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People at Centre Stage: Summary Report for Stakeholders

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Aims of the Summary Report:

The key objective of this report is to provide an overview of the key outcomes of the PACS trial. Significant outcomes from the quantitative and qualitative arm of the impact evaluation are presented.

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EXECUTIVE SUMMARY

Consumer-Directed Care (CDC) is central to the aim of rendering community aged care more flexible and responsive. In Australia, it builds on experiences of consumer-directed, community-based disability care and is intended to offer greater decisional authority to care recipients over the services they receive.

The People at Centre Stage (PACS) model was developed with direct input from both service users and service providers (details are provided below). It was designed to assist participants maintain/build their health, strengthen their capabilities and attain their preferred level of independence. It was specifically designed for people with complex care needs and places great emphasis on capacity building. It allows for a wide range of preferences regarding self-directing care services, yet always provides the necessary support and safeguards. The PACS model was evaluated over the course of 12 months in a cohort of 116 participants, with 68 in the intervention group and 48 in the control group, using a robust quasi-experimental, multi-methods design integrating quantitative and qualitative analyses.

One of the most important findings of this project is that only a very small minority of clients seek full control of the administrative and financial processes associated with their care or want to ‘cash out’ their package. Of 158 people who had their contact details referred to the research team, only 14 participants chose to take on parts of the administrative and financial tasks underpinning their care. Of these, three were interested in taking full control. This is very much in line with trends depicted in the international literature. A far greater number of clients were interested in retaining their decisional autonomy and being more directly involved in the care coordination process. To focus on administrative and financial control at the expense of affording greater decisional autonomy misses the point. A far greater number of clients wanted the case management agency to manage the financial arrangements, while they held the authority to make decisions regarding service delivery.
The evaluation demonstrates that the PACS model has numerous positive outcomes and very few negative implications. Where negative outcomes did occur they mainly resulted from unresolved administrative implementation issues. For the vast majority of intervention group participants, PACS generated positive results. For nine participants, predominantly self-directing at a higher level, PACS was a life-changing event. Another 35 participants reported positive outcomes related to PACS. A total of 17 participants, predominantly self-directing at Level 1 (the lowest level of self-direction), reported minimal or neutral outcomes. For the vast majority of participants, the main components of PACS (self-assessment, goal setting, care planning and coordination, and administrative/financial self-direction) worked well and represented a positive experience. Only two members of the intervention group would not recommend PACS to others but did not state their reason for this.

The evaluation demonstrates that the implementation of a CDC model can be challenging. For example, service providers found it difficult to deliver the financial transparency in the form of ‘real time’ financial statements that the PACS, as well as other CDC models, requires, as accounting and IT systems are not set up for this. Indeed, ‘real time’ financial statements could only be delivered at a substantial additional cost to service providers. As a result, not all participants were issued with monthly statements. More importantly still, numerous implementation and communication issues affected the financial transparency the model was to provide. This resulted in around a third of participants remaining unaware of their entitlements until the end of the trial.

Positive Outcomes
1. More say: Intervention group participants expressed that they had a greater say in their care and greater decisional authority. Moreover, some felt empowered to challenge the decisional authority of their case manager.

2. More flexibility: The majority of intervention group participants stated that their view of what could be achieved with their support services had changed significantly. They commented that they were able to use their resources more flexibly and that this had a positive impact on their lives.
3. **More control:** The majority of intervention group members stated that they had better control over their support service arrangements. They expressed that being able to negotiate directly with service providers had resulted in more consistent and responsive service delivery. Many stated that cutting out the middle man (the case manager) made a lot of sense and reduced bureaucratic processes.

4. **Better handle on finances:** Participants were more satisfied with their financial arrangements. They felt that the financial aspect of their care was much more transparent and comprehensive with PACS.

5. **Feeling more connected:** Interestingly and unexpectedly, intervention group clients felt significantly less lonely. A possible explanation for this is that they felt more engaged as a result of playing a more active role in their service delivery. More research is required to explore this outcome.

6. **Increased capacity:** The evaluation also suggests that the restorative/health maintenance approach in conjunction with the capacity building emphasis provided some participants with new skills (IT, care coordination, etc) and increased mobility. This improved their ability to do their paperwork, pay bills (via internet), and prepare meals.

**Negative Issues Associated With PACS**

Only a small minority of intervention group participants stated that PACS had impacted negatively on the quality of care they received. The management of paid care workers was the most important issue, raised by five participants. Having to carry through with a care plan, having less contact with a case manager, or losing an existing case manager was mentioned once.

**Key Barriers/Challenges**

PACS was regarded as a challenge by people with lower English language skills. However, the by far most significant barrier to self-direction was insufficient communication, information provision, and capacity building.
Consumer-Directed Care (CDC) is central to the aim of rendering community aged care more flexible and responsive. In Australia, it builds on experiences of consumer-directed community-based disability care and is intended to offer greater decisional authority to care recipients over the services they receive.

Since the 1990s, there has been growing interest among Australian community care providers, service users, and policy makers to ‘modernise’ and reform community aged care. A suite of reports (ABS 2004; Phillips & Schneider 2004; The Nous Group 2006; The Allen Consulting Group 2007; Productivity Commission 2011) were commissioned that highlighted the facts that that:

- fragmented programme arrangements in community care create planning and operational difficulties and inefficiencies;
- the current service provision model is too complex, making it difficult for lay people to access the services they need or are entitled to;
- funding gaps exist throughout the care pathways;
- the current system is inflexible and unresponsive to transitions in people’s lives and/or illness trajectories;
- the needs of a significant minority of care recipients are not sufficiently addressed, resulting in poor quality of care as well as resource wastage.

The People at Centre Stage (PACS) project aimed to address some of these issues. The aim of the project was to—within the limitations of current legislation and guidelines—develop, implement and evaluate an innovative community aged care model that gives care recipients with more complex needs the option to have as much control of their own care as they aspire to and feel comfortable with. As a result, the project intended to offer a continuum of care ranging from customary case management to CDC.
This summary report provides a brief outline of the results of this evaluation. It is structured in two parts: following a brief overview of the PACS model, Part 1 outlines the key findings from the quantitative analysis, while Part 2 offers an overview of the qualitative findings.

The PACS model was developed with direct input of service users and service providers. It was designed to assist participants maintain/build their health, strengthen their capabilities and enable them to attain their preferred level of independence. It was specifically designed for people with complex care needs and places great emphasis on capacity building. It allows for a wide range of preferences regarding self-directing care services—such as determining how a care budget is to be spent, choosing a service provider, managing service delivery and quality, and employing friends or family members as care workers through accredited agencies—yet always provides the necessary support and safeguards (for an overview of the PACS model, see the next section).

Most of the model components were developed with the input of service users, service providers, and case managers. They represent solutions responding to local systemic constraints. To some extent, the PACS model was developed by making use of pre-existing resources, such as the Self-Assessment form developed by In Control UK as well as a suite of tools facilitating person-centred planning designed by Helen Sanderson Consulting (UK). Also, the restorative/health maintenance aspects borrowed heavily from an approach developed by Mathew Parsons and his team in New Zealand. We adapted these resources to fit the local context. Numerous sub-projects were conducted to gather evidence regarding the efficacy of these tools. For a detailed description of the development phase and the model itself, see the Development Phase report (Ottmann et al. 2011).

The PACS model was evaluated over the course of 12 months using a robust quasi-experimental, multi-methods design integrating quantitative and qualitative analyses. There is increasing consensus among experts that this kind of evaluation design is most appropriate for impact evaluations of social interventions (Gabarino & Holland 2009). The evaluation design mirrors that of the well-known IBSEN study, a large-scale evaluation of CDC pilots in 13 English municipalities (Glendinning et al. 2008).
The actual evaluation design used differs from what was initially intended in several important points: 1) initially, we intended to recruit 200 participants for the intervention and another 200 for the control group. Reminiscent of the Cash and Counseling Demonstration Evaluation in the US and the IBSEN study, recruitment was a challenge. A total of 158 participants agreed to have their contact details referred to the research team for participation in the intervention group, and 107 for the control group. A total of 87 participants agreed to participate in the intervention group and 90 in the control group at the start of the evaluation (baseline). Of these, a total of 61 participants in the intervention group and 48 in the control group remained in the project until the end of the trial. Because of this small sample size, we decided to combine the two planned control groups into one. We were also forced to drop one of the data collection points (six months after the implementation) due to the resource intensity of the data collection process.
The PACS Model

The insights gathered from the literature review, focus groups, and the working groups led to the development of a draft model (for a detailed description of the development phase, see the PACS interim report, Ottmann et al. 2011). The PACS model provides integrated, case management-supported restorative health and self-directed care. Consultations with older people and caregivers led the researchers to develop the notion of \textit{assisted independence} from articulations of ‘independence’ and ‘autonomy’ by Sen (1985) and Nussbaum (2004; Nussbaum & Sen 1993). 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 the reduced abilities associated with old age. ‘Assisted independence’ is the philosophical foundation of the PACS model.

The assisted independence model addresses the concern of institutional 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 (Sawyer 2008). This is particularly the case for people with cognitive impairments whose involvement in decisions affecting their lives has been significantly diminished (Menne & Whitlatch 2007) and who require additional assistance to become involved in decision-making. The PACS model employs an \textit{enabling} approach. Rather than ‘disabling’ people and making decisions for them, the PACS model asks case managers to explore 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 the 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 (Peri et al. 2008). 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 programmes in the UK—in the UK this is sometimes referred to as ‘re-ablement’ (Pilkington 2008). 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 but tends to diminish at higher levels. Figure 1 overleaf provides an overview of the programme flow and levels of self-direction.

Key Programme Features

- Self assessment: 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 programme 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 ‘stored value 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 cooperation 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 1: Overview of the PACS Model

PACS Model: Overview

Referral
- Eligibility Assessment (ACAS, ACAT)
- Waiting List
- Intake
- Review & Analysis

Crisis Event?
- Yes
  - Full Case Management (Default Option)
  - Capability Building
- No
  - Self-Assessment & Entitlement Discussion
  - Budget Band
  - Transition to HACC

Capable & Comfortable

Level 1: Self-Directed Care Planning
- No
  - Continues with Model
- Yes
  - Introduction to Self-Direction Level 1

Level 2: Self-Directed Care Coordination
- No
  - Continues with Model
- Yes
  - Introduction to Self-Direction Level 2

Level 3: Self-Directed Administration & Finance
- No
  - Continues with Model
- Yes
  - Introduction to Self-Direction Level 3

Restorative/Health Maintenance (GPs, Allied Health, Community Nursing, Care Workers)

Facilitated Peer and IT Support & Circles of Support

Eligibility Assessment
- ACAS, ACAT

Waiting List

Intake

Review & Analysis

Full Case Management
(Defaults Option)

Capability Building

Self-Assessment & Entitlement Discussion

Budget Band

Transition to HACC

Continues with Model

Case Management Required?
Approach and Methodology

The methodology underpinning the evaluation of the PACS project employed a mixed method approach using quantitative and qualitative methods. The evaluation included a prospective longitudinal comparison study with one intervention group, ‘CDC’, and one comparison group, ‘case management as usual’. According to a growing consensus among evaluation experts, qualitative and quantitative methods and data are often more powerful when combined to evaluate the impact of social interventions (Gabarino & Holland 2009). Carvalho and White (1997) recommend three ways of combining qualitative and quantitative approaches: (1) integrating methodologies to facilitate improved measurement, (2) sequencing information to improve analytical insights, and (3) merging findings for better action. The PACS model evaluation incorporated these three processes.

The project received the approval of Deakin University’s Human Ethics Committee.

Procedures
Recruitment for the trial commenced in July 2010. Case managers of four community aged care services approached their clients providing them with information about the project. If interested, clients were provided with a Plain Language Statement (PLS) and a Consent Form. Furthermore, they were asked for permission to forward their contact details to the research team. Subsequently, a researcher contacted potential participants and made sure the content of the PLS was understood. If the client decided to participate in the project, they were asked to sign the Consent Form. Consent Forms were sent to the research team either directly by the participant or by the case manager.

Survey Instruments
In order to be able to compare our outcomes with other major studies, such as the IBSEN evaluation of a CDC trial in 13 municipalities in England, we adopted all instruments except for one—the quality of life tool—used in the IBSEN study. The tools used in that study were specifically designed to evaluate social care outcomes for older people and have produced
good internal reliability (Cronbach’s alpha >0.7). The survey instrument contained the following indicators and scales:

**Social care outcomes**

The Adult Social Care Outcomes Toolkit (ASCOT) measures seven domains ranging from decisional autonomy to social engagement. Participants are asked to indicate their level of agreement (strongly agree to strongly disagree) with statement such as ‘I feel in control of my life’. The assumption is that the tool can measure support needs related to these domains. In the large IBSEN study, the ASCOT achieved a Cronbach’s alpha of 0.74, demonstrating that it had good internal reliability (Glendinning et al. 2008).

**Self-perceived health**

There is increasing consensus that a person’s perception of his/her own health reliably predicts objective health and particularly functional decline (Ferraro 1980), chronic disease (Shadbolt 1997) and even mortality (Ilder & Benyamini 1997). The question developed as part of a European project on health indicators asks participants to rate their health on a five-point Likert scale (Robine et al. 2003, in Glendinning et al. 2008).

**Quality of life measure**

We used the well-known eight-item Personal Wellbeing Index developed by Cummins (International Wellbeing Group 2006). The scale has good construct validity, forming a single stable factor accounting for about 50 per cent of variance in Australia and other countries (International Wellbeing Group 2006). Its correlation of 0.78 with the Satisfaction of Life Scale (Diener et al. 1985) suggests a good convergent validity, as does a Cronbach’s alpha value of between 0.70 and 0.85 regarding reliability (International Wellbeing Group 2006).

**Satisfaction and quality of services**

Measures of satisfaction and quality of care were derived from the extensions to national User Experience Surveys for older home care service users and younger adults (Jones et al. 2007, in Glendinning et al. 2008; Malley et al. 2006). In the IBSEN study Cronbach’s alpha for the quality of care scale was 0.80, demonstrating that it has good internal reliability.
Data Collection

Baseline data, consisting of a demographics questionnaire and the above-mentioned survey instruments, were collected between September 2010 and January 2011. The repeat measure, consisting of a demographics update form, the survey instruments, and semi-structured interviews, was conducted between October 2011 and February 2012. All participants experienced at least 12 months of the PACS trial or control group conditions. The survey instruments were applied via phone, except on occasions where health reasons or disability did not permit this to occur. Participants were given the choice to complete the interviews via phone or face-to-face.

Participation and Attrition

A total of 177 older people participated in the baseline data collection (87 in the intervention group and 90 in the control group). At T2, 12 months later, a total of 109 individuals participated in the repeat measure (61 in the intervention group and 48 in the control group). This represents an attrition of 38.42 per cent, a figure that is commensurate with the wider attrition rates in community aged care and reflects the advanced age of participants (average 79.76 years). Withdrawal from the project occurred predominantly due to health reasons, transition to a nursing home facility, or death. A total of 56 individuals in the intervention group participated in the semi-structured interviews. The next section provides an overview of key demographic indicators.

Data Analysis

Quantitative data was analysed using SPSS. Alongside the usual descriptive statistics, we compared the different groups using Chi-square and frequency analyses. Comparing the intervention group at baseline and T2, we used a non-parametric repeated measures analysis, the Wilcoxon Signed Rank test.

Qualitative data was analysed using NVIVO. An inductive and deductive thematic analysis was used to identify the key themes. After a preliminary analysis of 15 interviews, the emergent key themes were discussed with the researchers who conducted the interviews. The themes were refined and sub-themes identified.
Limitations

The explanatory power of the methodology underpinning this evaluation is limited by the relatively small sample size. We compensated for the low numbers by employing less sophisticated analytical methods. Instead of employing a logistic regression we decided in favour of the Chi-square test and the Wilcoxon Signed Rank test. Moreover, older people evaluating the model often found it difficult to respond to the quantitative measures. Without prior knowledge of alternative ways of service delivery or some sort of benchmark, participants found it difficult to evaluate the services they received, stating that they were very satisfied. This ‘positive response bias’ resulted in a ceiling effect. Having responded very positively at baseline, participants had very limited options to express improvements in the way service were experienced. It is likely that this affected the overall outcome of the quantitative part of the study.
OUTCOMES

1. Quantitative Data

1.1. Profile of Participants at End of Trial (T2)
The mean age of participants was 79.76 years (SD=8.96). A total of 102 participants (72 women (50.3 per cent) and 30 men (21.0 per cent) completed the repeat measure at T2. Of these, 41 (28.7 per cent) lived alone, 32 (22.4 per cent) lived with a partner, and 20 (14 per cent) lived with family. Around 68 per cent of participants were born in Australia. A total of 77 participants received a CACPS package, 13 an Extended Aged Care at Home (EACH) package, seven an Extended Aged Care at Home–Dementia (EACH-D) package, and three received a Linkage package. Approximately 67 per cent of participants received a means-tested aged care pension and 7 per cent received a disability support pension. Around 11 per cent of participants rented their dwelling through the social support system. Around 38 per cent of participants stated that their highest educational qualification was primary or junior high school, 18 per cent had completed senior high school, 11 per cent had completed a trade or technical certificate, and 25 per cent went through university. Age was the only significant difference in terms of demographic data between intervention and control groups at T2. At T2, the control group was slightly older (approximately five years) than the intervention group.

1.2. Comparing Control and Intervention Groups at the Beginning of the Trial (T1): Chi-Square Analysis and Frequency Analysis of Survey Data
Comparing the intervention and control groups at T1 in terms of service satisfaction, quality of health, satisfaction with quality of case managers/carers and social and care needs, it emerges that members of the intervention group were slightly less satisfied with:

1) the information they received regarding their care,
2) financial arrangements,
3) the punctuality of their care workers, and
4) the information they received regarding changes in their care.
In addition, intervention group members felt slightly less in control of their lives.

1.3. Comparing Control and Intervention Groups at the End of the Trial (T2): Chi-Square Results and Frequency Analysis of Survey Data

Comparing the differences between the intervention and control groups at T2 in terms of service satisfaction, quality of health, satisfaction with quality of case managers/carers and social and care needs, it emerged that intervention group members felt more satisfied:

1) with their financial arrangements (Question A9), and
2) that they had a say in their care (Question A5).

In addition, intervention group members felt significantly less lonely than control group members (Question E36).

Question A5: ‘How satisfied are you that you have “had a say” in your care’
- A Chi-square test for independence indicated a significant association between the intervention and satisfaction with services in the way in which participants felt they had a say in their care needs, $\chi^2 (1, n=107)=4.13, p<0.05$.

Question A9: ‘How satisfied are you with the financial arrangement’
- A Chi-square test for independence indicated a significant association between intervention and satisfaction with financial arrangements. Clients in the intervention group felt that they were more satisfied with their financial arrangements at T2, $\chi^2 (1, n=104)=4.33, p<0.05$.

Question E36: Social and care needs—‘I feel lonely’
- A Chi-square test for independence indicated a significant association between the intervention and feelings of loneliness, whereby those clients in the intervention group reported that they experienced less loneliness compared to the control group, $\chi^2 (1, n=105)=9.63, p<0.05$. 

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1.4. Comparing the Intervention Group Data Before and After the Trial

We conducted a non-parametric repeated measures analysis using the Wilcoxon Signed Rank test to compare intervention group data before and after the trial. The following significant findings emerged:

1) Intervention group clients felt satisfied that they had a greater say in their care after being a part of the PACS model, $z=-2.00$, $p<0.05$ with a medium effect size ($r=0.30$) (QA5).

2) Clients reported an increase in their satisfaction with the way information was received regarding their care during the intervention, $z=-2.54$, $p<0.05$ with a medium effect size ($r=0.30$) (QA7).

3) Clients reported an increase in their satisfaction in terms of the way the services provided to them have changed their view of what can be achieved in life, $z=-2.84$, $p<0.05$ with a medium effect size ($r=0.30$) (QA10).

4) Clients reported a greater satisfaction with the quality of care they received in terms of their care workers coming at times that suit them, $z=-2.71$, $p<0.05$ with a medium effect size ($r=0.30$) (QC13)

5) Clients reported greater satisfaction in that they were able to see the same care workers during the intervention phase, $z=-2.31$, $p<0.05$ with a medium effect size ($r=0.30$) (QC18).

6) Clients in the intervention group reported a decrease in their level of loneliness, $z=2.14$, $p<0.05$ with a medium effect size ($r=0.30$) (QE36).

1.5. Comparison of the Number of Intervention Group Clients Who Needed Assistance with Daily Activities Before and After the Trial

A Wilcoxon Signed Rank test was conducted to evaluate the level of help clients needed in everyday activities, comparing those in the control group and those in the intervention group. The results indicated a significant reduction in help with cooking, $z =-2.44$, $p<0.05$, whereby clients at the end of the intervention needed less assistance with cooking tasks.
than before the intervention. Although the trial was not designed to measure the impact of the health maintenance approach that forms part of PACS, it is probable that the reduction in required help with cooking is a reflection of this health maintenance approach.

To summarise, the PACS participants were all around 80 years old. At the end of the trial, the intervention group participants were slightly younger than those in the control group. Quantitative data from the 12-month PACS trial illustrates that the PACS model generated a number of significant changes. Participation in the intervention group was associated with:

- increased satisfaction with care,
- improved satisfaction levels with information (including financial information) received,
- improved mobility and particularly ability to prepare meals, and
- an improved sense of engagement and social connectedness.

While the first three findings are congruent with the research hypotheses that underpin the study, the last point came as a surprise to us. Among the hypotheses we can offer to explain this outcome is the fact that the model increases people’s interactions with others. Over the course of the trial, most participants contacted care provider staff, gardeners, podiatrists, and GP clinics directly. This may have increased their sense of engagement and sense of purpose. Further research is required to explore this issue.
2. Qualitative Data

This section presents the data derived from the semi-structured interviews with intervention group participants. A total of 56 individuals participated in the interviews. The section is divided into 11 headings. Most of the sections contain a summary table providing a succinct overview of the key themes. The summary tables are followed by interview excerpts that allow for a more in-depth understanding of client sentiments.

1. Level of Self-Direction of Clients and Carers

Table 1 (below) shows the level of self-direction of the clients and carers by agency. The level of self-direction was obtained from the client demographic update data provided by the case managers. Some clients increased or decreased their level of self-direction during the course of the trial. For the purposes of the analysis, the final level of self-direction was used rather than the beginning level. For example, if the client began self-direction at Level 2 but moved to Level 3 during the course of the trial, then Level 3 was used in the analysis. A total of 8 participants moved between levels of self-direction during the trial.

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</table>

Table 1: The level of self-direction of PACS clients and carers by agency

2. Benefits of the PACS Model

Analysis of the data revealed many benefits associated with the PACS model. These are listed in Table 2 (below). A total of 31 individuals in the intervention group would recommend PACS to others.
<table>
<thead>
<tr>
<th>Ability to negotiate directly with service provider</th>
<th>Level 1</th>
<th>Level 2</th>
<th>Level 3</th>
</tr>
</thead>
<tbody>
<tr>
<td>Ability to use package for repairs and equipment</td>
<td>1</td>
<td>4</td>
<td>4</td>
</tr>
<tr>
<td>Availability of help and back-up</td>
<td>3</td>
<td>0</td>
<td>4</td>
</tr>
<tr>
<td>Client gained or maintained skills</td>
<td>1</td>
<td>1</td>
<td>0</td>
</tr>
<tr>
<td>Clients felt empowered to challenge paternalism of the system</td>
<td>0</td>
<td>0</td>
<td>2</td>
</tr>
<tr>
<td>Financial benefit</td>
<td>1</td>
<td>1</td>
<td>0</td>
</tr>
<tr>
<td>Greater decisional autonomy/control</td>
<td>5</td>
<td>5</td>
<td>7</td>
</tr>
<tr>
<td>Life changing and positive responses</td>
<td>3</td>
<td>2</td>
<td>4</td>
</tr>
<tr>
<td>Life is easier and more comfortable</td>
<td>0</td>
<td>0</td>
<td>2</td>
</tr>
<tr>
<td>Clients open to next level of self-direction</td>
<td>2</td>
<td>1</td>
<td>-</td>
</tr>
</tbody>
</table>

Table 2: The benefits of the PACS model, by level of self-direction

Interview excerpts:

i) Being able to negotiate directly with service provider (9 sources)

But what works well is being able to negotiate with the service provider about when people come and if there’s a change we can, because quite often there are changes (Level 3).

Before it was very difficult to get messages through because you had to go through the care manager and that didn’t always work (Level 3).

Well it simplifies changes and extras and so on by not having to go through the case manager who half the time isn’t there and it just slows everything up; where I can just ring the agency like I did today and say I want someone for two hours on Friday and it’s fixed. Oh well it’s short-circuiting the system. Going straight to the agencies instead of chasing through the care manager (Level 2).
ii) Being able to use the package for repairs and equipment

Examples of the sort of repairs and equipment that were arranged included the following: a non-slip floor (Level 3), a wheelchair (Level 3, Level 1, and Level 2), a ramp to enable carer to wheelchair into the car (Level 3), a scooter (Level 3), and a walking sling (Level 1).

iii) Availability of help and back-up (2 sources)

I: Everything’s changed for [name omitted] and I, hasn’t it, since we got involved with the project.
F: For the better or for the worse?
I: For the better.
F: Can you elaborate a bit on that?
I: Well, to feel you’ve got someone behind you to answer the questions, [name omitted], that you can’t answer yourself and know that no-one would be annoyed if you rang them up and asked for something, you know. No, it’s been really good, that connection, yes (Level 2).

iv) Clients gained or maintained skills (2 sources)

As far as this programme is concerned, because of my qualifications, I feel as though I haven’t lost control, because I’ve actually regained my life, I’ve regained control of my life with CDC and I’m able to sit there with my paperwork, like I even did this morning. I’ve learnt to use a computer, and I BPAY because I am in a wheelchair and it saves me having to go round to the banks and go to the Post Office and things like that. I just do it on the computer and I pay all my bills on the computer (Level 3).

v) Clients felt empowered to challenge the paternalistic nature of the system (7 sources)

I think it’s a great idea. There should be a lot more of it. I think it’s time that certain organisations stopped having this idea that they know all and you don’t need to know. Paternalistic. I guess there’s some people who would rather have it that way, but I don’t think, surely not most people (Level 3C).
vi) **Financial benefits** (14 sources)

Well, yes, we do have much more control, much more, well we have some more money (Level 3C).

Well, I think generally it’s made my life financially much easier. It’s made my life completely different than it was financially. I was always out of pocket for something. But now I don’t seem to be out of pocket for much. I’m able to manage much better. Now I’m able to—I was working, I had to work, but now I’m scaling down my work because I—because most of [client’s wife]’s stuff now is covered by the pack system.

vii) **Greater decisional autonomy and control** (23 sources)

The most striking benefit of the PACS model was the greater decisional autonomy experienced by clients and carers, especially those self-directing at Levels 2 and 3 who were in a position to make decisions about the things that were important to them.

Some key examples:

Well, it’s there are huge benefits. You feel as though you can organise your life instead of having it organised for you (Level 3).

F: All right, so what do you think is working well about the whole process?
I: Well, it’s choices.
F: Okay.
I: Choice to stay on it or not, choice to change or not (Level 3).

You’re not relying on other people to make decisions for you, you know. Yeah, if you can make a decision yourself then that's fine, instead of waiting for other people to ring up and say yeah or no, and we’re coming down to see you in a fortnight’s time or whatever, you know. I can say look, I need this and I need that and get it done, you know, instead of waiting for someone else to come down and have a look (Level 3).
I found that if I want to go to a concert that I can go. If I want to go to the ballet, I can go. I just have to ask my care manager to arrange or not arrange but can I use the taxi vouchers and things like that, you know. And if I want to do, now, I had a shopping girl who came once a fortnight but I don’t really need that. I need to be walking, I need to stay active (Level 2).

F: So it was much more flexible thereafter.
I: Yeah, because they were trying to manage me and now I can manage myself basically (Level 3C).

Well, it gives you sort of more I suppose fulfilment in a way, knowing that you can do it and you’re not relying on it, and the only thing is that they sort of probably don’t think you do know.

Well, I think just having that freedom and having the knowledge that they realise that they’re not the total end of you know, telling you what to do or what you need, as I said unless you had dementia. When I say young, I mean a reasonably healthy person has got a fair idea, and not make excessive demands—like we’ll go out to afternoon tea in a Rolls? I don’t think so (Level 2).

I: So when we had the meeting with Goetz and that at Overton Road, and [case manager] was there, I said to [case manager] can I save $50 a week out of my package towards my wheelchair?
F: So how long did it take you to save that amount?
I: The whole year... I stopped [case manager] paying for the gardener—I got [case manager] to cooperate with me... I stopped [case manager] paying for my incontinence pads—the only thing I got her to pay for was my service provider for the cleaning of the house. I did everything else. It was hard but I did it (Level 3).
[The case manager] often brought up now and again would I like to take a holiday and I said ‘No way will I put [the person being cared for] in any place at all, ever—even for a few days—unless it’s absolutely essential for some reason or other’ so she said ‘Well what about if you had a few days with a carer with you? We can always manage to get people...’ We’ve got a little cottage down at Blairgowrie which we used to love which unfortunately I rarely use now and unfortunately early on, [client] wouldn’t go there and she didn’t like the place, didn’t recognise it. We went down a couple of times and had dinner and came straight home again... She didn’t and so we didn’t go for years then. Last year we tried for a couple of days with the girl who comes here on the Wednesday and who’s excellent and she was happy to do it so we had a couple of days down there and in fact we’re planning one for March and [name of case manager] organises what help we could get and what else I’d have to pay for and so on. That was really her thoughts... (Level 1).

viii) Life changing and positive responses (9 sources)

F: So would you recommend the programme to others?
I: Oh, hell yeah. Without a doubt. It’s a bloody ripper (Level 3).

All those things have arrived out of this new project, yeah. So it’s changed my life completely from just a crossword bloke sitting home in a cell (Level 3).

It’s worked a wonder with me; it’s improved my thoughts on what’s going on and everything (Level 1).

ix) Life is easier and more comfortable (2 sources)

So, as I said earlier that it’s changed my whole situation. I’m much more comfortable in my style of living, and of course that alters with your health, but I’m very happy with the way things are and I feel very fortunate to be able to be in a project like this that really has helped me so much. As I’ve told you the benefits of the project has been wonderful to me, it’s just
been from zilch to everything. It’s really helped our lives, helped our way of living and everything (Level 3).

**One of the key issues with CDC is the degree to which people can self-direct with minimal administrative burden. The PACS evaluation demonstrates that administrative tasks associated with self-direction can be made easy. However, this requires substantial support and capacity building from the service provider.**

Also, most older people are still new to email. Utilising a fax machine might increase their capacity to self-direct.

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x) Clients open to more self-direction (3 sources)

I: Yes I would, because we’ve had one or two—I suppose you could—it sounds awful calling them let downs, but either a lady hasn’t arrived to do the shower or they’ve changed the hours and not told us at all, and when we’ve rung [case manager], [case manager]’s said they never said a word to me, and she’s had it out with them because she said to them, it isn’t fair. They need to know.

Well this is—yes, I’m wondering about that because last Friday she rang in the afternoon, told [name omitted] who was coming on Monday, and who was coming next Monday, who might be a constant one and so we felt better about it. But yes, I would be prepared to handle that.

F: Because it’s not a great change to go from Level 1 to Level 2; it just puts you as I said, a bit more in the driver’s seat and cuts out that middle man, so to speak. So instead of the agency ringing [name omitted] and [name omitted] having to call you. If she’s not available then they actually ring and talk to you directly, which would give you that more control over it.

I: I think that’s a really excellent idea. That other part that you mentioned about cutting out the third—the middle man—is in my book, a good thing because it’s been falling down a little bit on us and I hate to be left wondering am I going to get a shower today or who’s coming, don’t we? (Level 2).

F: Okay. So the next question says do you consider self-directing at the next level, and if not, why not, what stops you, but you’re actually saying you’re considering the next level at the moment?
I: I’d like to. I think the aim is to put more on the participant’s shoulders and it’s up to you whether you want to grasp that or not. Well, frankly, I’d like to grasp it, but by the same token I’d like to think that there’s some support there if and when I needed it (Level 2).

F: So they’re the types of things that you might have an opportunity to be more involved in, would that interest you?

I: Not at the moment but I could see it could in the future (Level 1).

### 3. Administrative Burden

A key finding of the study is that the administrative burden associated with the PACS model was minimal. However, it is important to note that participants received significant support with administrative tasks from care coordinators. Table 3 below provides an overview of responses regarding the administrative burden associated with PACS.

<table>
<thead>
<tr>
<th></th>
<th>Level 1</th>
<th>Level 2</th>
<th>Level 3</th>
</tr>
</thead>
<tbody>
<tr>
<td>Manageable</td>
<td>1</td>
<td>0</td>
<td>12</td>
</tr>
<tr>
<td>Onerous or problematic</td>
<td>0</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>Self-direction not difficult</td>
<td>0</td>
<td>0</td>
<td>5</td>
</tr>
</tbody>
</table>

**Table 3: Administrative burden associated with the PACS model, by level of self-direction**

Twelve clients or carers self-directing at Level 3 described the administrative burden of the PACS model as manageable. Only one of these participants alluded to any administrative difficulties, commenting that the process took longer than it should have:

Well basically the only administration of it was phone calls, which unfortunately took way longer than they should have, because there was just poor communication at every end. So what should have been a two-minute conversation to get a decision made would often turn into half an hour, three quarters of an hour and three or four phone calls before you actually got sorted. So, yeah, that was the only administration side of it that was difficult (Level 2C).
Generally, the administrative tasks took 15 minutes each week or one to two hours over the month and involved checking the hours that had been used and making sure that any paperwork was in order.

4. Challenges or Changes for the Worse as a Result Of PACS

A total of 17 participants did not report any changes as a result of PACS. This is largely due to the fact that the majority of these individuals were self-directing at the lowest level, Level 1. However, none of these individuals reported any negative outcomes.

A small minority of participants experienced events that they were not satisfied with. In part, these were related to implementation issues. In part, they represent issues connected with the trade-off at the core of CDC where contact hours with a case manager are exchanged for more resources for direct services. Only two participants would not recommend PACS to others. Table 4 below provides an overview of these issues.

<table>
<thead>
<tr>
<th>Challenge</th>
<th>Total Sources</th>
</tr>
</thead>
<tbody>
<tr>
<td>Financial or reimbursement concerns</td>
<td>3</td>
</tr>
<tr>
<td>Having to carry through with the care plan</td>
<td>1</td>
</tr>
<tr>
<td>Less contact with case manager</td>
<td>1</td>
</tr>
<tr>
<td>Losing an existing case manager</td>
<td>2</td>
</tr>
<tr>
<td>Reduced services</td>
<td>1</td>
</tr>
<tr>
<td>Resolving (paid) carer issues</td>
<td>5</td>
</tr>
<tr>
<td>Clients would not recommend PACS</td>
<td>2</td>
</tr>
<tr>
<td>Less resources than before</td>
<td>1</td>
</tr>
</tbody>
</table>

**Table 4: Overview of key challenges associated with PACS**
i) Financial or reimbursement concerns (3 sources)

I: I was told this yesterday—because they have an exercise group before the men’s group on Friday I was told that [de-identified] and myself could go to that group and do some general exercises in the mornings. Now I’m told that if we do, now that we’re on Level 3, we will have to pay full cost. Because we’re no longer in the social inclusion, or we no longer pay towards the social inclusion (Level 3C).

F: Can you give me an example of anything that changed for the worse?
I: Just waiting for reimbursement [laughs]. Because prior to that they just paid for everything (Level 3).

F: What sort of trouble do you think that some people might get themselves into, when you say that?
I: Dollars and cents.
F: So overspending or not keeping good enough records?
I: Yes, that one (Level 3).

ii) Resolving (paid) carer issues (5 sources)

Red tape:
The implementation of CDC generates substantial ‘back of house’ challenges. Financial transactions and disbursements in particular can result in substantial delays due to the need to adhere to accounting standards. The PACS model included the use of a debit or stored value card to allow clients to pay for minor expense directly without involving the agency. The account statement was used to audit expenses. This approach worked very well. It provided the requested flexibility and cut bureaucratic red tape, while still offering adequate accountability.

The use of debit cards within a CDC context should be explored further.

Managing Paid Carers:
Managing paid carers who have become ‘part of the family’ can be very difficult for self-directing clients. Capacity building or case management support may be required to assist clients in dealing with these issues.

Some clients find it hard to manage paid carers. For example a participant at Level 1 described how he felt reticent about approaching a care worker about some aspects of her work that ‘aren’t really being done as they should’. He acknowledged that he and his wife had become ‘very friendly’ with the care worker and described her as ‘marvellous’. This was a challenge for him given that he was now contacting the care worker directly and the case manager is to some extent, out of the picture.
iii) Clients would not recommend PACS (2 sources)

F: All right, so would you recommend the programme to others?
I: Not as it was.
F: Not as it was, okay; and so you’ve kind of talked about some of the ways it could be improved, what do you think is missing in the programme? Anything different to what’s...
I: No, as before.
F: As before, okay.
I: Planning and communication are the two issues.
F: Planning and communication, okay. What do you think is working well?
I: Nothing worked well (F034).

I: You know what it feels like, you want my honest opinion?
F: Yeah honest.
I: It feels like the government wants to bamboozle the family members with more crap on their plate than what they’ve already got, because all it seems to be every time you speak to someone—why don’t you want to take it back on, why, but you can do this and you can do that, help, that’s not help. I mean for some people it might work well for them but having gone through what I’ve gone through, and what my family has gone through, logically I can’t see anyone wanting to take on more work than what they’ve already got on their plate. I don’t get that concept, I really don’t, like why—if you go through what you go through on a day to day basis why would you take on the responsibility of every time a carer doesn’t come into work that they’ve got to ring you, and you’ve got to ring them, and then ring the company, because the [name of agency] have still got to be involved, they’re still in the funding part of it (Level 1).

5. Barriers to Clients Self-Directing at a Higher Level

The PACS project aimed at building the capacity of participants in order for them to progress to the level of self-direction they aspired to and felt comfortable with. Eight participants
moved between levels of self-direction during the trial. The following table (Table 5) outlines key barriers of self-directing at a higher level by agency and by level of self-direction.

<table>
<thead>
<tr>
<th>Implementation Issues</th>
<th>Level 1</th>
<th>Level 2</th>
<th>Level 3</th>
</tr>
</thead>
<tbody>
<tr>
<td>Client unaware of the potential for higher self-direction</td>
<td>3</td>
<td>1</td>
<td>0</td>
</tr>
<tr>
<td>Clients confused or unaware of their current level of self-direction</td>
<td>4</td>
<td>2</td>
<td>1</td>
</tr>
<tr>
<td>Difficulty with English</td>
<td>3</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>Lack of self-confidence and strength to speak up</td>
<td>0</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td>Perceived lack of knowledge, authority, expertise</td>
<td>8</td>
<td>4</td>
<td>0</td>
</tr>
<tr>
<td>Perceived loss of case manager</td>
<td>1</td>
<td>0</td>
<td>1</td>
</tr>
<tr>
<td><strong>Client Issues</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Previous experience of changing care arrangements</td>
<td>2</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>Reluctance to change existing arrangements</td>
<td>1</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>Time and not wanting extra work or responsibility</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Carers</td>
<td>5</td>
<td>2</td>
<td>0</td>
</tr>
<tr>
<td>Clients</td>
<td>2</td>
<td>1</td>
<td>0</td>
</tr>
<tr>
<td>Desire for a period of consistency or stability</td>
<td>0</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td>Don’t want to or don’t want to handle money</td>
<td>4</td>
<td>1</td>
<td>0</td>
</tr>
<tr>
<td>Health issues</td>
<td>1</td>
<td>0</td>
<td>0</td>
</tr>
</tbody>
</table>

Table 5: Barriers to moving to the next level of self-direction, by level

6. How Can PACS be Improved?

Around one third of PACS participants thought that PACS could be improved by revising communication pathways and information content. Unsurprisingly, the majority of people offering suggestions regarding how to improve the model were self-directing at Levels 2 or 3. A substantial minority (see the table below) of participants self-directing at a higher level felt that PACS was too restrictive. However, a closer look at the interview excerpts below suggests that the restrictions were the result of implementation issues. For example, the PACS model offered the option for participants to employ family members or friends as long
Table 6 provides an overview of issues identified by participants.

<table>
<thead>
<tr>
<th>Issue</th>
<th>Total Sources</th>
</tr>
</thead>
<tbody>
<tr>
<td>Better communication and information</td>
<td>16</td>
</tr>
<tr>
<td>Greater flexibility</td>
<td>2</td>
</tr>
<tr>
<td>I don’t think anything can be improved</td>
<td>11</td>
</tr>
<tr>
<td>Information for CALD and visually impaired people</td>
<td>1</td>
</tr>
<tr>
<td>IT support for people at Level 3</td>
<td>1</td>
</tr>
<tr>
<td>More client control of finances and care arrangements</td>
<td>7</td>
</tr>
<tr>
<td>More support and better access to it</td>
<td>5</td>
</tr>
<tr>
<td>Someone to look at the whole picture</td>
<td>1</td>
</tr>
</tbody>
</table>

Table 6: Overview of issues to be improved

i) Better communication and information (16 sources)

Overall, participants found the information provided regarding PACS difficult to understand and full of jargon. Moreover, they questioned the case managers’ ability to convey the essence of what PACS was about.

F: So what do you feel could be done better at this particular level of self-direction, to enable you to operate at this particular level?
I: Very clear guidelines. We don’t have any.
F: Have you found self-direction at this level, Level 3, difficult?
I: No. Well, it would be easier if I had more information, meaningful information (Level 3C).

F: Okay, all right. So, what was missing in the project do you think? So, was it the...
I: Contact information. Case managers with limited information. Prior communication from the case manager to us, just not enough information up front. Yeah, clear guidelines on contacts. Not just phone numbers but contact names of who you’re needing to contact because when we did receive contacts there was just a business name and a phone number; and often you’d contact an agency and they would ask you who you needed to
Communication underpins clients’ ability to take advantage of choices associated with self-direction. Information regarding CDC should be very comprehensive and easy to read. CDC may disadvantage people with communication issues, visual impairments, or a lack of English language skills. The inclusion of these minorities needs to be adequately resourced and facilitated.

At a systemic level, bureaucratic processes and governmental guidelines (or their interpretation) tend to limit the flexibility and responsiveness of services. When implementing a CDC project it is enormously important to keep bureaucratic processes simple and comprehensive. To achieve this, better IT systems are required. The use of simple devices such as debit cards or stored value cards can provide much flexibility without putting a person or his or her care outcomes at risk. It is essential for governmental guidelines (or their interpretation) to afford clients the flexibility they require to achieve good care outcomes.

At a cultural level, CDC depends on a successful shift in professional practice. This may be challenging for organisations and staff and requires much attention.

Capacity building and support are crucial if clients are to reach their full potential in terms of self-direction.

iii) I don’t think anything can be improved (11 sources)

F: What do you think is missing in the programme?

F: Do you find that statement useful and easy to understand?
I: Well I had to write it out myself in my own words so that I could follow, because it’s very small print and I don’t have very good eyesight. I don’t really understand the bit on the front (Level 3).

ii) Greater flexibility (2 sources)

I hate to mention money again, that should give more flexibility and more choice of doing things or going places. Yeah, that’s the sad thing that we all get, you don’t have an unlimited amount of goods or assets and therefore you’ve got to just make a very strict choice (Level 2).

Yeah, more flexibility in people being able to hire their own carers and not having to do it through an agency if you don’t want to. You might have to have somebody there, like I mean somebody to set up the package in the first place and review it. You’d have to have somebody because they would have to have somebody to do it, but the state government has outsourced that part of it. They just pay money into the bank account each month (Level 3).
I2: What’s missing in the programme?
F: Yes.
I1: I can’t see anything that’s missing. I think everything works very well.
I2: It does (Level 2).

iv) Information for CALD and visually impaired clients (1 source)
F: What if you had the information—you could hear it? What if you had the information on a CD and you could play it and hear it in your language? Would that be helpful?
I2: [interpreted] That would be good. If she doesn’t understand she can listen and replay it again. At the moment you don’t have any information on CD, do you?
I1: [interpreted] Yeah, I wish that I can have both Chinese printing material and English printing material, because some of the Chinese translation is not that accurate.
F: So what would be useful is to have it both in English and in the first language, that way you can see the authentic document in front of you and compare. If you had information in your first language, how would that make it better for you, in what way?
I1: [interpreted] Because I’m thinking about, you know, I don’t have to make too much effort by understanding it, because some important issues, I would like to have a look at the English one, the original paperwork (Level 2C).

v) More client control of finances and care arrangements (7 sources)
F: So what was missing?
I: Paying for things yourself, the reimbursement’s slack.
F: The reimbursement process is difficult and slow?
I: Very, yeah.
F: Okay. What additional supports would be required to improve the experience?
I: Paying for it yourself, being in charge of the money yourself because their figures and my figures don’t match and yeah, you know that you’ve got this set amount and if you had to maybe make a phone call or then they could bill you for that, you know, yeah. To be in ultimate control and pay yourself (Level 3C).

F: So would you prefer to have total financial control perhaps? Do you think that would be an improvement in the system potentially?
I: Well, I think it would make it a more efficient system. I mean, it’s more work for me but on the other hand if they’re looking at ways to short circuit the thing and perhaps save on some costing, and that costing then came back to our benefit, it would warrant me then saying, well, I’m saving $2,000 a year in administration and that could be used for even a holiday or something or other, another benefit (Level 3C).

F: What do you feel could be done better?
I: Have ultimate control. Be in charge of the finances. Have a card and, like if I buy anything I’ve got to wait a whole month to get my money back, sometimes even six weeks. Having a card, or an account that you can just pay, yeah, pay as you go.
F: Yeah, so not having to wait for reimbursement and just having the funding.
I: Yeah, and then if you use the funding up, then tough shit, you’ve used it up. You either know how to do it at the beginning or don’t do it. If there’s any chance of spending it on alcohol or cigarettes or drugs or whatever and not on services, then don’t hand over the card, or you can withdraw the card, yeah (Level 3).

I2: The only thing you can say is lacking is if you had complete control of it instead of case managers, you know.
F: So you wouldn’t mind that? You like that idea of having complete control instead of having the case manager?
I2: Well if—but that way you’d have to control your finances as well, you know. It wouldn’t worry me at all. I don’t think it will ever happen. It would certainly be easier if you knew what you were—exactly how much you were allowed to spend or whatever (Level 3).

F: Is there anything you think is missing in this programme?
I: I think it could go further than it is at the moment.
F: In what way? How would you...
I: More about the finance part of it (Level 3).

The only thing I would suggest, and it’s not really—it doesn’t affect me—but I always think its sort double handling in that to cancel the cleaner I have to ring you people and you have to ring them (Level 1).

I: [interpreted] So if I know the budget, so that if I only have $200 and I have to plan, I say this month I’ll do the cleaning of the house and I won’t be able to do two things at once, gardening and the house. So this month I can do the house cleaning first, and next month I can go for the garden (Level 2).

vi) More support and better access to it (5 sources)

Well, we did have one meeting which was really useful, where we met other people who are doing it, and that was quite good. A lot more of that and a lot more support from the other carers (Level 3C).

F: All right, and was there anything else that was missing like in terms of peer support potentially?
I: Yeah, very slack. They need to, well they should have set up a group, given us the chance to exchange phone numbers if need be with other carers. Yeah, got us all together in the initial stages instead of doing ten home visits to do it all at once and everyone gets the correct information (Level 3C).
Mm, well it could’ve been more supportive I think. I think what’s missing is time to talk to the care manager. They don’t have enough time. I can email her or I can leave a message but we don’t have enough face to face contact. They just seem very stretched. Well I don’t think we see enough of the care manager (Level 3).

Maybe contacting us direct about the forums, and following up, like is there anything we can do to help you get here. Yeah, that would be good. I know one of them last year I didn’t find out until the day before, and I had to change that many things to get there and that was in Frankston, but yeah, I didn’t find out until the day before. That was bloody slack. I don’t know whose fault it was, but it was bloody slack (Level 3).

F: Yeah, well other people have identified things too, like there’s things like perhaps the idea of having a support group of other people managing, self-directing their own care could have been useful?
I: [Client heard about a support group meeting]... but it was way over the other side of town somewhere. It was too far to go. But it was too early the morning, which I couldn’t get there because of [client] anyhow. It was a discussion group on people who were doing this sort of thing, you know. I forget just where it was again but it was ten o’clock in the morning, I had no chance of getting there. It takes me two hours to come good when I get out of bed (Level 3).

7. PACS Model Components
The following segment highlights client experiences with a number of model components: care planning, the restorative/goals setting approach, and the self-assessment process.
Overall, clients found the model components useful. Only a small minority felt that they were unhelpful.
A) Care Planning

The care planning process was unanimously viewed as a positive experience. Table 7 below outlines responses to the care planning experience.

<table>
<thead>
<tr>
<th>Positive Experiences</th>
<th>Total Sources</th>
</tr>
</thead>
<tbody>
<tr>
<td>Client or carer feels able to complete care plan</td>
<td>20</td>
</tr>
<tr>
<td>Client feels able but has difficulty communicating on the phone</td>
<td>1</td>
</tr>
<tr>
<td>Client feels able but would rather case manager did it</td>
<td>2</td>
</tr>
</tbody>
</table>

Table 7: Overview of responses to the care planning process

i) Positive experiences (7 sources)

Well the process of working out that new care plan did work well (Level 3). [Case manager] did discuss it with me but she’s done most of it herself and I praise her for it. I am very, very happy and don’t want to lose [name omitted] in any way at all... [Case manager] has been number one with me and it’s only a matter of—in fact, she’s coming here tomorrow for a talk with me. But I only have to pick up the phone and—in fact all the girls at [name of agency] have been very good; most of them know me by name and if I can’t get [case manager] they’ll try to assist me wherever possible (Level 1).

ii) Client or carer feels able to complete care plan (20 sources)

Well yes, because we went through different care managers, we finally I wrote our care plan and gave it to [case manager], and she took it away and she came back with a version of it, which it more or less covers but the one thing, for instance she put down providing the meals for nutritional supplement when in actual fact what I meant was having to pay for the Ensure that we were getting for [client] which was to try and fatten him up a bit. He lost so much weight (Level 3).
What I need? Yes I think I could, now. I think I would be capable of doing that now. Yes, when I first started I was at a loss to know what I had to do. I don’t think I was thinking logically at all. I lost my concentration terribly; I stopped reading and a lot of things happened to me that were very bad for me and I’m beginning to pick up now (Level 1).

iii) Client feels able but would rather case manager did it (2 sources)

I could do it, but I would rather not. I would rather have my case manager (Level 1).

B) Restorative Approach/Goal Setting

The majority of clients appreciated the restorative, goal setting approach and regarded it as valuable (see Table 8 below). Only 2 participants thought of the process as not useful. One client would have liked to participate in goal setting but apparently was not offered that option. Table 8 suggests that the perceived benefit of the restorative approach was not influenced by the level of self-direction.

<table>
<thead>
<tr>
<th></th>
<th>Level 1</th>
<th>Level 2</th>
<th>Level 3</th>
</tr>
</thead>
<tbody>
<tr>
<td>Client would like to have been asked</td>
<td>1</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>Discussion about goals positive and useful</td>
<td>7</td>
<td>6</td>
<td>5</td>
</tr>
<tr>
<td>Goals documented even though client not engaged in PACS</td>
<td>0</td>
<td>1</td>
<td>0</td>
</tr>
<tr>
<td>Goals identified and achieved—examples</td>
<td>4</td>
<td>4</td>
<td>4</td>
</tr>
<tr>
<td>Lack of consideration of carer’s goals</td>
<td>0</td>
<td>0</td>
<td>1</td>
</tr>
<tr>
<td>Language not right</td>
<td>2</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>Living day to day, surviving</td>
<td>4</td>
<td>2</td>
<td>0</td>
</tr>
<tr>
<td>Not useful</td>
<td>1</td>
<td>0</td>
<td>1</td>
</tr>
<tr>
<td>Unsure, vague or no recollection</td>
<td>5</td>
<td>3</td>
<td>2</td>
</tr>
<tr>
<td>Useful but unproductive</td>
<td>1</td>
<td>0</td>
<td>0</td>
</tr>
</tbody>
</table>

Table 8: Overview of responses regarding the restorative approach by level
i) Discussion about goals positive and useful (18 sources)

Okay, well I think from my point of view it was a good way of illustrating to the care manager just what [male’s] needs were (Level 3).

F: What do you think’s helpful about that process?
I: Well, the case manager’s trying to help you, you know (Level 1).

Well because it’s something I like doing, number one. Number two, it keeps your marbles going, it gives you a reason to get up and get dressed and go out and you’re communicating with other people (Level 2).

Oh well, some things that I mightn’t have known about that you know could be done for me (Level 1).

Well, basically expressing what I wanted to do with the tail end of my life. I mean, I keep saying, you look at retirement and the things that you’re going to be doing, well, now I’m just as restricted or more restricted than when I was working (Level 1C).

ii) Living day to day, surviving (6 sources)

Clients expressed that they were ‘too old’ or were past thinking about goal setting. A sense that it wasn’t relevant or worthwhile.

C) Self-Assessment Process

For the majority of participants, the self-assessment process was either an unmemorable or a positive/helpful experience. Nevertheless, people with cognitive or significant health
issues found it harder to complete the self-assessment form. Also, two people with a limited knowledge of English were unable to complete the process as the translator was unable to translate the meaning of the questions into the given language. For more information regarding the self-assessment process, see Ottmann and Milicer-Stagg (2012). Moreover, client scores were very similar to scores provided by their case managers.

<table>
<thead>
<tr>
<th></th>
<th>Total Sources</th>
</tr>
</thead>
<tbody>
<tr>
<td>Client unsure or unable to recall the self-assessment process</td>
<td>20</td>
</tr>
<tr>
<td>Self-Assessment was positive and helpful</td>
<td>20</td>
</tr>
<tr>
<td>Negative experiences</td>
<td>7</td>
</tr>
</tbody>
</table>

Table 9: Overview of responses regarding the self-assessment process

i) Clients unsure or unable to recall the self-assessment process
A large number of clients (n=20) had no recollection of the self-assessment form or process, or were unsure whether it was helpful.

ii) Positive and helpful
The same number of clients (n=20) described the self-assessment process as positive and helpful. The process assisted clients with the following:

- Becoming aware of what was available in terms of services and equipment (Level 2)
- Raising issues they may not have thought about
- Clarifying expectations

The self-assessment process also gave the agency a clearer picture of the client’s needs and what the client could and could not do (Level 2). The process was described as ‘straightforward’ (Level 3) and ‘quite easy to do’ and ‘not hard’ (Level 2).

iii) Negative experience
A smaller number of clients (n=7) had a negative experience of the self-assessment process. Here are some examples of what they said:
We went through a process of self-assessment which was quite, well it was confusing for me because it didn’t lead, it didn’t cover everything. There was no consideration of medical illnesses, in my opinion. It was all about social issues and all, I don’t know (Level 3).

That was a bit confusing. The terminology in that, when I spoke to someone on the phone, they went, ‘Oh, well, we took that from an English programme or something like that.’ Oh, I don’t really know what this is. When did I miss that bit in the writing? Most of it was okay but there was just one section and I thought, I have no idea what to say. Not particularly useful for us (Level 1).

8. Role of Case Managers within a CDC Model

The majority of participants were satisfied with the role the case manager played within PACS. Some participants explained what a case manager should do to improve the service. Communication issues were among the most frequently-mentioned issues to be improved. Table 10 provide an overview of these issues.

<table>
<thead>
<tr>
<th></th>
<th>Total Sources</th>
</tr>
</thead>
<tbody>
<tr>
<td>Ask what the client needs rather than assume</td>
<td>3</td>
</tr>
<tr>
<td>Assist with carers, respite and accommodation</td>
<td>5</td>
</tr>
<tr>
<td>Assist with issues as they arise</td>
<td>2</td>
</tr>
<tr>
<td>Be a backup and available</td>
<td>4</td>
</tr>
<tr>
<td>Be more thorough</td>
<td>1</td>
</tr>
<tr>
<td>Be more transparent about funding arrangements</td>
<td>5</td>
</tr>
<tr>
<td>Communicate—listen, anticipate questions and needs, keep in touch</td>
<td>7</td>
</tr>
<tr>
<td>Give client more control and independence</td>
<td>6</td>
</tr>
<tr>
<td>Help clients achieve goals</td>
<td>1</td>
</tr>
<tr>
<td>Nothing more than what is currently being done</td>
<td>29</td>
</tr>
<tr>
<td>Provide a better understanding of what is available</td>
<td>11</td>
</tr>
<tr>
<td>Respond in a timely manner</td>
<td>2</td>
</tr>
</tbody>
</table>

Table 10: Overview of responses regarding the role of case managers
The PACS evaluation demonstrates that, despite best intentions, case managers may limit the decisional authority of their clients. An ongoing mentoring process and peer discussion forum focusing on working with clients rather than for them works well to facilitate the required practice change.

Staff turnover and the presence of locums weaken the communication link with clients. Service providers have to put in place a thorough induction and handover process for new staff and locums if clients are not to be placed at risk. While this hold true for conventional case management, this is particularly the case for CDC.

As clients take on more responsibilities, communication links are weakened. The PACS evaluation suggests that older people self-directing at a higher level require additional safeguards in the form of agreed upon circles of support that transmit information and can step in in case of an emergency.

i) Ask what the client needs rather than assume (3 sources)

I would say that probably the biggest issue has been case managers coming in and believing they know what we need; rather than asking what we need. We have run into some real problems with that over time (Level 2).

ii) Assist with carers, respite and accommodation (5 sources)

The other thing which would be nice to know is for respite, which they say you must have, or are meant to have so much respite, which I don’t seem to get around to doing (Level 3).

I guess we seek guidance on the equipment side (Level 3).

iii) Be a back-up and available (4 sources)

Just be there as a back-up (Level 3C).

Well the ideal situation is that she’s there, she’s my backup, she’s—well, when I can find her—when she’s available—our only conversations these days is via email because I’m one of the very few people that have IT knowledge and that—we talk on the Internet (Level 3).

iv) Communicate—listen, anticipate questions and needs, keep in touch (7 sources)

Well I’d like her to keep in touch a little because she comes up with new information that I’m not necessarily aware of, so that would be one reason (Level 1).
Well, get some anger management for one thing and the other thing, listen to what I’m saying and well, don’t be so bossy (Level 1).

F: And you mentioned earlier that the previous case manager could speak Greek and that was helpful.
I: Yeah it was for my mum and my dad, like if my dad needed to ring to ask a question or whatever, at least he could communicate with that person (Level 1).

v) Give client more control and independence (6 sources)
Well, everything still has to go through them... I want to be in charge, 100 per cent (Level 3C).

My expectations would be for them to hand over more control (Level 3).

But as far as—I would much prefer if I had to change—I have an hour on Monday and an hour on Friday for just help with things that I haven’t been able to manage during the week and if I want to change those times it seems silly to me to ring [name of agency] who then gets in touch with the agency that they use. So I’d much prefer to go directly to the agency; that would be much better—I could manage that easily (Level 1).

Oh, eventually I would take right over. He’s very good so everything is—there’s much has been done, but you still have to go through certain people until this real consumer-directed care is understood by the agencies and the council. But it’s still work that they have to, but he’s very good. So ultimately I’d be doing it all myself if they believe (Level 2).

Well, I’ve always felt, because I’m still fit and I feel capable, I’ve always felt somehow it would be easier for me to contact various people. For instance when the Home Care people, when I couldn’t receive them here, it would be just as easy for me to ring direct and say, ‘Well, don’t come this week
because I won’t be available.’ Don’t ring the care manager and then she does it. I feel, myself, that those girls are usually pretty busy one way and another and if I can sort of do a little bit to help relieve them I’m perfectly willing (Level 1).

**vi) Provide a better understanding of what is available** (11 sources)

Oh, give some idea of what we can realistically ask for and be available if there are questions and visit occasionally (Level 3C).

Just to provide a better understanding of what services that we have available to us. I’ve never had a suggestion of anything from a case manager. Yeah, which I’ve just found interesting and a little bit disheartening. Like I say, it’s always been open to me to speak up and say what I want or need but by the same token there’s very little information about what I can and can’t ask for. So, I suppose in the carer’s role there’s a reluctance to even ask (Level 2C).

We want to have self-direction and more choices without making too much effort. Because we don’t want something that exceeds our strength (Level 2C).

Explain in detail what is it possible and what is not possible (Level 1).

**vii) Respond in a timely manner** (2 sources)

Well, you’ve still got to go back and get permission to add or change, there’s only a small window, 10 per cent or something, that you’ve got. So that’s a pain in the bum because you’ve got to either email or ring. Like, last week I asked something on the Monday and by the Friday I still hadn’t got a reply. That pissed me off [laughs] (Level 3).
9. Role of Paid Carers Within a CDC Model

A number of participants offered comments on what role paid carers should play within a CDC model. Table 11 provides an overview of these responses. Several provided incisive criticism regarding the performance of paid carers. In particular, several clients commented that their paid carers did not complete the tasks as requested.

<table>
<thead>
<tr>
<th></th>
<th>Total Sources</th>
</tr>
</thead>
<tbody>
<tr>
<td>Be a helper, have my care at heart first and foremost</td>
<td>7</td>
</tr>
<tr>
<td>To do what a client asks</td>
<td>5</td>
</tr>
<tr>
<td>Various issues with paid carers</td>
<td>8</td>
</tr>
</tbody>
</table>

Table 11: Overview of responses regarding the role of paid carers

i) Be a helper, have my care at heart first and foremost (7 sources)

To have my care at heart first and foremost. I consider a carer to be a helper, not a servant. No. Someone who’s helping me by doing those things that I can no longer do easily or properly (Level 3).

ii) To do what the client asks (5 sources)

Basically what you ask her to do, within reason, and not argue (Level 3).

Well, the carer that comes to your house, she’s fabulous, because she listens to me (Level 1).

ii) Carer issues (8 sources)

The responses indicate that the quality of paid carers differs widely. Whereas some participants reported issues regarding managing carers while getting emotionally attached to them, others described situations of professional misconduct, disrespect, and very poor caring skills. This is an issue that requires more attention from the agencies.
10. Implementation Issues
While all agencies worked hard to implement PACS, and the majority of case managers received praise for their effort in relation to PACS, some implementation issues undermined the trial and, ultimately, the ability of clients to self-direct their care package. Key among them were that some case managers continued to make important decisions for clients, rather than with them and that information about how much money was available to a client to purchase direct services was frequently not provided. For example, some case managers appear to have decided for their clients whether they are eligible for self-direction, at which level they ought to self-direct, or whether they should be involved in information sessions and only forwarded information to a select few.

Interestingly, clients self-directing at a higher level (and probably the most advantaged clients in the evaluation) were concerned that the ‘squeaky wheel’ effect would disadvantage them. For example, clients who were successfully self-directing felt that their case manager no longer regularly conducted reviews and that they were left to their own devices. It is imperative that face-to-face reviews, including a new self-assessment if conditions have changed, are conducted either in three-monthly (if the client is new to self-direction) or six-monthly (if the client appears to self-direct successfully) intervals. Moreover, it is important that the client is aware of the review process.

Case managers are very well regarded on the whole, but they are also universally forgiven by their clients for being ‘so busy’ that they do not visit very often, and for not advising the client about moving to other levels, or for not formalising the level that they are operating at. A number of clients clearly performed at Level 2, but did not receive the financial incentives associated with that level.

In a few cases, high turnover of case management staff or the involvement of locums led to confusion and a lack of continuity in carrying out the project with participants.

A) Involvement in Care Planning and Decisions about Level of Self-Direction
The PACS project aimed to increase clients’ decisional autonomy. Despite this, case managers appeared to have made important decisions for clients rather than with them.
Table 12 summarises participant responses regarding their involvement in the decision making process.

<table>
<thead>
<tr>
<th></th>
<th>Total Sources</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Decision about level of self-direction made by agency</strong></td>
<td>6</td>
</tr>
<tr>
<td>Decision about level of self-direction made by client</td>
<td>8</td>
</tr>
<tr>
<td>Decision about level of self-direction made collaboratively</td>
<td>13</td>
</tr>
<tr>
<td>Client unsure who made decision about level of self-direction</td>
<td>1</td>
</tr>
<tr>
<td>Clients/carers were involved in care planning process</td>
<td>24</td>
</tr>
<tr>
<td><strong>Client or carer had limited or no involvement in care planning</strong></td>
<td>7</td>
</tr>
<tr>
<td>Client unable to complete own care plan</td>
<td>5</td>
</tr>
<tr>
<td>Clients/carers lack knowledge or confidence to complete care plan</td>
<td>5</td>
</tr>
<tr>
<td><strong>Old care plan was copied without revision or client involvement</strong></td>
<td>2</td>
</tr>
</tbody>
</table>

**Table 12: Responses regarding involvement in decision making**
i) Decision about level of self-direction made by agency (6 sources)

The decision was made for us. I had been asking for some time and then the care manager I think she rang up and she said there’s a position available for self-directed. Now, what I have since found out—yesterday—is that we actually are fully on self-directed care as well as apparently being on it with PACS as well (Level 3C).

Well the decision was made for us, we could now have Level 3... See it says in here that we were meant to go before a self-direction team, I had that noted, but I have never seen them (Level 3).

I was just told, ‘You’re on it.’ Yeah, case manager just said you’d be good at this (Level 3C).

F: Do you remember making a decision that the case manager would take on the task of phoning up workers?
I: No, no, no, no. No, they just told me they had a housekeeper for me and that was it (Level 1).

ii) Clients/carers were involved in care planning process (24 sources)

F: Would you say to what degree were you involved in preparing the care plan?
I: A lot... Where I suppose we did most because they maybe suggest, but they don’t dictate. We did most.

iii) Client or carer had limited or no involvement (7 sources)

Prior to the package that she’s on now I was never part of it and it all happened before I was a full-time carer. So the package
that she’s on now yeah, I was consulted to a degree. I was more told how it was going to be. Mmm, it wasn’t open to a lot of discussion (Level 2C).

No, I didn’t decide. They decided (Level 1).

At that time being first off no, I had no say in nothing, no. I was almost becoming a vegetable in the way that I couldn’t shower myself. Most of the times I had to be fed, and then like I wasn’t even thinking properly and sometimes without knowing it I’d be talking about things that I didn’t even know I was talking, it would just come out of my mouth, you know and I thought now why’d I say that for, you know (Level 2).

Well it’s inadvertent that we came up with a good plan, because we were probably told this was what we had to do, and what was unfortunate was all the cloak and dagger about doing it. Of course the frustrating issue of it was that all of that could have been discussed with us and we would have been completely agreeable to it (Level 2).

I: I think the case manager sort of came into it. She arranged everything.
F: Have you ever seen your care plan? Have you seen what it looks like? Your actual care plan?
I: No, and I don’t want to see it (Level 2).

iv) Clients/carers lack knowledge or confidence to complete care plan (5 sources)

No. Because I don’t know the prerequisites. I don’t think I have enough information (Level 2).

Solely by ourselves? No, I don’t think so. Probably if I was shown what was involved in doing a plan, yes, but just thinking straight off no, probably need a bit of direction (Level 1).
v) Old care plan copied or care plan ‘ready prepared’ (2 sources)

They just copied the old care plan, so they stuck with that (Level 3C).

I think in the beginning there wasn’t, I don’t believe, a satisfactory care plan because it came ready prepared, we didn’t really, I asked what could we have and I was told well you tell us what you want. That became a bit of a stalemate because I wasn’t sure what I could ask for. I was waiting for direction and it didn’t come, because, yeah. When I was working in my role I used to give people guidelines. That’s right, and we didn’t have, I expected follow-up visits from the care manager which didn’t happen (Level 3).

B) Financial Information and Transparency Issues Undermining Clients’ Decisional Autonomy

Despite the fact that financial transparency was one of the key aims of PACS, around half of the participants in PACS were unaware of the money available to them for care services. Moreover, 20 participants did not receive financial statements. Table 13 provides an overview of responses regarding financial transparency and issues regarding the way in which the information was provided.

<table>
<thead>
<tr>
<th>Issue</th>
<th>Level 1</th>
<th>Level 2</th>
<th>Level 3</th>
</tr>
</thead>
<tbody>
<tr>
<td>Client grateful, not wanting to argue about financials</td>
<td>1</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>Clients not receiving statements</td>
<td>11</td>
<td>6</td>
<td>3</td>
</tr>
<tr>
<td><strong>Clients unaware of money available for care services</strong></td>
<td><strong>16</strong></td>
<td><strong>12</strong></td>
<td><strong>3</strong></td>
</tr>
<tr>
<td>Money from CAPS packages used for social inclusion programme</td>
<td>0</td>
<td>0</td>
<td>1</td>
</tr>
<tr>
<td>Need for more explanation and transparency</td>
<td>6</td>
<td>2</td>
<td>5</td>
</tr>
<tr>
<td>Statements - late, hard to understand, contain inaccuracies,</td>
<td>3</td>
<td>2</td>
<td>8</td>
</tr>
<tr>
<td>missing important information</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Table 13: Issues with financial information and transparency, by level of self-direction
i) **Clients unaware of money available for care services** (32 sources)

F: Okay, so do you know how much money there is available to purchase care services for your Nan?

I: No.

F: So you don’t know? No. So you don’t remember how that amount was determined and...

I: No, it’s a definitive no. I don’t have and I have never had any idea of what... (Level 2C).

I just want to know how much in advance. Because there’s ways I would rearrange things if I knew exactly how much money was there (Level 3).

F: In terms of the care package do you know how much money you have available to purchase care services?

I: Yes, and I know we’re overspending it.

F: Okay [laughs]. So you do know...

I: I didn’t until quite recently. The only thing that I was disappointed in is that there was nowhere written down what could be done. It was, ‘What would you like done?’ and unless we know what can be done you don’t know what to ask for (Level 2).

F: So your case manager in this instance organised a change of a service provider to another in this case, meal assistance. Is that something that you could have... Could you have done that for yourself?

I: No, up to a point I could have, but I wasn’t sure whether we were allowed that many meals.

F: So you weren’t aware of your budget really.

I: No.

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*Financial transparency forms the very basis of CDC. Without financial transparency, clients are unable to make informed decisions. Before implementing any other aspect of CDC, service providers should make sure that their clients are informed about their entitlements and care budget and receive regular financial statements that are easy to read.*
F: So you weren’t aware of your budget, but if you were aware of your budget, could you have gone ahead and got in contact with the dining room here and...
I: Oh yes we could have done that, yes (Level 2).

ii) Need for more explanation and transparency (13 sources)
Yeah. I felt the financial point of view was not listed, satisfactorily wasn’t listed. I felt that you needed more of a breakdown or explanation of that.

The only thing that I was disappointed in is that there was nowhere written down what could be done. It was, ‘What would you like done?’ and unless we know what can be done you don’t know what to ask for (Level 2).

Yes so she’s always saying ‘Can’t afford this, can’t afford that’ and I think Well... what can I afford? How much is there? (Level 1).

Yeah, you know what would be good, I get an invoice sent out to me every month about when the money is gone, what would be good would be like an Excel spread sheet that could get done by the case manager to say right with these individuals this is how much is allocated out of the fund to them. Then you’ve got so much left over, so this is what we’ve got to play with, so you can maybe get an extra couple of massages for your mum, or get an extra couple of days here in home care help. You might have all the funds in the world there and if you don’t use it you lose it and it goes to somebody else that’s gone over their budget, and they pull that money out of your loved one’s package to subsidise someone else’s, that’s what I’m saying about the Excel spreadsheet, I don’t know exactly if my mum is using her full capability of her package (Level 2).
iii) Statements—late, hard to understand, contain inaccuracies, missing important information (14 sources)

Well, fairly easy to understand except the figures at the front are not terribly easy to understand. They talk about CACP packages and CDC packages and previous. The dates, well the care manager did tell me that on the November/December statement—which I got together—they put wrong dates anyway. So, but it’s relatively easy to understand except that what I get here, apparently, is what was available for January. Well, January’s nearly over so it’s a little bit late to know. But, I suppose it’s not possible if the bills haven’t come in. The other thing that doesn’t happen is the CabCharge bill is not on it at all and we have been using CabCharge to go to Glen Iris to see a specialist for my husband; and that’s quite a bit. It’s over $40.00 each way using his half fare voucher. So it’s at least $80.00 a month for that (Level 3C).

Always makes mistake, there’s 90 per cent of each month I’ve had to email and say—I still haven’t got December, which is very slack—even the last one I received, November, there was a mistake, overcharged me on something (Level 3).

It was always a month behind when we got it, so we’d get November at the beginning of January, say (Level 1).

F: Do you receive a monthly financial statement?
I: Yes, which I can’t quite understand I must say. So, yes, I can see that the two services, the two house services what they’re costing me. But I couldn’t; ‘notional monthly budget,’ well, I gather that’s notional. I must have a monthly budget. But, notional, I don’t know what the notional—I must have a fixed monthly budget, mustn’t I? (Level 1)
C) Enrolment Process

A total of 28 of the participants enrolled in PACS commented that they received sufficient information about the project, principally from their case managers:

Yes, [case manager] was very good. I was very happy and very contented and at ease with [case manager]. She had a way of condensing, and the same as you, you’re very much like [case manager] in the way you [unclear]. No, I think that goes to the level of experience of our case manager. She would always ask the questions and help us to fill in the forms. It didn’t seem any strain (Level 2).

However, a number of participants voiced criticism regarding the enrolment process:

i) Insufficient explanation or information during enrolment in PACS (3 sources)

It was very patchy and it came without explanation or whatever it seemed to say it was contradicted by people I spoke to (Level 3C).

Oh I remember having a discussion with [name omitted], my case manager, and we’ve had two or three discussions about it and the times that we’ve had to put in, [name omitted]’s had to put it aside because there’s been other things that I wanted to talk to her about that took time and she’s a busy woman too. She’s giving us as much attention as she can with it, and I think that it does tend to get a bit over the fence, the paperwork (Level 1).

ii) Poor planning and communication (3 sources)

F: So, how would you describe your experience of enrolling in the People at Centre Stage project?
I: Yeah, confusing. It was a great concept with what seemed to be very little planning and quite poor communication. Yeah, and if I found it

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Written information that explains the CDC process should be very comprehensive and easy to understand. Make sure that the key message is summarised in not more than one page. Augmentative communication tools may be useful to explain CDC.
difficult as a carer I can only imagine how elderly people found it (Level 2C).

Yeah, it seemed a great concept but just not thought out thoroughly. You know, what occurred to me reading it was that it was filled with a lot of modern legal jargon that at times I sat there shaking my head. It did occur to me, I thought if this is problematic for me what’s this going to be like for someone elderly who doesn’t understand all this? That was probably the predominant thing when reading it, yeah. I thought that’s too difficult for people in Nan’s position, yeah. A wee bit more plain English, perhaps (Level 2).

iii) Too much information or difficult to understand (5 sources)

Well, some of it was a bit complicated. We might have struggled a bit sometimes—when you get a bit older, you know—so yeah (Level 3).

Yes I think I understood what the whole idea is behind it: to be more independent, manage my own affairs and everything like that. So I have got a good overall view but I wasn’t sure of the smaller details like when it was actually coming into effect and what I was exactly expected to do. You know I still didn’t know if I should be ringing the case manager or what. So perhaps I didn’t quite get the whole gist (Level 1).

I: I think I was supposed to do that, and she was supposed to come back and pick it up but she never came back to pick it up.
F: So you did receive that, but she didn’t come and pick it up?
I: Yeah.
F: Did you look through it at the time?
I: Yes.
F: How did you find that information? Did you find it easy to understand?
I: No (Level 1).
D) Timely Access to Technology

Two participants commented on the lag and lack of follow-through regarding technological aids.

Yeah, which you can’t do the research to find out which service provider is the best one until you’ve got a service provider so that’s been very slow. We had a couple of patches, case manager went on long service leave, had sickness, another bash of long service leave, you know. Sometimes it might all flow better than we found it but he’s been good doing stuff but... it just seemed incredibly slow. We got this beautiful big monitor and I managed to make the actual cursor bigger. That’s the other thing, too. Someone from Deakin said, ‘Oh, we can do that with a laptop. Oh, I think there’s one sitting around here.’ We never heard any more about that. That was 12 months ago.

E) Circles of Support

Although case files generally stated that a circle of support had been established, only two clients knew of this. It is unlikely that a circle of support provides much support to a client if s/he is unaware it exists.

F) Support

While the majority of PACS participants felt that sufficient support and information was provided, a minority expressed that more support and capacity building was required for them to be able to take advantage of self-direction. Table 14 provides an overview of associated responses.
<table>
<thead>
<tr>
<th>Sources of support:</th>
<th>Total Sources</th>
</tr>
</thead>
<tbody>
<tr>
<td>Sufficient support with PACS and self-direction</td>
<td>25</td>
</tr>
<tr>
<td>Insufficient support with PACS model and self-direction</td>
<td>6</td>
</tr>
<tr>
<td>Case manager or agency</td>
<td>27</td>
</tr>
<tr>
<td>Family or community</td>
<td>10</td>
</tr>
<tr>
<td>PACS research team</td>
<td>8</td>
</tr>
<tr>
<td>Unsure if support was adequate</td>
<td>2</td>
</tr>
</tbody>
</table>

Table 14: Overview of responses regarding the level of support provided

G) Communication
A significant number of clients (13) had no recollection of being told about PACS or had a poor understanding of PACS:

I’ve never heard of it until I got what you were saying, I’m trying to write it down, you know (Level 1).

To some degree, this may be related to the cognitive decline some of the participants experienced. However, around half of this group experienced case management issues during the PACS trial (locum, long service leave etc.) and may not have been adequately informed.

H) Management of Client Expectations
A number of clients did not know how their budget was established or how much money they were entitled to. This lack of transparency contradicts the basis of PACS and should be urgently addressed.

I think my case manager [de-identified] is willing to do but I don’t think she got money to do things, you know, to pay people. So I don’t think I could say that because if you not have sources to do, how can I say what she has to do? Yeah, I think they are getting shorter with money and they have problem and not going in, but I don’t say what she has to do because she has no hand open to do whatever she would like to do, maybe, I don’t know, but whenever I talk for something they are short of fund (Level 1).
She knows; she has to do the things that I needed; to organise. I don’t know. [Interpreted] Okay, so if there was more financial availability that would be good (U029).

11. Other Issues

It appears that the physical and mental health needs of a number of clients we interviewed were insufficiently addressed. For example, clients had to discontinue the interview because they were in too much pain or because they were too depressed. Indeed, health challenges and complex medical conditions made it difficult for some participants to take in the idea of self-direction. Some participants seemed to feel overwhelmed with the day to day challenges of their illness or chronic condition and did not seem to have the energy to think about self-direction.

Also, participants had varying levels of support from family carers. Some were quite isolated and had high levels of dependence on services/case manager as their support.
DISCUSSION

The tiered approach of PACS brings to light more clearly the preferences of older people regarding self-direction. By self-selecting into the different levels of self-direction, participants indicated the aspects and extent of self-direction they were interested in and willing to take on. Out of a total population of approximately 660 older people receiving aged care packages (Linkages, CACPS, EACH or EACH-D) eligible to participate in the intervention arm of PACS, a total of 158 expressed interest. Of these, 87 clients signed the informed consent form and enrolled in the intervention group at baseline. Of these, 61 participants remained in the intervention group at the end of the trial: 29 were self-directing at Level 1, 18 at Level 2, and 14 at Level 3. In other words, out of a total population of around 660 potential participants, 14 clients (or around 2.1 per cent of the total eligible population) chose Level 3 in order to exercise greater control over administrative and financial tasks. This figure is in line with the international research literature focussing on the UK and the US (Foster et al. 2005). Figure 2 below provides a graphic overview of these outcomes. Hence, older Australian’s preferences regarding self-direction are only in a very limited sense motivated by greater control over finances. A by far larger number of clients (around 77 per cent of the people in the intervention group) were interested in self-directing aspects of their care resulting in greater decisional authority or better and more direct access to services. Hence, a focus on financial aspects of self-directing at the expense of other aspects misses the point.
The PACS model delivered important improvements to participants’ care outcomes in the domains of decisional authority, responsiveness of services, and social connectedness. However, participants at the different levels of self-direction experienced PACS in distinctly different ways:

**Level 1:** At Level 1, participants were overall less well engaged with the project and with the idea of self-directing care. There were a variety of reasons for this lack of engagement, some related to the personal preferences of participants. Others appeared to be related to circumstances including complex health and medical issues, a decline in health, confidence and capacity to cope with managing their affairs. In some cases there also seemed to have been a lack of engagement with the project on the part of some case managers, and a lack of information about the project flowing through to participants. In some cases the disengagement appeared to be the result of a high turnover of case manager staff during the project timeframe.

Participants at Level 1 generally reported high levels of satisfaction regarding services provided by agencies and case managers. Case managers were sometimes perceived as a
crucial support person in participants’ lives. Many at this level did not express a great deal of motivation to take more control of the administration of their care package, with some exceptions.

**Level 2:** Participants self-directing at Level 2 generally demonstrated a higher level of awareness of the PACS project and a greater familiarity with the concept of self-direction. Their reluctance to progress to the next level of self-direction appeared to issue from a number of sources, including health and medical issues, a lack of energy, or a perceived lack of skills (IT, bookkeeping). Others felt reluctant to challenge the status quo in relation to their case manager.

Participants at this level of self-direction generally appreciated the greater efficiency of coordinating their own care workers by cutting out the middle man, and not having to communicate with paid carers via their case managers. Some participants were positive about the greater flexibility it gave them to re-schedule visits on the spot instead of having to wait for their case manager to change arrangements. They also commented positively on the fact that they were able to have a greater influence in the hiring of paid carers.

Barriers to progression to Level 3 included a lack of confidence regarding bookkeeping, computers, and email. Others stated that they did not enjoy dealing with financial decisions. In some cases, health and medical conditions made it difficult for participants to contemplate taking on responsibility for budgeting tasks.

**Level 3:** This group of participants was largely composed of very active family carers who were committed advocates for the people they cared for. Some had experienced the disability support system. One participant overcame the limitations of a very debilitating condition and was highly motivated to self-direct the care package. Participant at this level were generally very confident with the idea of self-directing their own or their family member’s care and keeping track of financial information. Some participants had a career background in management or had professional knowledge of the health sector. Most had taken the initiative to investigate their options and were aware of CDC (see also, Glendinning et al. 2008).
All carers/participants at this level seemed very positive about the idea of self-direction and liked the greater control it afforded them. One participant expressed that he was regaining control over his circumstances and that this had improved his satisfaction with his life in general. The majority of participants stated that their case manager was very supportive.

Some participants expressed frustration at the lack of clarity about what they were entitled to in their care package. Some expressed frustration about the fact that there was a delay in receiving financial statements from some agencies, which resulted in an increased challenge to plan ahead in terms of budget spending and allocation of funds for services and items. Some carers wanted complete control over their packages. Others were frustrated about the delay in communication due to the part-time engagement of care professionals. Several participants would have liked more choice in service providers. For example, one participant expressed that he would have liked to have employed the same gardener as his neighbour as they shared a driveway and some garden. However, this particular gardener was not approved by the agency. One participant carer expressed that she had felt unsupported by one particular previous case manager in her goal for increased self-direction, leading to a certain amount of conflict. Some participants commented on a lack of clarity regarding roles and boundaries between case managers and carers. Several carers commented on occasional communication breakdowns between them and their case managers.

Some participant carers expressed that more peer support group access would have enabled them to share information and support with others. Around 10 support forums were held over the course of the project. It appears that participants at that level were unable to attend most due to a variety of reasons.

Participants at Level 3 experienced the boundaries imposed on the project by government guidelines and legislation. The issues experienced were the inability to have complete financial control of their family member’s package and limited choice in relation to service providers.
While the benefits experienced as a result of PACS were more clearly felt at a higher level of self-direction (see also, Glendinning et al. 2008), the PACS model generated positive outcomes for all three groups. However, particularly at lower levels of self-direction, older people’s ability to take advantage of self-directed care depended largely on support, encouragement, and capacity building. Without these elements in place, it is likely that CDC is of benefit only to a small, rather privileged minority of clients. The vast majority of participants found the planning process and administrative burden associated with PACS manageable. The PACS evaluation suggests that if kept minimal and comprehensive, older people deal well with self-directing aspects of their care services. Bureaucratic processes in conjunction with a restrictive interpretation of guidelines tend to limit flexibility and choice. Simple solutions, such as a debit or stored value card can be used to cut red tape and facilitate flexibility without placing participants at risk. CDC depends on the provision of easy to understand financial information. This information should be as comprehensive as possible. Augmentative communication tools may be used to facilitate the delivery of key information.

The PACS evaluation also suggests that a health maintenance approach has potential when employed with older people with more complex care needs. However, the PACS evaluation suggests that the infrastructure in place to facilitate health maintenance lacks integration and resourcing. While a health maintenance approach has the potential to improve the health and mobility of participants, paid carers needs to be educated and remunerated to work with clients towards such outcomes. The evaluation also suggests that some participants have health needs that are not met by the primary health system. An investigation of the context in which this occurs is urgently needed.
CONCLUSION

The evaluation demonstrates that the PACS model has numerous positive outcomes and very few negative implications. For the vast majority of intervention group participants PACS generated positive results. For nine participants self-directing at Levels 2 and 3, PACS represented a life-changing event. A further 35 participants reported positive outcomes resulting from PACS. A total of 17 participants, predominantly self-directing at Level 1, reported neutral outcomes. For the vast majority of participants, the main components of PACS (self-assessment, goal setting, care planning and coordination) worked well and represented a positive experience. This report has provided an overview of the evaluation outcome generated by the PACS model. Moreover, the report has included some insights regarding key aspects of the PACS model and implementation issues associated with them. CDC can be a positive experience for older people. However, its success hinges on the support, encouragement, and capacity building offered to older people.
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