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# People at Centre Stage:

## Evaluation Summary Report

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## Aims of the Summary Report:

This report provides 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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# PROJECT PARTNERS

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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 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 authority and being more directly involved in the care coordination process. To focus on administrative and financial control at the expense of affording greater decisional authority 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 what they termed a 'life-changing event'. A total of 35 participants reported positive outcomes related to PACS. A further 14 participants had only a vague or minimal recollection of PACS. Thirteen participants, predominantly self-directing at Level 1 (the lowest level of self-direction), reported minimal or neutral outcomes. Although the model did not generate negative outcomes, PACS had fewer positive outcomes for some of the older old and participants experiencing significant health issues. This outcome resonates with the international CDC literature (see, for instance, Foster et al., 2005). For the majority of respondents, 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.

### 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) reduced bureaucratic processes.

4. **Changed view on possible life achievements.** They felt that the PACS service had significantly improved their view on what they could achieve in life. Intervention group

participants felt more motivated and had a better sense of the resources available to them and how these resources could be used in their endeavour to achieve major and/or minor life goals.

5. ***Feeling more connected:*** Interestingly and unexpectedly, intervention group clients felt 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

Eight 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.

# INTRODUCTION

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:

- fragmented programme arrangements in community care create planning and operational difficulties and inefficiencies;
- the 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 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 a 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. 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. Part 2 deals exclusively with the experience of people participating in the intervention group.

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 aimed to provide 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 presented 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 with permission from each party. 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 12 months using a 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 Individual

Budgets Evaluation Network (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 (Glendinning et al., 2008, Brown et al., 2007, Foster et al., 2005), 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 ***'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. By enhancing their capabilities, older people are assisted to make informed choices and exercise their decisional authority regarding the care services they receive. '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 '***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). Ideally the approach involves multidisciplinary 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 participants 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

- Co-assessment: Care recipients are invited to assess their own needs in discussion with their case managers and explore resource implications.
- Care recipients receive clear information about their entitlements and the monetary value of their support package.
    - A comprehensive monthly financial statement detailing expenditure and balance is provided.
-

- A suite of person-centred tools provide an intuitive and structured approach to exploring a person’s likes, dislikes, identity, aspirations, and support networks 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.
    - A short biographical outline for people with communication issues facilitates interaction with health and community care professionals.
- Care recipients have access to a health maintenance 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.
    - Motivational goals, sub-goals, and restorative aims become the main drivers of the care plan.
    - Care recipients are invited to provide feedback regarding the usefulness and success of the restorative plan.
- Care recipients have access to a capacity building and mentoring program during which they gain knowledge about the relationship between good nutrition, hydration, medication management, and exercise and good decision making. They are also introduced to the tasks and choices associated with the different levels of self-direction.

- 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 prior consultation with a case manager.[1]
    - Can negotiate what services their case manager should provide.
    - Are compensated for the responsibility they assume and receive a resource supplement that is commensurate with the administrative tasks they perform.[2]
    - Can save a percentage of their care package in order to make larger one-off purchases.
    - A capped percentage of a care recipient's package is retained as an emergency fund.
    - During a period of ill health or crisis, care recipients automatically revert to full case management. They can choose to re-engage with their preferred level of self-direction when their situation improves.
- A 'Circles of Support' approach strengthens care recipients' social support network. The 'Circle of Support' approach is mandatory for participants self-directing at higher levels.
- Care recipients have access to peer information sessions where they receive information about the scheme and can exchange ideas about how to use the flexibility of their package to their advantage.
- 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.

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[1] Due to implementation issues, only 14 participants self-directing at Level 3 were issued with 'stored value cards'.

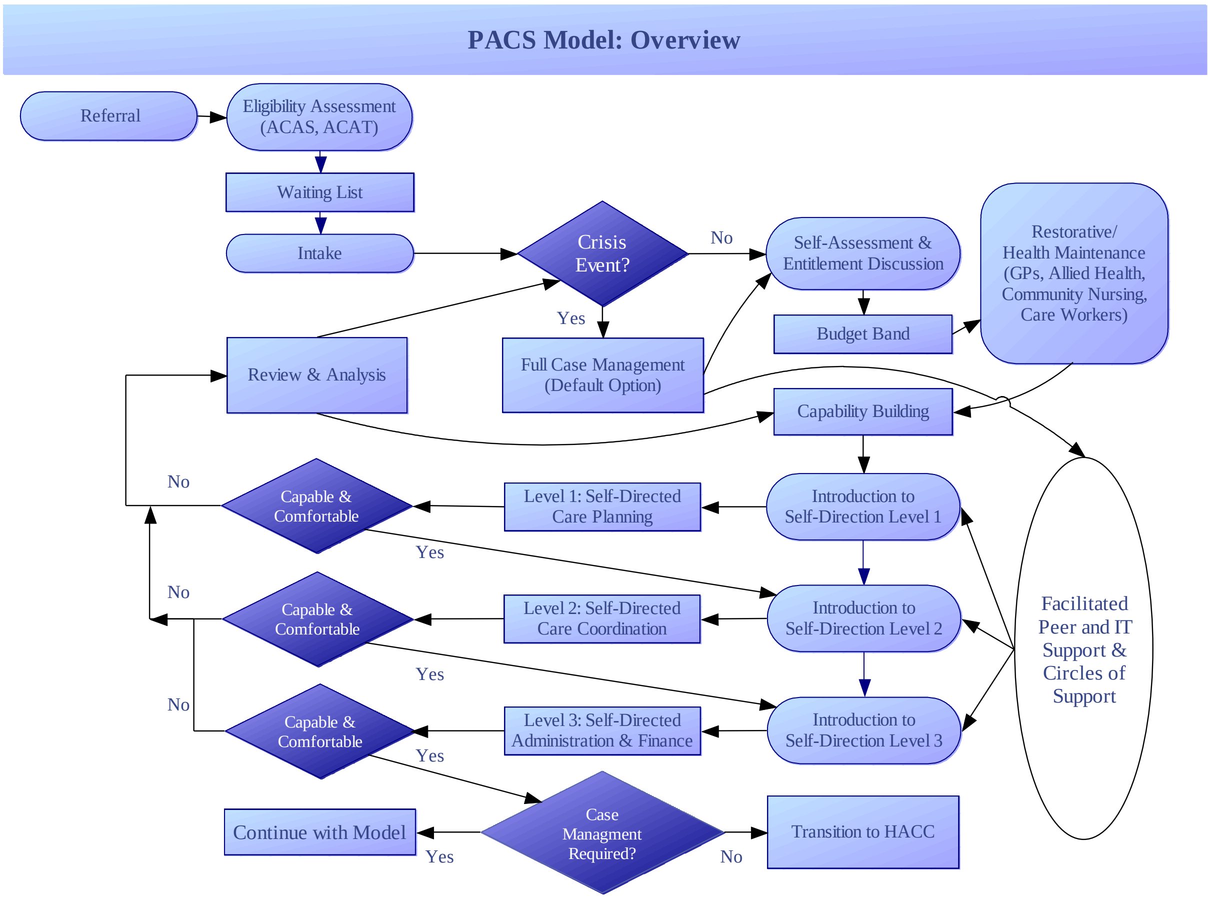
[2] Resource supplements were determined according to a formula in which participants were eligible for up to an additional 30% of a 'nominal' value of their care package. The 'nominal' value amounted to around 50-60% of the total care package.

- 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.

A copy of the Implementation Guide and associated tools can be downloaded from the project website:

https://sites.google.com/site/pacsprojectsite/

## Figure 1: Overview of the PACS Model



# 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 (EC 206-2008).

**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 (Glendinning et al., 2008), 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 four indicators and scales:

1. *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).

### *2. Self-perceived health*

We employed a self-perceived health scale developed as part of a European project on health indicators. The survey question asks participants to rate their health on a five-point Likert scale (Robine et al. 2003, in Glendinning et al. 2008). 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).

### *3. 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).

### *4. 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 for this to occur. All intervention group 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 agreed to participate in the semi-structured interviews.

### 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. The older people evaluating the model often found it difficult to respond to the quantitative measures (see, also, Bauld et al., 2000). 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 possible that this affected the outcome of the quantitative part of the study. We managed this issue by employing a qualitative evaluation bringing to light key themes and idiosyncrasies that may have otherwise remained hidden.

## 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 and 30 men) completed the repeat measure at T2. Of these, 41 lived alone, 32 lived with a partner, and 20 lived with family. Around 68 per cent of participants were born in Australia. A total of 77 participants received a Community Aged Care Package (CACPs), 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.

For a summary of the data collected at Baseline and at the end of the trial, please refer to the Appendix.

### 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 A10: ‘Has the services changed your view on what you can achieve in life’

- A Chi-square test for independence indicated a significant association between intervention and satisfaction with financial arrangements. Clients in the intervention group felt that the service increased their understanding of what was possible in terms of possible life achievements at T2, **$\chi^2$ (1, *n*=104)=10.06, *p*<0.01.**

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, $p<0.01$.**

### 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 participants 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 ($r=0.30$) (Question A5).
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 ($r=0.30$) (Question A7).
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 ($r=0.30$) (Question A10).
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 ($r=0.30$) (Question C13)
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 ($r=0.30$) (Question C18).
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 ($r=0.30$) (Question E36).

*The PACS evaluation offers a glimpse of the enormous potential of a motivational goal setting/health maintenance approach. Remarkable improvements can be achieved with limited resources. However, currently the service system does not cater well for people who would benefit from a health maintenance approach. Such an approach needs to be appropriately resourced: older people need priority access to allied health services. Paid carers need to be trained and paid to provide basic health maintenance support.*

### 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.

Other changes in outcome measures were not statistically significant and are not reported in this summary report.

To sum up, 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 sense of what could be achieved in life,
- 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. Of 68 participants in the intervention group, a total of 56 individuals chose to participate 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 participant 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. 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.

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

| | BCC Frankston | BCC Mornington | UAC Strathdon | UCCO | Total |
|---|---|---|---|---|---|
| Level 1 | 11 | 3 | 0 | 14 | 28 |
| Level 2 | 3 | 7 | 2 | 2 | 14 |
| Level 3 | 11 | 2 | 1 | 0 | 14 |
| Total | 25 | 12 | 3 | 16 | 56 |

### 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 35 individuals in the intervention group commented that the PACS model resulted in positive changes to the care they receive. Thirty-one stated that they would recommend PACS to others. A further 14 clients had only a vague or no recollection of the trial (the question whether they would recommend PACS was not directed at these participants) and two participants would not recommend the model to others. The following table (Table 2) summarises the key benefits as reported by intervention group participants.

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

| | Level 1 | Level 2 | Level 3 |
|---|---|---|---|
| Ability to negotiate directly with service provider | 1 | 4 | 4 |
| Ability to use package for repairs and equipment | 3 | 0 | 4 |
| Availability of help and back-up | 1 | 1 | 0 |
| Client gained or maintained skills | 0 | 0 | 2 |
| Clients felt empowered to challenge paternalism of the system | 1 | 2 | 4 |
| Financial benefit | 4 | 3 | 7 |
| Greater decisional autonomy/control | 5 | 10 | 12 |
| Life changing and positive responses | 3 | 2 | 4 |
| Life is easier and more comfortable | 0 | 0 | 2 |
| Clients open to next level of self-direction | 2 | 1 | - |

**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 1, 2, 3), 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)[3].

**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:

> So being able to use the care package for non-traditional things like massage three times a week has really made a difference (Level 1).
>
> 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).

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[3] The tag 'C' implies that the response came from a 'family carer'.

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).

I: Yes, swapping agencies [homecare providers] was good. … I always give people a second chance, and sometimes even a third chance, but after three chances if you can't get it right, sorry [laughs] it's not rocket science.

F: All right, so what stands out for you in terms of your experience self-directing at level three?

I: Ah, having power … You get what you want (Level 3).

It's sort of managing your life, right, and being more efficient about it. You know what days you can go out and what days you can't go out. You know

> who's coming, and of course there's always the odd thing that comes up, but yeah, there's no worries about that at all (Level 3).
>
> 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 3).

**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).

**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.

*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.*

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 case managers and care coordinators. Moreover, participants were not obliged to take on all the responsibilities associated with a level of self-direction (e.g. at Level 2 all care coordination tasks and at Level 3 all administrative and financial aspects of their care) and were able to choose the elements they wanted to direct. Table 3 below provides an overview of responses regarding the administrative burden associated with PACS.

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

| | Level 1 | Level 2 | Level 3 |
|---|---|---|---|
| Manageable | 1 | 0 | 12 |
| Onerous or problematic | 0 | 0 | 0 |
| Self-direction not difficult | 0 | 0 | 5 |

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 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).

For people self-directing at Level 3, the administrative tasks typically 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 13 participants did not report any changes as a result of PACS. This is largely due to the fact that 11 of these individuals were self-directing at the lowest level, Level 1. Also, some of the older participants and participants experiencing significant health issues found it difficult to take advantage of the opportunities provided by the model. Table 4 depicts the responses of individuals who reported no change as a result of PACS by level of self-direction.

**Table 4: Individuals reporting no change as a result of PACS**

| | Level 1 | Level 2 | Level 3 |
|---|---|---|---|
| No change as a result of PACS | 11 | 1 | 1 |

Eight 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. On one occasion, the issue was associated with the fact that the agency held the funds for the package and not the participant. Two participants would not recommend PACS to others. Table 5 below provides an overview of these issues.

**Table 5: Overview of key challenges associated with PACS**

| | Total Sources | Level |
|---|---|---|
| Reimbursement concerns | 1 | 3 |
| Book keeping responsibility, having to be organised | 1 | 3 |
| Less contact with case manager | 1 | 1 |
| Losing an existing case manager, high turnover of CMs | 1 | 2 |
| Managing Care Attendants | 3 | 2 |
| Fewer services | 2 | 1/3 |
| Request to change agency | 1 | 3 |
| Would not recommend PACS | 2 | 1/2 |

**i) Financial or reimbursement concerns** (3 sources)

Requested to provide greater financial transparency, the agencies costed each service they provided to the participant. As a result, participants often found themselves confronted with the choice between different services. As a result, some participants commented that their services had been cut due to the fact that they participated in the

PACS project. Others commented on the lag between expenditures they incurred and reimbursement of the same. The need to be organised and keep the books in order was another issue raised.

> I: I was told this yesterday [that I] could go to that [exercise] 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)

Some clients find it hard to manage paid carers. For example a participant at Level 2 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.

*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.*

**iii) Clients would not recommend PACS** (2 sources)

Two clients stated that they would recommend PACS to others. One cited a lack of planning and communication as the main reason; the other questioned the political motives underpinning CDC.

> 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 (Level 2).

> 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 6) outlines key barriers of self-directing at a higher level by agency and by level of self-direction.

**Table 6: Barriers to moving to the next level of self-direction, by level**

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

## 6. How Can PACS be Improved?

Around one third (26) participants thought that PACS could be improved by revising communication pathways and information content. 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 as they were employed through approved providers and had to satisfy their minimum standards. Hence, the agency was not following PACS procedures. Table 7 provides an overview of issues identified by participants.

**Table 7: Overview of issues to be improved**

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

**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 speak to as if you knew. So that was inadequate. Just better planning, better coordination between the [agency] and the carer services prior, yeah (Level 2C).

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).

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

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

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?

*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.*

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 section highlights client experiences with a number of model components: care planning, the restorative/goals setting approach, and the self-assessment process. Overall, clients found aspects of the model useful. Positive aspects of the model identified were:

### A) Care Planning

As part of PACS, participants were mentored to complete their own care plan. At the end of the trial, 22 participants felt able to complete their own care plan, whereas nine participants did not feel able to complete their own care plan. Six participants were unsure whether they would be able to complete a care plan. While ten participants found the process helpful and positive, seven participants commented that their case manager did not invite them to participate in the care planning process.

**Table 8: Overview of responses to the care planning process**

| | Total Sources |
|---|---|
| Experiences regarded as positive and helpful | 10 |
| Client or carer feels able to complete care plan | 22 |
| Client or carer unable to complete care plan | 9 |
| Unsure whether able to complete a care plan | 6 |
| Client not invited to participate in care planning process | 7 |

**i) Positive experiences** (10 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)

> 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 not invited to participate in care planning process** (3 sources)

> F: So, how did you decide that you needed a cleaner, for example?.
>
> No, I didn't decide. They decided. (Level 3)

> At the beginning they just copied the last care plan that I had and went with that.
>
> They didn't sit down and do a new care plan.
>
> F: So would it have been valuable, do you feel that it would have been valuable to do a new one at that stage?
>
> Yes, and I actually was prepared and said this is what I want. … I had to bring it up. (Level 1)

**B) Restorative Approach/Goal Setting**

A total of 18 clients appreciated the restorative, goal setting approach and regarded it as valuable (see Table 9 below). 10 participants were ambivalent about the process or were unable to remember it and two participants commented that 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 9: Overview of responses regarding the restorative approach by level**

| | Level 1 | Level 2 | Level 3 |
|---|---|---|---|
| Client would like to have been asked | 1 | 0 | 0 |
| Discussion about goals positive and useful | 7 | 6 | 5 |
| Goals documented even though client not engaged in PACS | 0 | 1 | 0 |

| | | | |
|---|---|---|---|
| Goals identified and achieved–examples | 4 | 4 | 4 |
| Lack of consideration of carer’s goals | 0 | 0 | 1 |
| Language not right | 2 | 0 | 0 |
| Living day to day, surviving | 4 | 2 | 0 |
| Not useful | 1 | 0 | 1 |
| Unsure, vague or no recollection | 5 | 3 | 2 |
| Useful but unproductive | 1 | 0 | 0 |

**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).

*Clients found the care planning process relatively easy. This outcome builds on an effective capacity building process.*

*A transparent and reliable assessment process that comprehensively communicates assessment criteria and resulting entitlements to clients is an absolute necessity if clients are to make informed decision regarding their care. Research evidence highlights that a self-assessment process couched within a more complex co-assessment leading to an ongoing exploration of needs between clients and case managers can achieve very positive outcomes. However, a self-assessment process has to cater for people with health, communication, and language issues and disabilities.*

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)

Six participants expressed that they were 'too old' or were past thinking about goal setting. They expressed a sense that it was not relevant or worthwhile.

### C) Co-Assessment Process

For 20 participants, the co-assessment process was either a positive/helpful experience. Another 20 were unable to recall the process. 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 Millicer-Stagg (2012).

**Table 10: Overview of responses regarding the self-assessment process**

| | Total Sources |
|---|---|
| Client unsure or unable to recall the self-assessment process | 20 |

| | |
|---|---|
| Self-Assessment was positive and helpful | 20 |
| Negative experiences | 7 |

**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**

Seven clients had a negative experience of the co-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 (n=29) of respondents were satisfied with the role the case manager played within PACS. A total of 22 participants explained how case management could be improved. Communication issues were among the most frequently-mentioned issues to be improved. Table 11 provide an overview of these issues.

**Table 11: Overview of responses regarding the role of case managers**

| | Total Sources |
|---|---|
| Nothing more than what is currently being done | 29 |
| Provide a better understanding of what is available | 11 |
| Communicate—listen, anticipate questions and needs, keep in touch | 7 |
| Give client more control and independence | 6 |
| Assist with carers, respite and accommodation | 5 |
| Be more transparent about funding arrangements | 5 |
| Be a backup and available | 4 |
| Ask what the client needs rather than assume | 3 |
| Assist with issues as they arise | 2 |
| Respond in a timely manner | 2 |
| Be more thorough | 1 |
| Provide guidance regarding equipment | 1 |
| Provide assistance with planning ahead | 1 |
| Help clients achieve goals | 1 |

**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).

*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.*

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

In an ideal situation I'd like my case manager to take on more of the running around, the research, making the phone calls in terms of finding good respite homes for two week respite care (Level 1).

**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 [over how resources are being spent] (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 within existing guidelines** (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. All of the issues raised concern *the provision of paid care services in general and **are not specific to the PACS model***. Table 12 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 12: Overview of responses regarding the role of paid carers**

| | Total Sources |
|---|---|
| Be a helper, have my care at heart first and foremost | 7 |
| To do what a client asks | 5 |
| Various issues with paid carers | 8 |

**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.

I: They're doing all that they can do as it is and look if there's any issue that I have that sometimes they're not respectful of the fact that there are other people living here, because my son's here half the time.

So sometimes Nan will be in the shower and the door will be left wide open which is not respectful to her and it's not respectful to us either. … Sometimes I might have a friend over for a coffee or whatever and they'll bring her through the house half naked or… (Level 2)

They seem to run out of ability to be with other people. I have seen them just sit down read books and when I arrive they - I could see the body language changing that, oh, I shouldn't be doing this.

The husband has just arrived. I shouldn't be reading book. I shouldn't be watching television. I should be doing - maybe talking to [client]. I know that is very difficult to do for hours; the time that they are here. But I don't know how they become diversified with their way of thinking to care for someone sitting down doing nothing, listening. They can't even play cards (Level 2)

F: So did she used to bring her daughter to work with her?

I: Yeah, … , I was sorry for her daughter, I was sorry.

F: They're not supposed to bring their family members to work.

I: She is grab me, look, look that man want me, that man want me but only for the sex and show me that mobile and I say - next time I say have you seen him, no, no, I love this one, but [unclear] they want to work and she noted the times often start to play up with me so she is gone (Level 1).

I felt I was being blackmailed [client was told that they could not have a personalised wheel chair after client refused to comply with one of carer's requests] (Level 1).

## 10. 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.

> *Some of the participants we encountered did not have their health needs met. The circumstances that contribute to this outcome need to be explored in detail.*

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

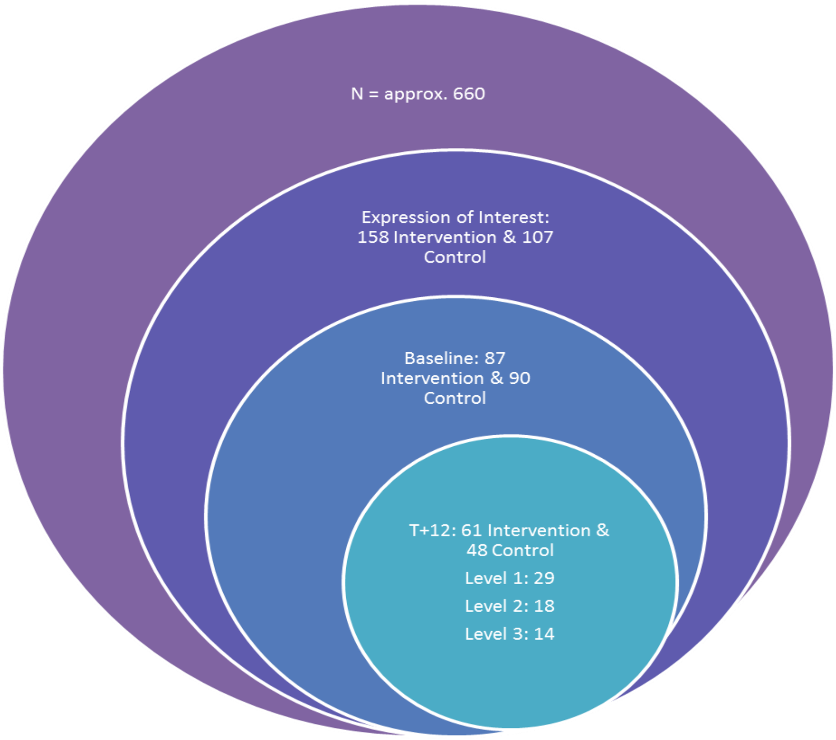
# DISCUSSION

The PACS evaluation suggests that participation in the intervention group was associated with:

- increased satisfaction with care,
- improved sense of what can be achieved in life,
- improved mobility and particularly ability to prepare meals, and
- an improved sense of engagement and social connectedness.

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 until 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. Figure 2 below provides a graphic overview of these outcomes. While communication issues may have impacted on this outcome, it is unlikely that this would have majorly affected these outcomes. Also, this figure is in line with the international research literature focussing on the UK and the US (Foster et al. 2005) foregrounding that older people tend to have a lower updake of CDC models of care than people with disability. Bearing in mind the low takeup of self-direction at Level 3, it appears that older Australian's preferences regarding self-direction are only in a very limited sense motivated by greater oversight of financial and administrative processes. A 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. In other words, it appears that having greater decisional authority and more direct access to services are key drivers when designing CDC models of care for older Australians.

**Figure 2: Self-direction preferences of older people in perspective**



The PACS model delivered 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. Barriers in terms of progressing 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). Some participants felt reluctant to question the authority of case managers who had determined the clients' level of self-direction.

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 composed of very active family carers who were committed advocates for the people they cared for and of care recipients who were interested to explore new service options. 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 family 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.

A CDC model that focuses on capacity building and health maintenance requires well-trained care attendants working hand in glove with clients and care managers as well as the support of allied health professionals. This evaluation brought to light numerous cases of sub-standard home and personal care. Poorly trained and unmotivated care attendants are of little value to older people – especially within a health maintenance-focused CDC context. Without better resourcing and integration of downstream aged care services, the substantial capacity of health maintenance approaches within the context of CDC and their potential to enable clients to stay in their own homes longer will be substantially diminished.

## CONCLUSION

This report has provided an overview of the evaluation outcome generated by the PACS model. The evaluation suggests that a tiered model that focuses on capacity building and capacity maintenance has the potential to benefit older people with complex care needs. While such a model benefits predominantly people self-directing at higher levels – the base level (Level 1) being predominantly a capacity building phase – a tiered CDC approach has flow on effects for people at the lower end of the self-direction spectrum as service providers make available more flexible service choice across the board. Crucially, however, the success of such a model hinges on the support, encouragement, and capacity building offered to older people. Hence, a tiered CDC model has to be adequately resourced to deliver the promises it harbours. Without the necessary support only a small minority of, predominantly well-educated, carers will be able to take advantage of the benefits that a CDC model has to offer.

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# APPENDIX:

## A. Adult Social Care Outcomes Toolkit (ASCOT)

| | | At Baseline | | | | At End of Intervention (BL+12) | | | |
|---|---|---|---|---|---|---|---|---|---|
| **Client Satisfaction with Services (%)** | | Group | | Chi- Square | | Group | | Chi- Square | |
| Variable | | Control | Intervention | $\chi^2$ | p | Control | Intervention | $\chi^2$ | p |
| A1 - Satisfaction with overall help received | Satisfied | 98.9 | 98.0 | 0.17 | 0.68 | 91.8 | 93.2 | 0.00 | 1.00 |
| | Dissatisfied | 1.1 | 2.0 | | | 8.2 | 6.8 | | |
| A2 - Satisfaction that opinions and choices were respected | Satisfied | 98.9 | 91.8 | 3.8 | 0.05 | 89.8 | 93.2 | 0.09 | 0.77 |
| | Dissatisfied | 1.1 | 8.2 | | | 10.2 | 6.8 | | |
| A3 - Satisfaction that treatment was dignified and respectful | Satisfied | 100.0 | 96.1 | 0.4 | 0.53 | 96.0 | 94.9 | 0.00 | 1.00 |
| | Dissatisfied | | 3.9 | | | 4.0 | 5.1 | | |
| A4 - Satisfaction with care options | Satisfied | 95.3 | 91.8 | 0.26 | 0.61 | 91.7 | 98.3 | 1.34 | 0.25 |
| | Dissatisfied | 4.7 | 8.2 | | | 8.3 | 1.7 | | |
| A5 - Satisfaction that client “had a say” in care options | Satisfied | 93.1 | 92.2 | 0.03 | 0.87 | 89.8 | 100.0 | 4.13 | 0.04* |
| | Dissatisfied | 6.9 | 7.8 | | | 10.2 | - | | |
| A6 - Satisfaction with care expectations | Satisfied | 97.7 | 87.8 | 2.31 | 0.13 | 98.0 | 89.7 | 1.86 | 0.17 |
| | Dissatisfied | 2.3 | 12.2 | | | 2.0 | 10.3 | | |
| A7 - Satisfaction with information received regarding care | Satisfied | 94.2 | 76.0 | 9 | .00** | 93.6 | 93.0 | 0.00 | 1.00 |
| | Dissatisfied | 5.8 | 24.0 | | | 6.4 | 7.0 | | |
| A8 - Satisfaction with support and planning process | Satisfied | 98.7 | 95.5 | 1.37 | 0.24 | 91.1 | 97.7 | 0.80 | 0.37 |
| | Dissatisfied | 1.3 | 4.5 | | | 8.9 | 2.3 | | |
| A9 - Satisfaction with financial arrangements | Satisfied | 97.6 | 87.0 | 7.8 | .00** | 95.8 | 80.4 | 4.33 | 0.04* |
| | Dissatisfied | 2.4 | 13.0 | | | 4.2 | 19.6 | | |
| A10 - Service changed your view on possible life achievements | Satisfied | 64.4 | 66.7 | 0 | 1 | 66.7 | 93.0 | 10.06 | 0.00** |
| | Dissatisfied | 35.6 | 33.3 | | | 33.3 | 7.0 | | |

** p < .01

* p < .05

### B. Self-Perceived Health Scale

| | | **At Baseline** | | | | **At End of Intervention (BL+12)** | | | |
|---|---|---|---|---|---|---|---|---|---|
| **Quality of Health (%)** | | Group | | Chi- Square | | Group | | Chi- Square | |
| Variable | | Control | Intervention | $\chi^2$ | p | Control | Intervention | $\chi^2$ | p |
| B11 - General Rating | Very good | 74.1 | 68.6 | 0.87 | 0.35 | 80.0 | 74.5 | 0.2 | 0.66 |
| | Poor | 25.9 | 31.4 | | | 20.0 | 25.4 | | |

### C. Satisfaction and Quality of Care (%)

| | | At Baseline | | | | At End of Intervention (BL+12) | | | |
|---|---|---|---|---|---|---|---|---|---|
| **Client Satisfaction with Services (%)** | | Group | | Chi- Square | | Group | | Chi- Square | |
| Variable | | Control | Intervention | $\chi^2$ | p | Control | Intervention | $\chi^2$ | p |
| C12 - Satisfaction with overall paid help from care workers | Satisfied | 96.5 | 90 | 1.15 | 0.29 | 100.0 | 96.5 | 0.35 | 0.55 |
| | Dissatisfied | 3.5 | 10 | | | - | 3.5 | | |
| C13 - Care worker always comes at times that suite me | Agree | 90.5 | 76 | 2.47 | 0.12 | 95.7 | 94.7 | 0 | 1 |
| | Disagree | 9.5 | 24 | | | 4.3 | 5.3 | | |
| C14 - Care workers are in a rush | Agree | 27.1 | 22 | 0.15 | 0.7 | 12.5 | 10.7 | 0 | 1 |
| | Disagree | 72.9 | 78 | | | 87.5 | 89.3 | | |
| C15 - Care worker always arrives on time | Agree | 96.5 | 73.5 | 10.2 | .00** | 95.8 | 89.5 | 0.73 | 0.39 |
| | Disagree | 3.5 | 26.5 | | | 4.2 | 10.5 | | |
| C16 - Care worker do things that I want done | Agree | 88.4 | 90 | 0.22 | 0.64 | 93.8 | 96.5 | 0.04 | 0.84 |
| | Disagree | 11.6 | 10 | | | 6.3 | 3.5 | | |
| C17 - Care worker do things their way | Agree | 44.4 | 42.6 | 1.18 | 0.28 | 44.9 | 34.5 | 0.77 | 0.38 |
| | Disagree | 55.6 | 57.4 | | | 55.1 | 65.5 | | |
| C18 - I see the same care workers | Agree | 83.5 | 70.8 | 0.7 | 0.4 | 79.2 | 85.7 | 0.38 | 0.54 |
| | Disagree | 16.5 | 29.2 | | | 20.8 | 14.3 | | |
| C19 - I am always kept informed about care changes | Agree | 95.3 | 80.9 | 4.4 | .04* | 87.8 | 80.7 | 0.52 | 0.47 |
| | Disagree | 4.7 | 19.1 | | | 12.2 | 19.3 | | |
| C20 - Care worker always treats me with dignity and respect | Agree | 100 | 94 | 1.98 | 0.16 | 100.0 | 94.6 | 1.11 | 0.29 |
| | Disagree | - | 6 | | | - | 5.4 | 1.11 | 0.29 |

** $p < .01$
* $p < .05$

## D. Personal Wellbeing Index

| | | At Baseline | | At End of Intervention (BL+12) | |
|---|---|---|---|---|---|
| **Satisfaction with Life (%)** | | Group | | Group | |
| Variable | | Control | Intervention | Control | Intervention |
| D21 - Satisfaction with life as a whole | Mean | 6.66 | 6.19 | 6.36 | 6.38 |
| | SD | 2.51 | 2.76 | 2.34 | 2.59 |
| D22 - Satisfaction with living standards | Mean | 7.48 | 7.47 | 6.94 | 7.77 |
| | SD | 2.42 | 2.43 | 2.65 | 2.06 |
| D23 - Satisfaction with health | Mean | 5.72 | 4.94 | 5.44 | 5.33 |
| | SD | 2.56 | 2.67 | 2.44 | 2.49 |
| D24 - Satisfaction with what you are achieving in life | Mean | 6.56 | 5.58 | 5.98 | 6.16 |
| | SD | 2.71 | 2.85 | 2.49 | 2.65 |
| D25 - Satisfaction with personal relationships | Mean | 7.68 | 2.27 | 7.34 | 8.13 |
| | SD | 7.44 | 2.66 | 2.67 | 2.25 |
| D26 - Satisfaction with safety | Mean | 7.13 | 7.62 | 7.53 | 7.95 |
| | SD | 2.72 | 2.31 | 2.18 | 2.1 |
| D27 - Satisfaction with feeling part of your community | Mean | 6.69 | 6.34 | 6.71 | 6.96 |
| | SD | 2.52 | 2.73 | 2.73 | 2.51 |
| D28 - Satisfaction with further security | Mean | 6.34 | 6.71 | 6.85 | 6.61 |
| | SD | 2.47 | 2.7 | 2.34 | 2.53 |
| D29 - Satisfaction with your spirituality or religion | Mean | 7.75 | 7.15 | 7.58 | 7.43 |
| | SD | 2.51 | 2.58 | 2.5 | 2.5 |

### E. Social Care Needs

| | | At Baseline | | | | At End of Intervention (BL+12) | | | |
|---|---|---|---|---|---|---|---|---|---|
| **Social Care Needs (%)** | | Group | | Chi- Square | | Group | | Chi- Square | |
| Variable | | Control | Intervention | $\chi^2$ | p | Control | Intervention | $\chi^2$ | p |
| E30 - I feel in control of my daily life | Agree | 84.9 | 80.4 | 3.9 | .04* | 84.0 | 84.5 | 0.00 | 1.00 |
| | Disagree | 15.1 | 19.6 | | | 16.0 | 15.5 | | |
| E31 - I feel worried about my personal safety | Agree | 39.1 | 33.3 | 2 | 0.16 | 36.0 | 30.5 | 0.16 | 0.69 |
| | Disagree | 60.9 | 66.7 | | | 64.0 | 69.5 | | |
| E32 - I feel clean and able to wear what I want | Agree | 96.6 | 92.2 | 0.05 | 0.16 | 95.9 | 93.2 | 0.04 | 0.85 |
| | Disagree | 3.4 | 7.8 | | | 4.1 | 6.8 | | |
| E33 - Mt home is as clean and conformable as I'd like it | Agree | 86.2 | 80.4 | 0.11 | 0.83 | 92.0 | 86.4 | 0.38 | 0.54 |
| | Disagree | 13.8 | 19.6 | | | 8.0 | 13.6 | | |
| E34 - I am able to eat meals when I like | Agree | 93 | 90.2 | 2.03 | 0.74 | 90.0 | 83.1 | 0.59 | 0.44 |
| | Disagree | 7 | 9.8 | | | 10.0 | 16.9 | | |
| E35 - I have a good social life | Agree | 65.1 | 68.6 | 0.98 | 0.15 | 66.0 | 64.3 | 0.00 | 1.00 |
| | Disagree | 34.9 | 31.4 | | | 34.0 | 35.7 | | |
| E36 - I feel lonely | Agree | 48.2 | 45.1 | 0.67 | 0.32 | 59.6 | 27.6 | 9.64 | .00** |
| | Disagree | 51.8 | 54.9 | | | 40.4 | 72.4 | | |
| E37 - I am fully occupied in activities of my choice | Agree | 67.4 | 67.3 | 0.88 | 0.35 | 64.0 | 62.1 | 0.00 | 1.00 |
| | Disagree | 32.6 | 32.7 | | | 36.0 | 37.9 | | |
| E38 - I have nothing much to do and am usually bored | Agree | 31.8 | 20.8 | 1.26 | 0.26 | 32.0 | 16.1 | 2.89 | 0.09 |
| | Disagree | 68.2 | 79.2 | | | 68.0 | 83.9 | | |

** $p < .01$

* $p < .05$

**Intervention Group Analysis- Number of Clients (%) who needed assistance in daily activities at Baseline and BL+12**

| Variable | | Time | | Wilcoxon Signed Rank | |
|---|---|---|---|---|---|
| | | Baseline | BL+12 | Z | p |
| Walk Outdoors | Yes, needs help | 50.00% | 28.30% | -1.88 | 0.06 |
| | Sometimes needs help | 23.50% | 35.80% | | |
| | No, doesn’t need help | 26.50% | 35.80% | | |
| Walk Indoors | Yes, needs help | 20.00% | 19.20% | -0.71 | 0.48 |
| | Sometimes needs help | 21.00% | 15.40% | | |
| | No, doesn’t need help | 59.00% | 65.40% | | |
| Use of Toilet | Yes, needs help | 24.00% | 17.60% | -0.58 | 0.57 |
| | Sometimes needs help | 11.00% | 11.80% | | |
| | No, doesn’t need help | 65.00% | 70.60% | | |
| Cooking | Yes, needs help | 54.40% | 30.80% | -2.44 | .02* |
| | Sometimes needs help | 21.40% | 36.50% | | |
| | No, doesn’t need help | 24.30% | 32.70% | | |

* $p < .05$