worked closely with residents to build capacity for them to control their own care – including through the negotiation of an individual care plan based around what was important to them. Examples of how residents chose to exercise choice and control included changing the time of day care was delivered, installation of private medication storage cabinets within rooms, and supported engagement or re-engagement with community activities or friends outside of the residential care home.

Feedback from residents and staff was positive. Residents appreciated having more choice and felt more in control of their lives. One resident expressed increased satisfaction at simply being able to go shopping at the shopping centre she used before she lived at the home. Staff felt more engaged at seeing positive changes in the residents, and were pleasantly surprised to find residents were able to do more than had been thought. One staff member noted that ‘it is hard to change and I thought that the whole thing was ridiculous at first and wouldn’t work, but I can see the change in residents now. I was wrong.’ Two residents with developmental delay using the CDC approach demonstrated improved wellbeing and reduced behavioural incidents.

There were funding implications, including additional staff hours and additional expenses (the cost of which were negotiated with the resident).

*Indicators of CDC in this example:*

- Person-centred, goals-based assessment.
- Choice and control for residents.
- Person-centred care.


Consultations conducted for this project indicated strong support for participative person-centred care, and several stakeholders observed that person-centred approaches have underpinned better

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practice in residential aged care for some years. However, some stakeholders suggested that whilst the concepts were indeed widely understood, the effectiveness of their application was variable.

This was particularly the case for some consumers with special needs, although perceived deficiencies or room for improvement in person-centred practice was not limited to consumers with special needs. It was difficult for stakeholders to judge the scale of ‘better practice’ person-centred care – although the majority of stakeholders affirmed that, in their experience, most providers are attempting to deliver person-centred care, where possible, they are challenged by perceived funding and time constraints that meant aged care workers are often unable to deliver genuine person-centred care.

**Individualised funding and transparency**

International studies of direct payments for self directed approaches to long-term care and support in community settings consistently report positive impacts on individual and carer satisfaction, feelings of independence, well-being, enhanced quality of life and care.68 69 70 71 However, the concept of individual budgets or direct payments as a component of CDC in residential care is not well developed.

A direct payments trial for people living in residential care has recently commenced in the UK. Thirteen of the 18 participating local councils will be offering individual budgets to older people living in residential care.72 Direct payments are cash payments made to people assessed as needing care services. Direct payments allow people greater choice and control in meeting their eligible care needs within an individual budget. Direct payments have become increasingly common in community care settings in the UK over the past decade. Given the early stage of the pilot, available information at this time focuses only on what the trial sites intend to implement. Features of the models that pilot sites intend to implement to facilitate direct payments include:

- personalised needs assessment and planning processes;
- expansion of brokerage services currently offered in community care; and
- options of full and part-funding of care services via direct payment.

In preliminary work, the pilot sites focused on identifying the actual costs of delivering services in residential care facilities, developing a Resource Allocation System to match the needs assessments of individuals with the costs of services in order to determine the direct payment amount, and developing approaches to contracting service providers.

The preliminary report for the pilot evaluation highlights several concerns and perceived risks by the sites, including skepticism as to whether direct payments will result in any additional actual choice, concern about resident interest and uptake, potential impact on providers’ financial viability due to

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A shift in the distribution of funding, and how to deal with resident choices that do not align with health and safety standards. Further published information on progress with the evaluation is expected in mid-2015.

One example of an individual budget approach in a residential care setting was identified from the disability sector in the UK, where block funding for the accommodation and support providers was partially redistributed as individual budgets for residents. Early evidence indicates that it has been successful – but it should be noted that the client group (adults with high needs mental illness) is not directly comparable to older people. This example is further described in the box below.

**Example: CDC with individual budget in supported accommodation, London, UK**

Look Ahead, a disability housing and care provider in London, trialed a personalised model of long-term supported accommodation for people with high-needs mental illness between 2009-2010. This involved introducing an individual budget for consumers to design and direct their own supports, within a service model that was historically block funded to provide accommodation and care services for a cluster of residents. The aim was to offer a suitable alternative to the individual budget model operating for people living independently in the community.

Look Ahead developed a ‘core and flexi’ model to develop individual budgets for the personalisation trial. Core refers to the fixed range of supports required by all consumers to run the service. Flexi refers to the individual support for consumers. Seventy-four per cent of the contract funding for the service was allocated as ‘core’. The remaining 26 per cent was allocated as ‘flexi’, comprised of 8 per cent which was used as a cash allocation to consumers (£40 per consumer per week) to purchase external supports of their choice in accordance with their personal plan, and 18 per cent was flexible support hours (about 3.5 hours per consumer per week) for support delivered by service staff at the direction of the consumer. Consumers created their own plans in collaboration with their doctor and care coordinator.

Early results from an evaluation show that consumers value being able to take control of their own support and having genuine choice over who delivers their care, or at least a portion of their care. Consumers felt that they had more involvement in making decisions about their own care and indicated a positive shift in the balance of power from key worker to consumer. Relationships between consumers and staff also improved because consumers had a choice over who delivered their care, and staff were able to spend longer quality time with consumers.

One of the notable changes in staff attitudes during the trial was their approach to risk. Attitudes moved from ‘defensive’ to ‘defensible’ or ‘enabling’, meaning that some activities previously deemed too risky were now permitted to occur – with reported high social and health benefits for consumers.

**Indicators of CDC in this example:**

- Person-centred, goals-based assessment.
- Individualised funding or direct payment.
- Choice and control for residents.
- Supplementary or ‘extra’ services.
- Person-centred care.

**Sources:** Look Ahead Housing and Care (n.d.) *Choice, Control and independence: Personalising block contracts in supported housing*, Look Ahead Housing and Care, London.

The question of individual budgets was the most controversial and divisive issue to arise during the consultations for this project. In contrast to those areas where stakeholders almost unanimously
agreed (such as the importance of built form and creating a home-like environment to enable CDC, and the need for CDC efforts to focus on residents’ quality of life to redress a perceived historical imbalance that has overly focused on quality of care), stakeholders disagreed on whether an individual budget was necessary or desirable for a CDC approach in residential aged care.

Some stakeholders considered an individual budget to be an essential component of CDC, because the holder of the funds decides how and where they are expended and this is achieves the exchange of power from provider to consumer that underpins CDC. Others considered it was not essential to have an individual budget to have a CDC approach, focussing on the potential improvements to quality of life by making service more responsive to consumers. Most provider stakeholders also felt that it would be unfeasible to offer individual funding under the current funding structures and within the current funding levels. One stakeholder suggested that:

ACFI funds essential care for a person based on their assessed level of dependency, whereas home care packages fund a person based on their capacity and independence which makes it easier to accommodate personal goals. In residential care, there is no money left for wellbeing and reablement after the essential care is provided.

More than any other issue explored in the consultations, the individual budget discussion highlighted the current lack of a shared vision and clear aim of CDC in residential aged care.

Other stakeholders took the view that it could be possible, but that it would probably be difficult to develop and require time to do. The majority of stakeholders did not present concrete suggestions for how an individual budget might work, but there were three high-level suggestions:

1) that a proportion of ACFI funding for an individual be set aside for their direction, after paying for ‘core’ services;
2) that residents control all or most of their funding with an option to purchase care services from other providers outside of the aged care home to be delivered to them in the aged care home (this would effectively be a separation of accommodation from support services, giving the resident the power to decide who provides their care services); and
3) that ACFI funding for an individual be allocated to that individual, rather than the aged care home, thus making funds portable and giving the resident power to purchase care at any accredited aged care home (residents theoretically have choice of home now, but in reality this choice is often very limited).

**Supplementary or ‘extra’ service**

**Findings from the literature review**

Under CDC, consumers should have opportunities to supplement their care and services with additional or ‘extra’ service from their own resources (where they have capacity to pay). Currently in Australia, a relatively small number of residential aged care services provide defined ‘extra service’, which are hotel-type services that residents can purchase such as a larger room, internet, pay TV, therapies such as massage, better quality food and beverages such as wine, and leisure/entertainment facilities and activities. The number of extra service providers was previously capped, effectively also capping the number of consumers with access to these services. This changed from 1 July 2014, when all homes became able to provide additional amenities for a fee.

Unlike the issue of individual budgets, there was wide agreement and support in the consultations that access to on-demand, price-controlled extra service was a key platform for moving towards a CDC approach in residential aged care.
Consumers with special needs

There is little literature concerning the delivery of CDC for people from special needs groups. This is an area that could be explored further in the consultations. One notable facility, which could be described as having a CDC approach in that it promotes individual choice and autonomy for a group of older people who frequently have very limited choice and autonomy – people with dementia – is the ‘dementia village’ of Hogeweyk in the Netherlands, which is described in the box below.

Example: CDC for people with dementia in residential aged care, The Netherlands

Hogeweyk is a residential care facility in Weesp, The Netherlands designed for people with dementia. Designed as a village over a four hectare site, Hogeweyk has several different styles of high needs accommodation, a town square, gardens, restaurants, a theatre, a pub, shops and a salon. The theatre is partially open to the wider community and commonly used for events that residents also attend.

The residents live in communal apartments with live-in care workers. Residents are free to move about the village as they wish, and can choose what they do and when they do it. Care workers and nurses dress in street clothes to replicate a ‘real’ town community.

Compared to traditional nursing homes, Hogeweyk residents are more active and require less medication. Residents have maximum mobility and an opportunity to lead a normal daily life, making decisions to the extent that they can in the same way they did throughout their lives. They can go for walks accompanied or alone, go shopping, and visit restaurants if they choose to.

The construction cost of Hogeweyk was around $20 million, of which around two thirds was met by government and the remainder through community fundraising. The $7,000 monthly care fees for each resident are paid by the Dutch government social insurance scheme.

Hogeweyk demonstrates the potential for the physical environment to provide choice and control options to people with dementia, by giving them more freedom. Some aspects of the approach have been used in the UK, Germany and Australia, but the high financial outlays may inhibit a wider replication of this model.

Indicators of CDC

- Person-centred, goals-based assessment.
- Choice and control for residents.
- Person-centred care.

Sources:


The consultations conducted for this project identified a number of other considerations for consumers with special needs. The needs of three such groups were specifically explored:
- For people living with dementia, there may be a need for more tailored assistance or advocacy to articulate their preferences and to exercise choice and control. These consumers may also be more likely to have one or more family members actively involved in their care, which often helps in the identification of preferences and options but can also create additional administrative work for service providers – and can, in some cases, create challenges where family members do not agree.

- For people from Aboriginal and Torres Strait Islander backgrounds, there is likely to be a need for additional, culturally safe assistance to develop their capacity to engage with CDC and exercise choice and control (similar to the NSW initiative, Services Our Way, which aimed at developing the capacity of Aboriginal and Torres Strait islander consumers and communities to successfully engage with, and indeed to co-design, disability supports that meet their needs). Concepts of CDC are likely to be very different for these communities. In traditional communities, the importance of return to country will be paramount. For urban communities, the importance of residents being able to maintain strong, active and authentic links to their community and culture is emphasised.

- For people who identify as gay, lesbian, bisexual, transgender or intersex (GLBTI), the ability for people to be themselves, feel safe and be free from discrimination and victimisation in residential aged care homes are overriding concerns. CDC will be important in empowering GLBTI older people to speak for themselves and to make choices which suit their own needs.

Choice, in particular, is a critical aspect of the CDC approach for GLBTI older people – including choice of care and support staff and providers (staff who are accepting, providers who are inclusive and can provide an environment where a person feels safe and free from discrimination and where they can be themselves), choice of types of care and support, as well as choice about who they live with (to be free from discrimination from other residents). Where GLBTI consumers are empowered, are able to make choices and have some influence in the way that care and support is provided to them, this is likely to contribute to a more inclusive aged care sector.

Stakeholders also noted that GLBTI older people may need additional support during CDC planning processes – particularly given many GLBTI older people may not have family support (or choose not to involve their family) and that provider openness to allowing friends and GLBTI community organisations to support older people during the planning process is particularly important.

4.1 Evidence of benefit of CDC in residential care settings

Most literature describing CDC approaches comes from the US. Since the early 1990s, a number of groups such as Eden Alternative have offered aged care homes what are, essentially, ‘CDC models in a box’. In other words, they offer operational tools, training and support to reorient homes from management and provider-directed to person-centred, and towards consumer-direction. Several of these approaches have been evaluated, including a very small number of randomised control trials.

A 2008 meta-analysis of US evaluations of CDC in residential aged care (focussed on the ‘culture change’ movement) concluded that, while the evidence demonstrating the impact of such models is weak overall and primarily descriptive rather than evaluative, there is still some evidence of positive
improvements in resident, staff and organisational outcomes attributable to a CDC approach.\textsuperscript{73} It must be noted, however, that there is currently lack of standardised, validated tools for measuring CDC within the residential environment, which can make comparison and generalisation of findings difficult.\textsuperscript{74} A small number of tools have been developed to measure the extent to which choice is routinely offered to residents,\textsuperscript{75} or the scale to which is home is person-centred in its care delivery.\textsuperscript{76} 77

**Consumer benefits**

The evidence of consumer benefits from a CDC approach is mixed. A recent (2013) systematic review of research and person-centred and resident-directed approaches found improved satisfaction, psychological status of residents (lower rates of boredom, helplessness and depression), reduced behavioural and psychological symptoms of dementia, and increased family satisfaction.\textsuperscript{78} 79 80 81 82 Some comparison studies of homes using CDC approaches and traditional approaches have found little differences in resident mortality, cognition, nutrition, functional status, infection rates or cost of care.\textsuperscript{83} In other words, the *quality of clinical care* appears no different under a CDC or non-CDC model, but the *quality of life and wellbeing* may be higher.

\textsuperscript{73} Mueller, C. (2008) *Nurses’ involvement in culture change: Opportunity for improving residents’ quality of care and quality of life (funded by the Commonwealth Fund)*, Hartford Institute for Geriatric Nursing/New York University College of Nursing.

\textsuperscript{74} Ibid.


Provider and system benefits

A recent (2013) systematic review of research and person-centred and resident-directed approaches found positive associations with staff outcomes (satisfaction and capacity to provide individualised care). CDC approaches are also associated with increased staff retention.

Although some of the stakeholders consulted for this project were aware of (or, in some cases, had participated in) small scale trials of various aspects of CDC in residential aged care settings, which were usually focussed on improving choice and control for residents in one or two nominated areas, there was little evidence available from these activities at this time. Potentially, this lack of evidence of provider and system benefits of CDC contributes to wariness or resistance to CDC in the residential care sector.

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5. Challenges and enablers for CDC reorientation

This section draws on the findings from the literature review and consultations outlined in the previous sections to describe key challenges and barriers, as well as the key structural and practice enablers, for the process of reorienting residential aged care homes towards a CDC approach.

5.1 Challenges

There are many challenges and barriers to be considered in a reorientation to CDC in residential aged care. A 2007 project in the US to provide support for nine aged care facilities to reorient to person-centred practice found that only three of the sites were able to make significant practice changes; a further four made moderate change and the remaining two made no or minimal progress. The study identified existing culture and understanding of person-centeredness, the level of involvement of care staff in the culture change program, and management support and attention to sustainability of changes as key positive differentiators for the homes able to make significant change.

Conversely, a number of challenges and barriers were identified in the other homes that prevented or delayed reorientation: where managers and staff viewed the project as additional work and person-centred care was not a core established value of the organisation; where there was high turnover of staff and/or managers; and where there was poor follow through on decisions.87 This demonstrates the significant challenge of driving a reorientation to CDC in the residential aged care sector, and suggests the need for multi-pronged, staged approach to reform with a strong focus on cultural change.

The literature shows that, even where staff and managers want to be more person-centred, the realities of resource limitations (particularly staffing levels) can impede progress with reorientation.88 Staff perception of competing priorities (compliance with regulation, or enabling choice for residents), and a lack of ‘change champions’ to drive change are other key barriers to change.89 In some cases, staff believe they are already offering choice to residents, when in fact they are not offering genuine choice at all.90 A concern with statutory obligations such as the duty of care to residents is another barrier to enabling consumer choice and control that is common across the literature.91 92 93 These findings were supported by the consultations for this project, which suggests that a key consideration for reorientation to CDC will be attitudinal and cultural change processes.

Other specific challenges and barriers cited by stakeholders included:

• The current lack of a shared national vision, definition and strategy for CDC in the residential aged care setting.

• Concern about the timing of a reorientation to CDC in residential care and the risk of ‘reform fatigue’ by providers, given the substantial reform agenda already underway.

• Concern about the boundaries between consumer choice and control, and provider duty of care.

• Lack of clarity around the extent of choice and control that will/should/could be provided, and the potential impact of this on the residential aged care business model (i.e. will providers become unviable if the current ‘one-stop-shop’ for bundled accommodation, clinical care and hospitality/social services is dismantled, allowing consumers to purchase these elements from different providers with their ACFI funds and personal contributions?).

• Concern about the potential administrative burden of CDC, given the anecdotal experience of CDC implementation of home care has been that the administrative burden on providers has been considerably greater than anticipated.

• Questions around who is ‘the consumer’ where the resident and their family/nominated representative have differing wishes, and/or where the family members do not agree (this is particularly relevant for consumers with dementia or cognitive impairment).

• Questions around how to build the capacity of consumers (including those with special needs) and families/nominated representatives to engage with CDC.

• Inadequate attention to person-centred approaches and CDC principles in existing vocational training for the aged care workforce.

• Overcoming environmental challenges as most aged care homes have been traditionally been built in a cost-effective, institutional, quasi-hospital-like form that is not consistent with the home-like environment promoting independence, autonomy and freedom of movement that underpins the built form of better practice CDC approaches for residential care.

Several stakeholders suggested that the required cultural change processes for CDC reorientation could be assisted by greater information and knowledge sharing (i.e. identification and promotion of emerging good practice for CDC in Australia, and dissemination of evidence/results that emphasise the consumer benefits as well as the staff/provider/system benefits of adopting elements of a CDC approach).

5.2 Enablers

Key practice and structural enablers for CDC in residential aged care are summarised in the table below. These were initially identified from the literature, and then refined based on the project consultations.

It should be noted that this is a list of enablers that should be in place to support a reorientation to CDC; some or indeed many of these enablers may already be in place at an organisational level for a number of residential aged care providers. However, the enablers must exist at a system level to support reorientation to CDC. The enablers thus provide an indicator of system readiness to support a move towards CDC.
### Table 3: Key enablers for CDC in residential aged care

<table>
<thead>
<tr>
<th>Structural enablers</th>
<th>Related practice enablers</th>
</tr>
</thead>
<tbody>
<tr>
<td>Management and staff understand person-centred care and the CDC continuum</td>
<td>Management and staff understand where their practices currently sit on the continuum</td>
</tr>
<tr>
<td>Management and staff are provided with information and education to enable understanding and learning</td>
<td>Tools and support are available to help assess where homes are on the continuum</td>
</tr>
<tr>
<td>Staff have adequate time and ‘permission’ to provide participative person-centred care within a CDC ethos</td>
<td>Tools and support are available to help homes reorient towards consumer-direction</td>
</tr>
<tr>
<td>Governance and management commitment to reorientation of practice / embedding of person-centred values</td>
<td>Staff have positive attitudes towards CDC, skills/capacity to deliver participative person-centred care</td>
</tr>
<tr>
<td>Residents are enabled to exercise choice and control, with a clear underpinning safeguarding framework</td>
<td>Staff work with consumers/families to provide individualised, participative person-centred assessment and planning focused on choice and quality of life, balanced with their duty of care</td>
</tr>
<tr>
<td>Flexible daily care options are available to facilitate choice and control where possible</td>
<td></td>
</tr>
<tr>
<td>Consumers and families have access to information, education and independent support to maximise their capacity to exercise choice and control</td>
<td>Information is accessible to all consumers (including CALD, people with dementia)</td>
</tr>
<tr>
<td>Funding and service delivery is structured to maximise choice (this includes access to tailored ‘extra services’)</td>
<td>Independent planning advice and advocacy is available to all consumers</td>
</tr>
<tr>
<td>Funding structures and cost models support the flexible use of funds to permit a level of individual consumer control</td>
<td>Funding and costs of services are transparent to consumers</td>
</tr>
<tr>
<td></td>
<td>Consumers are assisted to develop individualised plans and to make choices</td>
</tr>
</tbody>
</table>

*Source: KPMG*
6. Conclusions

The available evidence suggests that a reorientation to CDC for residential to aged care would be consistent with contemporary international practice, and is generally supported by key aged care stakeholders. There is broad agreement on the key elements of CDC identified in this report.

However, there are currently a number of challenges and barriers to CDC reorientation. Primarily, there is a lack of a shared vision, definition and scope of CDC for residential aged care in Australia. This is compounded by inconsistent practice distinctions between person-centered approaches and CDC, a lack of knowledge and informed discussion about emerging CDC practice, and considerable cultural barriers within the sector and concerns about how to balance provider duty of care with enhanced consumer choice and control principles and apprehension about the possible impacts on current practice of an individual budget, if that were to form part of the reorientation to CDC.

Currently, there is no single ‘CDC model’ for residential care that could be implemented in an Australian context. It is suggested that reorientation to a CDC approach should be considered as a process to be developed over time, rather than a specific ‘model’ to be implemented.

The conclusion of this report is that a staged reorientation to CDC should be considered. This could involve the following stages:

• Firstly, developing a shared vision, definition and scope for CDC in residential aged care, which could inform a national development and implementation strategy;

• Secondly, addressing cultural barriers to CDC reorientation through a research and knowledge sharing agenda to identify, assess and promote emerging CDC practice in Australia, highlighting practical considerations as well as benefits for consumers, providers and staff;

• Thirdly, developing, assessing and comparing several provider-led trials of reorienting current services to incorporate elements of CDC. Initially, these need not be full ‘CDC models’ per se but should include various CDC elements such as implementation of goals-based planning, enhanced choice and control of care and services, and, possibly, some form of individual budget. This may also include some experiments with changes to the built environment to promote and enhance CDC.

• Finally, drawing on learnings from the development stages, a general CDC model of care could be developed and implemented across the sector.

6.1 Critical pre-conditions for moving to a CDC approach

Irrespective of the timing and staging of reorientation to CDC, there are some critical pre-conditions that need to be in place to support the reorientation. Drawing on the findings from the literature and consultations, this report proposes the following critical pre-conditions to support a reorientation towards CDC in residential aged care.

Pre-condition 1: System level settings support reorientation to CDC

Providers can reorient their current service models towards person-centred approaches now, under the current service system settings, and there is evidence that some aged care homes have done or are doing just that. However, there are a number of system level settings that need to be considered to support any kind of reorientation beyond person-centredness, towards CDC.
This includes:

- agreement on a definition of CDC that is relevant to and implementable by aged care homes – this is likely to be at least slightly modified from the definition now being applied in home care;
- agreement on the scope of CDC in residential aged care, and whether there are some care types and services that will be defined as ‘core’ that consumers could not trade off;
- resolution of the perceived ‘regulatory compliance versus consumer choice’ conflict that providers consider impedes the facilitation of meaningful choice and control by residents – this includes resolving how providers will balance their duty of care with the ‘dignity of risk’ inherent in allowing consumers to make their own choices about care and services;
- potentially adjusting the current funding settings so that care and hospitality services can be individually costed in ACFI funding (allowing for transparent reporting of costs to consumers, which will then facilitate their ability to make choices);
- clarity around how additional care and services will be funded under a CDC model; and
- identifying and promoting emerging good practice for CDC in residential aged care, including description of the benefits of CDC (to providers and staff as well as consumers and families).

Pre-condition 2: Providers understand and support the CDC continuum

Once the system level settings are in place, there will be a need for clarity among providers about what the CDC continuum is and an understanding of person-centred practices. This is identified as one of the key enablers for CDC, but it is also arguably a pre-condition for reorienting towards CDC. It is not currently clear how many homes understand and/or apply person-centred approaches or CDC, nor the level of self-awareness that homes have about where they currently sit along this continuum and what would be required of them to change practice.

Pre-condition 3: Planning for reorientation

Reorienting aged care homes towards consumer-direction is a significant change to existing service models and practices, which have developed in response to the current market demands and the current funding and policy settings by government. It will take time and planning to reorient homes towards consumer-direction, and this will need to occur well before implementation of any kind of ‘CDC model of care’. These are linked to the CDC enablers and include:

- helping providers to self-assess their current readiness for reorientation;
- training and capacity building for management and staff in person-centred practice and CDC;
- clear guidelines on the application and parameters (if any) of CDC in residential aged care;
- development of ‘models of care’ to operationalise CDC;
- development of specific approaches, if needed, to provide CDC for people from special needs groups and people with dementia;
- development of tools – preferably standardised – to measure readiness and monitor progress on reorientation at the home level (i.e. resident health and quality of life, resident satisfaction and wellbeing, staff satisfaction and capacity); and
- supporting changes to the traditional built form of aged care homes to promote the development of more ‘home-like’ settings consistent with CDC practice.
A. Semi-structured interview guide

Introduction

KPMG has been engaged by the Department of Social Services to undertake research on the applicability of consumer-directed care (CDC) principles in residential aged care.

Our research has identified the key elements of CDC:

- Greater choice and control for consumers about the types of care and services accessed compared to a traditional provider-directed approach;
- Greater choice and control for consumers about who delivers care and services, and when, compared to a traditional provider-directed approach;
- Active application of participative person-centred and/or goals-based approaches to assessment and planning, which may include independence, wellness and re-ablement goals that are meaningful to consumers; and
- Transparency to consumers about how services are funded, which may include elements of individualised funding or an individualised budget for some consumers.

We are talking to 15 stakeholders to gain further insight and understanding about the applicability of CDC principles in residential aged care. The interview will take about an hour.

Do you have any questions before we begin?

Questions

1. Briefly, how would you describe your organisation’s experience with or interest in CDC?

2. Thinking about what CDC means, would you agree with the key elements identified above? Is there anything you would change or add to this list?

3. Generally, do you think that these elements should or could apply to residential aged care? Why or why not? Are some more relevant than others?

4. What do you think needs to change so that aged care residents can exercise choice and control over their care?
   - Consider choice and control over daily routines, access to extra services, activities, individual budgets
   - Consider practice changes, staff and management attitudes, funding and regulatory structures

5. What would be the key benefits from adopting a CDC approach in residential aged care homes? Do you think these benefits be measured?
   - Consider benefits to residents, families, management, staff, the aged care system

6. What would be the main barriers or challenges to adopting a CDC approach in residential aged care homes? What would need to happen to overcome those barriers?
   - Consider benefits to residents, families, management, staff, the aged care system
   - Consider training and education, funding, service models
7. Are you aware of any current examples of CDC in a residential aged care or similar setting? If yes, what makes it CDC? Does it align to some or all of the indicators above?

8. Do you have any other comments?
B. References


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