This is the published version:

Ottman, Goetz, Laragy, Carmel, Allen, Jacqui and Feldman, Peter 2011, *People at centre stage: interim report : development phase*, Uniting Care Community Options / Deakin University, Melbourne, VIC.

Available from Deakin Research Online:

[http://hdl.handle.net/10536/DRO/DU:30041066](http://hdl.handle.net/10536/DRO/DU:30041066)

Reproduced with the kind permission of the copyright owner.

**Copyright**: 2011, Uniting Care Community Options / Deakin University, Melbourne
November 2011

People at Centre Stage: Interim Report

Development Phase

Goetz Ottmann (PhD)
Carmel Laragy (PhD)
Jacqui Allen (RN, M Psych)
Peter Feldman (M H Prog. Eval.)

Uniting Care Community Options
Deakin University
Aims of the Interim Report:

The key objective of this report is to provide a summary of the findings derived from each step underpinning the Development Phase (Phase One) of the People at Centre Stage (PACS) project. It explains how individual program features of the PACS project were derived and developed, leading to the design of a final model. An overview of this model is provided.

Suggested Citation:
TABLE OF CONTENTS

<table>
<thead>
<tr>
<th>Section</th>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td>TABLES AND CHARTS</td>
<td>iv</td>
</tr>
<tr>
<td>Project Partners</td>
<td>v</td>
</tr>
<tr>
<td>EXECUTIVE SUMMARY</td>
<td>1</td>
</tr>
<tr>
<td>INTRODUCTION</td>
<td>4</td>
</tr>
<tr>
<td>APPROACH &amp; METHODOLOGY</td>
<td>6</td>
</tr>
<tr>
<td>Governance &amp; Project Management</td>
<td>6</td>
</tr>
<tr>
<td>Three Phases</td>
<td>7</td>
</tr>
<tr>
<td>Phase One: Model Development</td>
<td>7</td>
</tr>
<tr>
<td>User and Carers Group 1</td>
<td>10</td>
</tr>
<tr>
<td>User and Carer Group 2</td>
<td>12</td>
</tr>
<tr>
<td>The Service Provider Group</td>
<td>13</td>
</tr>
<tr>
<td>The Advisory Group</td>
<td>13</td>
</tr>
<tr>
<td>OUTCOMES:</td>
<td>15</td>
</tr>
<tr>
<td>1. Literature Review</td>
<td>15</td>
</tr>
<tr>
<td>2. Focus Groups</td>
<td>19</td>
</tr>
<tr>
<td>3. User and Carer Groups</td>
<td>25</td>
</tr>
<tr>
<td>4. Service Provider Group</td>
<td>31</td>
</tr>
<tr>
<td>5. Advisory Group</td>
<td>33</td>
</tr>
<tr>
<td>The PACS Model</td>
<td>34</td>
</tr>
<tr>
<td>References:</td>
<td>39</td>
</tr>
</tbody>
</table>
TABLES AND CHARTS

Charts

Figure 1: Overview of Research ................................................................. 7
Figure 2: Overview of Research Steps – Phase 1 ........................................... 8
Figure 3: PACS Assisted Independence Model - Overview ............................. 37

Tables

Table 1: Date and Participant Details of Focus Group Sessions ....................... 9
Table 2: Demographic Overview of UCG1 Participants ................................. 11
Table 3: Focus Group Themes: Overview .................................................... 19
Table 4: User and Carer Working Group 1: Overview of Findings ................. 26
Funding Partners:
Australian Research Council
Helen Macpherson Smith Trust
Percy Baxter Charitable Trust
B. B. Hutchings Bequest
John William Fleming Trust

Project Partners:
Uniting Care Community Options
Deakin University
Brotherhood of St Laurence
Uniting Aged Care (Strathdon, Trewint, St. Albans)
Uniting Care Ageing, New South Wales
Carers Australia Victoria
Alzheimer's Australia, Victoria
Council on the Ageing (COTA)
EXECUTIVE SUMMARY

The People at Centre Stage (PACS) project aims to develop, implement and evaluate an innovative community aged care model that offers (a) greater degree of integration with the wider care system, (b) provides care recipients with case management to maximize clinical outcomes preventing unnecessary institutionalization and hospital use, and (c) gives care recipients the option to have as much control of their own care as they aspire to and feel comfortable with. Hence, the PACS model is a hybrid community care model bringing together elements of integrated care, case management, and consumer-directed care (CDC). The PACS model aims to assist participants to maintain/build their health, strengthen their capabilities and enable their preferred level of independence. It is specifically designed for people with complex care needs and places great emphasis on capacity building.

This interim report documents the process and evidence used to develop the PACS model during the development phase (Phase One) (January 2009 to March 2010). Phase One consisted of a systematic literature review, interviews with six focus groups involving carers, and a 12-month-long action research project involving three working groups made up of service users, carers and service providers, as well as government and peak body representatives. The findings from Phase One informed the development of the PACS model which will be evaluated in later phases. The key findings from the development phase were:

1. Older people with complex care needs want greater flexibility and independence regarding their aged care packages.
2. Older people want a continuum of options so that they can choose any combination from full case management to fully planning and managing their own care.
3. Older people with complex care needs value case management and do not want to lose this option if they accept some CDC responsibilities.
4. Many older people do not want to be responsible for the financial and administrative tasks associated with their care (e.g. employing staff, procuring services, and accounting for expenses).
5. When exploring CDC options, case managers should assist older people to explore their interests, set goals and priorities, and develop independence as much as possible.

6. CDC should not be offered during times of crisis. When care recipients face a crisis point, the care should revert to full case management or an option pre-determined by the person.

7. In recognition of their fluctuating health conditions and changing circumstances, older people require shorter review cycles than those used for younger adults with disabilities.

8. Mentoring by case managers should be available to older people who choose to self-direct their planning and care arrangements.

9. Many older people and carers want to know their funding allocation and other entitlements. They want clear information and regular financial statements that outline how their resources are being spent. However, some older people find it difficult to comprehend the financial statements and may require assistance.

10. Self-directed structures should be simple and require a minimum of paper work for participants.

11. Older people participating in CDC programs, including those who are socially isolated, should be aided by professionals to create the necessary safeguards and support structures.

12. Older people with complex needs and their carers regard restorative and health maintenance activities as a crucial part of their care.

13. The Australian community aged care system remains difficult to navigate for older people and their carers. Older people require simple, clear information about their options and responsibilities.

14. In order to ensure a smooth functioning of a community care system that brings together the above features, better communication between health, case management, and home/personal care services is required.

The PACS model resulting from the development phase is designed to (a) encourage inter-professional collaboration, (b) maintain or restore health and social engagement, and c)
enable older people and their carers to make informed choices about the care they receive. It will offer them the opportunity to influence and shape their care arrangements at all stages. The model will present older people and their carers with a range of CDC options. It is expected that CDC will begin at a relatively low level with participants taking some responsibility for the development of their care plan. As they become more comfortable dealing with the aged care system, they may assume care coordination responsibilities. At the highest level of CDC, participants may opt to take on responsibilities for administrative and bookkeeping tasks. Participants will be under no obligation to take on all responsibilities associated with a particular level of CDC but may opt to self-direct certain tasks and not others. Case management support is available at all levels of CDC.

Older people and carers participating in Phase One anticipated that numerous CDC and other features would be attractive:

- the opportunity to contact care attendants (home/personal care workers) and service providers directly without having to draw on their case manager;
- involvement in the decision-making process underpinning the employment, training, and deployment of home and personal care workers;
- the ability to utilise their packages more flexibly (i.e. to pay for minor services such as gardening, taxi services, or therapeutic massages) without having to involve a case manager);
- having access to a percentage of their package in the form of a fund (debit card) they could draw on to pay for minor items and services such as taxi fares, a therapeutic massage, or a gardening service; and
- having access to a case manager when needed.
- the option to work with community care professionals on restorative or health maintenance activities identified through motivational goal setting (carers found this particularly attractive).
INTRODUCTION

The People at Centre Stage (PACS) project aimed to develop a flexible and responsive, yet safe, community aged care model that empowers and enables older people and their carers to shape and direct the services they receive. Its ultimate aim is for participants, assisted by formal and informal supports, to arrive at the maximum level of independence they aspire to. It emerged over the course of the project that participants wanted health maintenance, case management and to self-direct some of their support services.

The PACS project has its origins in the Victorian Community Care Coalition (VCCC). The VCCC was established in 2003 by a group of community care service providers and peak organisations with the aim of improving the quality of the Australian community aged care system. It commissioned two reports (1, 2) that highlighted a number of major shortcomings of this system. These included:

- The aged care service provision model was extremely complex, making it difficult for lay people to access the services they needed and were entitled to.
- There was no single access point and there were funding gaps throughout the caring pathways.
- The aged care system was unresponsive to transitions in people’s lives and/or illness trajectory.
- Collaboration between the formal/health and informal/social care sector was poor.
- The needs of some care recipients were not sufficiently addressed by service programs resulting in poor quality of care as well as resource wastage.

The reports featured a number of strategies to address these issues and CDC was featured among them (2).

CDC is an approach to community care, which gives greater control over the allocated funds to service users or their representatives. Funds can be used more flexibly to meet the user’s needs and services, and equipment can be purchased either directly in the market place or through established social service agencies. CDC programs vary in their design and there are numerous ways of assessing needs, allocating funds and providing support, but the common
aim is to give the service user greater control and choice. In general there is less reliance on case managers. It is important to point out that the Australian legislative context restricts CDC. In Australia, community care funding goes to the service provider and not the individual. Consequently funds cannot be moved between providers and are not ‘portable’. It is within these constraints that the PACS model aims to maximise participant control.

To develop the PACS model, the PACS research team interwove several strands of evidence including a systematically-conducted literature review. The values and preferences of service users and their carers, as well as the expertise and perspectives of community aged care professionals were collated. In addition, the PACS team invited the views of service provider agencies, peak bodies, and government representatives in order to take into account resource, legislative, and operational issues and constraints. Therefore, the design of the PACS model ensured the views of service users, carers and providers, as well as government and peak body representatives were taken into consideration. Further, the major design features were tested and appraised by some service users before they became part of the model for trial. The program features had to display a ‘goodness of fit’ with the needs and preferences of service users before they were included in the PACS model.
The method underpinning the project was developed collaboratively with representatives from four stakeholder organisations (Uniting Care Community Options - UCCO, Alzheimer’s Australia Victoria, Carers Vic, and the Council on the Ageing - COTA). From the outset, representatives agreed that the project would involve the entire spectrum of stakeholders, including older people with complex care needs, carers, aged care broker organisations, aged care service providers (home care, community nursing, and community health), older people’s advocacy organisations, aged care industry peak bodies, aged care assessment organisations, as well as local, state, and federal government representatives. Importantly, older people using the services and their carers were central to the project and were involved directly in the development of the PACS model. It was agreed that an action research framework (the coproduction approach mentioned below) would guide the development phase of the project. Ethics approval was obtained from Deakin University and RMIT University.

Governance & Project Management

Representatives of the original partner organisations (UCCO, Brotherhood of St Lawrence (BSL), Uniting Aged Care (UAC) Strathdon, Alzheimer’s Australia Vic, Carers Vic, COTA) formed a Steering Committee. This committee oversaw the development of the PACS model and provided ongoing consultation. The Project Manager coordinated the development phase and was a member of the Research Team. The Research team conducted the literature review that further contributed to the model’s development. Financial governance (disbursing and accounting) was provided by Uniting Care Community Options and Deakin University.

Program Logic (PL), a project management system, helped to structure the model’s development by providing a framework for the action research process. PL has been used effectively in the development and evaluation of community-based health programs (3) (4).
Three Phases

The project is structured in three phases. Following Phase 1 (the development phase), Phase 2 will pilot and implement the PACS model at three sites using iterative, formative cycles. Each cycle will invite feedback from participants which will be analysed and integrated into the next cycle. Phase 3 will consist of a mixed method evaluation that will appraise the viewpoints and experiences of users, carers, and managers at the core partner organisations. Figure 1 provides an overview of the three phases underpinning this research project. Phases 2 and 3 will be presented in separate reports.

Figure 1: Overview of Research Phases

Phase One: Model Development

The PACS model was developed using a 'coproduction' approach. Coproduction, a form of action research used within a policy making context, has become synonymous with innovative approaches to public service delivery in Australia and European Union countries.
Coproduction is premised on the insight that the involvement of consumers in the design and implementation of public services has the potential to improve the quality and responsiveness of public services (10), increase the effectiveness of services and reduce public spending (11), and strengthen and invigorate citizenship, social capital, and democracy (12).

The development of the PACS model involved three steps: literature review, five focus groups and four working groups (two Users and Carers Groups, one Service Provider Group and one Advisory Group). These are presented diagrammatically in Figure 2.

**Figure 2: Overview of Research Steps - Phase 1**

![Diagram](image)

**Step 1:**
In Step one, the literature was methodically reviewed and appraised (13) providing a solid research evidence base. A total of 277 relevant articles related to consumer-directed
services were identified and sourced. Of these, 39 articles satisfied the inclusion criteria. The literature was appraised and the study design features were coded according to criteria for evaluation designs (14, 15). These included: reporting of study aims and ethics approvals, fit between methods, data analysis and the aims of the study, identification of limitations to study findings and interpretation of results in practice/policy contexts. Characteristics of the CDC programs/models were also captured in this protocol. The summary of study findings included the study aims, methods, recruitment and sample, outcome findings, implications for model development and level of evidence. Data analysis involved application of the evaluation protocol to the inclusion of studies and coding of quantitative and qualitative findings on the variables of interest. These findings (data) were tabulated for ease of presentation. Publications were evaluated by three reviewers with discrepancies resolved by a process of peer moderation. Quantitative data were not statistically pooled due to the use of variable measures created by the respective evaluation teams to capture outcomes from a diverse range of CDC programs.

Step 2:
Step two included five focus group sessions conducted between February and May 2009. Four of these sessions involved members of already established Carers Australia, Victoria support groups comprising primary carers for older people with dementia, multiple sclerosis or psychiatric disorders. One further focus group was recruited during the launch of the PACS project in March 2009 and included older people and carers of various backgrounds. During the launch, the researchers invited all older people and carers to participate in this focus group. A total of 44 individuals participated in the discussions. Of these, three individuals participated in two meetings. Approximately sixty per cent of participants were female. All focus group sessions followed a set protocol. Focus groups were tape recorded and transcribed. Informed written consent was gathered from participants following explanation of the project in a Plain Language Statement. Participation details in regard to the five focus groups are summarised in Table 1 below.

Table 1: Date and Participant Details of Focus Group Sessions

<table>
<thead>
<tr>
<th>Date of session</th>
<th>Group</th>
<th>Number of Participants</th>
</tr>
</thead>
<tbody>
<tr>
<td>23 Feb</td>
<td>Carers for people with</td>
<td>7</td>
</tr>
</tbody>
</table>


Step 3:

Step three involved the formation and running of four working groups: two service User and Carer Groups (UCG1 and UCG2), a service Provider Group (PG), and an Advisory Group (AG) comprised of industry and government representatives. Findings from the literature review and the focus groups guided the agenda and discussions in these four working groups. The aim of UCGs 1 and 2 was to identify major gaps and shortcomings in the way care services were provided, indicate preferences for CDC program features, and collaborate with the researchers in developing a flexible model of community aged care designed to meet the needs and preferences of older people. The aims of the PG and the AG were to identify model implementation issues as well as constraints, and consider solutions to systemic and legislative barriers.

User and Carers Group 1

The service User and Carers Group (UCG1) met on 15 occasions over 2009-2010. It was initially composed of 8 older people with complex care needs aged 59 to 88 years, and 6 carers aged 35 to 75 years. Seven service users and five carers attended meetings regularly. Two participants died during the course of the year. UCG1 included older people of Slavic origin, first generation Italian and Sri Lankan immigrants, and people of Anglo-Celtic descent. The group consisted of middle class professionals and people from lower socio-economic backgrounds. Table 2 provides an overview of the demographic characteristics of UCG1 participants.

<table>
<thead>
<tr>
<th>2009</th>
<th>dementia</th>
<th>2009</th>
<th>PACS launch (mixed group of carers, aged care package recipients, interested elders, and reps from advocacy groups)</th>
<th>13</th>
</tr>
</thead>
<tbody>
<tr>
<td>4 March 2009</td>
<td></td>
<td>18 Mar 2009</td>
<td>Carers for aged partners with psychological disorders</td>
<td>8</td>
</tr>
<tr>
<td>6 May 2009</td>
<td>MS carers group</td>
<td>8 May 2009</td>
<td>FG1 &amp; FG2</td>
<td>9</td>
</tr>
</tbody>
</table>

Location of Sessions: Melbourne’s Inner Eastern Region

Table 2: Demographic Overview of UCG1 Participants

<table>
<thead>
<tr>
<th>Gender</th>
<th>Ethnicity</th>
<th>Illness and severity</th>
<th>Package type</th>
<th>Support received</th>
</tr>
</thead>
<tbody>
<tr>
<td>Gender</td>
<td>Ethnicity</td>
<td>Diagnosis and Health Care Details</td>
<td>Service Provider</td>
<td>Transport Assistance</td>
</tr>
<tr>
<td>--------</td>
<td>-----------</td>
<td>-----------------------------------</td>
<td>-----------------</td>
<td>---------------------</td>
</tr>
<tr>
<td>F</td>
<td>Russian</td>
<td>Severe heart disease, poor mobility due to spinal injury</td>
<td>CACP</td>
<td>Home care &amp; transport</td>
</tr>
<tr>
<td>M</td>
<td>Hungarian</td>
<td>Severe stress, high blood pressure, heart disease</td>
<td>CACP (deceased August 2009)</td>
<td>Home care, respite &amp; transport</td>
</tr>
<tr>
<td>F</td>
<td>Anglo-Celtic</td>
<td>N/A is primary carer</td>
<td>CRCC (husband deceased Oct 2009)</td>
<td>Respite</td>
</tr>
<tr>
<td>M</td>
<td>Anglo-Celtic</td>
<td>N/A is primary carer</td>
<td>CRCC</td>
<td>Respite</td>
</tr>
<tr>
<td>M</td>
<td>Anglo-Celtic</td>
<td>Cancer, stroke, heart problems</td>
<td>Linkages</td>
<td>Home care &amp; transport</td>
</tr>
<tr>
<td>M</td>
<td>Anglo-Celtic</td>
<td>Osteoarthritis, stroke</td>
<td>CACPS</td>
<td>Personal care, home care &amp; transport</td>
</tr>
<tr>
<td>F</td>
<td>Anglo-Celtic</td>
<td>Parkinson’s, cancer, high blood pressure, survivor, extreme frailty</td>
<td>EACH</td>
<td>Personal care, meals, transport &amp; allied health</td>
</tr>
<tr>
<td>F</td>
<td>Anglo-Celtic</td>
<td>Severe emphysema, high blood pressure, osteoporosis</td>
<td>Linkages (now in residential care)</td>
<td>Home care &amp; transport</td>
</tr>
<tr>
<td>F</td>
<td>Polish</td>
<td>Severe osteoarthritis</td>
<td>CACP</td>
<td>Home care, transport &amp; gardening</td>
</tr>
<tr>
<td>F</td>
<td>Sri Lankan</td>
<td>Severe osteoarthritis</td>
<td>CACP (now Linkages as at April 2010)</td>
<td>Personal care, home care &amp; transport</td>
</tr>
<tr>
<td>F</td>
<td>Anglo-Celtic</td>
<td>N/A is primary carer</td>
<td>CRCC</td>
<td>Respite</td>
</tr>
<tr>
<td>M</td>
<td>Anglo-Celtic</td>
<td>N/A is primary carer</td>
<td>CRCC</td>
<td>Respite</td>
</tr>
<tr>
<td>F</td>
<td>Anglo-Celtic</td>
<td>N/A paid carer</td>
<td>N/A</td>
<td>N/A</td>
</tr>
</tbody>
</table>

Criteria for inclusion in UGC1 were the ability to attend face-to-face meetings, converse in the English language and/or have access to a carer able to interpret, and an interest in participating in a consumer-directed care project.

Participants were recruited through UCCO case managers. The case managers introduced the project using a Plain Language Statement. Case managers invited care recipients to participate in the development of the model. With the client’s permission, the Case Manager forwarded their contact details to the research team. The research team, subsequently, contacted the client and formally invited them to participate in the Users’ and Carers’ group. The PLS and consent form were discussed in detail during the first meeting between the client and research team ensuring that UGC1 members understood the implications of participation. Signed consent forms were collected at that point.
The UCG1 sessions encouraged participants to:

1. imagine a new social care system that could address the needs of older people,
2. identify how the care older people received could be improved,
3. reflect on proposed solutions to the issues identified from the literature,
4. indicate their preferences and needs regarding CDC program features, and
5. evaluate a suite of service provision tools and processes.

Participants were given an overview of ‘traditional case management’ and an example of CDC models at the outset of the meetings. Practical, everyday examples were given over the course of meetings to demonstrate the utility of CDC and to provide group members with a concrete context for the discussions. Subsequent group discussions also recorded the needs and preferences of the participants regarding CDC.

User and Carer Group 2
During the second half of 2009 a second UCG (UCG2) was formed in order to augment the research findings derived from UCG1. The second UCG provided responses from an older client group receiving services through a different aged care provider agency - Uniting Aged Care Strathdon (UACS). Unlike the agency providing brokered services to UCG1 members, UACS directly employed home care workers. The recruitment process for UCG2 was the same as for UCG1 and informed consent was obtained from all participants. A total of five older women participated in UCG2. UCG2 participants were all of Anglo-Celtic descent and were approximately 10 years older than UCG1 members. The group met on five occasions. Group members were presented with the key issues raised with UCG1. Responses were recorded and compared with those of UCG1. The responses gathered from the UCG 2 coincided in all major points with those of the UCG 1, albeit participants were less interested in the self-direction of administrative and financial tasks. As the needs and preferences stated by UCG 2 members were similar to those voiced by the UCG 1 outcomes of UCG 2 are not reported in detail.
The Service Provider Group:
The Service Provider Group (PG) met on six occasions. A letter of invitation was sent by the researchers to the 11 service providers with a large share of home care contracts in Melbourne's eastern region and an interest in CDC. In addition, representatives of assessment and community care nursing services were invited to participate in the PG. In order to be eligible for participation, service provider agencies needed to agree to participate in monthly meetings over 2009-2010. Thirteen organisations representing local government aged care branches, private sector and not-for-profit homecare providers, a community nursing agency, and a representative of the state's aged care assessment team agreed to participate. Of these, three agency representatives transferred into the Advisory Group after 3 meetings. In addition, one UCCO staff member representing broker organisations attended the meetings. Informed consent was obtained during the first meeting.

The Advisory Group
The Advisory Group (AG) met on three occasions. Participants were selected with advice from UCCO staff. The researchers sent a letter of invitation to key industry peak bodies, advocacy organisations, as well as local, state, and federal government agencies with an interest in consumer-directed service delivery in Melbourne's inner east. Representatives from 14 organisations representing all of the above sent representatives. The Federal government declined to attend meetings due to a perceived conflict of interest. Informed consent was obtained during the first meeting.

Procedures:
Between February 2009 and February 2010, problems associated with service provision and associated systems' issues identified by the UCG1 were presented to the other two working groups (PG, AG) to consider solutions. The proposed solutions developed by the PG and AG were presented back to the UCG1 by the research team for comment and appraisal. In addition, the research team embarked on a lengthy negotiation process with the partner organisations that were to implement the project. The negotiations focused on how program features evolving from discussion between UCG1, the PG and AG could be
implemented. The information obtained from the above meetings informed the development of a draft service model, guidelines, and operational forms. Operational forms were developed in collaboration with case managers from the three participating agencies. The draft model and its operational forms were pilot tested with members of the UCG1 and a group of volunteer case managers employed by all three implementing agencies. Their comments and suggestions shaped the final draft service model.

Data Collection:
Data were collected between January 2009 and March 2010. The focus groups, User and Carers' Groups and Service Provider Group were audio recorded and transcribed. Detailed minutes were kept of each User and Carers' Groups, Service Provider Group, and Advisory Group meeting and sent to group participants for reflection and comment. Additionally, group facilitators for each of these groups observed group interaction and recorded field notes during each meeting.

Data Analysis:
User and Carers' Groups, Service Provider Group, and Advisory Group data transcripts, facilitator field notes and meeting minutes were thematically analysed. A hybrid approach of inductive and deductive coding and theme development integrating data- and theory-driven codes was used to interpret raw data (16). Whereas insights derived from the research literature provided a starting point for the development of the codes, initial code categories were reshaped in light of the data generated. In other words, code categories were not derived organically from the 'ground up' drawing exclusively on field work materials but were, at least initially, shaped by our knowledge of the research literature.
OUTCOMES:

1. Literature Review

Consumer-directed care (CDC) has its origins in the United States (US) and Canada in the disability-rights and independent living movements of the 1970s (17). The first CDC-inspired programs were piloted in the mid-1970s. As participants were allowed to hold the funds and spend them in the open market, programs can be defined as Consumer Directed Care (CDC). The CDC approach gained momentum among participants and service providers during the 1980s and expanded in the 1990s. From the mid-1990s onward, evidence highlighting the benefits of CDC programs began to mount. Numerous studies suggested that CDC in community based aged and disability care resulted in increased consumer satisfaction, quality of life, control and independence in conjunction with lower costs (18-30). Such findings proved attractive to governments in most developed countries. Over the last decade, CDC has become an integral part of a menu of service options in North America, Europe (29, 31-39) and Japan. CDC programs differ significantly between countries, states, and even municipalities. In this report we provide a brief overview of the reviewed literature from the US and the United Kingdom (UK). For a detailed account of how we appraised the literature and established levels of evidence, see Ottmann et al. (13). A copy of the full report (13) can be downloaded from the following website address: https://sites.google.com/site/pacsprojectsite/.

Most of the reviewed literature (40-76) focuses on Cash-for-Care schemes. Cash-for-Care schemes typically involve the provision of cash payments or vouchers to enable care recipients to purchase their own care instead of receiving in-kind help at home (77 in Arksey 2008). It is not clear if the Cash-for-Care programs provide the choice that resonates with the preferences of many older people because, with the exception of Cash-for-Care schemes in California and Washington, programs were primarily aimed at and designed for people with disabilities. There is a gap between older people's expressed interest in Cash-for-Care projects and those actually participating in these initiatives. For instance, whereas approximately 35% of surveyed older US citizens expressed interest in cash-for-care schemes, less than 8% actually enrolled in such programs (59, 78) and attrition was
common. Participation in CDC schemes implemented in the UK was uneven and tended to be better in areas where authorities followed person-centred care principles (49). In 2004/05 less than 1% of people aged 65 or older were enrolled in a CDC scheme. This increased to approximately 2.6% in 2007/08 (79).

Older people who did enrol in Cash-for-Care schemes tended to be satisfied with their care outcomes. Most research indicates that Cash-for-Care programs generate either similar or better outcomes, especially in the domains of service satisfaction and self-determination, with marginal detectable increase in risk, when compared with traditional agency-directed services (Ottmann et al 2009). The research also indicates that positive outcomes are directly linked to appropriate user supports. Care recipients who hired family members as carers reported extra benefits in terms of safety and service satisfaction. However, it is not clear how these arrangements influence the wellbeing of the paid family members, apart from providing extra income.

CDC was found to have some positive impacts for informal carers who were not employed (Ottmann et al 2009). However, it is important to point out that Cash-for-Care schemes do not automatically reduce the overall caregiver burden. Carer burden is related to available hours of paid care assistance (Ottmann et al 2009). Only adequate levels of funding and better incentives for paid carers to enter the labour market in conjunction with other programmatic and structural changes can ensure better outcomes for care recipients and carers. The relative expense of running a Cash-for-Care program compared with the traditional agency-directed approach appears to be cost neutral, although findings are contradictory and this area is still being investigated.

The following key recommendations were derived from the literature review (Ottmann et al 2009):

1. Program Implementation:
   - CDC programs should have a system-wide focus and address systemic, educational, and cultural concerns as well as community involvement issues. The successful implementation of CDC is dependent upon:
• Well-designed and clear policies on risk management, duty of care, and client review procedures that balance agency and worker responsibilities with the self-determination aspirations of their program and its participants;
• Extensive and thorough staff training and organisational change management prior to implementation addressing ageism in professional culture and concerns of aged care professionals regarding abuse, neglect, fraud, exploitation, contractual agreements, as well as the capacity of older people; and realistic workload assessments.

- A programmatic review and continuous improvement process should be in place to improve care outcomes.

2. Case Management Approach:
- Organisations provide holistic, single-point-of-contact, family-focused case management services. Good practice case management is based on:
  • An authentically implemented culture of person-centred care and planning;
  • An ongoing and mutually respectful relationship;
  • The principle that case managers are facilitators and the care recipients and their families have control and make decisions; and
  • A cooperative approach including the interests of informal carers and families.

3. Consumer-Directed Care Program Design:
Older people want to greater control over their care arrangements, however many do not want the added responsibility and paperwork associated with budgeting and procuring services.

1. The overall program structure needs to be simple requiring a minimum of paper work.
2. Eligibility criteria should include and enable older people rather than exclude them from CDC.
   • Age and mental health status are not in themselves sufficient criteria for inclusion or exclusion from CDC.
Eligibility should be regarded as a process during which program participants, aided by social care professionals, construct the necessary safeguards and support structures to enable them to direct their own care arrangements.

3. CDC should not be offered during times of crisis.

4. In recognition of their fluctuating health conditions and changing circumstances, older people:
   - Should be able to move between CDC and full case management as needed and or preferred;
   - Require shorter review cycles than those used for younger adults with disabilities.

5. Older people should be able to choose from a menu of service options ranging from agency-led case management services to fully self-directed consumer-directed care services.

6. Case managers should explore the interests and perspectives of potential participants encouraging older people to set goals and implement them through self-direction where appropriate.

7. Participants should receive simple, clear information to help them understand their program options and responsibilities and to help them develop and implement their care plan.
   - Agency staff should use applied examples when providing information. Case managers should check, not assume, that information has been understood.
   - Where participants are to take over care coordination functions, or contractual and financial responsibilities, they must receive full training and support in these activities and there must be regular monitoring.

8. Older people and especially more frail, socially isolated elders should have access to adequate safeguards.
   An enabling risk management process is necessary to balance the client's risk and protective factors and determine appropriate social supports.
   - A 'circle of support' program as well as peer and volunteer support should be considered when care recipients prefer less agency involvement.
9. The employment of friends and family members should be a possible option. Safeguards have to be in place to assist care recipients to manage such employment relationships.

2. Focus Groups

The focus group sessions aimed to gather attitudes towards CDC in community aged care from a cross-section of Melbourne’s population. They represented an attempt to include people from different geographic locations across Melbourne as well as different socio-economic and ethnic backgrounds. It was expected that findings from these focus groups would inform, balance, and strengthen the findings derived from the UCGs. Initially, the focus groups were designed to include both older people with complex needs as well as carers and participants were members of already established support groups coordinated by Carers Vic. Although they included older people with chronic health issues, the majority of participants were carers of chronically ill people. One focus group including older people and carers was held in conjunction with the official launch of the PACS project. The focus group sessions resulted in an overview of how carers experienced the community aged care system. Participants delivered an account of the confusion they experienced before entering the system, their relief after an Aged Care Assessment Service (ACAS) assessment, their appreciation when they received services, their ambivalence in response to the gaps in services provided, and the lack of financial transparency and confusion regarding their entitlements. Table 3 presents an overview of focus group themes and sub-themes.

Table 3: Focus Group Themes: Overview

<table>
<thead>
<tr>
<th>Theme</th>
<th>Sub-theme</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Complexity &amp; Lack of</td>
<td>• The functioning of the Australian community aged care system is confusing and difficult to understand for older service users.</td>
</tr>
<tr>
<td>Information</td>
<td>• People entering the aged care system are unaware of the support they are eligible for and how to receive it.</td>
</tr>
<tr>
<td></td>
<td>• Lack of information about the system and individual entitlements</td>
</tr>
<tr>
<td>2. Relief &amp; Gratitude</td>
<td>• After a crisis event and the significant insecurities associated with it, care recipients are relieved and thankful for the certainty and support that aged care professionals provide.</td>
</tr>
<tr>
<td></td>
<td>• Case managers help care recipients navigate the aged care system.</td>
</tr>
<tr>
<td>3. Waiting lists</td>
<td>• Long waiting lists are burdensome and cause frustration.</td>
</tr>
<tr>
<td>4. The need for Transparency &amp;</td>
<td>• Lack of flexibility in the aged care system and lack of information generates a significant burden for carers</td>
</tr>
<tr>
<td>Flexibility</td>
<td>• Flexibility and choice are associated with control and autonomy.</td>
</tr>
<tr>
<td>-------------</td>
<td>------------------------------------------------------------------</td>
</tr>
</tbody>
</table>
| 5. Self-directing a consumer-directed care package | • Lack of information about the aged care system, care planning, and procurement of services  
• Lack of time to coordinate and administer care (carers)  
• A third party may be required to manage financial transactions  
• Care recipient’s anxiety regarding their ability to cope during a crisis event  
• Need for mentoring provided by case managers or peer support groups in regard to self-direction. |

1. Complexity & Lack of Information
Despite efforts of governments, hospitals and care agencies to inform care recipients about the aged care service environment, the community aged care system remains a bewildering and unpredictable ‘black box’ to older people about to receive community aged care services. People often enter the system in crisis or after years of managing at home alone, unaware how to access the assistance they are eligible for:

   *How do people even find out that there are things out there to help them in their despair? I didn’t know about any of these things, and my husband started to get memory problems way back in 2001.*

   *I would like to know what is available. I don’t know how to access what may be available to me.*

2. Relief & Gratitude
When an aged care assessment is completed, it results in considerable relief for carers:

   *I was relieved at last that my husband was assessed.*

   *The ACAS assessment was excellent. The nurse came out for an hour, asking various questions. She recommended we go into an EACH-D program (Extended Aged Care at Home – Dementia). She organised a carer’s allowance for me. It was of enormous assistance.*

20
Focus group participants were generally highly appreciative of their case managers and especially their ability to navigate the care system for them. When asked 'What is the value of a case manager to you', typical comments were:

To be able to ring someone up who has lots of experience, knows the system and say ‘help me’ and they do it. Whereas I don’t have to ring five agencies and explain my story and hope that they might help me. A professional case manager knows where things are and what to do. I see that as an advantage. They know the system. If I need more care hopefully they will know where to go and how to get it.

Me without a case manager I would be lost.

Case managers were also appreciated for being ‘caring’, ‘supportive’ and ‘encouraging’, and always available to help in a crisis. Moreover, case managers were called upon to help mediate family conflicts.

3. Waiting lists
Following an assessment, people can be left on a waiting list for months, unaware of the background processes or the time it can take to receive a package:

We were on a waiting list for 11 months then we got a phone call out of the blue asking “What do you want?” We did not get a letter saying that we had reached the top of a waiting list, just a gruff phone call and it was left ‘leave it with me I will get back to you.’ It’s not very encouraging.

4. The need for transparency & flexibility
Sometimes there is a good fit between the needs and preferences of care recipients and the services they receive. However, for a significant minority of care recipients, this is not the
case. Among the queries raised by focus group participants were issues, such as the lack of transparency and information provided and a sense of inequity underpinning packaged care.

*I was given very little information ... they were only telling us what they think you ought to know.*

*I have no idea what we are entitled to or where the money comes from. Any help is good, but they should tell us what we are entitled to.*

In the words of focus group participants, the dissatisfaction with the care system that surfaced over time was exacerbated by the poor fit between the care services and the care recipients’ needs:

*I have a greater burden dealing with the inflexibilities than directly looking after my dad.*

As a result, some focus group participants withdrew from a system that did not meet their needs.

4. Self-directing a consumer-directed care package

One participant had negotiated with his care agency and the Federal Government to gain financial control of his mother’s care package.

*I dispensed with the package altogether. I was on one package. I felt there was too much control [from the broker agency]. I have to say I knew my way around structures from my previous occupation as a careers counsellor.*

*I ended up with 20 hours of care a week and it was my choice. I could negotiate directly with my agency that provided the care. If I didn’t like the carer they got short shift. If I wanted to change the hours of care I could do that. It was very flexible; I didn’t have to go back to the broker when I wanted to change it. I was in control, I made the choice.*
However, only two individuals with extensive social services backgrounds advocated dispensing with agency management altogether. Most focus group members did not feel sufficiently knowledgeable to navigate the system to manage on their own.

For the vast majority of participants, CDC was an intimidating proposition:

*How would you know what to buy with it? Where would you go for advice about it? What to buy, what you need ... I wouldn’t have time to go and organise it myself. If you’re a carer, the demands upon your time are unceasing. You just don’t have time to organise that sort of thing yourself.*

Moreover, some group participants voiced concerns regarding the loss of a potential economy of scale:

*The services that I have and the case manager are very professional and very efficient, and much cheaper than if these services were organised by the carer because of course they have the ability to bulk purchase care services.*

Others were concerned about the obligations and liabilities they would incur if they employed and directed care staff:

*What about Workcover? You’d have to pay it yourself. And your own insurance company would be an issue too. Would you have to account for all the moneys spent? Would it be taxed? You’d need to get expert advice about what employer’s liabilities are.*

Participants noted that it would be essential to know the amount of money allocated and know about available services to be able to make informed choices. Further, individual’s needs would require periodic re-assessment in recognition of the changing needs of older people over time.
Participants in two focus groups suggested that a financial intermediary, such as a case management agency, should hold the package funds and manage the accounting:

To give money to people like that is not a good thing. A lot of people can handle money and a lot of people can’t. You can pay for it from the agency. It’s got to come through an agency, you can’t give it to people just like that.

Due to the complexity of the community care system, the overburdening of carers, and the fluctuating needs of the care recipients and carers themselves, many people favoured retaining the case manager for support. Also, focus group participants regarded the case manager as the appropriate person to learn from if they should want to fully self-direct their allocated funds at a later date. Peer groups and peer mentors too were nominated for this role:

I can’t see how, initially anyway, I don’t see how a person could operate without a case manager … – but once you have got all that, and been in a carers group, you can learn such a lot from them.

I have often thought to myself that when they make the initial assessment at that stage they should provide a mentor to that particular person, someone who has experienced the system, been a carer themselves.

Many focus group members regarded CDC as an attempt by government to save money:

I am very suspicious that they are trying to wean me out of the system rather than get me more services at this stage.

The focus groups indicated that only a small number of carers would feel confident that they had the skills and knowledge to fully self-direct their own care packages. The vast majority expressed that they required substantial assistance, mentoring, and — at least
Initially, case management support. Key among the issues raised by carers was their lack of knowledge of the system, their lack of time and the responsibilities that employer status would bring under a CDC program. Although, most carers expressed that the services they received through community aged care did not meet their needs and that a degree of self-direction could bring greater flexibility, they preferred a hybrid system where they could self-direct while still having access to case management support.

3. User and Carer Working Group (UCG1)

Over 2009-10, five older people and four carers participated regularly in UCG1 meetings. The brief of the UCG1 was to develop, in collaboration with stakeholders, a new model of home-based aged care that would allow care recipients to access a ‘sliding scale of options’ ranging from conventional case management to consumer-directed care. During the first three meetings, participants were given an overview of various CDC models and their outcomes for service users. Practical, everyday examples were given to demonstrate the utility of CDC features and to provide group members with a concrete context for the discussions. Group feedback generated the design components of the PACS draft model.

Features attractive to service users and carers participating in the Phase One development stage were

- the potential to contact personal care workers and other service providers directly without having to apply to their case manager;
- involvement in the decision-making process underpinning employment of personal care workers, training, and deployment of home and personal care workers;
- the ability to utilise their packages more flexibly (i.e. to pay for minor services directly without having to access a case manager);
- having access to a percentage of their package in the form of a fund (debit card) they could draw on to pay for minor items and services; and
- having access to a case manager who helped them remain as independent as possible by mentoring them to understand the aged care system and by facilitating their decision making.
All service users and carers preferred a model of CDC which offered a range of options where they could select those elements they felt comfortable self-directing. They did not want to ‘cash out’ their budget nor did they want highly independent modes of care management at the expense of case management support. Table 4 presents an overview of themes and sub-themes from UCG1.

<table>
<thead>
<tr>
<th>Theme</th>
<th>Sub-theme</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Case Management &amp; Security</td>
<td>• Case managers were greatly valued and group members wanted to retain the option of having case management support within the context of consumer-directed care.</td>
</tr>
<tr>
<td>2. Motivational Goal Setting &amp; Restorative Health Approach</td>
<td>• Participants and particularly carers thought that it would be valuable to have a motivational goal setting approach leading to activities aimed at maintaining or improving the wellbeing of older people.</td>
</tr>
<tr>
<td>3. Appointments &amp; Scheduling of Care</td>
<td>• Case management was seen as a support but also as a potential barrier to greater independence by creating dependence.</td>
</tr>
<tr>
<td></td>
<td>• Participants were willing to undertake care coordination as this would result in greater flexibility, reduce bureaucracy, and free up case managers for more valued tasks (e.g., planning for health crises, mentoring regarding legal issues associated with decision making, etc.).</td>
</tr>
<tr>
<td></td>
<td>• They were not interested in self-directing all their care if they were required to take on accounting and employer responsibilities.</td>
</tr>
<tr>
<td>4. Crisis Events &amp; Safety</td>
<td>• Participants wanted reassurance that if they directed some or all of their care they could revert to full case management if preferred, or if they experienced a crisis.</td>
</tr>
<tr>
<td>5. Provision of Knowledge &amp; Informed Decisions</td>
<td>• Participants stated that they needed more information about the aged care system if they were to effectively self-direct their care.</td>
</tr>
<tr>
<td>6. Self-Direction &amp; Choice</td>
<td>• Most participants considered that aspects of self-direction were well within their capacity.</td>
</tr>
<tr>
<td></td>
<td>• Participants wanted to have a menu of self-direction options they could choose from.</td>
</tr>
<tr>
<td></td>
<td>• Most participants preferred not to take on budgeting, accounting, and employer responsibilities.</td>
</tr>
<tr>
<td>7. Financial Transparency &amp; Independence</td>
<td>• Participants wanted to have a clear idea of what they are entitled to and how the money in their package was being spent.</td>
</tr>
<tr>
<td></td>
<td>• Having financial oversight was seen as an important part of their independence.</td>
</tr>
<tr>
<td></td>
<td>• Participants wanted to have more flexible access to cash and to be able to pay for small repairs or maintenance jobs without having to involve a case manager.</td>
</tr>
<tr>
<td></td>
<td>• Participants regarded the current framework of guidelines regulating packaged care as too restrictive to enable greater choice and flexibility.</td>
</tr>
</tbody>
</table>
1. Case Management & Security
Initially, UCG1 participants were apprehensive about self-directing consumer-directed care packages because they feared they might lose access to their case manager when needed. This prompted accounts of how much case managers were needed and appreciated and that case management services were irreplaceable (see also CSIP and Bartlett 46, 80). All participants highlighted the importance of their case manager. Their responses echoed that of focus group participants. Throughout 2009-10, UCG1 participants reported that they valued their relationship with their case managers. They did not want changes to their care regime that would undermine their relationship with their case manager. In the eyes of participants, case managers:

- were trusted friends, allies, and counsellors,
- provided security in case of illness and financial difficulties,
- could provide the impetus for greater independence,
- defused difficult and stressful family situations and other crisis situations, and
- provided crucial information about services and the way they could plan ahead.

Most participants were prepared to take responsibility for care coordination [e.g. change times when attendant carers were to visit], as much as possible, in order for case managers to have the time to focus on the services that mattered most to care recipients, such as planning ahead. Several group members thought that relying too heavily on a case manager, would make them 'lazy' and that this would ultimately undermine their independence. Rather than arranging services for users, UCG1 participants argued that case managers should act as 'capacity builders' to support older people to be as independent as possible.

2. Motivational Goal Setting & Restorative Health Approach
Participants were introduced to the ‘reablement’ approach implemented in the UK during which older people have access to 4-6 weeks of intensive rehabilitation when eligible for community care. Participants felt that this would be very valuable, particularly carers who expressed interest in motivational goal setting.

Create in their mind a vision of what you want to do. Your health and everything works towards that.

27
Some participants expressed concerns that un-realistic goal setting could lead to a sense of failure:

*The goals should be within their general capabilities. They should be realistic so that they don’t think they are failing. We want to feel a sense of achievement.*

Overall, there was strong support for a restorative approach that would bring together the service user and carer, case managers, personal/home carers, allied health professionals, and GPs in a team working collaboratively towards the goals articulated by the participant.

3. Appointments & Scheduling of Care

UCG1 participants valued some services from their case manager more than others. For instance, participants almost unanimously agreed that the components of case management they most appreciated were the provision of a safety net (someone to contact when facing a personal or health crisis), counselling, information, and advice that mattered most to them.

*Working with the case manager to get the most independence is using them best. The case manager is central to how we manage our lives. I see the load on the case manager with mundane things limits their ability to really [be of benefit to us]. We should establish a system where we can take on the nuts and bolts and give them time to relate to the more fundamental things – like, how long will we be able to manage things on our own.*

In contrast, appointments and care scheduling were not as highly valued. Indeed, most participants wanted to undertake scheduling tasks because this could be more efficient for them and it would provide more time for the case manager to undertake the important and valued tasks of support and planning. Participants were frustrated that they were not allowed to undertake simple tasks such as hiring a contractor directly for home repairs or re-
scheduling services. They considered that their case managers wasted time and administrative effort coordinating routine maintenance activities.

I tried to get my door fixed. I had to go to my case manager.

My home care couldn’t come so they said they would send someone else and they did not turn up. I called [the agency] and they said call my case manager.

Also, group members expressed a desire to have greater input and control over the hiring, rostering, and management of care attendants. Continuity of care was seen as tremendously important, an insight that is also borne out by other research (64, 72).

4. Crisis Events & Safety
Initially, UCG1 group members raised concerns about their perceived limitations in undertaking care coordination responsibilities, and about managing their lives in general. Their concerns were similar to those of the focus group participants. Most UCG1 members were concerned about the unpredictability of their health and that their fluctuating health condition would become a barrier to their aspirations to self-direct their care:

We manage on a day to day basis, but what will you do when things go wrong?

With the exception of one carer, all participants expressed a desire to undertake care coordination as long as they had the option to revert to ‘full case management and care coordination’ should this be required for their health and safety.

5. Provision of Knowledge & Informed Decisions
Most UCG1 participants expressed a lack of knowledge regarding how the aged care system functioned, what kind of services were available to them, and how they could access additional services if required. All participants agreed that information about the aged care
system would be crucial if they were to self-direct (see, also, 80). Again, these findings resonate with the views of focus group participants.

6. Self-direction & Choice

When UCG1 participants gained an understanding of the various modalities of self-directed consumer-directed care, role play was used to explain the concepts of care planning, care coordination, budgeting, financial oversight), some recognised that they were already coordinating some aspects of their care. They employed personal care workers privately to 'top up' the hours of care or improve the quality of care they were receiving and scheduled their care by contacting service providers to change shifts. They thought it appropriate and useful undertaking these tasks.

Only one carer wanted to fully self-direct all aspects of their support services and others wanted the option to choose aspects of their care that they would feel comfortable directing.

Some carers in UCG1 who had experience with budgeting and procurement of care found the tasks too demanding. One carer who had planned, budgeted, and coordinated 30 respite hours did not want to continue with this major task:

I kept a journal in which I keep track of how much I am spending and what services I am buying. But agencies send their accounts at different times and there is a time lag. You have to be very organized to keep on top of this. I would not want to do this all the time...

Others, who had not coordinated their support, felt that undertaking extra tasks would require too much time, energy and knowledge that they did not have:

To take on an extra thinking role is beyond me. I employ extra people [students] already.
I wouldn’t want to use my energies in finding out about services.

In particular, budgeting and accounting were unpopular tasks. Thus, rather than wanting to self-direct all their services, participants preferred to choose elements of self-direction for themselves (see, also, 46, 53):

I would not mind managing my own affairs to a degree; I still would need the case manager...

If I were to go on my own [to self-direct care], some things I would do, others I wouldn’t.

7. Financial Transparency & Independence
UCG1 participants wished to maintain control over their finances. All participants, and particularly those with a background in finance, demanded a greater degree of financial transparency. In particular, they wanted to know how much money was in their package and how much was available to them. Moreover, they wanted greater flexibility and freedom regarding how they could spend their package and they found the proposition of a debit card they could use to cover minor expenses appealing.

4. Service Provider Working Group (PG)
Thirteen managers representing agencies providing home and personal care, service broker organizations, community nursing services, assessment services, allied health services, and municipal aged care services (Home And Community Care – HACC provider) participated in the Service Provider Working Group (PG). Three managers representing local government as well as the regional health system, transferred into the Advisory Group (AG) after three meetings.
Participants were particularly concerned about risk management issues. Most of the issues raised concerned the possibility of care recipients ‘cashing out’ all case management and fully self-directing. Participants were concerned this would make it difficult to identify any abuse, neglect, financial exploitation or inappropriate expenditure of funds. They were also concerned about the ability of people with cognitive impairment to make informed or appropriate decisions. PG participants sought information about eligibility criteria for full self-direction, what factors would trigger a review of self-direction status, and who would mentor care recipients about the aged care service system. They were concerned that they would be financially responsible for care recipients who had overspent their budgets and had no funds to pay for services delivered by their agency. In addition, some were concerned that a self-directed care model would transfer care coordination and client contact tasks, tasks for which they were not paid for, to service provider agencies because of a possible reduction in case management hours and because they would deal with care recipients directly. Some of these queries and concerns arose from some PG participants’ experiences with a CDC model designed for people with disabilities. PG participants discussed all their concerns in terms of operational issues requiring resolution prior to the implementation of an aged care CDC model. PG participants noted that for a PACS model to work in practice, improved inter-professional communication and collaboration were required. Other issues to be resolved included:

1. Better communication between all tiers of community aged care service provision
2. Invoicing and payment systems for home and personal care services
3. Guidelines for hiring family members as care workers
4. Improved communication and information exchange between Community Care Agencies, self-directing care recipients and Provider Agencies
5. Guidelines for triggering a review of self-direction status available
6. Greater involvement of Home and Personal Carers in restorative/health maintenance activities
5. Advisory Group (AG)

Fourteen representatives of key industry peak bodies, advocacy organisations, as well as local, state, and federal government agencies with an interest in consumer-directed service delivery in Melbourne’s inner east met on three occasions. Several key issues were presented to this group: the possibility of care recipients holding packaged care funds themselves (without having to rely on a broker organisation); and greater flexibility as to how funds can be spent than that specified in the Aged Care Guidelines. As these matters were under the authority of the Federal Government, whose representative declined to participate in the AG, no decisions could be made by the group. Instead, separate negotiations were held directly with the government department. As a result, the AG became a forum for the dissemination of research results.
The PACS Model

The insights gathered from the literature review, focus groups, and the working groups led to the development of a draft People at Centre Stage (PACS) model by the end of Phase One. The PACS model addresses the concerns raised in this report and provides a model of integrated, case management-supported restorative health and self-directed care. These consultations led the researchers to develop the notion of 'assisted independence' from articulations of 'independence' and 'autonomy' by Sen (85) and Nussbaum (86). Assisted independence is based on the premise that throughout life people require assistance to make good decisions. Moreover, people value and need assistance to maintain independence and autonomy when faced with reduced ability associated with old age. ‘Assisted independence’ is the philosophical foundation of the PACS model.

The ‘Assisted independence’ model addresses the concern of dependency raised in the literature. While a key focus of care agencies is client safety, risk management and risk averse policies and practices may inadvertently ‘disable’ and ‘institutionalise’ people (81). This is particularly the case for people with cognitive impairments whose involvement in decisions affecting their lives has been significantly diminished (82) and who require additional assistance to become involved in decision-making. The PACS model employs an ‘enabling’ approach. Rather than ‘disabling’ people and making decisions for them, the PACS model asks case managers to explore together with care recipients (and their families) the roles and responsibilities they would like to undertake and to build the support structures needed to translate individual preferences and choices into desired outcomes.

The model also seeks to restore or maintain the cognitive, physical, and social capabilities of each person. To this end, PACS includes a motivational goal setting approach that has proven successful in New Zealand (83). The approach involves multi-disciplinary teams comprised of health and community care professionals, such as social workers, general practitioners, allied health professionals, and home care workers, alongside community groups. These teams focus on restorative health and activities that the participant wants to engage in to achieve their identified goal. A similar restorative/health maintenance phase
has been successfully implemented in many community care programs in the UK – in the UK this is sometimes referred to as ‘reablement’ (84). Its core idea is that people need additional support to restore their functioning and health after an accident or illness. The restorative health approach aims for care recipients to be in the best possible position to enhance their independence.

The three levels of self-direction in PACS:

The PACS model is designed to enable older people and their carers to make informed choices about the care they receive. It offers them the opportunity to influence and shape their care arrangements at all stages. In the model, older people and their carers are presented with a range of self-direction options. Typically, self-direction begins at a ‘lower level’ with participants responsible for the development of their care plan (Level 1). As they become more comfortable dealing with the aged care system, they may assume care coordination responsibilities (Level 2). At the ‘highest’ level of self-direction, participants undertake responsibilities for administration and bookkeeping (Level 3). Participants are under no obligation to undertake all responsibilities associated with a particular level of self-direction and can opt to self-direct certain tasks and not others. Case management support is available at all levels of self-direction. Figure 3 overleaf provides an overview of the different domains and levels of self-direction.

*Key Program Features:*

- Care recipients are invited to assess their own needs and explore resource implications with their case managers.

Care recipients receive clear information about their entitlements and the ‘dollar’ value of their support package.

- A monthly financial statement detailing expenditure and balance is provided.

- Care recipients have access to a restorative program based on motivational goal setting.
• To the extent they choose, care recipients explore with case managers strategies to maximise independence opportunities by identifying health promoting activities and obstacles to functional ability and decision making capacity.
• A multi-professional team may be involved to establish the best possible restorative approach.
• Case managers ensure that service users have access to all relevant sources of funding.

• Care recipients can choose their level of self-direction from full case/care management to full self-direction. They:
  • Can choose to care plan, budget, care coordinate, and manage their finances.
  • May be eligible for a ‘debit card’ allowing them to spend, within ‘spending guidelines’, a percentage of their budget on services without having to consult a case manager.
  • Can negotiate what services their case manager should provide.

• Core case management services such as monitoring and review are continued to maximise client safety in their own home.
  • The complete ‘cashing out’ of case management is not supported by the model and some monitoring and review is always provided

• Person-centred practice involving:
  • A detailed ‘personal profile’ of the care recipient.
  • A goal setting approach identifying personal motivators to maximise independence.
  • ‘Enabling’ risk management by encouraging self-direction combined with the necessary support and assistance.
  • A focus on peer support and social inclusion connecting people with their wider community.

• Closer co-operation between care recipients, case managers and allied and health services with the aim to maximise flexibility and quality outcomes, and to actively
involve provider agencies and care workers in assisting care recipients to achieve their personal goals.
Figure 3: PACS Model Overview

Definitive Care Management

Facilitated Peer and IT Support

Crisis Event?

Pre-Self-Directed Stage: Assessment Level Setting

Crisp Self-Directed

Introduction to Self-Directed

Self-Directed Care Planning

Level 1: Self-Directed Care Coordination

Level 2: Self-Directed Care Coordination

Level 3: Self-Directed Administration and Finance

Capable & Comfortable

Capable & Comfortable

Capable & Comfortable

Capable & Comfortable

Capable & Comfortable

Capable & Comfortable

Capable & Comfortable

Level 1: Self-Directed Care Planning

Level 2: Self-Directed Care Coordination

Level 3: Self-Directed Administration and Finance

Continue with PACS

Case Management Required

Facilitated Peer and IT Support
References:


57. Henwood M, Hudson B. Evaluation of the self-directed support network: An
58. Keigher SM. The interests of three stakeholders in independent personal care for
Fall;23(2):136-60.
Consumer preferences for a cash option versus traditional services: telephone survey results
60. Matthias RE, Benjamin AE. Abuse and neglect of clients in agency-based and
62. Meng H, Friedman B, Wamsley BR, Mukamel D, Eggert GM. Effect of a consumer-
directed voucher and a disease-management health-promotion nurse intervention on home
63. Micco A, Hamilton ACS, Martin MJ, McEwan KL. Case manager attitudes toward
64. Poll C, Duffy S, Hatton C, Sanderson H, Routledge M. A report on In Control’s first
65. Priestley M, Jolly D, Pearson C, Ridell S, Barnes C, Mercer G. Direct payments and
2007;37(7):1189-204.
and Direct Payments: A UK Comparative Study 2006.
67. San Antonio PM, Eckert JK, Simon-Rusinowitz L. The importance of relationship:
elders and their paid family caregivers in the Arkansas Cash and Counseling Qualitative
68. Schore J, Foster L, Phillips B. Consumer enrollment and experiences in the Cash and
69. Sciegaj M, Capitman JA, Kyriacou CK. Consumer-directed community care:
Race/ethnicity and individual differences in preferences for control. Gerontologist.
70. Shen C, M. A. Smyer, Mahoney KJ, Loughlin DM, Simon-Rusinowitz L, Mahoney EK.
Does mental illness affect consumer direction of community-based care? Lessons from the
Arkansas Cash and Counseling Program. Gerontologist 2008;93-104.
71. Simon-Rusinowitz L, Bochniak AM, Mahoney KJ, Marks LN, Hecht D. Implementation
Fall2000;24(3):34-.
72. Simon-Rusinowitz L, Mahoney KJ, Marks LN, Zacharias BL, Loughlin DM. The Cash
and Counseling Demonstration and Evaluation: focus groups inform design of a consumer-
73. Spandler H. Friend or foe? Towards a critical assessment of direct payments. Critical
74. Stainton T, Boyce S. 'I have got my life back': users' experience of direct payments.