

## Self-directed community services for older Australians: a stepped capacity-building approach

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### What is known about this topic

- Consumer-directed care has the potential to increase older people's satisfaction with domiciliary care outcomes.
- Older people require substantial support to self-direct their care.
- The evidence base indicating what programme components work well is sparse.

### What this paper adds

- A stepped approach may improve the acceptability of consumer-directed care.
- Only a small minority of older Australians is interested in a cash or voucher option. A larger segment is interested in having greater say and more direct access to care.
- A capacity-building approach can improve older people's satisfaction with the way they are treated, their sense of control over care services, their satisfaction with their living standards and their view of what they can achieve in life.

### Abstract

Consumer-directed care (CDC) is increasingly widespread among aged care service options in Organisation for Economic Co-operation and Development (OECD) countries. However, the evidence base regarding the programmatic and contextual factors that affect the outcome of CDC interventions is surprisingly small. This paper reports on a self-directed care approach for older Australians with complex care needs. A multi-methods longitudinal comparative cohort study was employed comprising 4 survey tools and 56 semi-structured interviews. Participation rates were around 20%. A total of 185 (98 in the intervention and 87 in the control group) older people and carers were recruited at baseline. Eleven months later, 109 participants (59 in the intervention and 50 in the control group) completed the repeat measure. Attrition rates were around 40%. Data collection occurred between July 2010 and April 2012. The data suggest that intervention group participants were likely to be more satisfied with the way they were treated ( $P = 0.013$ ), their care options ( $P = 0.014$ ), the 'say' they had in their care ( $P < 0.001$ ), the information they received regarding their care ( $P = 0.012$ ), what they were achieving in life ( $P = 0.031$ ), that the services changed their view on what could be achieved in life ( $P = 0.020$ ) and with their standard of living ( $P = 0.008$ ). The evaluation suggests that while only a very small segment of older people is interested in a voucher or cash option, a substantially larger group would like to have greater say over and more direct access to their care, without, however, assuming administrative and financial responsibilities. The paper concludes that a stepped capacity-building approach to CDC may improve the acceptability of CDC to older people and generate synergies that improve older people's care outcomes.

**Keywords:** aged care, capacity building, community care, consumer-directed care, domiciliary care, self-directed care

### Introduction

Consumer-directed care (CDC) features increasingly among a suite of domiciliary aged care options readily available in Organisation for Economic Co-operation and Development (OECD) countries. Yet, the evidence base regarding the programmatic and contextual factors that affect the outcome of CDC interventions including their uptake rates is surprisingly small (Low *et al.* 2011, Ottmann *et al.* 2013). As a result, policy makers have only limited information at their disposal when designing CDC programmes. This paper, the last in a series of three, addresses this issue by reporting on the outcomes of a stepped capacity-building-focused

self-directed care (SDC) project designed for older Australians with complex care needs. The article provides an overview of the outcomes for domiciliary aged care (hereafter 'community aged care') recipients and highlights key obstacles in the way of older people benefiting from SDC arrangements. The paper suggests that a stepped, SDC approach that focuses on capacity building may be more acceptable to older people and has the potential to improve older people's sense of satisfaction, control over care options, their perceived standard of living and outlook on what they can achieve in life.

The CDC models and initiatives are designed to place the control over home-based care in the hands of consumers (Ottmann *et al.* 2013). Approaches differ significantly between countries, states and municipalities (Low *et al.* 2011). Cash-for-care schemes predominate in the research literature to date. These typically involve a cash or vouchers option to enable care recipients to purchase required care services in accordance with their self-determined care plan. Cash-for-care schemes thereby emphasise budgeting and marketisation of care (the purchase of aged care services in the marketplace as opposed to the provision of aged care by government agencies) as the key to more choice. In such schemes, skills development and support services are often outsourced to third parties available to clients at a cost. In this paper, we present the evaluation findings of a SDC programme. SDC programmes tend to be more focused on empowerment and capacity building, enabling older people to take advantage of the benefits associated with self-directing their care arrangements.

A growing body of research suggests that there are numerous benefits associated with the delivery of CDC programmes as compared with conventional community care support packages. In the US, older people enrolled in CDC programmes tend to be more likely than those receiving conventional case management to report good satisfaction with CDC models (Doty *et al.* 1996, Benjamin *et al.* 2000, Benjamin & Matthias 2001, Heumann 2003, Hagglund *et al.* 2004, Simon-Rusinowitz *et al.* 2005, Brown *et al.* 2007, Wiener *et al.* 2007). Moreover, researchers focusing on the UK note that CDC has been found to deliver greater consumer choice, sense of control and satisfaction with services (Henwood & Hudson 2007, Glendinning *et al.* 2008). Researchers also report that CDC has a positive impact on carer satisfaction and carer burden (Brown *et al.* 2007, Davey *et al.* 2007, Glendinning *et al.* 2008, Newbrunner *et al.* 2011). Yet, evaluation findings from two large-scale CDC demonstration projects conducted in the US and UK indicate that older people were less interested in SDC

programmes and were more likely to withdraw than their younger counterparts with disabilities (Brown *et al.* 2007, Davey *et al.* 2007, Glendinning *et al.* 2008, Newbrunner *et al.* 2011).

A small number of research articles outline some of the obstacles that either limit older adults' opportunity for self-direction or reduce the appeal of such programmes to clients. Research focusing on the US and UK suggests that older people tend to have less access to support from families and friends than younger people with a disability (Benjamin & Matthias 2001); experience more rapid and frequent health status changes (Benjamin *et al.* 2000, Benjamin & Matthias 2001, Matthias & Benjamin 2003); and have substantial support needs regarding decision-making, administrative tasks and advocacy (Glendinning *et al.* 2008, 2009, Newbrunner *et al.* 2011). There is some evidence that good support in the form of training and assistance with administrative and accounting tasks may increase older people's acceptance of and preparedness to enrol in a CDC programme (Sciegaj *et al.* 2004, Foster *et al.* 2005, Simon-Rusinowitz *et al.* 2005, Brown *et al.* 2007). A more detailed review of the literature outlining the quality and limitations of the research has been published previously (Ottmann *et al.* 2013).

The People at Centre Stage (PACS) project was developed with these insights in mind. The aim of the project was to develop a community aged care model that would give care recipients the option to have as much control of their own care as they aspired to and felt comfortable with. The model was to offer participants a continuum of options ranging from case-manager-led care to full SDC. The model was developed within the confines of the Australian Aged Care Act (112/1997), the Fair Work Act (2009), Work Health and Safety Act (2011) and community packaged care guidelines. The most important limitations were that clients/carers could not be the funds holders, packages could not be 'cashed out', budget items had to address participants' direct care needs and service providers paid through packaged care funding had to be approved providers contracted by the host agency and had to fulfil a number of requirements that are onerous for small operators. The PACS project offered a number of 'work arounds' for participants who required more flexibility, such as debit cards allowing participants to purchase goods and services without having to involve case managers and the ability to contract family members or friends through approved providers. Model development was based on an extensive co-production process involving older people, carers and aged care service provider staff (Ottmann *et al.* 2011). The coproduction process led the researchers to develop the notion of

'assisted independence' from articulations of 'independence' and 'autonomy' by Sen (1985) and Nussbaum (2004).

The model incorporated a case-management-led capacity building and a restorative health approach. The restorative health approach borrowed heavily from research developed by Mathew Parsons and his team in New Zealand (Parsons & Parsons 2012). The approach includes client-ranked health priorities addressed by means of motivational goal setting. At a health promotion level, capacity building consisted of an ongoing discussion alerting clients to the importance of good nutrition and hydration, gentle regular exercise, consistent medication management, and reducing accident and safety hazards. Self-direction-specific capacity building included a three-tiered approach where case managers trained participants in the self-direction skills (identifying care needs, budgeting, co-ordinating care, administration and quality control) that allowed them to take on progressively more responsibility and control. A client self-assessment process (if required assisted by carers or case managers) of direct care needs resulted in a score that was translated into a budget band. The self-assessment score was then compared with scores generated by an aged care professional and budget band was discussed with case managers who were instructed to make necessary adjustments particularly when clients underassessed their needs. Typically, self-direction began at a lower level with participants taking on the development of their care plan (Level 1). To achieve this, participants were mentored by case managers. As participants became comfortable with designing their own care plan, they could assume control of care co-ordination responsibilities (Level 2). Again, participants received the support of case managers until they felt comfortable to manage service providers. At Level 2, participants had access to comprehensive lists of service providers, their hourly rates and the scope of services provided. Moreover, participants had access to an information pack outlining the most important services in their municipal region. Once comfortable with Level 2, they could elect to manage care services more directly, assuming financial, administrative and bookkeeping responsibilities (Level 3). In the PACS project, Level 3 took the form of a voucher option with a minor cash component made available in the form of a debit card. Core services such as home and personal care were paid through a broker agency rather than directly by the client. Only peripheral services such as massages or complementary therapies were paid directly by clients. Information technology (IT) and bookkeeping tutoring as well as peer support groups and general

mentoring were available to participants at that level. Participants were under no obligation to undertake all responsibilities associated with a particular level of self-direction and could opt to self-direct certain tasks and not others. Also, participants who felt ready to commence self-directing their care at a higher level could do so. Case management support was available at all levels of self-direction, but tended to diminish at Levels 2 and 3. As case management decreased, social and communal safeguards, such as Circles of Support (a group of people who are intentionally invited to come together to support an older person), tended to increase at higher levels of self-direction. Participants were financially compensated for taking greater responsibilities of their care adding up to 15% to the total value of their budget for direct care services. The PACS model was designed to be cost-neutral and could be implemented within an existing packaged care environment. Figure 1 provides an overview of the programme flow and levels of self-direction. For a more detailed description of the model, readers are referred to the project evaluation report (Ottmann *et al.* 2012).

## Methods

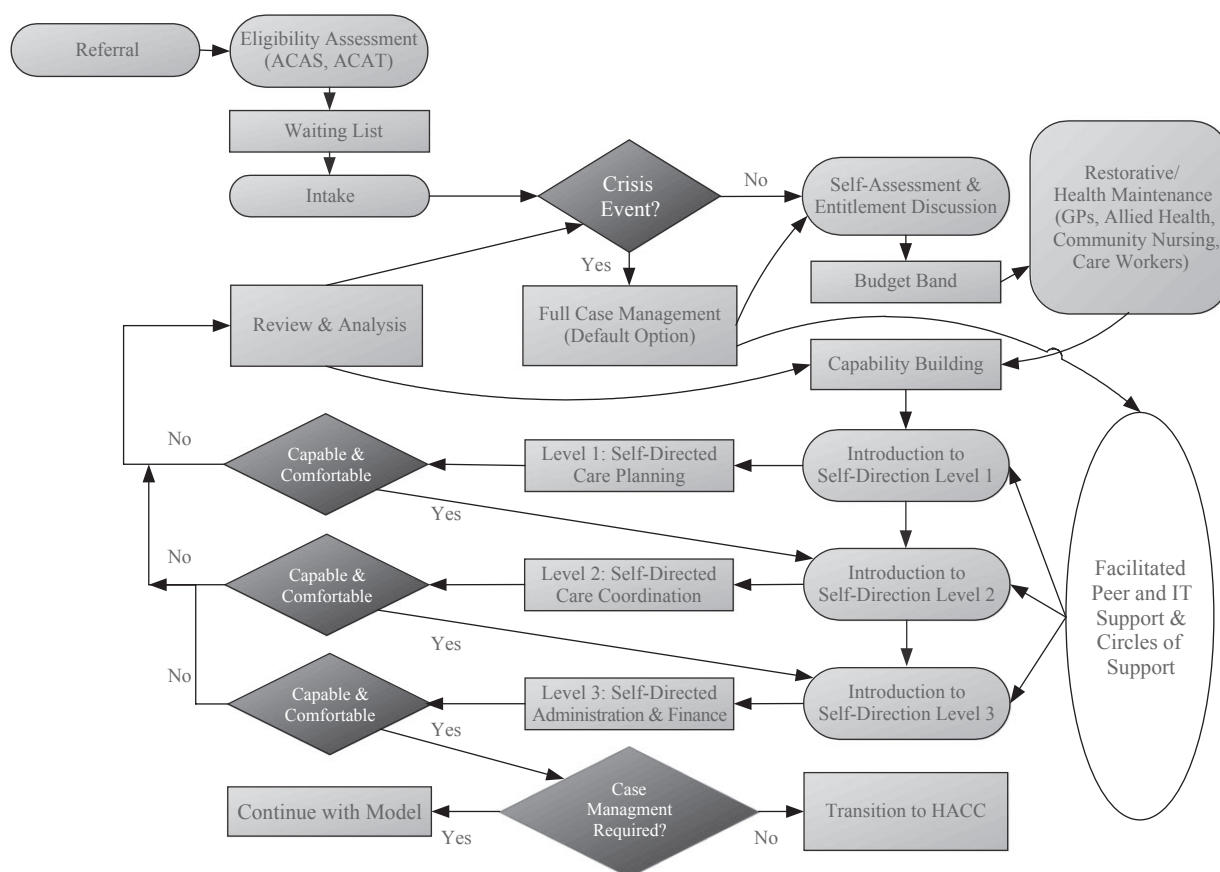
The methodology underpinning the evaluation of the PACS project employed a mixed-method approach employing quantitative and qualitative methods (Gabarino & Holland 2009). The evaluation included a non-randomised prospective longitudinal comparison study with one intervention group exposed to the PACS model, and one comparison group receiving case management 'as usual' involving pre/post measures for each group allowing for within-group as well as between-group comparisons. Quantitative and qualitative data integration followed an approach outlined by Carvalho and White (1997).

The project received the approval of Deakin University's Human Ethics Committee (EC 206-2008).

## Recruitment

To participate in this project, individuals had to be eligible for a community aged care package administered by the participating aged care service provider agencies. When the study was conducted, aged care packages consisted of Commonwealth Aged Care Package (CACPs) and Linkage packages (low care), Extended Aged Care at Home (EACH) (high care) and Extended Aged Care at Home Dementia (EACH-D) (high care with dementia supplement). Around 660 clients of three participating community aged care providers operating in Melbourne's southeastern

## PACS Model: Overview



**Figure 1** Overview of the People at Centre Stage (PACS) model. HACC, Commonwealth Home And Community Care.

and southern metropolitan regions were eligible to self-select into the intervention group and were contacted by their case managers. Of these, 158 (23.9%) expressed interest in the project. Around 1100 clients of three aged care providers operating in Melbourne's northern and Sydney's northwestern metropolitan regions were eligible to participate in the control group. A total of 550 were contacted by their case managers. Of these, 107 (19.5%) expressed an interest to participate in the project. Control group participants were matched to intervention group participants focusing on age, country of birth and socioeconomic background. Eligible individuals were contacted by their case managers or care co-ordinators and were provided with an outline of the project, a Plain Language Statement (PLS) and a consent form. A researcher contacted interested participants and ensured that they had understood the content of the PLS. The signed PLS was forwarded to the researchers. Case management practices were comparable across the four participating organisations, three

of which operated under the same umbrella organisation. As the delivery of CACP-funded services is monitored at a national level, the same legislation and package care guidelines applied to the four sites.

### Procedures

The intervention was implemented by three community aged care providers located in the eastern metropolitan region of Melbourne, Australia. The evaluation of the PACS model was planned to take place between January 2011 and December 2011. However, this had to be extended to March 2012 due to implementation delays. Compliance with the model was monitored using three-monthly audits. Notwithstanding the inability of one agency to implement Level 3 within the trial period, the intervention proceeded according to plan. Baseline data, consisting of a demographics questionnaire that included a basic assessment of support needs and the below-mentioned survey instruments, were

collected between July 2010 and April 2012 with a few individuals requiring follow-up during the following 2 months. The repeat measure, consisting of a demographics update form, the survey instruments and semi-structured interviews with intervention group members, was conducted between November 2011 and April 2012. All participants experienced at least 10 months of the intervention or control group conditions. The survey instruments were applied over the phone, except on occasions where health reasons or disability did not permit for this to occur, in which case participants were visited in their homes. All intervention group participants were given the choice to complete the interviews over the phone or face to face.

### Survey instruments

The four tools used in the study were specifically designed to evaluate social care outcomes for older people. With the exception of the quality of life tool, they were used in the evaluation of the Individual Budget project in the UK and are described in detail in publications associated with that project (Glendinning *et al.* 2008). The first tool was a version of the Adult Social Care Outcomes Toolkit (ASCOT) (Netten *et al.* 2011) modified for Australian community aged care comprising 19 questions ranging from decisional autonomy to social engagement measuring seven domains encapsulating the quality of case management. Participants are asked to indicate their level of agreement on a 4-point Likert scale with statements such as 'I feel in control of my life'. The second tool that was a self-perceived health scale developed as part of a European project on health indicators asked participants to rate their health on a 5-point Likert scale (Robine *et al.* 2003). The third was the eight-item Personal Wellbeing Index (International Wellbeing Group 2006) that asked participants to rate their agreement on a 10-point Likert scale with statements such as 'I feel satisfied with life as a whole'. The scale has good construct validity, forming a single stable factor accounting for about 50% of variance in Australia and other countries (International Wellbeing Group 2006). Its correlation of 0.78 with the Satisfaction of Life Scale suggests a good convergent validity. The fourth was the Australian context modified version of the extensions to the UK-focused User Experience Survey For Older Home Care Service Users and Younger Adults, which contained nine questions that measure participants' satisfaction with and quality of direct care services. Participants are asked to rate their agreement on a 4-point Likert scale with statements such as 'My care workers always come at a time that suits me' (Malley *et al.* 2006, Jones *et al.* 2007).

Sample size was calculated for univariate ordinal logistic regression to compare intervention and control groups involving ordinal variables comprising four categories with close to average expected prevalence in each category and the overall study. Different scenarios were considered to resemble all ordinal scales used in the study. A sample size of 105 in each group was required to detect statistically significant difference in ordinal odds ratios of 2.8 or larger ( $\alpha = 0.05$ ) with 80% power.

The qualitative interview schedule used at the end of the evaluation period comprised 10 open and closed questions directed at all intervention group participants and 10 further questions directed at participants self-directing at Levels 2 or 3. Box 1 provides an overview of the interview questions.

### Data analysis

Quantitative data were analysed using SPSS (IBM SPSS Statistics, Rochester, MN, USA) and Stata (Stata Corp. LP, College Station, TX, USA). Alongside the usual descriptive statistics, intervention and control groups were compared at baseline in terms of demographic profile using chi-squares for categorical variables and *t*-test for continuous factors. Furthermore, we compared the intervention and control groups using ordinal logistic regression. A generalised estimation equation approach was used to adjust for the baseline scores to deal with the repeated ordinal nature of the data. The intervention and control group comparisons were adjusted for any statistically significant demographic factors at baseline. Due to insufficient sample size for fitting multivariate models, a 'one variable at a time' method was used for adjusting significant factors.

Qualitative data were analysed using NVivo (QSR International, Doncaster, Victoria, Australia). An inductive and deductive thematic analysis was used to identify the key themes (Fereday & Muir-Cochrane 2006). 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.

### Results

A total of 265 individuals (158 in the intervention and 107 in the control group) expressed interest to participate in the study. Of these, 185 older people (98 in the intervention and 87 in the control group) completed baseline data collection. A total of 109 participants (70.3% women and 29.7% men) completed the repeat measure. Their mean age was 77.4

**Box 1** Overview of interview questions

1. *Expectations and concerns related to self-directed care:* In an ideal situation, what would you like your case manager to do for you? Is this in any way different from what your case manager does now? In an ideal situation, what should the home carer do to be of use to you? Is this in any way different from what the home carer does now?
2. *Experience of enrolment in the People at Centre Stage (PACS) project:* How would you describe your experience of enrolling in PACS?
3. *Determining the level of self-direction:* At what level are you self-directing? How did you make this decision? Who made this decision?
4. *PACS outcomes:* What changed for you as a result of your involvement in the project?
5. *Experience of programme documentation:* What did you think of the PACS documentation you were given?
6. *Experience of self-assessment process:* Do you remember filling in this form (show form)? Did you think this was useful for you? How difficult was it to complete it?
7. *Knowledge of care package:* Do you know how much money you have available to purchase care services? [If yes,] can you remember how this amount was determined? PACS clients receive a monthly statement like this one (show budget). Have you seen this? If yes, did you find it useful?
8. *Experience of restorative approach:* Do you remember when your case manager asked you about your goals? What did you think about this process?
9. *Experience of support planning:* Who decided what kind of support services you would receive? Were you part of this decision?
10. *Overall feedback:* In your view, how could PACS be improved? Would you recommend the programme to others? What do you think is missing in this programme? What do you think is working well?

For clients self-directing at Levels 2 and 3

11. *Overall experience:* What stands out for you in terms of your experience self-directing at level [2/3]?
12. *Level of control:* Do you feel that PACS has made a difference in terms of the control you have over your care arrangements?
13. *Benefits of self-directing at Level 2 only:* What do you think are the benefits of co-ordinating your care?
14. *Risks:* Do you think there are any risks to co-ordinating your care? [If yes,] How do you think these risks can be minimised?

For clients self-directing at Level 3

15. *Benefits self-directing at Level 3:* Did self-direction at Level 3 make a difference in terms of the care [you/the person in your care are receiving]? If yes, provide example. What were you not able to do?
16. *Review and monitoring:* Have you been able to meet regularly with your case manager to review your situation?
17. *Challenges self-directing at Level 3:* Did you find self-direction at Level 3 difficult?
18. *Support:* Were you adequately supported to make the most of PACS? What additional supports would be required to improve the experience?
19. *Administrative burden:* How did you experience the administrative tasks you had to take on as a result of self-directing at Level 3? How many hours did you spend on these tasks every week?
20. *Planning for the future:* How do you think your need for self-direction will change as you grow older?

(intervention group) and 82.7 (control group). Of these, 40.8% lived alone. Around 68% were born in Australia. Table 1 provides a demographic snapshot of intervention and control group participants taken at baseline and at the repeat measure.

### Comparing intervention and control groups at baseline

Comparing intervention and control groups at baseline in terms of demographic profile, it emerged that the intervention group attracted a statistically significantly higher proportion of proxy responses ( $P = 0.012$ ) than the control group and a significantly greater proportion of low care packages ( $P = 0.019$ ). Control group participants were somewhat older ( $P = 0.002$ ). While more control group participants required interpreters (12.0% vs. 6.7%), an appraisal of language skills revealed that English language capabilities in the intervention and control group were similar (see Table 1).

Eleven months after the implementation, a total of 109 individuals (59 in the intervention and 50 in the control group) participated in the repeat measure. This represents an attrition rate of 39.8% for the intervention group and 42.5% for the control group. The relatively high attrition rate reflects the frailty of the participants and is commensurate with attrition rates recorded by Australian community aged care providers. A number of demographic characteristics of those withdrawing from the evaluation compared with those who remained in the study varied by more than a tenth of the repeat measure percentage. Table 1 shows that those who withdrew from both the intervention and the control group were more likely to have a dementia diagnosis, a 'high' package type or own their own residence, and less likely to have received only primary education or trade schooling. In addition, those who withdrew from the control group were more likely to have completed trade school and less likely to be university-educated. Reasons for withdrawing from the evaluation were in

**Table 1** Characteristics of participants at baseline and repeat measure

Indicators	Baseline (%)			Repeat measure (%)		Attrition (%)	
	Intervention (N = 98)	Control (N = 87)	P value	Intervention (N = 59)	Control (N = 50)	Intervention (N = 39)	Control (N = 37)
Age	79.2 (SD 9.7)	83.4 (SD 8.1)	0.002	77.4 (SD 8.8)	82.7 (SD 8.2)	81.0 (SD 10.4)	84.23 (SD 8.0)
Gender							
Female	65.1	70.6	0.973	66.7	73.9	63.5	66.7
Male	33.9	28.2		31.9	26.1	36.5	30.8
Proxy response	31.8	13.8	0.012	11.9	8.0	19.9	5.8
ATSI	0.9	0.0	0.272	1.8	0.0	0.0	0.0
Interpreter required	6.4	11.8	0.899	8.8	13.3	3.8	10.3
Difficulty reading/writing English	–	–	0.269	20.6	15.4	–	–
Difficulty expressing in English	–	–	0.478	15.9	12.8	–	–
Dementia diagnosis	16.5	5.9	0.095	12.3	4.3	21.2	7.7
Package type							
Low	64.2	88.2	0.019	66.7	89.1	61.5	87.9
High	21.1	5.9		17.5	6.5	25.0	5.1
High-dementia	10.1	2.4		10.5	2.2	9.6	2.6
Living alone	33.9	51.8	0.088	31.6	50.0	36.5	53.8
Private residence owned	70.6	75.3	0.960	66.7	69.6	75.0	82.1
Highest level of education							
Primary	9.2	17.6	0.329	10.5	21.7	7.7	12.8
Secondary	42.2	43.6		35.1	43.4	50.0	43.6
Trade school	9.2	11.8		14.0	6.5	3.8	17.9
University	22.9	21.2		22.8	26.1	23.1	15.4

ATSI, Aboriginal or Torres Strait Islander.

There were small numbers of missing values for each indicator. Percentages are marginal percentages. *P* values are based on matched data.

most cases transfer to a residential aged care facility, ill-health or death.

### Comparing intervention and control groups at the end of the trial

#### *Unadjusted comparison: univariate repeated ordinal logistic regression*

It emerged that that the ordered odds of participants' satisfaction with the overall care they received (A1) were 4.5 times higher in intervention group participants ( $P = 0.007$ ). Moreover, intervention group participants were more likely to be satisfied with the way they were treated ( $P = 0.013$ ) (A3), their care options ( $P = 0.014$ ) (A4), the 'say' they had in their care ( $P = 0.000$ ) (A5), the information they received regarding their care ( $P = 0.012$ ) (A7) and more likely ( $P = 0.020$ ) to agree that the services changed their view on what could be achieved in life (A10). Also, they were more likely ( $P = 0.013$ ) to disagree with the statement that they felt lonely (A17), more likely ( $P = 0.008$ ) to agree that they were satisfied with their

standard of living (C2) and with what they were achieving in life ( $P = 0.031$ ) (C4).

#### *Adjusted comparison: multivariate repeated ordinal logistic regression*

Controlling for the age difference at baseline, results for A1 (Satisfaction with overall help received), A17 (I feel lonely) and A19 (I have nothing much to do and am usually bored) were no longer statistically significant. Controlling for package type and proxy response differences at baseline, all results remained significant. Table 2 provides an overview of statistically significant odds ratios and confidence intervals.

#### *Qualitative data*

Of 59 participants in the intervention group who completed the four survey repeat measures, 56 individuals chose to participate in the interviews. Of these, 14 clients had only a vague or no recollection of having experienced the model. Interview responses were collected, audio taped and transcribed. Each of the questions was thematically analysed. This process

**Table 2** Comparison of statistically significant 'client satisfaction with services' indicators at baseline and repeat measure providing marginal percentages, univariate and multivariate ordinal repeated logistic regression outcomes

Client satisfaction with services (%)		At baseline (%)		Repeat measure (%)		Controlling for age		Controlling for package type		Controlling for response		
Variable		Control	Intervention	Control	Intervention	OR (95% CI)	P	OR (95% CI)	P	OR (95% CI)	P	
<b>A – Ascot</b>												
<b>A1 – Satisfaction with overall help received (N = 102)</b>												
Very satisfied	81.8	60.8	60.5	70.6	0.22 (0.07, 0.66)	0.007	0.30 (0.09, 1.04)	0.057	0.23 (0.08, 0.69)	0.009	0.19 (0.06, 0.59)	0.004
Satisfied	18.2	37.3	30.2	23.5								
Dissatisfied	0.0	2.0	9.3	5.9								
<b>A3 – Satisfaction that treatment was dignified and respectful (N = 102)</b>												
Very satisfied	86.1	68.6	65.9	76.5	0.21 (0.06, 0.72)	0.013	0.13 (0.03, 0.61)	0.010	0.23 (0.07, 0.81)	0.023	0.22 (0.06, 0.74)	0.015
Satisfied	14.0	27.5	29.6	19.6								
Dissatisfied	0.0	3.9	4.6	2.0								
Very dissatisfied	0.0	0.0	0.0	2.0								
<b>A4 – Satisfaction with care options (N = 99)</b>												
Very satisfied	58.1	44.9	50.0	60.8	0.30 (0.11, 0.78)	0.014	0.26 (0.09, 0.80)	0.018	0.32 (0.12, 0.88)	0.027	0.31 (0.12, 0.81)	0.017
Satisfied	1.9	44.9	42.9	39.2								
Dissatisfied	0	8.2	7.1	0.0								
Very dissatisfied	0	2.0	0.0	0.0								
<b>A5 – Satisfaction that client 'had a say' in care options (N = 102)</b>												
Very satisfied	63.6	45.1	50.0	70.0	0.19 (0.08, 0.48)	<0.001	0.20 (0.07, 0.59)	0.003	0.21 (0.08, 0.54)	0.001	0.19 (0.07, 0.47)	<0.001
Satisfied	9.6	47.1	38.6	30.0								
Dissatisfied	4.6	7.8	9.1	0.0								
Very dissatisfied	2.3	0.0	2.3	0.0								
<b>A7 – Satisfaction with information received regarding care (N = 101)</b>												
Very satisfied	59.1	34.0	48.8	44.9	0.33 (0.14, 0.78)	0.012	0.30 (0.12, 0.78)	0.013	0.33 (0.13, 0.84)	0.02	0.35 (0.14, 0.84)	0.019
Satisfied	36.4	44.0	43.9	49.0								
Dissatisfied	4.6	20.0	7.3	4.1								
Very dissatisfied	0.0	2.0	0.0	2.0								
<b>A10 – Service changed your view on possible life achievements (N = 101)</b>												
A lot	58.1	54.9	35.7	57.1	0.29 (0.10, 0.83)	0.020	0.23 (0.06, 0.85)	0.027	0.31 (0.10, 0.93)	0.037	0.30 (0.10, 0.90)	0.031
A little	30.2	33.3	31.0	34.7								
Not at all	11.6	11.8	33.3	8.2								
<b>A17 – I feel lonely (N = 100)</b>												
Strongly agree	11.6	9.8	11.9	6.0	2.40 (1.20, 4.77)	0.013	1.81 (0.74, 4.48)	0.196	2.81 (1.33, 5.93)	0.007	2.55 (1.27, 5.12)	0.008
Agree	30.2	33.3	42.9	20.0								
Disagree	34.9	31.4	26.2	44.0								
Strongly disagree	23.3	25.5	19.1	30.0								
<b>A19 – I have nothing much to do and am usually bored (N = 98)</b>												
Strongly agree	11.6	2.1	6.8	6.3	2.27 (0.99, 5.22)	0.054	1.95 (0.72, 5.25)	0.189	2.51 (1.05, 5.99)	0.039	2.34 (1.00, 5.47)	0.050
Agree	16.3	18.8	25.0	12.5								
Disagree	25.6	50.0	40.9	41.7								
Strongly disagree	46.5	29.2	27.3	39.6								



**Table 2** (continued)

Variable	Client satisfaction with services (%)		At baseline (%)		Repeat measure (%)		Controlling for age		Controlling for package type		Controlling for response	
	Control	Intervention	Control	Intervention	Control	Intervention	OR (95% CI)	P	OR (95% CI)	P	OR (95% CI)	P
C – Personal well-being index												
C2 – Satisfaction with living standards												
Very satisfied	47.7	41.2	28.6	38.0	2.80 (1.31, 5.99)	0.008	2.81 (1.19, 6.64)	0.018	3.07 (1.38, 6.80)	0.006	2.87 (1.30, 6.36)	0.009
Satisfied	27.3	31.4	33.3	42.0								
Neutral	20.5	17.6	26.2	14.0								
Dissatisfied	2.3	3.9	4.8	6.0								
Very dissatisfied	2.3	5.9	7.1	0.0								
C4 – Satisfaction with what you are achieving in life												
Very satisfied	37.2	12.0	16.7	22.5	2.39 (1.08, 5.30)	0.031	2.84 (1.18, 6.83)	0.019	2.40 (1.04, 5.56)	0.041	2.49 (1.07, 5.76)	0.034
Satisfied	18.6	36.0	28.6	28.6								
Neutral	30.2	34.0	40.5	30.6								
Dissatisfied	9.3	10.0	7.1	8.2								
Very dissatisfied	4.7	8.0	7.1	10.2								

**Box 2** Overview of the themes generated by three open-ended evaluation questions asked at the repeat measure

- Benefits of the People at Centre Stage (PACS) model
  - Improved quality of care
    - Choice
    - Flexibility
    - Involvement in decision-making process
    - Better assistive technology
    - Responsiveness of services
  - Improved quality of life
    - Financial benefits
    - Social engagement
    - Control/Autonomy
    - Easier/More comfortable
- Key challenges associated with PACS
  - Administrative tasks
    - Reimbursement delays
    - Required organisation skills
    - Managing care attendants
  - Case management
    - Reduced contact with case managers
    - Change of case manager
  - Quality of care
    - Loss of services
    - Loss of continuity
- Barriers to self-directing at next level
  - Empowerment
  - Clients' perceived lack of authority and expertise
  - Lack of encouragement
  - Information and knowledge
  - Information provision, lack of clients not informed about programme options
  - Lack of financial transparency
  - Clients unaware of entitlements, clients do not receive financial statements
  - Limited use of translation services and translated documents
  - Health and psycho-social support
  - Lack of self-confidence
  - Health issues
  - Client/Carer preferences
  - Desire for a period of consistency or stability
  - Reluctance to change existing arrangements
  - Lack of time/Not wanting extra work or responsibility (carers and clients)
  - No desire to handle money

generated 84 themes. Around half of these themes were of a binary nature reflecting the closed interview questions. While a complete reproduction of the coding table is beyond the scope of this article, Box 2 provides an overview of the themes generated by three of the open-ended interview questions (benefits of PACS, key challenges associated with PACS and barriers to self-directing at next level).

The qualitative data highlighted a number of benefits and challenges associated with the PACS model. Reflecting on the model, 35 of 56 individuals in the intervention group commented that the SDC model resulted in positive changes to the care they received.

A total of 23 participants, of which 22 chose a higher level of self-direction, reported that the PACS model had given them greater decisional autonomy and control:

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, client)

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, client)

You're not relying on other people to make decisions for you, 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, client)

In addition, a number of participants mentioned that they appreciated the increased flexibility and that they could use the package to pay for repairs and equipment.

These sentiments regarding greater decisional autonomy were also shared by some carers:

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. (Level 2, carer)

...[T]hey were trying to manage me and now I can manage myself basically. (Level 3, carer)

Fourteen participants and particularly carers self-directing at a higher level commented on the financial benefits they reaped from participating in the intervention group:

Well, I think generally it's made my life financially much easier ... I was always out of pocket for something. But now I don't seem to be out of pocket for much. (Level 3, carer)

Nine people commented on the perceived benefit of negotiating directly with service provider agencies:

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 2 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, client)

A further nine participants reported that the PACS model had considerable positive outcomes for them:

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, client)

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

In addition, some participants felt empowered to challenge the authority of their case managers, appre-

**Table 3** Responses highlighting the benefits of the People at Centre Stage (PACS) model, by level of self-direction

	Level 1	Level 2	Level 3	Total
Greater decisional autonomy/control	8	10	16	34
Financial benefit	4	3	7	14
Ability to negotiate directly with service provider	1	4	4	9
Life-changing and positive responses	3	2	4	9
Clients felt empowered to challenge paternalism of the system	1	2	4	7
Clients open to next level of self-direction	2	1	N/A	3
Availability of help and backup	1	1	0	2
Client gained or maintained skills	0	0	2	2
Life is easier and more comfortable	0	0	2	2

ciated the fact that help and backup were available, felt that they were able to gain or maintain skills and reported that life was more comfortable. Table 3 summarises responses outlining the key benefits as reported by intervention group participants by levels of self-direction.

*Barriers to clients self-directing at a higher level.* By far, the most important barrier was a lack of perceived knowledge, authority and expertise followed by feeling overwhelmed, not wanting to take extra responsibilities and not having sufficient time for self-direction. Moreover, some individuals lacked the desire to handle money, experienced difficulties with the English language, negative experience with changing care arrangements, lack of self-confidence, fear of losing a case manager, a reluctance to change existing care arrangements, as well as health concerns. Table 4 outlines key barriers of self-directing at a higher level by agency and by level of self-direction.

*Negative views towards the model.* A small number of people voiced several minor concerns in relation to their experience of the model. Concerns associated with changes inspired by the model included the slow pace of reimbursements (one participant), having to be organised to stay on top of the bookkeeping task (one participant), less contact with a case manager (one participant), a greater turnover of case managers (one participant), managing paid carers (three participants), receiving fewer services (two participants) and an agency's lack of response to a

**Table 4** Barriers to moving to the next level of self-direction, by level

	Level 1	Level 2	Total
<b>Implementation issues</b>			
Lack of information, knowledge and expertise	15	7	22
Difficulty with English	3	0	3
Lack of self-confidence to speak up	0	1	1
Perceived loss of case manager	1	0	1
<b>Client issues</b>			
Lack of time and not wanting extra work or responsibility			
Carers	5	3	8
Clients	2	1	3
Don't want to handle money	4	1	5
Previous experience of changing care arrangements	2	0	2
Reluctance to change existing arrangements	1	0	1
Health issues	1	0	1

**Table 5** Number of participants at levels of self-direction by agency at repeat measure who completed an interview

	Agency 1	Agency 2	Agency 3	Total
Level 1	14	0	14	28
Level 2	10	2	2	14
Level 3	13	1	0	14
Total	37	3	16	56

participant's demand to change agencies. Two participants would not recommend PACS to others. One participant cited a lack of planning and communication as the main reason; the other questioned the political motives underpinning CDC.

*Levels of self-direction.* At the end of the trial, of those who completed an interview a total of 14 intervention group participants self-directed at Level 3 (financial and administrative responsibilities), 14 at Level 2 (care coordination responsibilities) and 28 at Level 1 (care planning responsibilities). Eight intervention group participants moved to the next level of self-direction during the trial. Table 5 provides an overview of numbers of participants in the intervention group who completed an interview at the end of the intervention by level of self-direction.

## Discussion

Reminiscent of other models inspired by CDC philosophy, the PACS model generated perceived improvements in terms of client satisfaction with their care options and involvement in the decision-making process (see also Doty *et al.* 1996, Benjamin *et al.* 2000,

Benjamin & Matthias 2001, Heumann 2003, Hagglund *et al.* 2004, Simon-Rusinowitz *et al.* 2005, Brown *et al.* 2007, Davey *et al.* 2007, Henwood & Hudson 2007, Wiener *et al.* 2007, Glendinning *et al.* 2008, Newbrunner *et al.* 2011). Satisfaction with information provided was only significant because the control group's satisfaction with this item decreased, whereas the intervention group's level remained the same. This resonates with semi-structured interview outcomes that highlighted information and communication deficiencies.

It is important to note that satisfaction with services at baseline was high (see Table 2). In fact, baseline responses regarding satisfaction with services and paid care were substantially higher than those recorded by the Individual Budgets evaluation team in the UK (Glendinning *et al.* 2008). When responding to key indicators regarding quality of care, such as 'satisfaction with overall paid help from care workers', more than 90% of participants in the intervention and control group responded to be 'satisfied' or 'very satisfied'. Also, more than 80% felt in control of their daily lives. The domains that attracted significantly fewer 'satisfied' or 'very satisfied' responses at baseline from intervention group as compared with control group members were associated with the arrival on time (D4), arrival at opportune times (D2) and lack of continuity (D7) of paid care workers; care expectations (A6), the support and planning process (A8) and information provision in general (A7), issues not dissimilar from those predicted by Mahoney *et al.* (2002) in the above-mentioned preference study. While at the end of the PACS evaluation, considerably more intervention group members were either satisfied or very satisfied with all of these issues; these changes were statistically significant only in one case (A7) and this was only because of a significant drop in control group satisfaction levels. It is likely that the model's limited impact on direct care services was in part due to the above-mentioned constraints imposed by the various acts and guidelines on the provision of direct aged care services.

Whereas the results suggested few unmet home and personal care needs, almost half of the participants felt lonely (A17) and one-third felt that they did not have a good social life (A16) and were not fully occupied with activities of their choice (A18). The intervention's main impact was on the perceived quality of case management services, engagement and living standards. The PACS model led to the outcomes that intervention group participants were significantly more likely to express satisfaction with the way they were treated, information they received regarding their care and were less likely to disagree

with the statement that the service had positively changed their view about what they could and were achieving in life. Moreover, they were more likely to express satisfaction with their care options, their involvement in the decision-making process and their standard of living. In addition, intervention group participants were less likely to agree with the statement that they were lonely or that they were usually bored and had nothing to do. However, these later two outcomes were no longer significant when controlling for age – but not package type or proxy response. It is possible that concurrent multiple regressions with a larger sample size would have yielded statistically significant outcomes in these and other domains. The intervention suggests that improvements to older people's sense of choice and control, being respected, as well as their overall outlook on life can be achieved by placing greater importance on capacity building and psycho-social supports alongside more 'typical' CDC support features.

These results stand in contrast with the findings from the above-mentioned Individual Budget evaluation where some older people reported increased anxiety as a result of the intervention (Glendinning *et al.* 2008). While further research is required to explore the impact of these social supports in greater detail, it is reasonable to suggest that the PACS evaluation highlights the benefits of a capacity-building approach.

### Outcomes by levels of self-direction

The PACS evaluation suggests that only a small minority of older people are interested in taking on financial and administrative responsibilities. Out of a total eligible population of around 660 potential intervention group participants, only 14 clients (or around 2.1% of the total eligible population) chose Level 3 to exercise greater control over administrative and financial processes and to benefit from associated financial benefits (see also Foster *et al.* 2005). Bearing in mind the substantially larger group of individuals interested in Levels 1 and 2, it appears that older Australian's preferences regarding self-direction are only in a very limited sense motivated by a voucher/cash option and greater financial and administrative control and responsibility. A far larger number of clients were interested in self-directing aspects of their care, resulting in greater decisional authority and better and more direct access to services.

The tiered approach of PACS brought to light more clearly how older people responded to SDC. Participants at Level 1 were the least involved in the

project and only one individual was interested in progressing to Level 2. There were a variety of reasons for this. Some related to the personal preferences of participants; others appeared to be related to circumstances including cognitive status, complex health and medical issues, a decline in health and confidence levels and a lack of willingness to take on administrative tasks. Similar barriers have been reported in connection with the Cash and Counseling Demonstration and Evaluation project in the US (Foster *et al.* 2005). However, the single most important barrier reported by Level 1 participants was the lack of information, knowledge and expertise.

Participants self-directing at Level 2 were generally more aware of the PACS project and demonstrated a greater familiarity with the concept of self-direction. Participants at this level of self-direction generally appreciated the greater efficiency of coordinating their own care workers by circumventing the broker agency 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. While barriers in terms of progressing to the next level of self-direction appeared to issue from a number of sources, almost half of the participants at this level commented on a lack of information provision, general communication issues and a perceived lack of skills (particularly IT and bookkeeping).

The group of participants enrolled at Level 3 was composed of family carers and clients who were interested to explore new service options. Some had experienced the disability support system, a career background in management or professional knowledge of the health sector. Most had taken the initiative to investigate their options and were aware of CDC (see also Mahoney *et al.* 2002, Glendinning *et al.* 2008). Participants at this level were very positive about self-direction and liked the greater control and financial benefits it afforded them. Again, inadequate communication was the most frequently raised issue. Overall, participants at Level 3 were comfortable with the financial and administrative tasks associated with this level. This suggests that, if kept minimal and comprehensive, some older people deal well with these aspects of SDC (see also Mahoney *et al.* 2002).

Communication, encouragement and capacity building emerged as key factors underpinning the ability of older people to take advantage of SDC options. Although the PACS model comprised a range of capacity-building programmes, some participants self-directing at lower levels would have bene-

fitted from more support. Indeed, older people have substantial support needs regarding decision-making, administrative tasks and advocacy (see also Mahoney *et al.* 2002, Sciegaj *et al.* 2004, Foster *et al.* 2005, Simon-Rusinowitz *et al.* 2005, Brown *et al.* 2007, Glendinning *et al.* 2008, 2009, Newbrunner *et al.* 2011). Crucially, participants need to know that they are entitled to good quality care, the different service options they have under a SDC approach and the level of financial resources that are at their disposal to procure direct services and supports. The key challenge that has remained underexplored to date is to ascertain how to provide the required support in a manner that resonates with the needs of older people. Repeat sessions and visually supported learning experiences worked well with some of the participants in this study. However, the preferred learning styles of older adults within an aged care context require more systematic exploration.

### Limitations

There are a number of limitations to this study. The relatively small sample size of this study, demographic differences between intervention and control groups at baseline, the non-randomised convenience sample and the considerable attrition clearly represent limitations. Particularly, the fact that the intervention group attracted a larger percentage of carers of people with cognitive issues than the control group represents a confounding factor. Also, some of the older people evaluating the model found it difficult to respond to the quantitative survey questions (see also Bauld *et al.* 2000) and required substantial support from interviewers.

### Conclusion

This paper provided an overview of the evaluation of a capacity-building-focused SDC model for older people. The evaluation pinpoints that there is a substantial opportunity to improve the care outcomes of older people enrolled in SDC programmes by adopting a stepped approach and by paying more attention to capacity building and to the psycho-social and health needs of participants. More holistic support and mentoring have the potential not only to increase older people's sense of choice among and control over care services, they can also contribute to a better outlook on life. This paper argues that to unleash the full potential of SDC, a stepped approach in combination with support services are required that assists older people to build their capacity in a broad range of domains. More research is required to explore how

SDC components and support structures can be designed to improve care outcomes for older people enrolled in SDC programmes.

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